

**ASSOCIATION OF
PAEDIATRIC
CHARTERED
PHYSIOTHERAPISTS**

NEWSLETTER



AUGUST 2013

ISSUE
NO. 13

Well, in keeping with the British obsession with weather, I hate to disappoint! It's currently nearly 30 degrees which personally I love but just seems to give a lot of people something different to moan about!

Another British obsession is sport and we seem to be doing well at the moment, Wimbledon has just finished triumphantly, the Lions had a successful tour down under, the cricket is interesting (allegedly, I just put that bit in for those of you with a Y chromosome) and QPR have spent £56 million on footballers and still got relegated!

Following on from our fantastic Conference in London last year, and as a bit of a legacy of the wonderful Paralympics, APCP has recently made some links with a few sporting charities, CP Sport, Wheelpower and the English Federation for Disability Sport (EFDS) and we are planning some joint working. Hopefully we will be better able to signpost you to sporting opportunities for young people, funding for sports related equipment and we are also planning a series of publications for young people's inclusion into sport. APCP are very excited about this joint working venture and we are initially planning a questionnaire, written in partnership with the charities, to find out who, where and what the children you work with are able to access. Some areas keep better databases of disabled children than others and targeting resources is a big challenge so

please try and fill the survey out when it arrives in your inbox! I am not going to apologise for this rather sport-heavy edition, these groups have given me such wonderful information and although I feel paediatric physiotherapists have a key role in encouraging their children to be fit and active, finding appropriate activities isn't always easy, I hope it helps!

Do make sure you visit the APCP website regularly and make use of the publications. A lot of these are free to download and are now available for non-members or parents to download directly. We hope to make improvements to the website in the coming year so that you will be able to pay online, and receive bulletins highlighting new content.

I hope you enjoy the content of the newsletter this time, as always I would love to hear your comments or criticisms and am always on the lookout for new items for the next one so please put pen to paper, or rather finger to keyboard and get in touch.

I look forward to seeing you at Conference in Bristol this year, see inside for the exciting programme.

The Editorial Board does not necessarily agree with opinions expressed in articles and correspondence, and does not necessarily endorse courses or equipment advertised

Kerry McGarrity
Editor



APCP Annual Conference 2013

‘Extending Minds and Practice’

8th & 9th November 2013

The Holiday Inn, Filton Road, Bristol

A packed 2-day programme with a parallel neonatal programme on the Friday, organised by the APCP Neonatal Group

An opportunity to network with paediatric physiotherapists from around the UK to share practice and expertise

PRINCIPLE SPONSORS



Extending Minds and Practice
Main Programme*,
Friday, 8th November 2013 – Sequoia Suite

- 08.00-09.00 Registration
- 09.00-09.10 Welcome and introduction
- 09.10-09.40 **Exploring the challenges of consent when working with children, young people and their families**
 Dr Geraldine Hastings PhD LLM BSc(Hons) MCSP – Lecturer, School of Healthcare Studies, Cardiff University
- 09.40-10.10 **The medico-legal world demystified**
 Susan Filson MCSP – Physiotherapy Consultancy & Lorna Stybelka MCSP – Specialist Paediatric Physiotherapist
- 10.10-10.30 **Panel Discussion**
- 10.30-11.00 Break and exhibition
- 11.00-11.45 **Safeguarding**
 Dr Deborah Stalker - Consultant Paediatrician and Name Doctor for Safeguarding, Musgrove Park Hospital, Taunton
- 11.45-12.30 **Acupuncture in paediatrics: are we missing the point?**
 Jon Hobbs MSc MCSP FHEA - Director of AACP and AACP Accredited Tutor
- 12.30-13.00 **Free Paper Session**
- 13.00-14.00 Lunch and exhibition
- 14.00-14.30 **Physiology and paediatric pain**
 Dr Jacqui Clinch MBBS FRCPC – Consultant Paediatric Rheumatologist, Royal National Hospital for Rheumatic Diseases NHS FT
- 14.30-15.00 **Chronic pain and physical rehabilitation**
 Sarah Wilson MCSP, BSc (Hons), MSc – Clinical Specialist Physiotherapist, Bath Centre for Pain Services
- 15.00-15.30 **CP Pain Management**
 Speaker to be confirmed
- 15.30-16.00 Break and exhibition
- 16.00-16.45 **Pilates: why is it clinically relevant and how to adapt it for use with children**
 Jo Ferris MCSP - Specialist Neuro Physiotherapist and Certified Classical Pilates Instructor
- 16.45-17.00 **English Federation of Disability Sport**

LOC - Specialists in Paediatric Orthotics



Since its formation in 2005 the London Orthotic Consultancy (LOC) has developed a national and international reputation for its orthotic management and treatment of common and not so common medical conditions. Our team of experienced clinicians work alongside Physiotherapists to assess and design the most suitable orthosis for each patient. LOC has on site manufacturing facilities at its Kingston headquarters. All adjustments and changes to alignment can be made while the patient waits.

Below is a list of the most common conditions treated; this is by no means exhaustive.

- CP
- SDR
- Hypermobility
- Transverse Myelitis
- Scoliosis
- Guillian Barre syndrome
- Muscular Dystrophy
- Spina Bifida



Bivalved Spinal Brace



Fixed AFO with Neuro Footplate



Contracture Correction Arm Orthosis



Hinged DAFO



Carbon Fibre Response AFO



Night AFOs



LOCband Plagiocephaly Helmet

LOC has Orthotic clinics in Kingston (headquarters), Bristol and Leicester.
To refer a patient or to ask for more information please ring:

020 8974 9989 or e-mail: info@londonorthotics.co.uk



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E: info@londonorthotics.co.uk
W: www.londonorthotics.co.uk

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Neonatal Programme*

Baby Brains – Research and Outcomes Friday, 8th November 2013 - Orchard Suite

- 08.00-09.00 Registration
- 09.00-09.15 Welcome and introduction
- 09.15-10.00 **Neuropathy of hypoxic-ischaemic encephalopathy**
Dr Hemmen Sabir - Neonatologist, University Hospitals Dusseldorf, Germany
- 10.00-10.45 **Functional brain imaging in vulnerable newborns**
Dr Axel Heep – Consultant Neonatologist, Southmead Hospital and Senior Clinical Researcher, School of Clinical Sciences, University of Bristol
- 10.45-11.15 Break and exhibition
- 11.15-12.00 **Methods of neuro-protections in hypoxic-ischaemic encephalopathy**
Dr Hemmen Sabir - Neonatologist, University Hospitals, Dusseldorf, Germany
- 12.00-12.20 **Functional outcome 6 years after neonatal encephalopathy - a pilot study**
Adare Brady – Consultant Neonatal Physiotherapist
- 12.20-12.30 **Parent Information Leaflets**
Helen Robinson – APCP Neonatal Group
- 12.30-13.30 Lunch and exhibition
- 13.30-14.15 **Neonatal Pain**
Dr Judith Meek – Consultant on Neonatal Care, University College London Hospitals NHS FT
- 14.15-15.00 **Neonatal seizures: is there a need for structured neurodevelopmental surveillance?**
Dr Karen Luyt - Consultant Neonatologist, St Michael's Hospital, Bristol and Senior Lecturer, School of Clinical Sciences, university of Bristol
- 15.00-15.30 Break and exhibition
- 15.30-16.15 **Treatment Strategies for Neonatal Hydrocephalus**
Mr Mike Carter – Consultant Neurosurgeon, North Bristol NHS Trust
- 16.15-16.45 **Prediction of Cognitive and Motor Developmental Outcome Using MRI and CUS in PHVD**
Sally Jary – Clinical Specialist Physiotherapist, Bristol Royal Hospital for Children
- 16.45-17.00 Round-Up and Close of Programme



It is well recognised that there is a need to establish **Effective Postural Management** for **Children with Special Needs**.

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Extending Minds and Practice

Main Programme * Saturday, 9th November 2013 – Sequoia Suite

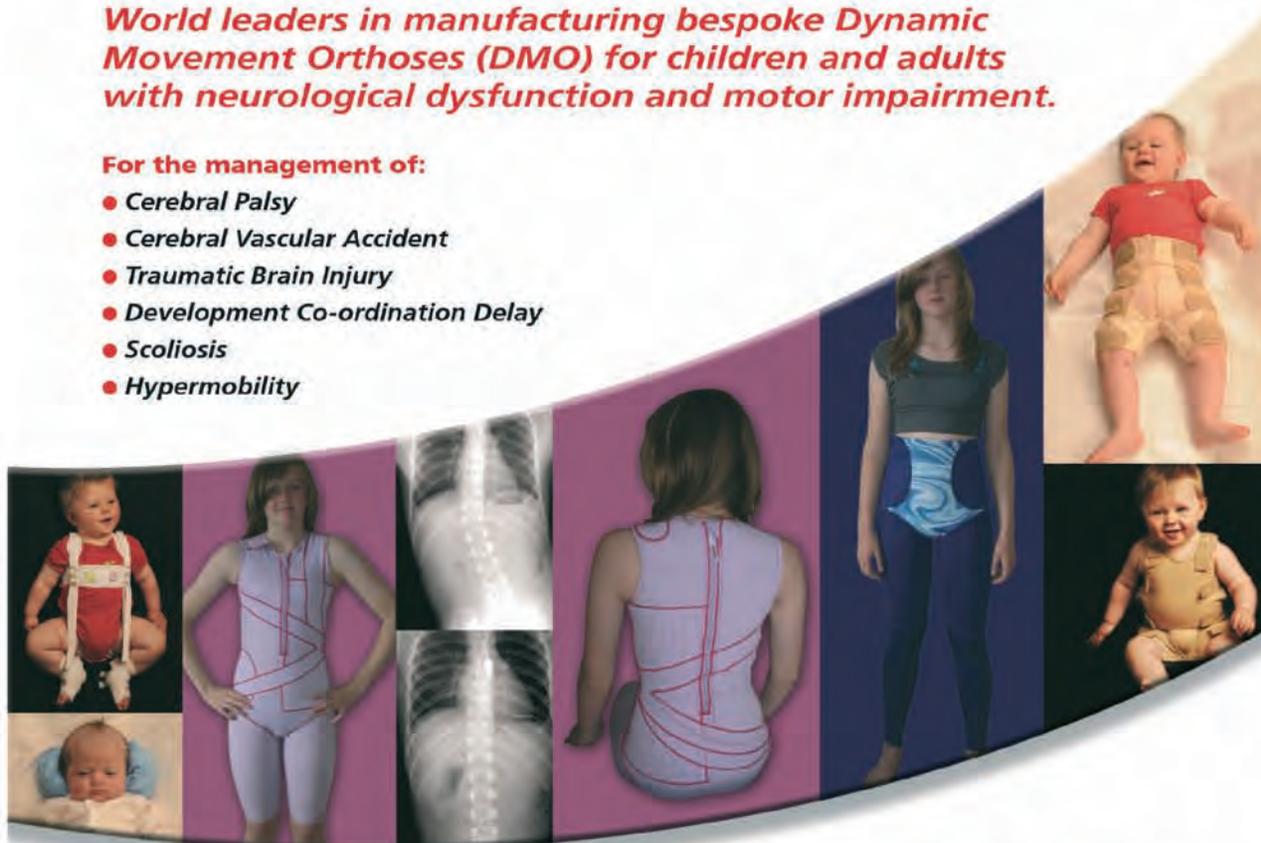
- 08.00-09.00 Registration
- 09.00-09.10 Welcome and introduction
- 09.10-09.55 **Ventilatory function in children with severe motor disorders using night-time postural equipment**
Dr Nicola Dawson BM - GPVTS1, Royal Hampshire Hospital
- 09.55-10.30 **Long Term Ventilation**
Speakers to be confirmed
- 10.30-11.00 Break and exhibition
- 11.00-11.30 **The role of PPIMS Group in APCP**
Juliet Goodban – APCP PPIMS Group Chair
- 11.30-12.00 **Free Paper Session**
- 12.00-12.30 **APCP AGM**
- 12.30-13.30 Lunch and exhibition
- 13.30-14.15 **Differential diagnosis – when we should be concerned about cancer in our young people**
Dr Stephen Lewis – Paediatric Oncology Consultant, University Hospitals Bristol NHS FT
- 14.15-15.00 **The management of acute spinal cord injury in children and young people**
Speakers to be confirmed
- 15.00-15.30 Break and exhibition
- 15.30-16.15 **Management of spinal cord injury in the community**
Speakers to be confirmed
- 16.15-16.45 **Orthotic treatment of paediatric cerebral palsy: a comparison of traditional orthotics and functional electrical stimulation.**
Michael Alexander - Orthotist
- 16.45 Close

**The programme may be subject to change – see www.apcp.org.uk for up-to-date information about the conference programme and trade exhibitors.*

World leaders in manufacturing bespoke Dynamic Movement Orthoses (DMO) for children and adults with neurological dysfunction and motor impairment.

For the management of:

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- Hypermobility



Effective treatment for movement disorders backed by research evidence



- Improving sensory feedback and biomechanical alignment
- Improving core stability
- Can be used as part of a child's 24hr postural management

...Scoliosis suits can clinically, over the years result in re-learnt spinal symmetry and a reduced referral to the Orthopaedic Dept"

(Matthews SOSORT Milan 2012)

" The DEFO scoliosis suits appear to work by providing heightened proprioceptive input to the brain coupled with dynamic corrective forces to correct and re-align the spinal segments."

(Matthews & Crawford 2006)

...with the use of dynamic orthoses the typical diplegic gait pattern can be reduced providing an opportunity for the re-learning of movement patterns.

(Matthews et al, 2009)

....improvements in function appeared to occur almost immediately.

(Watson et al, 2007)

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APCP National Conference 2013 Extending Minds and Practice

8th & 9th November 2013

BOOKING FORM

PLEASE COMPLETE ALL FIVE SECTIONS BELOW:

SECTION ONE - Personal Details

Name:		
Postal address:		
	Postcode:	
Phone numbers:	Home:	Work:
Email:		
Place of Work (to appear on delegate badge)		
APCP Membership No.		
Do you have any special needs / dietary requirements?		

SECTION TWO - Conference Booking Options

Please tick 1 option from the 5 options listed below with the relevant delegate rate.

1) <input type="checkbox"/> Full Residential Package <i>(includes attendance on both days, en suite <u>twin</u> accommodation for 1 night with breakfast, refreshments and lunch on both days, Conference dinner on Friday night)</i>	<input type="checkbox"/> £200.00 - APCP members early bird booking (for bookings received before Friday 6 th September 2013)
	<input type="checkbox"/> £215.00 - APCP members (for bookings received after Friday 6 th September 2013)
	<input type="checkbox"/> £300.00 - non-members
	<input type="checkbox"/> £200.00 - students / therapy assistants.
You will be allocated a room to share with another Conference delegate unless you choose to pay the single person supplement (below). If you have a colleague you would like to share with please print their name here:	
2) <input type="checkbox"/> Full Residential Package with Single Person Supplement <i>(as above but with single occupancy accommodation)</i>	<input type="checkbox"/> £220.00 - APCP members early bird booking (for bookings received before Friday 6 th September 2013)
	<input type="checkbox"/> £235.00 - APCP members (for bookings received after Friday 6 th September 2013)
	<input type="checkbox"/> £320.00 - non-members
	<input type="checkbox"/> £220.00 - students / therapy assistants.

3) <input type="checkbox"/> 2-Day Day Delegate <i>(includes attendance both days, lunch and refreshments)</i> <input type="checkbox"/> <i>Tick here to add attendance at Conference Dinner (add £35.00 to the cost of your package opposite)</i>	<input type="checkbox"/> £130.00 - APCP members early bird booking (for bookings received before Friday 6 th September 2013)
	<input type="checkbox"/> £150.00 - APCP members (for bookings received after Friday 6 th September 2013)
	<input type="checkbox"/> £220.00 - non-members
	<input type="checkbox"/> £130.00 – students / therapy assistants.
4) <input type="checkbox"/> 1-Day Day Delegate – Friday <i>(includes attendance, lunch and refreshments on Friday only)</i> <input type="checkbox"/> <i>Tick here to add attendance at Conference Dinner (add £35.00 to the cost of your package opposite)</i>	<input type="checkbox"/> £70.00 - APCP members early bird booking (for bookings received before Friday 6 th September 2013)
	<input type="checkbox"/> £80.00 - APCP members (for bookings received after Friday 6 th September 2013)
	<input type="checkbox"/> £120.00 - non-members
	<input type="checkbox"/> £70.00 – students / therapy assistants.
5) <input type="checkbox"/> 1-Day Day Delegate – Saturday <i>(includes attendance, lunch and refreshments on Saturday only)</i> <input type="checkbox"/> <i>Tick here to add attendance at Conference Dinner (add £35.00 to the cost of your package opposite)</i>	<input type="checkbox"/> £70.00 - APCP members early bird booking (for bookings received before Friday 6 th September 2013)
	<input type="checkbox"/> £80.00 - APCP members (for bookings received after Friday 6 th September 2013)
	<input type="checkbox"/> £120.00 - non-members
	<input type="checkbox"/> £70.00 – students / therapy assistants.

SECTION THREE - Programme Options

Friday, 8th November 2013

Delegates need to select one of the following programmes if attending on Friday – please note that delegate will not be permitted to ‘dip’ into both programmes.

- A - Main conference programme
- B - Neonatal parallel programme – Baby Brain – Research and Outcomes
- NOT APPLICABLE (not attending Friday’s programme)

N.B. - we will contact you if your first option is unavailable before confirming your booking.

SECTION FOUR – Additional Accommodation

Please tick if you wish to book accommodation at the Holiday Inn for Thursday, 7th November*:

- Single occupancy (£55.00)
- Twin occupancy (£65.00 per room)

* All bookings subject to room availability

SECTION FIVE - Payment Details

Booking options and costs are detailed above – please enter total amount due:

PAYMENT OPTIONS: please tick as applicable:

- Cheque – I enclose a cheque payable to 'APCP'
- Direct personal transfer - please send invoice for payment
- Funding has been agreed – please send invoice for payment*

** Please complete details for invoicing below:*

NAME (to whom invoice should be addressed):

ADDRESS (to send invoice):

Send with completed application form to:

APCP, PO Box 610, Huntingdon, PE29 9FJ or va@apcp.org.uk

Please note that cancellations received before the end of September will be reimbursed the full cost minus a 10% administration charge; later cancellations may not be eligible for reimbursement.

CLOSING DATE FOR APPLICATIONS:

RESIDENTIAL PACKAGES & ACCOMMODATION – Wednesday, 9th October 2013

DAY DELEGATE BOOKINGS – Friday, 18th October 2013.

**ASSOCIATION OF PAEDIATRIC
CHARTERED PHYSIOTHERAPISTS**

40th ANNUAL GENERAL MEETING

SATURDAY 9 NOVEMBER 2013 12.00

**THE HOLIDAY INN,
FILTON ROAD, BRISTOL**

There are vacancies on the National Committee.
Please could any enquiries and nominations be
sent to va@apcp.org.uk as soon as possible

EAST ANGLIA

Hello Everyone

The committee has been busy preparing for the advanced Elaine Owen course in July which we are pleased to say is now fully booked. We are also organising this year's Introduction to Paediatrics course which is being held at the Radisson Blu Hotel at Stansted. The course runs for 3 days starting on the 9th September. We have a very thorough programme with some wonderful speakers.

After these two courses have finished we will be looking to run more courses next year. If anyone has any ideas on what they would like please let us know.

We are also looking for a new committee member so if you are interested please contact me.

Enjoy your summer everyone.

Simone Philpott
simone.philpott@nnuh.nhs.uk

LONDON

Ladies and Gentlemen,

I hope by the time this lands on your door mats that summer will have decided to arrive!

Thank you to everyone who has been attending the lectures in recent months. We have had excellent turn out. The talk on "CP or not CP" in April had phenomenal attendance and was full within 48 hours of being advertised, which is amazing. For those who did not get the opportunity to attend don't worry, we will be repeating the lecture in October and those who were on the waiting list from the first event will have first refusal.

In May we had an update on CF, from Louisa Hill, Specialist Physiotherapist in CF at Great Ormond Street Hospital, who talked both on physiotherapy management of CF and emerging treatments in CF. In June we had a

lecture from Denise Watson, Extended Scope Practitioner in Paediatric Orthopaedics on assessing the Newborn Foot. Both were very well attended and have received excellent feedback.

For those who have been attending the lectures, you may have seen many new faces on Committee. We have had a baby boom on London Committee, so firstly congratulations to the new mummies and mummies to be, Lynn, Anne and Fran and thank you to the new members who have taken their places, Holly, Faye, Lindsey and Ellie. We have a full committee and a waiting list to join! Thank you for being such an enthusiastic bunch.

We are now on a roll with lectures and have plans for a lecture on Osteogenesis Imperfecta, a networking event, on activities for children with disability in the London area and a lecture on Medicinal Management of Spasticity and Dystonia (together with the AGM) over the next few months.

The aim for the networking event will be to share knowledge on access to sports and activities for children with disabilities and share ideas and good practice. We will then put a pack together for members mapping out what is available across London. Please come along, or contact us with any information you have. The more information we receive the better the resource will become!

As always we rely heavily on feedback from members on what they would like to hear about and the format of the lectures, so if you have any ideas or topics you would like to hear about please do let us know and we will endeavour to find a speaker and put something together.

Sinead Barkey
barkes@gosh.nhs.uk

NORTH WEST

Well it's that time again, I cannot promise as much culture, as in the last report, but let's give it a go. We have just finished collating the feedback from our Acquired Brain Injury study day, held at the Cheshire Conference Centre, Stockport. Feedback has generally been positive with some mixed feelings about the venue and sound system. With these comments in mind the committee are planning to review the locations used for study days and will endeavour to ensure a more conducive learning environment in the future. In contrast to the mixed feelings following Acquired Brain Injury, the DCD twilight session was a rip roaring success, with very positive feedback being provided by all who attended.

The AGM held at the study day was a fairly dour affair, although we did our best to inject some light hearted fun during the meeting. As a committee we are still looking for new members to attend our quarterly meetings. We have a couple of vacant positions that need to be filled and will therefore require additional willing victims, sorry volunteers, to help out with committee roles. Committee is certainly not an onerous commitment, travel expenses are paid to all venues and it certainly looks good on the KSF or if you go for an interview (personal experience!).

No decisions have been made regarding future twilight sessions and study days. We have a committee meeting booked for the 1st July at Broadoaks Child Development Centre at 1600hrs. Any suggestions please forward to me or to any of the other committee members. The National Committee are also looking for articles for the newsletter; any subjects are welcomed from Hippotherapy to treadmill training or Macdonald's therapy! (Any guesses what that is?).

A point of note for all North West members, we as a committee are now able to offer bursaries once again, so if anyone needs some financial assistance towards a course or other related topic, drop us a line.

I think I have failed miserably on the culture

front, but there you have it. Remember your committee needs you.

"So long and thanks for all the fish".

Tara

Harry Harrison
mark.harrison@cumbriapct.nhs.uk

NORTH EAST

During March the North East region hosted an evening learning about SpineCor and the treatment approach for scoliosis. The team have written up their views about the evening and some of the things which we took away from it which is included as a separate article within the newsletter. Tim, our main speaker for the evening, made a request that the equivalent of his speaker fee could be sent as a donation to the Strong Bones charity which his team work to support (further information about this charity has also been included for people to find out more about the work that the charity do).

Typically the weather on the weeks leading up to the course were fine, and then the snow set in the week of the course. As a team we felt we would still go ahead as the venue for the evening was just off the M1 so access should be clear at that end, and it would be too late to cancel. I think several of us thought it would be a very quiet evening as people would cancel their attendance- we were wrong, very wrong! It seems as a region you never fail to amaze us as you turned out in force (including some people we really weren't expecting). The room was packed out, there was a scramble for extra cups and more importantly, packets of biscuits and after a delay at the start to a projector screen which was held up on the motorway we were able to make a start.

We had hoped to put on an evening session in June for people to find out more about the HCPC audit should people be picked at re-registration time, however for several reasons this has had to be postponed but we are hoping to get a date for it next year.

We hope you continue to support the local

events and those of the other regions at the study events which take place, however it is really useful if people can pre-book as we do not always have the additional room and handouts for those who turn up on the day.

As always anyone who has any ideas for future courses which they would like to see, please forward your suggestions.

Lastly, we are part-funding two places for Conference this year, please email me by mid-September, names will be drawn at random.

Thanks Helen.

Helen Chamberlain
helen.chamberlain@humber.nhs.uk

SCOTLAND

Hello to all the Scottish membership! Hopefully by the time this goes to print and drops through your doors, we are basking in a glorious summer.....!! Anyway, back to reality!

So as ever, your Scottish Committee members continue to work hard to bring high quality training opportunities to Scotland. We try extremely hard to listen to the thoughts and feedback of our members in order to meet your learning needs. Unfortunately the long-awaited Elaine Owen 3-day Gait Analysis and Orthotics course arranged for May 2013 at Queen Margaret College had to be cancelled due to low application numbers. This was very disappointing all round as it had taken a couple of years to secure Elaine's availability. However, the Committee are very aware that the issue of difficulties for therapists accessing CPD is not just a Scottish issue, but one which is affecting all regions in the UK. It is the intention of the Scottish Committee to provide some practical advice and suggestions on how to go about finding alternative sources of funding besides that from the physiotherapy budget. We hope to have this in the next newsletter so keep an eye out for this. In the meantime, for NHS physios, it is always worth checking with your NHS Board or NES for other pots of money that can be accessed for training. Practise Education Facilitators within your locality may also be

able to point you in the right direction.

Following on from this, our AGM was held on 6th June 2013 in Perthshire, which had been postponed following the cancellation of the Gait Analysis course. No APCP members besides those on the Committee attended and we used the time afterwards for a planning meeting for future events. A further study day is currently being planned for the autumn. Early work is underway to put together a one-day community respiratory physiotherapy training day. Further details of this will be available on the APCP website and in Frontline as soon as details are confirmed, so keep your eyes open for this.

Following on from the very successful Introduction to Paediatric Physiotherapy course in late 2012...this time it is National Conference 2014! Scotland are delighted to be tackling the challenge of hosting the annual conference next year, which will be the third biggest event in Scotland, after the Commonwealth Games and the Referendum!! We are taking on the additional challenge of hosting the first day of the conference in partnership with our Paediatric OT colleagues. This has never been done before, but early planning is going well with the likely focus of the event to be Early Intervention. The second day of the conference will have a parallel programme run by PPIMS. We are making good inroads with early planning, and are delighted to have welcomed Nicola Tennant, Judith Hutson, Gillian Taylor, Barry Johnstone and our old friend Julie Burslem (former APCP Scotland Chair) on to the organising committee. More volunteers to help with the event to be held in November 2014 will be recruited in due course. So if you are interested in being involved then get in touch with us via email: apcpscotland@gmail.com.

Other news, includes the exciting official launch of the Cerebral Palsy Integrated Pathway Scotland (CPIPS). A very successful launch event for the Hip Surveillance Project was held on 17th May at the Royal Infirmary of Edinburgh, where attendees were lucky enough to hear amongst others, Paediatric Orthopaedic Surgeon Gunnar Hagglund presenting on the founding work of CPUP in Sweden. APCP Scotland is delighted to have been able to

financially support the CIPS project. All APCP Scotland members will shortly be receiving a copy of the manual and DVD which have been sponsored by APCP Scotland, free of charge. A considerable amount of work has gone in to this project, and APCP Scotland are proud to be a part of what is set to be an exciting period for the future, as data is collected and analysed.

We are delighted to be sharing with you the three top case studies which were submitted as part of the Introduction to Paediatric Physiotherapy Course. 35 physiotherapists/physiotherapy assistants submitted case studies following on from the 3-day course. Successful case studies resulted in a Certificate of Completion of the course. Felicity Vann, Louise Myeni and Sarah Mayberry were the three physiotherapists whose case studies were assessed by the markers to be of Grade A standard – awarding them 70% and over (according to set written guidelines). All three physiotherapists have agreed to the publishing of their case studies in this newsletter, and we wish to congratulate them, along with all other successful physiotherapists, on their hard work in constructing and submitting their case studies. The course is being run again this year, hosted by East Anglia Region. More details will become available on the APCP website in due course.

Finally, as a Committee we would like to say a heartfelt thank you to Heather Morrison and Pam Chimiak who have both recently stepped down from their Committee member roles after 5 and 6 years service. We will miss you both! Former treasurer Jenny McKee has also stepped down in order to concentrate on being a Mummy to new baby Manus! Congratulations to Jenny and husband Tony, and thank you for all your help on the Committee over the last few years. Jenny has handed the 'books' to Fiona McGrane who we are delighted to welcome back on the Committee after her recent maternity leave. Although we have recruited new members to help with conference planning we are also still looking for permanent representatives to join the Committee from Ayrshire and Aran, Inverclyde and West Lothian. If you would be interested in joining our dynamic and very lively and active group, or would like some more information about

what is involved, then please get in touch via email: apcpscotland@gmail.com.

Phew! I think that's it! Until next time, enjoy the sunshine!!

Kirsteen Grieve
kirsteengrieve@gmail.com

SOUTH EAST REGION

The SE region started the year with a hugely successful study evening in March at Valence School in Kent; it was attended by over 80 people, which means that we must have got something right! The study evening included a talk from Adam Shortland from the One Small Step Gait Lab, based at Guy's Hospital. Adam spoke to us about his research on 'Development of Muscle Deformity in Children with cerebral Palsy' he originally presented at APCP conference 2012. This is a topic which has huge implications for paediatric physiotherapists and especially how we approach these children and their management.

The second talk was one that I had heard at the 2012 APCP conference and was titled 'CP or not CP?' This talk was given by Lesley Katchburian and Karen Edwards both from Great Ormond Street Hospital. It was another hugely interesting talk on the differential diagnosis of cerebral palsy. Lesley and Karen had succeeded in making the talk interactive by showing several video clips and inviting the audience to make their own diagnosis.

We were hoping to organise our next study day for July on paediatric MSK topics, but for various reasons we have had to put this on hold until the autumn. We have a venue near Lewes and the date will be 1st October, once the programme have been confirmed we will advertise this course on the APCP website and by email to the SE region members. We also hope to offer another study evening in November.

This year we are going to offer a full 2013 APCP Conference Package to any member of the SE

Region regardless of what AfC band you are, it will be run as a draw, the only catch is that you will have to submit an article for the APCP newsletter if you win the package. The article can either be about the conference or any other topic that interests you and is relevant to the newsletter. To apply please email me with your details, name, APCP number, place of work and contact information at nicola@burnettfamily05.wanadoo.co.uk

The committee have continued to meet throughout the year, either virtually on Skype, which can be more reliable than face to face meetings, especially when the M25 gets closed and everyone is stuck in traffic for several hours like our last meeting! We have a committee of 8 people but have recently said goodbye to Johann Delpont who was with us for 3 years, if you have attended any of our recent study evenings Johann was the one who wouldn't let you have a certificate unless you had given him a completed evaluation form! Johann is an RFU referee and he is progressing onto a National level, so we will look out for him at Twickenham! We also have a few people who are due to stand down at the next AGM having completed their maximum term of office and I would really like to hear from you if you are interested in joining the dynamic team!

Finally if you have any ideas for topics you would like to hear covered in the future or if you have any suggestions of a good venue, it needs to seat at least 30 people and have reasonable parking then please contact me.

Nicola Burnett
nburnett@valence.kent.sch.uk

SOUTH WEST

The SW Region held our AGM and an interesting study day in June on Outcome Measures with a focus on CP, presented by Virginia Knox.

During the AGM it was noted that some of our committee are due to step down from the committee, but have agreed to stay on until after Conference in November. We will be

aiming to hold our next AGM in the early part of 2014 to elect new members on to the SW committee.

If you are interested please contact your current locality member, or myself. It would be good to have representation from all parts of the SW region, so if your area is not represented on the committee please consider this opportunity.

Our focus this year is preparing for National Conference. The draft programme and booking details are included in this issue. We look forward to seeing you at Conference, with as many delegates from the SW as possible on the 8th and 9th of November.

Katherine Heffernan
Katherine.heffernan@glos.nhs.uk

WEST MIDLANDS

As usual, your West Midlands committee have been working hard to organise study days to support you in your practice. If you have any ideas or subjects that you would find particularly valuable, then please do get in touch with us and we will do our best to accommodate. You can also apply to us for bursaries to support you with the cost of courses, and not just those organised by APCP.

We held a successful study day on Outcome Measures in Paediatrics presented by Virginia Knox on 9th March 2013. We had a good turn out with 40 delegates and the feedback was very positive. The day consisted of presentations on a variety of outcome measures including selecting the appropriate measure for practice with some practical activities and workshops. The study day was enjoyable, informative and easily applicable to practice.

The next event we are planning will be a study afternoon on Thursday 19th September, covering some aspects of paediatric pain management, with a variety of knowledgeable speakers and plenty of opportunity for discussion. Venue and time to be confirmed, but please put the date in your diary now! As always, make sure your contact details are up to

date with va@apcp.org.uk to ensure you are kept informed of all that is going on in our region.

Katie Roberts
katie.roberts@bhamcommunity.nhs.uk

WALES

APCP Wales had a well-attended AGM in Merthyr Tydfil, followed by a practical and inspiring kinesiotopeing session for children. There are now plans underway for a follow up paediatric course, which, if possible, can be certificated.

The joint APCP/Cardiff University research dissemination event was poorly attended but very worthwhile for those who came. First year students presented on reflection models they had found useful; a third year student on physiotherapist students' fitness levels and attitudes to encouraging their patients to be more physically active; a recent Welsh statementing review; the final results of the Cardiff research into the effects of dynamic cycling on children with CP and finally, and only as an aperitif, the recent PhD work on values of paediatric physiotherapists working in the community.

Geraldine Hastings will be invited to present her PhD study more fully at an evening event in the autumn.

The next APCP Celtic Kids Exhibition is planned for Wednesday 7th May 2014. For this we are hoping to put together an education/CPD strand for the first time and we are now collaborating with our local OT colleagues for this event. Any suggestions for topics either for parents or therapists would be very welcome. Please let your colleagues and families know!

It's pretty nippy as we speak but I do hope there will be summer sunshine around the corner...Enjoy!

Gabriela Todd
gabrielatodd@btinternet.com

NORTHERN IRELAND

In February this year Aubrey Bingham from Disability Action NI advised us of the numerous sports activities available in Northern Ireland for children and young people with disabilities. These include swimming, boccia, new age curling, athletics, archery, wheelie active clubs, badminton, wheelchair basketball, football and sailing.

In April, Ruth Graham, physiotherapist at the NI Children's Hospice hosted a hydrotherapy update. This included information on various treatment concepts and a practical session to work through case scenarios and demonstration of techniques. Unfortunately Ruth's co-trainer Alison Mounstephen was unwell, however we were grateful for the training material she provided and Ruth was still able to lead a very informative evening.

In May we worked with the Gait Analysis Lab staff from Musgrave Park Hospital in Belfast to run a Paediatric Orthopaedic Update. The day was attended by 130 delegates including paediatric physiotherapists and medical colleagues. The day included a range of presentations on management of orthopaedic problems from a surgical, orthotic, pharmacological and rehabilitation perspective, as well as foot deformities and the normal variation in gait.

The 2013/14 programme will begin with a Junior Paralympics Fun Day in Lisburn Leisureplex on 21st September. Children will get the opportunity to try a variety of sports. Places are limited and application forms are available from email@dsni.co.uk.

Other provisional events for the year ahead include:

26/09/13 Alternative Therapies Information Evening

26/11/13 DMD Update

27/02/14 Pilates for children. Speaker: Kay McCarthy MCSP

29/04/14 Gait Analysis. Speaker: Dr Brona McDowell MCSP

We also hope to run a 2 day course on Therapeutic taping next Spring. Check the website for updates details regarding the programme.

Sheila McNeill
sheila.mcneill@belfasttrust.hscni.net

TRENT

The Trent region is back!

It was with great enthusiasm tinged with hesitation that a small group of 'interested parties' met for the first rekindled Trent regional meeting. Flurries of emails had been circulating and it was a bit like a surprise party to see who managed to come along. With such a vast geographical area from Skegness in the east to Derby in the west, Sheffield in the north and Leicester in the south, a central point, never

mind a time and day was a stab in the dark. Nevertheless, a committed merry band under Robin, Oh no wrong story ...Dan have now met twice and managed to devise and circulate a members and potential members survey. This will sample the needs, travel and day preferences for the regional committee meetings and potential study days. Thanks once again to Fiona (VA) for facilitating that.

Now it is for us to turn that energy into actions so watch this space. It is hoped that we will be able to find suitable venues in several areas within our region, to allow meetings to be held in different places in order to make them as accessible as possible to Trent region members. We are also hoping to hold at least one study day/evening before the end of the year. We are very grateful to the people who have already shown their support and attended the first meetings of this group and would like to welcome any other therapists who are interested in getting involved.

Sarah Westwater-Wood & Sarah Bacon
sarah.westwater-wood@nottingham.ac.uk

NEONATAL GROUP

It has been a busy time in neonates with lots of different projects on the go, most notably the organisation of our second parallel conference day which will take place on Friday the 8th of November in Bristol. The majority of the organisation has been undertaken by Helen Robinson who has done an outstanding job in creating a day which is full of interesting topics with first class speakers. The title for the parallel study day is 'Baby Brains- Research and Outcomes'.

Meanwhile the former chairs of the Neonatal Committee have been very productive. Fiona Price is working on Respiratory Competencies for neonatal physiotherapists which will be very welcome indeed. Adare Brady is putting the finishing touches to the business case templates which will be of great value to those not only trying to create a post but also those of us who have to justify our roles.

There was also a very successful 4 day LAPI training course held at the Royal London Hospital in April run by Adare Brady and Peta Smith. Having helped organise LAPI training in the past I know how much effort Adare and Peta put into it. I would also like to thank the neonatal staff at the Royal London Hospital for their invaluable contribution to the organisation of the course. Joan Lacey the founder of the LAPI sadly passed away in hospital just the week before the course ran. What a legacy she has left for us, a truly inspiring Physiotherapist.

I look forward to seeing you all at conference.

Hilary Cruickshank
Chair of the Neonatal Group

PPIMS

We had a national meeting and study day in Birmingham on 13th May. We discussed the purpose and function of PPIMS as part of APCP; looking at the relationships that PPIMS has with APCP National Committee, and CSP managers support networks.

The outcome of the meeting was that the group is a valued networking group and support for Clinical Leaders. We reviewed the information on the APCP website and considered that this was a true relationship of the description of PPIMS and highlights the membership well.

With this in mind, we then considered the attendance to national meetings; challenging why, with 175 members of PPIMS, it is usually the same 25 members who attend or send apologies.

The action is, therefore, to survey the members to ask what they would like from PPIMS and if there are any themes as to why contact with the group is limited; eg time, venue location, agenda.

It was proposed that we set up regional networks with strategic planning and implementation roles. These would follow the 8 regions currently identified in order to develop local networking and sharing of good practise.

A representative from each region would then be invited to attend the national meetings for a committee for PPIMS. This committee would review work streams and action plans, and provide a focus for interpretation of national guidelines and recommendations that affect clinical strategy.

The meeting then moved on to review the recommendations laid out in the Francis report and highlight specific points that required consideration by Paediatric Physiotherapy Service Leads.

A briefing paper was presented about Green Paper proposal for SEN. This will be available via the website. The CSP Quality Assurance Standards were shared and the audit tools introduced briefly as a tool to aid demonstration of our quality services.

The long awaited Outcome Measure Tool was also updated, and plans for this to be available via the website as an "interactive" tool was presented. Watch this space!

Our AGM is planned for 21st Oct 13.

Juliet Goodban
Chair of PPIMS

MSK GROUP

The MSK group met recently and we welcome a few new members. We are intending to look at guidelines and pathways for a range of common conditions, starting with literature reviews and looking at best practice, with a view to producing a parent information leaflet alongside best practice guide for physios. We will be doing this for one condition at a time rather than tackling a multitude of conditions simultaneously.

We are also considering running an 'Introduction to MSK' course, similar to the neonatal introductory course with a possibility of running it at regular intervals.

We meet again on the 20th of September so hope to have more news for you then.

Vicky Easton
MSK Rep

NEUROMUSCULAR GROUP

The neuromuscular group are holding a study day on Management of Spinal Muscular Atrophy in Leeds on Thursday 12th September. The day is a first for APCP as the meeting is being opened to parents to attend. As this is a first, we do not know how many parents it will attract. If it is successful, the day will be repeated in the south of England later on. Further information on the course can be found on the APCP website or by contacting Fiona at va@apcp.org.uk

The annual North Star Network meeting was held on 21st May at The National Hospital for Neurology and Neurosurgery, Queen Square in London. There was a lot of discussion about the databases for DMD and SMA. 600 boys with DMD are on the database with a large amount of longitudinal data being collected. Information on steroids, fractures, loss of ambulation, respiratory and cardiac issues and more is captured. Reports taken from the data are extremely helpful for informing practise. Neuromuscular physiotherapists wishing to make use of the data for audit or research purposes need to contact the steering committee.

The neuromuscular group is open to all members of APCP but to be most effective – the members need to let us know what they want from the group. While there are standards of care for DMD, CMD and SMA, they have little direct impact on physiotherapy practise. If there are leaflets or information the group could produce – please let us know.

Marion Main, Anna Mayhew, Lindsey Pallant, Cheryl Pretty and Rosanna Rabb.
Neuromuscular Group

RESPIRATORY GROUP

We will shortly be sending out a questionnaire to scope respiratory intervention in the community to help us better understand where and how you work and what support, documents or guidance would be helpful and also a training strategy going forwards

We are planning to meet with the remainder of the committee in the school holidays to decide how to recruit more people and to decide on our priorities for this year.

My other thought is to produce a commissioning tool for a community respiratory service as I'm getting a lot of contact about information to help with commissioning services.... I was planning on getting together the information for the existing services around cost savings found relating to community respiratory input for children as it is on the NHS outcome framework this year so it would be great to encourage people to put together business cases for services to provide this input.

I am also finishing off the editorial around the NICE quality standards for Asthma and there has been one sent out for comments regarding NICE quality standards for respiratory intervention for neuromuscular weakness which I am happy to help with where needed.

Leanne Turner
Community Respiratory Group



Playskill is a charity which provides pre-school parent and child playgroups with intensive therapy input for children with physical difficulty or delay. It has Physiotherapy, Occupational therapy and Speech and Language Therapy input in the group, training and working with the parents working on mutually agreed short term goals. There is built in support for the parents with a number of the key workers being parents of older children with Special needs working as key workers. In addition to the groups parents evening training is run termly led by therapists, and daytime training and breakfasts with relevant speakers on the subject of benefits, access to support for education, respite etc occur. Family coping and bonding is supported by parties and trips arranged throughout the year. Currently the charity is operating in the Hertfordshire area, but the aim of the charity is to support other Therapists in setting up groups in the country using the experience gained already.

In 2005 I was working part-time as an independent physiotherapist in my local area of Hertfordshire, but I started to become very aware that I was unable to respond to the needs alone. It was clear that the families I met felt concerned and isolated, and that their needs and the needs of their children, were not understood. They were telling me that they felt socially excluded and misunderstood, and in severe cases the stress of their children's conditions were impacting on the whole family with their marriages breaking down and families fragmenting under the pressure of the burden. Equally they wanted time to discuss the reasons for their child's needs and to understand why treatments were being suggested by the NHS, but there was not enough time to talk, despite often dedicated professionals trying their best with busy caseloads to cover.



Messy play with sand led by our Occupational Therapist

In Northwick Park Hospital, Harrow I had worked with the NHS in a group run there by education which had included the participation of local NHS therapists, and I had seen the success that weekly targeted group work with parents could bring. In 2005 I went to see the local Watford based SCOPE worker Cherry Handbrook to discuss my concerns and the potential help that could occur by bringing parents together. This was in part also born out of the my original dissertation at the University of Birmingham for my degree which had been on carers and carers of stroke patients, where from that research I had become aware that a source of informal support for Carers was getting together to share their concerns.

The Initial Pilot Group

Cherry encouraged my view that felt that if I were able to bring a team of therapists to provide intensive help for the children in blocks in a play setting training the parents and then older parents working as key workers together to provide support and a listening ear, children, parents/carers and siblings could be helped at once. The community would then begin to become more inclusive, informed and fulfilled as it worked with the children and families. I also was grateful for support from Heather Holgate Occupational Therapist at the Bobath Centre for a chance to discuss these ideas and formulate them with her at this time. The initial funding for the group came through a SCOPE Partnership grant to set up the pilot project in Watford, also applying to UNLTD a funding body for money as a Social Entrepreneur to get money to try out the idea.



Messy play with baked beans and standing in my frame

The First Pilot Group in Watford

Key Qualities of the group

- Therapy input within the group working with parents/carers and children
- Specialist resources including use of a soft-play/ sensory room, access to a Toy Library.
- Networking and informal support for parents/carers
- Group dynamics (children inspiring other children to gain new skills)
- 3 SMART goals for each child set in conjunction with parents and local therapists if possible.
- Videos and photos of the group in action to evidence the SMART targets achieved
- Questionnaire for the parents at the end of the group.

Results from the Watford Pilot

Results from the summer pilot group were very positive with 100% wanting the group to continue, 86% felt they had learnt skills to carry on with their child and 100% wanted another place for the next group. 71% felt the group had met all their expectations with 29% saying it had surpassed them. 79% of the children's individual targets were achieved at the end of the group.



Choosing with our SALT and practising standing....

Watford Groups

Funding for Playskill Watford AM as a voluntary group came from the Community Champions Fund and then the Local Network Fund and Awards for All to fund 2006-2007. Working with the local CVS [Council for Voluntary services], has allowed me to learn the skills of writing funding bids and about governance. Playskill then became a charity in February 2008. For 2008 onwards the group had Children in Need funding for basic costs from 2008 to 2010 inclusive. All other funding was sought through charitable, statutory and fundraising sources. In 2009 Parents Support groups started and family trips and outings for the future, all of which needed fund raising for. From 2011 onwards funding was secured for Watford from the Big Lottery, funding a further afternoon nursery group to continue the work of preparation for school reception for children with difficulties.



Whipsnade trip June 2013

The Hemel Hempstead Pilot Group

By 2010 it had become obvious that there were children in the Dacorum area who would not be able to access the Watford group due to the transport issues involved. It was therefore decided to pilot a group in the Hemel Hempstead area to see if this would be of use to the local community. All places were taken on the pilot group with an extra child also.

- The results of the group were 74 % SMART targets achieved with 2 children learning to walk, vocalising for the first time etc.

All parents wanted the group to continue -

"I really, really hope that there will be another course and if there is, could you please put us forward as we would be there like a shot!!"

Playskill Hemel Hempstead

As a result of this the group was established, in 2010 funding was established for baseline costs only from Children in Need. In addition local Children's centres and voluntary groups have supported this project. Woodfield School a local school for children with severe learning difficulties has a purpose built community room that we now use for this work.



The Playskill Hemel AM pilot group 2010

Unexpected Outcomes

It has been a constant learning curve doing this project. It has been so rewarding playing with the children and seeing what can be achieved when we get to know each other well by having fun together as well as doing therapy. This builds up trust so when we practise standing and walking children will do a lot more, even those who often cry at individual appointments in clinic!

The value of the parties and social events cannot be underestimated. When a child died recently many of the child's old group came to the funeral, and it has been a loss that has been shared in the community as a result. Many of this family's best memories are of the trips and parties we have all shared. One of our parent's wrote recently;

"We discovered Playskill from both William's physio and our health visitor. It was very early days for us as William had not yet been diagnosed, we just knew he was very delayed. Discovering Playskill was a revelation and to spend time with other parents that are going through the same thing as us as well as the unknown was so uplifting."

The Charity has given us so much more insight as to the real everyday issues for the families and therefore enables us to support them much more effectively. None of this would be possible without a huge amount of hard work on the part of volunteers and this is especially so for Trustees who have to do a lot of backdoor work to make this possible.

Playskill is really keen to support other therapists who are passionate to help children and families in their local area and would be very happy to give guidance and advice, and share any work that would make this an easier journey. Playskill's website is www.playskill.org or contact number is 07572 465504.

Andrea Clarke
B.Phys [Hons] MCSP

STRONG BONES CHILDREN'S CHARITY TRUST

In March, the North East region hosted a SpineCor Spinal Matters study evening which was led by Tim from the company. Tim declined his speaker fees and instead has requested that the equivalent money was sent to the Strong Bones Children's Charity Trust. This is a charity which the company support when possible, therefore we thought the region may like to find out a bit more about the charity trust and the work they carry out. (The following information has been taken from the charity website).

Strong Bones Children's Charity Trust is a national registered charity set up to help alleviate the pain, suffering and financial burden of families who have children suffering from brittle bone disease, bone cancer, scoliosis, arthritis, and all other conditions of the bone. The charity has now been registered for nine years, which gives us years of experience in our field. This experience has allowed us to assist children and their families with guidance on how to make their conditions more manageable and enhance their quality of life to an optimum level.

Our aims are to take children out of social isolation and give them the ability to participate in everyday life. We also relieve the family's financial burden whilst they come to the realisation that their child has a long-term incurable disability that will have a life changing impact on the whole family.

A majority of the children we encounter come from the most poverty stricken sections of society coupled with the fact that many of these parents have had to give up employment to provide round the clock care for the life altering conditions of their children.

We are sure you appreciate it takes much strength and resilience to care for a disabled child, and we often feel society overlooks this as a whole, leaving carers and their children feeling severed from the outside world. Below is an extensive list of the work we carry out, but the trustees are always open-minded to innovative projects exclusive to children under our criteria.

- We provide sensory equipment, sensory rooms and practical advice regarding construction of sensory rooms.
- We provide walking frames, wheelchairs, specialist buggies and adapted trikes to enable children to gain access in the community.
- We provide outdoor play equipment and the installation of soft play areas, to enable children to play with optimum safety.
- We provide advice to families in accessing welfare benefits. This includes disability benefits and disabled facilities grants that they may be entitled to receive.
- Adaptations to properties and medical equipment to be installed, this allows families to live as normal as possible. We also build extensions to homes to enable children to be cared for on ground floor level where the use of stairs is inappropriate.
- We purchase and install hydrotherapy baths to provide pain relief.
- We provide funds for social activities/day trips to take children out of social isolation.
- We own respite homes that are fully adapted for children with disabilities on the coasts of the U.K.
- We also provide vital medical equipment such as sleep systems to enable children to sleep with the correct posture and aid pain relief.
- We purchase specialist computers and laptops with expert educational software, to enable children to be home educated and continue tutoring at home whilst in recovery periods or unwell.

Hardship grants to help with essential bills, household appliances and clothing.



What is key working?

Key working is an approach that builds on partnership working with the children and young people with disabilities and their family and the practitioners working with them to facilitate the coordination of an integrated package of solution focused support. Key working is one of the most important elements of support for children, young people and their families – it helps them to live ‘ordinary lives’ and enables the growth of strong and resilient families.

The ‘*What is key working*’ article is a brief and simple guide to key working prepared by Early Support. Early Support is a framework for action to drive the culture change required to enable the SEND provisions of the Children and Families Bill to be implemented effectively. Early Support promotes, enables and provides evidence for what works in:-

- Partnership working with families
- Co-production and participation of parent carers and young people
- Person-centred planning approaches
- Joint decision-making
- Integrated working between agencies and services.

Early Support is multi-agency in concept and scope and actively supports the integration of support provided by education, health and social care partners so that coordinated and tailored support is provided to children and young people from birth to adulthood and their families. Early Support is involved with implementing the Government’s strategy to bring together the services families need into a single assessment and planning process covering education, health and care.

Early Support provides a wide range of free resources and training to support children, young people, families and service deliverers.

What difference can Early Support make?

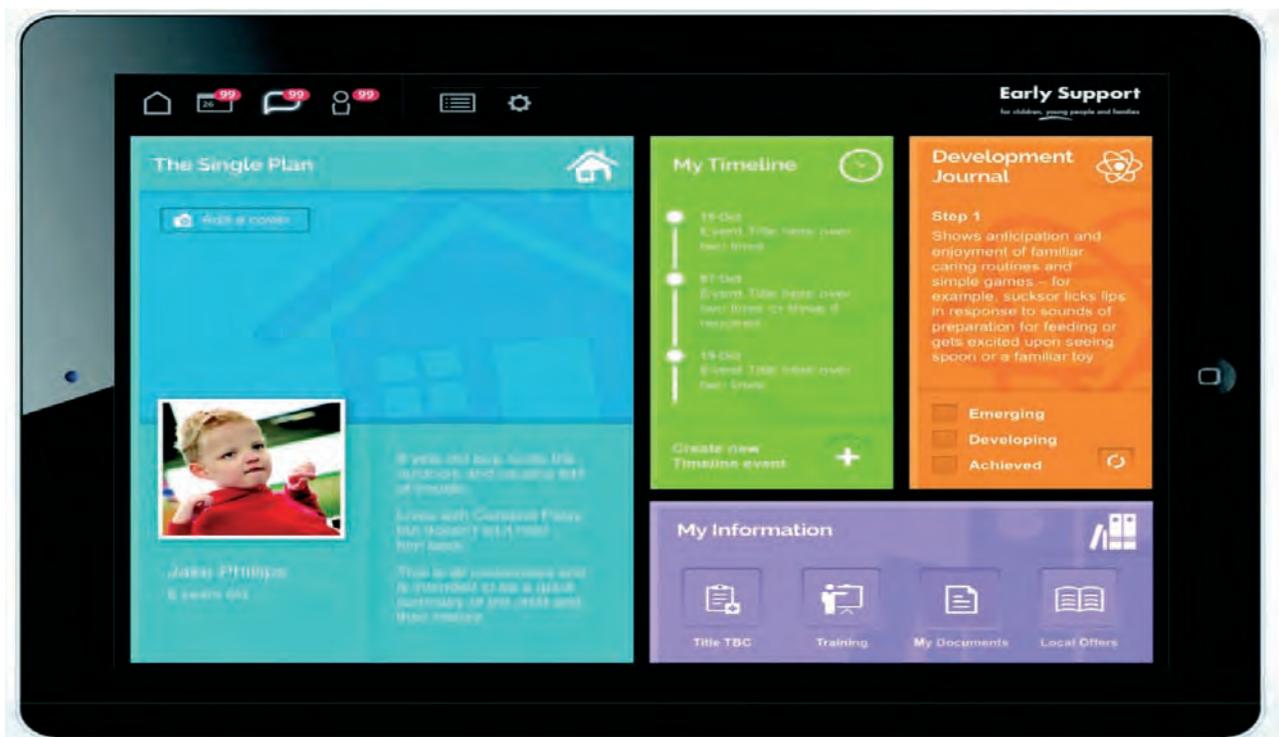
Early Support’s practical resources and training enable a way of working that:

- Helps practitioners and managers to put children, young people and their families at the centre of holistic, coordinated and seamless service delivery.
- Supports children, young people and their families to take control of their lives, gain a firm basis of knowledge and communicate their expertise in a way that enables them to: make informed choices; take the lead in decision making, become active partners in service planning, improvement and delivery.
- Provides the context in which services can work in an integrated way within a single assessment and planning process.

The Early Support practical resources include:

- Papers such as 'What is key working?'
- Information resources on specific conditions for parent carers and young people
- Background information resources for parent carers and young people
- 'Our family' and 'My life' (both include a single Education, Health and Care Plan format)
- *Multi-agency Planning and Improvement Tool (MAPIT)*
- Informed choice resource
- Developmental journals
- Film materials
- Training – *key working in practice; key working and working in partnership; parent carer workshops; using MAPIT; using the developmental journals (coming soon); key working workshops for strategic managers*

And the newest development is the **Early Support App**



This product, when its use is underpinned by the Early Support Principles, enables parents and young people to store, record and share information in multiple formats and with safety. It can be used as an app download for Apple iOS or via web access.

The app places information about the child and family under their control. They can share it at will with practitioners, professionals and their personal support network, and can define for themselves what is important about their own context.

Both professionals and parents are looking forward to its launch. Keep a look out on the website!

www.ncb.org.uk/earllysupport for further information on Early Support, the App and access to the free resources and training opportunities.



You may also have seen this report?

It makes very interesting reading and this is just one extract from the report.

Linda Fisher is a paediatric physiotherapist by profession and now involved with the on-going developments of Early Support (birth to adulthood).

Lindafisher.es@btinternet.com

Tel: 0742 944 7444

Key working is referenced within the Children and Young People's Health Outcome Forum Report: July 2012. 'The Forum recommends that a composite indicator be developed to look at the provision of integrated care for children and young people with a long term condition, disability or complex needs. Essential elements of this indicator are that each child or young person with a long term condition, disability or special educational needs, and each looked after child or young person or care leaver, has a coordinated package of care, including a quality assessment, access to key working and appropriate equipment; and that the individual's and their family's experience of the service is measured.'

A BRIEF GUIDE TO KEY WORKING



What is the aim of key working?

The overall aim of key working is to ensure the provision of holistic care and support to meet the individual needs of the child or young person and their family. EVERY child, young person and family who would benefit from key working support should get access to it.

‘Parents with disabled children are likely to face higher levels of stress and they value the practical and emotional support of key working’.
Support and Aspiration: A new approach to special educational needs and disability
 (DfE 2011)

What is key working?

Key working is:

- A way of enabling effective support, underpinned by the Early Support principles, that helps build strong and resilient children, young people and families
- Defined by a set of functions
- Based on person centred thinking and partnership approaches to working
- Family focused as well as child or young person focused
- Underpinned by an approach that enables open, equality promoting and supportive relationships
- A way to facilitate the coordination of an integrated package of support for children, young people and families

Who is key working for?

Key working is for children and young people who have additional needs, from birth to adulthood and their families.

What are the key working functions?

<p>Providing emotional and practical support as a part of a trusting relationship</p> <p>Enabling and empowering for decision making and the use of personal budgets</p> <p>Coordinating practitioners and services around the child, young person and family</p> <p>Being a single point of regular and consistent contact</p> <p>Facilitating multiagency meetings</p>	<p>Supporting and facilitating a single planning and joint assessment process</p> <p>Identifying strengths and needs of family members</p> <p>Providing information and signposting</p> <p>Advocating on a child’s, young person’s and/or family’s behalf</p> <p>Facilitating clinical and social care seamlessly, integrated with specialist and universal services in an equality promoting approach</p>
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Who can undertake key working?

The person providing key working support:

- May come from health, social care, education or the voluntary, community or private and independent sector (or it may be provided by the parent carers or young people themselves)
- Should be selected according to the specific needs of the child or young person and their families
- Is likely to be someone from the team working with the family, who is identified in discussion with the family, who has the skills, training, time and support to ensure that key working is effective and that the family are the pivotal part of all discussions and decision making
- May undertake all of the functions required by a family themselves; OR they may facilitate some of the required functions to be fulfilled by other members of the team working in partnership with the family.

Does every family need every function all of the time?

No! The level, intensity, frequency and number of the key working functions that children, young people and their family may require is determined by a number of things, including the complexity of the package of support and the family's resilience and support networks. This is likely to vary over time.

- **For families requiring a moderate level of support:** the person providing key working support may only deliver a few of the functions (for example, single point of contact; coordinating; empowering decision making). Key working is likely to be light touch, short term and just part of the way that a practitioner works.
- **For families requiring a high level of support, who require services from a number of agencies:** the person providing key working support is likely to ensure that more of the functions are undertaken at a higher level of intensity. In the early stages ensuring frequent and regular proactive contact may be essential, but the intensity should quickly reduce. The key working practitioner could be any member of the team around the family and should be the one who is 'best placed' in terms of the needs of the family and the individual's skills, capacity and relationships. After discussion with the family, the key working practitioner may undertake all of the required functions or facilitate another person from the team around the family to fulfill some of the functions (for example, someone else undertakes advocacy).
- **For families requiring an intensive level of support, who require services from a number of agencies, including extensive specialist input, and complex packages of support:** these families will probably have a statutory Education, Health and Care Plan and access to a personal budget. The person providing key working is likely to need to ensure that most (possibly all) of the functions are undertaken, at a high level of intensity and possibly over an extended period of time. It is likely that the key working practitioner will come from a specialist service and could dedicate a significant amount of their time, at least in the early days or at times of crisis. After discussion with the family, the key working practitioner may undertake all of the required functions themselves or facilitate another person from the team around the family to fulfill some of the functions (for example, someone else facilitates clinical care).

What local structures need to be in place?

To enable and support a key working approach, each area will need to consider:

- Accountability structures
- Joint commissioning
- Information sharing agreements
- Supervision and management
- Professional development
- Awareness raising

For more detail on each of these areas, as well as more on the evidence that supports key working, please refer to our paper *Key working: improving outcomes for all - Evidence, provision, systems and structures*, available from: <http://ncb.org.uk/early-support/key-working>

THE RAPID PROJECT

The Health Transition Service has been in existence since January 2009. It was initially set up to support young people who have long term medical conditions which result in a physical impairment, as they transition from Children's Services into the adult world. Today the team also support young people with other long term medical conditions such as asthma, allergies, eczema and type 1 diabetes.

The objectives of the Health Transition Team include:

- Active management of transition.
- Provision of accessible information about services.
- Provision of a system to help young people to develop self advocacy skills and the ability to manage their health condition competently.
- Minimise the risk of young people failing to access adult services successfully and therefore failing to manage their own condition competently resulting in long term implications on their health and well-being.
- Ensure that young people have the opportunity to make a positive contribution, enjoy and achieve, and achieve economic well-being by accessing appropriate education, employment and leisure opportunities.

The objectives are achieved using a variety of strategies. One such strategy is the RAPID Project. Inspired by Laura Chapman, a successful director of "Equality Training" (www.equalitytraining.co.uk), RAPID aims to **Realise Aspirations and Prosperity for Individuals with a Disability**.

The vision was to create a network for support, advice and mentoring for youngsters with physical disabilities which will empower them to raise their expectations, achieve their goals and realise their dreams. It was envisaged that the support would come from other youngsters, disabled and able bodied adults from local industry and business and positive role models from all walks of life who have been successful in their chosen fields to

- support their transition from school to further education or into employment.
- raise awareness of what opportunities there were for young disabled people and how they could access these.
- address issues such as housing adaptations, direct payments, mobility, transport and how to effectively manage health

The team organises 3 to 4 themed workshops and information sessions a year, to address the common issues raised by the young people. RAPID days are delivered in response to requests from our caseload usually identified by common themes appearing from our assessments. The workshops are held at a local community centre or more recently, a purpose built Youth Centre, away from any clinical setting. The workshops aim to raise awareness of opportunities and services for people with disabilities and how to access them. Experts are invited to lead sessions to ensure that young people are given up to date accurate information.

Very often these experts have a physical impairment themselves and act as role models for the youngsters. Exposure to positive role models helps to raise the expectations of the young people and therefore, their aspirations.

RAPID workshops have included -

- Relationships and Self Esteem which was run by our Young Peoples Health Advisors.
- Leisure, which included talks from the Outdoor Pursuits Centre manager, Riding for The Disabled, Disability Sports Development Officer for West Bromwich Albion FC and Young peoples Health Advisors.
- Driving with a Disability, which included talks from Regional Driving Assessment Centre, Motability, SIRUS, a local company who adapt cars, Paul Hunt, Chris Gordon and Natasha Wood who all have a physical impairment and drive adapted cars. Adapted cars were available for our youngsters and their parents to see what adaptations were available.
- Facing Challenges and Achieving your Potential, which included tips on CV and cover letter

writing, disclosure and physical and emotional challenges of moving on to university, college or into work.

- “Raising Aspirations” led by Action Jackson, Fix Up Seminars. Feeling good about yourself, making the most of your opportunities and how to ask for what you want and need without losing your cool.
- Independent Living. Centre for Independent Living, Personalisation and Canine Partners.
- “Are You Ready for Change?”
- Relationships and dealing with difficult situations. Strategies to find solutions, building emotional resilience, effective communication, negotiation, problem solving, esteem / confidence building and assertiveness
- Sport
- Leisure and holidays

We have also used professional speakers - Action Jackson, Fix-Up Seminars whose workshop was entitled “Raising Aspirations”. He talked about feeling good about yourself , making the most of your opportunities and how to ask for what you want and need without losing your cool

Wendy Garcarz is an executive coach, who offers insightful, personal and professional development coaching for leaders and senior managers. Her first workshop was “Are You Ready for Change?” and the second workshop was entitled “Managing Change” For young people in transition change is inevitable. Wendy talked through understanding change, experiencing change, and controlling reaction to change.

Spurgeons were commissioned to facilitate a workshop “Dealing with Difficult Issues” to give young people strategies to deal with difficult situations and relationships.

We also actively source speakers who have a physical impairment and have achieved in their chosen field. We have been supported by two paralympic athletes –

- Richard Whitehead, a British athlete who runs on prosthetic legs and who won Gold in the men’s T42 200metres at London 2012 Paralympic Games,
- Louis Speight who is a T33 wheelchair athlete
- Marie Tidbull is an Oxford graduate who has congenital absence of limbs. She ran a workshop on CV writing, job applications, cover letters and disclosure.

Our biggest supporter has been Natasha Wood, an actress and playwright who has Spinal Muscular Atrophy www.rollingwithlaughter.com

Her website says about her “She has had a jet set life in England with a fairy tale marriage, quirky parents, siblings and a job as production manager at the BBC – but she can’t lift a pint of milk or walk”. She has appeared on “This Morning”, “Children in Need”, “The One Show” and has worked with Gok Wan on “How to Look Good Naked with a Difference” She has been our guest speaker on many occasions and is a firm believer in the RAPID project.



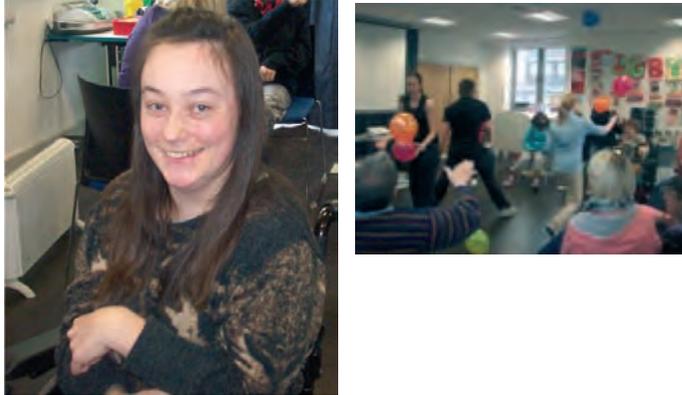
In June 2011 Natasha supported us during the making of a short film about the project for the NHS Alliance. In an interview she said –

“It’s about making a difference to young teenagers. Knowing myself, as someone who has a disability, and had it from birth, that there was such little support when I was growing up. As a teenager you want to grow, you want to be something, you want to achieve something and I think if there’s something out there that can actually show you all different angles of life and experience and expertise, then to me a programme like this is just absolutely essential in life.”

We have worked with our Lifestyle Management team to incorporate health promotion into RAPID . An example of this was an exercise and activity session run by our Physical Activity Team

We are also “growing our own” speakers. Emma has been on our caseload since the inception of the service. With the support of her case manager, she has adapted to accepting care from care providers rather than from her mum. This in turn increased her confidence and opened up opportunities such as moving away from home to study at University. With support from her case manager, she arranged academic support at University, equipment and accommodation and now employs her own PA’s for personal care. Later this year Emma will be presenting at a workshop

about moving away to University. She has offered to speak about introducing people to the idea of being away to study, being away from family for the first time, care plans, new friends, independence, learning new skills and things about yourself, confidence and useful contacts - all her own suggestions from her own experiences.



The feedback from the young people and their motivation and enthusiasm has been very supportive. They have developed a strong cohort who are supportive of one another and are gaining in confidence and independence. Meeting others with similar physical disabilities provides a network of emotional support for the young person which promotes positive mental and emotional health. As new young people approach the Transition age of 14 years and become involved with the HTT they are introduced to the current cohort through RAPID days and are supported by them.

RAPID gives young people accurate information, develops their knowledge about services that are available to support them, and develops their confidence and self-advocacy skills. All these things contribute to enabling them to be empowered to take control of their medical condition, their lives and their future.

“I think the workshops help young people such as myself to have a bit more of an independent lifestyle. The workshops have helped me to build up my self-confidence and realise that I am not the only one going through tough times.” Zakia

“The information you give us is priceless because we learn things that we may never have found out about which will help us in transition into adults.” Daisy

“I think your service is the best thing ever. It has helped me so much and given me the confidence I didn’t know I had. I love the workshops and I have made so many friends through the workshops.” Laura



Photographs from our most recent workshop with Natasha Wood.



We believe that this project contributes to the outcomes of “Every Child Matters” and embraces the concept of “Aiming High for Disabled Children” and the NSF for Children, Young People and Maternity Services.

AHDC

One of the key areas identified within Aiming High for Disabled Children (AHDC) is Transition.

1. Information

Disabled children, young people and families can expect information that covers:
Key transition points

The NSF for children, young people and maternity services:

EPP and RAPID contribute to the following standards.

NSF 1: Promoting Health and Well-being Identifying Needs and Intervening Early

NSF 3: Child, young person and family centred services.

NSF 4: Growing up into adulthood

NSF 8: Local Implications for Disabled Young People

NSF Standard 8 2004: Disabled Children and Young People and those with Complex Health Needs. Disabled young people

NSF 9: The mental health and psychological well-being of children and young people

**Julie Hykin MCSP SRP
Carrie James RNC, Bsc (hons), PG Dip, QN
Case Managers for Health Transition**

Joan L Lacey, Dip Phys, MAPA Obituary

Joan Lacey died peacefully on the evening of 15.05.2013 in Bowral, Australia after a six month battle with illness. Her final days were spent, with her family surrounding her, in the area of New South Wales that she loved the most. Joan was born in 1935.

Joan had a varied career in physiotherapy. She was a pioneer researcher whose remarkable career in the field of neonatal physiotherapy spanned over 34 years.

She graduated from the University of Sydney in 1956, and practised general physiotherapy at Concord Repatriation Hospital until 1958 when she took 12 months leave to travel overseas. On her return she continued at Concord until she married her beloved husband Tony, in 1961.



At this point in her life she retired from her professional work to raise her daughter, Catherine, and sons, Anthony and Patrick.

In 1974, the Labour Government in Australia introduced a 're-entry programme' for many professions. Joan took advantage of this programme and completed the physiotherapy re-entry course at the Royal Prince Alfred Hospital, RPAH, University Hospital, Sydney.

On completion of the course she was chosen to continue employment at the hospital and had continued dedicated service there for almost 30 years, until her retirement in 2000.

Joan initially started work in the neurology department, treating patients following severe head injuries and stroke. Knowledge of her capability spread around the hospital and Professor David Henderson-Smart, who was Head of the Neonatal Intensive Care Nursery, asked her one day if she would examine a premature baby and give an opinion on its neurological condition. In 1978 she was invited to provide a Neonatal Physiotherapy Service in the John Spence Nurseries at RPAH providing an infant stimulation programme for the babies in the Intensive Care Nursery. To her such a programme was inappropriate for the highly vulnerable and fragile infants admitted to the Unit.

She quickly understood that the then available neurological assessments were not specific or reliable enough for the needs of the preterm infants under her care and so she commenced observation and documentation of the development of preterm infants.

By utilising the physiotherapy skills of observation and analysis of preterm babies' spontaneous movements and their development of antigravity postures and movements she was able to document the infants' progress longitudinally during their stay in the neonatal nurseries, at the same time ensuring minimal handling of these tiny vulnerable babies.

Joan's exemplary clinical practice was strengthened by her commitment to education and research. This documentation was the start of what has been an intensive study of the neurological status of premature infants.

Throughout this period she continued with her clinical role in the hospital but also embarked upon successful research collaboration with Professor Henderson-Smart spanning many years. Joan's contribution was to assess and document the motor development and rate of maturity of the premature infants in the nurseries.

Over the years Joan has had many articles published in reputable international scientific journals, including Early Human Development, Developmental Medicine and Child Neurology and Paediatric & Child Health.

In 1988 she was awarded a research grant to investigate the Preterm Neurological Assessment and the predication of later handicap. This research and world-wide publications led her to develop the **Lacey Assessment of the Premature Infant (LAPI)**, which has become her legacy.

The LAPI assessment tool is a safe, reliable method for neonatal physiotherapists to observe, analyse and document the unique development of premature infants in the neonatal intensive care environment. It is able to distinguish the 'usual' movements and resting postures of the majority, who will have a normal outcome and the 'atypical' development in a much smaller minority of infants that would indicate an abnormal outcome. The LAPI is also a unique assessment tool to guide the design of early intervention plans for infants in the NICU.

In a 2004 publication, a study of 203 infants born < 31 weeks gestation, when assessed using the LAPI after 33 weeks post menstrual age, the diagnostic accuracy of the LAPI had 86% sensitivity and 83% specificity for blinded three year old outcome. The identification and documentation of atypical features correctly predicted the outcome for 29 out of the 36 infants later found to have cerebral palsy. Comparatively, cranial ultrasound achieved this for only 16 of the 36 infants.

The success of the LAPI has been documented extensively in peer reviewed articles in highly respected international Journals. Over the years, Joan has been invited to present her research at International Perinatal Conferences in the Netherlands, Rome, London and Australia. Joan has highlighted the importance and benefits of Physiotherapy in the Neonatal Intensive Care Unit throughout her career.

Joan herself has taught her assessment procedure throughout Australia, and since 1996, several courses in the UK, the last course she was able to travel to was held in Edinburgh in 2007. Since 2007, APCP has sponsored the delivery the LAPI assessment courses in the UK, in Edinburgh in 2010 and most recently in London at the Royal London Hospital in April 2013, by the recognised UK LAPI tutors Adare Brady and Peta Smith. Joan has also taught the course herself in Israel, and Dubai.

Joan continued to mentor and supervise local physiotherapists in the regional and major hospitals of New South Wales via bi-monthly teleconference meetings and occasional hospital courses for physiotherapists and medical and nursing staff working in the Intensive Care Nurseries until this recent illness prevented her from doing so.

Joan was very highly regarded and respected by her colleagues and was an inspiration to all who worked with her and also to the wider professional community of physiotherapy and neonatology.

In 1996 Joan was the first physiotherapist in New South Wales NSW to achieve a Level 6 grade, in recognition of her leading research and international teaching commitment.

She was appointed to the position of Assistant Director of Physiotherapy at RPAH, in 1997 managing the physiotherapy department also continuing to teach medical, nursing and physiotherapy staff in the management of neonates. Joan held this position until she retired from RPAH.

In 1999 Joan was awarded the King George V Medal, in recognition of "Excellence in Practice and Service" at RPA. The same year she was also presented with an Excellence in Clinical Research

award at the 1999 NSW Branch Australian Physiotherapy Association, APA, Conference for her unique professional knowledge and skills.

Her research and teaching career continued to flourish after her retirement in 2000 when she was appointed the first and only Honorary Consultant Physiotherapist by the Neonatal Intensive Care Nursery at RPAH.

In 2009 at the APA National Conference, Sydney Convention Centre, Darling Harbour, Sydney, Joan was awarded the 2009 National Paediatric Group Chairperson Award: In recognition of the contribution to the development of Physiotherapy Services for Children, teaching & mentoring of upcoming paediatric Physiotherapists, and ongoing support of the APA National Paediatric Group. The National Group Chairperson Award is a biannual award.

In 2011 at the Australian Physiotherapy Association Conference, Brisbane Convention Centre, Joan was honoured by the Physiotherapy profession with the highest award for National Paediatric Physiotherapy in the country, the 'National Paediatric Group Yvonne Burns Award'. This award is highly contested by selected representatives from each of the States and Territories of Australia. The award is *"in recognition of outstanding contribution resulting in the improvement of the health and well being of children and their families, as well furthering the development of the physiotherapy profession"*

After her retirement in 2000 most of her time was spent enjoying life on the family farm at Bundanoon in the Southern Highlands NSW where the family breed and Show Australian Stock Horses and breed commercial Angus cattle.

Joan touched the lives of many throughout her lifetime, both professionally and socially. She loved good food, red wine and had an amazing sense of humour.

Joan's easy lecturing and teaching style, combined with an open sharing of expertise and discussion, has proven to be a valuable learning experience for everyone who is lucky enough to be taught by her.

Throughout her distinguished career Joan has pioneered and developed many of the services provided to premature infants and their parents. Along with this she has readily provided information and practical assistance and experience to post graduate physiotherapists entering this challenging area.

Joan has been a great mentor and friend to both Adare and I and we have admired and respected her immensely. We will miss her guidance, support and most of all her friendship, but will continue to try to ensure her legacy, the use of the Lacey Assessment of the Preterm Infant in the Neonatal and Special Care Intensive Care Units throughout the UK by specialist neonatal physiotherapists working in this challenging, advanced subspecialty area of practice of paediatric physiotherapy care.

Peta Smith and Adare Brady

Para Kent Cycling project

“That was brilliant!” “Great!” “When can we do that again” “I’ve always wanted to ride a bike.” These were just some of the comments made by a group of disabled young people after spending some time on the Cyclo Park track at Gravesend, Kent. www.cyclopark.com This session had achieved participation, fun, socialising, health and fitness all rolled into one and the young people wanted more.

The group has been set up as part of the Project Ability Programme which is funded through the Youth Sport Trust, www.youthsporttrust.org whose aim is to encourage all children into participating in sport whatever their ability. Project Ability is specifically involved with getting more young disabled people to take part in competitive sport, and this is being achieved through its 50 Lead Project Ability Schools, which are spread out through the country. These lead schools have been asked to look for pathways for young people with disability to get into a sport that they may never have previously tried and then be able to take this forward into a competitive setting like the School Games.



Valence School in Kent is a Lead Project Ability School and they have set up the Para Kent cycling project. Cycling was an obvious choice as Brand’s Hatch in Kent was where the Paralympic cycling events took place last summer. Young people with disability from both mainstream and special schools in Kent were invited to join together for one assessment session and 6 track sessions, which will lead to a competition at the end of the programme. The funding they have received has been put towards hiring the Cyclo Track and a Coach, and hiring in some adapted cycles from Quest 88. The Cyclo park has a selection of trikes, and bikes and adapted bicycles but not enough for the whole group to cycle together and at the same time.

None of these young people had experienced cycling on a track before this event and although I was aware of other cycling projects like Pedal Power in Cardiff this was the first time I had seen the freedom that cycling gave these young people. The ability to move (quite fast in some cases!) independently out on a track and to experience fresh air, exercise all with a competitive element certainly fulfils many of the criteria for participation in terms of the ICF (WHO 2002).

This is just a short term project run by Valence School this year but it is hoped that Cyclopark will be successful in finding additional funding from other sources to run the project themselves and be offered to more groups of children with disability. I was amazed by the range of adapted cycles available, these include hand cycles, recumbent cycles, and tricycles for the more independent cyclists, but there are also many cycles that can be used with an assistant either 2 person cycles where both pedal or even platform cycles that take a wheelchair so the young person can experience the motion and sensory side of cycling even if they cannot physically use the cycle themselves.

Nicola Burnett

COURSE FEEDBACK

Reflections on the 'Advancing Paediatric Physiotherapy' Masters Degree at Sheffield Hallam University



I had been thinking of undertaking a Masters degree for quite a few years, since 2004, but had been placing it in the pending pile until early 2011, when I gave it some serious thought again... I had been qualified and practicing nearly 17 years so it seemed time to act and I was interested in another period of extended study, since it had been 10 years since completing the 6 month Bath Hydrotherapy Course in 2001. Overall I wanted to spend some extended time examining the latest research in my area of paediatrics and so ensure I was up to date with the latest thinking.

There were some Masters courses out there in Paediatric Physiotherapy, completed on a part-time basis in as little as 3 years or you could take up to 5 years. Most used a combination of distance learning and some 2-3 day block attendance at the institution itself. Sheffield Hallam fitted the bill because the modules were relevant to my practice and it was not too far away geographically. The modular system is user-friendly and flexible, as the credits can stand alone or you can add to them to make post-graduate certificates (60 credits), post-graduate diplomas (120 credits) or full masters (180 credits). I was also able to import 15 credits from an Aquatic Rehabilitation module at the University of Hertfordshire to add to my total.

The first module was 'Integrated Paediatric Practice' – there were different options....orthopaedics, respiratory or neurology, but I chose neurology, as it is my area of practice, which gave me a chance to examine the cardinal principles of practice in this area and start to critically appraise articles of different types. Next was 'Research Methods for Practice' – a mandatory module, to give you the foundation you need to critically analyse research. It provided the valuable context of quantitative and qualitative research within physiotherapy and how the traditional hierarchy of evidence is being re-thought by the increasing value put on qualitative research. Lastly in year one was 'Measuring Health Outcomes' – so relevant to the current NHS situation, where you need to justify inputs, provide evidence of clinical effectiveness and gather evidence on patient reported outcome measures and quality of life measures. Safely through to the second year, the next module on 'Childhood Disability and Inclusive Practice' was incredibly relevant to my daily practice.

Thus far I can reflect on time well spent; although still a work in progress, I do feel I have improved my skills in essay writing and creating PowerPoint presentations....learning the art of expressing ideas succinctly, but effectively. However more than that, I felt I had changed, less narrow in my focus on impairment, vindicated in my promotion of disability sports, better equipped to critically appraise research with more patience to sit down and read articles and a deeper understanding of the issues. One early conversation with a lecturer has stuck with me, when she encouraged me to give myself permission 'to think less like a physio'; at first it seemed counter intuitive, but now I am beginning to understand why that was important and how it makes me a more rounded clinician.

Having the opportunity to focus on areas of clinical interest has been a privilege... e.g. paediatric neurology, hydrotherapy, disability sports and inclusive practice/integration and co-location, which I hope to focus on in the next clinical practice module; as there is considerable scope within modules to personalise the assignments. A Masters provides a chance to stand back from the busy day to day practice and look in depth at a case study or clinical scenario. You would simply not get the opportunity to reflect deeply in this way unless you actively put time aside to do so, which is what this kind of extended study enables you to do. One of the best things is how each module has built on ideas previously encountered; one example is ICF and a different way of thinking beyond

impairment to include activity and participation.

Time demands – an MSc course does make demands on your personal time and there is no avoiding that fact. A colleague who had previously done a Masters described her experience as having no social life at all when assignments were due in. I would imagine that someone with a family and a full-time post would need to be incredibly organised to simultaneously juggle the work/life/study balls in the air. However the modules were a mixture of distance learning via a virtual learning environment, which means you can flexibly study at a time when you choose....1 in the morning, if you liked. Personally, I also valued the opportunity to meet fellow students when attendance was required at Sheffield, which consisted of some 2/3 day blocks.

So now with 90 credits in the bag and another 30 to acquire before the end of the second year, then it will be time to face the ultimate challenge...the final 60 credits and the 3rd year dissertation! It will be a test, but hopefully an opportunity to bring to the table all the knowledge and skills gained in the previous 2 years.

Sue Booth

LAPI COURSE 22ND – 25TH APRIL 2013 at the Royal London Hospital

Calling all neonatal physiotherapists who have not trained in the Lacey Assessment of Preterm Infants!

Having completed a four day course at the Royal London, we thoroughly recommend this to you. We have had fantastic opportunity to learn from two very passionate and experienced neonatal physiotherapists who know this assessment inside out. There has been a real mixture of theory, practical hands-on sessions on the neonatal unit, and group discussion. We have had plenty of opportunity to practice using and scoring the assessment. We have enjoyed the chance to assess babies on the unit and all look forward to the next few weeks trying it out on our units. Group work has been invaluable and has given us the opportunity to link with our peers (as well as form new friendships) and we look forward to meeting up in 18 months with our findings on the update day.

“The Red Group”



LAPI 2013 Evaluation results

Evaluation: In order to maintain the quality of teaching and provide us with feedback, we are keen to have your comments on the LAPI presentations and assessment sessions.

(1 = Poor, 3 = Average and 5 = Excellent).

a) The venue and facilities

13 people scored 5; 4 scored 4

b) The pre-course reading list

11 people scored 5; 6 scored 4

c) The discussion sessions (e.g. Standardisation criteria, Consistent/ Contradictory, Usual/Monitor)

11 people scored 5; 6 scored 4

d) The standard of teaching and understanding of the lectures

13 people scored 5; 3 scored 4; 1 scored 3

e) The sequencing of the course

14 people scored 5; 3 scored 4

f) The video for feedback on my handling and assessment

16 people scored 5; 1 scored 4

g) The use of formative assessment to assist understanding of new concepts

7 scored 5; 8 scored 4; 2 scored 3

h) The LAPI manual to provide an indexed reference of the assessment and its items

13 scored 5; 4 scored 4

Comments/suggestions:

"Christa was very welcoming"

"Very well organized and the detail of maps etc. fantastic"

"Good to be so close to NICU/SCBU"

"Formative assessment – terrifying but very useful!"

"Found some of the research/stats difficult to follow"

"Teaching has been outstanding. It is obvious how passionate the lecturers are for neonatal PT and this is infectious".

"The opportunity to discuss babies with peers has been fantastic"

"More time on follow-up lecture"

"More time on last day to discuss"

"I really appreciated that the course took place in view of Joan's passing. It exceeded my hopes and I'll go back feeling less intimidated by SCBU....."

APCP NE Study Evening; the SpineCor approach.

On Wednesday 27th March the North East APCP Branch held a twilight course “ SpineCor – Spinal Matters” at the Ramada Encore Hotel, Barnsley delivered by Tim and Alison

The SpineCor study event proved to be a bust evening with several extra people turning up on the day giving us just under 50 delegates. Despite a slight glitch with the projector screen being late to arrive the remainder of the evening went smoothly. From speaking to people in the room and comments made in the feedback forms few people had heard of the approach to treating scoliosis, and were keen to find out more information.

After reviewing briefly Scoliosis in the paediatric population most of the lecture was devoted to Idiopathic Scoliosis which accounts for 80% of paediatric scoliosis. Tim explored the knowledge around etiology, recent diagnostic and assessment methods before exploring all treatment options presently available and the clinical reasoning behind these. He then explored the new etiopathogenic concept of idiopathic scoliosis resulting from research carried out in Canada. The SpineCor dynamic spinal bracing system was developed as part of this research project

The SpineCor approach incorporating spinal bracing alongside a home exercise programme is a fresh approach to the ones many of us come across in our current daily life, where spinal rodding and fixed jackets are well known. The idea that the SpineCor approach can reduce the need for surgical intervention is a welcoming one. Like most approaches you need to select the individual wisely, as the approach requires you to wear the bracing solution for continuous periods throughout the day with brief breaks twice a day.

Both Tim and Alison work for SpineCor at NHS clinics and privately assessing and fitting the dynamic brace. Interestingly this treatment model is used with a very scoliosis specific physiotherapy exercise programme designed to suit each client. Alison demonstrated how to fit the brace and explained how it was designed to be used with mobile scoliosis's to prevent the scoliosis developing due to destructive gravitational forces on vertebral growth plates

The approach is being used by a few Trusts across the UK, and we discussed the importance of having an orthotist on board with the approach. Due to the cost implications it can appear expensive when you consider the cost of the suits, however they do last for over a year (dependent on growth of the child) and undoubtedly would be cheaper than a surgical procedure and hospital stay. There is nothing that can't be done in the dynamic bracing other than perhaps swimming and water based activities.

Throughout the evening Tim was a very confident speaker who had a wealth of knowledge about the types of scoliosis and research about the product.

As an audience it would appear that delegates were receptive to the idea of the SpineCor approach but felt that they need to get their local orthotists and orthopaedic consultants on board with the concept. It will certainly be “one to watch” to see how this concept could be embraced and used with increased awareness and knowledge.

Introduction to Paediatric Physiotherapy Course: Case study 1

The following case studies were submitted for the recent APCP Introduction to Paediatrics course held in Scotland

Introduction:

Patient X was referred by his GP for joint pain in his lower back, hips, knees, ankles and shoulders. The referral gave the information that the patient was twelve years old and at three years of age had been diagnosed with hypermobility syndrome. The patient had recently transferred to secondary school and was struggling to keep up with his peers.

Benign joint hypermobility syndrome (BJHS) is a connective tissue disorder in which people have increased mobility in a certain number of joints with the occurrence of musculoskeletal symptoms without rheumatologic disease. It is classified using the Brighton diagnostic criteria. This was adapted in 2000 from the Carter and Wilkinson scoring system that has been used for years to recognise hypermobility in patients. A high Brighton score alone does not diagnose BJHS it confirms that the patient has widespread hypermobility. Joint laxity commonly occurs in healthy individuals; hypermobility without systemic disease occurs in 4-13% of the population (Simpson, 2006). To diagnose BJHS the child must have a Brighton score (attachment 1) of more than 4/9 alongside arthralgia for more than three months in four or more joints (Knight & Bird, 2010).

Assessment:

A thorough assessment is a fundamental part to a good quality physiotherapy treatment plan. Thonnard and Penta (2007) describe the information gained within a physiotherapist's assessment as facts that supplement the medical diagnosis and allow the appropriate intervention to be chosen and to monitor the patient's recovery and assess outcome. The subjective assessment allows the full picture to be reviewed with the knowledge of the patients' site, nature, behaviour and onset of symptoms as well as previous illness', medications and social history. After a subjective assessment it is possible to draw some hypotheses as to the cause of the patient's pain and therefore direct your assessment appropriately and plan the suitable physical tests (Porter, 2008).

From patient X's subjective assessment (attachment 2) I learnt that the patient had also been diagnosed with dyspraxia and that he had a family history of joint pain and joint laxity. The patient has also had previous physiotherapy but found it did not help. He described it as 'boring'. The subjective assessment allowed me insights into what was important to patient X and what he enjoyed doing. Patient X reportedly enjoyed playing on his X box, riding for the disabled, swimming and art at school.

Looking at the body chart (attachment 3) and subjective assessment from patient X, it was possible to start to develop hypotheses for the possible causes of the pain. Firstly because the patients' joints are hypermobile it means that the soft tissues around the joints are likely to be more lax and therefore prone to instability and injury. Alongside this the patients' recent growth and change in lifestyle could increase the stress on his joints, and cause muscle imbalance resulting in pain. Murray and Woo (2001) highlight the increased incidence of lower back pain in children with hypermobility syndrome in the adolescent years and propose that this is linked to the coinciding increase in physical and sporting activities. It is also important to be aware of other possible causes of the pain, including rheumatological conditions due to the number of joints affected therefore it would be important to look for signs of inflammation on assessment. However this diagnosis is unlikely because of the 24 hour pattern of pain that was described was pain after activity and in the evenings. Other possibilities could be; Osgood Schlatter's for the knee pain, Perthes for the hip

pain, Severs for the ankle pain however all of these are unlikely to occur at the same time in the same patient.

Following a subjective assessment it is possible to plan your objective assessment. The aim of the objective assessment is to find abnormalities of function through active and passive tests. Porter (2008) highlights the importance of being objective in your assessment instead of trying to make the findings fit a hypothesis.

The objective assessment demonstrated that the patient had a very poor posture with an increased lumbar lordosis and a compensating thoracic kyphosis therefore resulting in protracted shoulders and a protruding chin. The patient was hypermobile in a number of joints namely, ankles, knees, elbows and shoulders, Murray and Woo (2001) draw attention to the importance of early recognition of joint laxity for the successful management of BJHS. The assessment revealed patient X had tight hamstrings, gastrocnemius and soleus on both of his legs. He was also found to be weak in his rotator cuff, core stability, quads and ankles. The weakness and laxity in patient X's ankles was accompanied by poor proprioception and balance. The global weakness identified above could be explained by the patients' reduction in activities causing a reduced exercise tolerance and the patient to become deconditioned. This is documented as a particular problem for children with symptomatic joint hypermobility and hypomobility (Engelbert et al, 2006). It is also important to note that a study by Fatoye et al (2008) into proprioception and muscle torque deficits in children with hypermobility syndrome found that children with BJHS demonstrated impaired knee joint proprioception and weaker knee extensor and flexor muscles than healthy controls.

Outcome Measures:

The objective assessment is the time to highlight outcome measures that will allow the effectiveness of the treatment to be assessed throughout (June, 1994). The importance of precise and reliable outcome measurement has been widely documented over the last 15 years (Poutney 2007). Outcome measures can allow critical evaluation of current treatment to see if it could be improved. The white paper 'Choosing Health: Making Healthier Choices Easier (Department of Health, 2004) emphasised the importance of evidence based practice and the evaluation of clinical effectiveness.

On the initial assessment of patient X, I used the following outcome measures;

- Visual Analogue Scale (VAS) is a 10cm line with 'no pain' at one end and 'worst pain imaginable' at the other end (see attachment 4). The patient is asked to rate the level of pain they are currently experiencing. Schofield et al (2007) describe it as a simple tool with wide application. It is prescribed as appropriate for use with children age 5 years and upwards however Shields et al (2003) concluded that it was understood and completed better by children over nine years of age.
- 6 minute walk test is used to assess exercise tolerance. It is often used with children with respiratory conditions but is also appropriate for musculoskeletal patients. A patient is asked to walk down an enclosed quiet corridor and the distance walked in 6 minutes is measured. Poutney (2007) describes the walk test as 'an easily interpreted clinical tool, with good standards of reliability and validity which have been extensively tested in a variety of populations'.
- The single leg stance test is a simple, quick assessment of static balance. The patient is asked to stand on one leg with arms crossed over chest. The patient is then timed and the timer stopped if the arms become uncrossed or the foot touches the ground or the time exceeds 45 seconds (Seale, 2010). Zumbrunn et al (2011) assessed the use of a single leg stance balance test in children and concluded that it was a useful assessment for diagnosing balance impairments in children.

- Hamstring flexibility was measured by measuring the popliteal angle. This measure is taken with the patient in supine and their hip is passively flexed to 90 degrees and the knee extended to a point where it becomes tight. The popliteal angle is measured in relation to a line drawn parallel to the femur and the angle that forms between the tibia as measured from the foot (see attachment 5). White et al (2009) chose to use this as a measure of hamstring flexibility as it is reported to have 'excellent' reliability.

Treatment Planning and Goal Setting:

Following the assessment a detailed treatment plan was devised with the patient and his mother with the aim to reduce the patient's pain and achieve the goals set with the patient. The first and most important part of the treatment was to explain the findings of the assessment to the patient and his mother and to educate them about BJHS. Simmonds and Kerr (2007) highlight the need for education as part of the treatment for hypermobile patients. Understanding of the diagnosis is important to encourage compliance and adherence to a treatment plan. Murray and Woo (2001) also discuss the importance of education as treatment for BJHS highlighting the importance of not only educating the child but the parent also as the nature of the condition as this reduces anxiety. Goals are used in physiotherapy to include the patient in their rehabilitation programme and focus the treatment on the needs of the individual. Porter (2008) highlights the need to use SMART (Specific, Measureable, Attainable, Realistic, Time-framed) goals for good physiotherapy practise. In the first treatment session with patient X we set the following goals:

1. He decided that he wanted to reduce the number of tablets he had to take for his pain; a goal was set for the patient to be taking one tablet or less a week in 6 weeks time. He was currently having pain relief daily.
2. He wanted to participate in school sport by the start of the next school year (three months).
3. He wanted to be able to participate in swimming lessons in three months.
4. He wanted to improve his handwriting. No time goal was set for this as it was discussed that the patient would be referred to the Occupational Therapist to achieve this goal.

The treatment plan for patient X had to motivate him to participate in the exercises as this had previously been a problem in the past with physiotherapy. Non adherence to physiotherapy treatment programmes within paediatrics is a clear issue as stated by Chappell and Williams (2002) however there is little research into the reasons behind the non-adherence. It was important to therefore find out what patient X was interested in and what his personal goals were. Using this information it was possible to develop an exercise plan that the patient could work on at home and at school to improve his muscle length, strength, proprioception and overall exercise tolerance (see attachment 6). Patient X's mother reported that they had a wobble board at home; therefore this was bought into the home exercise programme. Wobble boards can be used to improve proprioception in joints and therefore may improve symptoms of BJHS (Simpson, 2006).

I discussed with the patient when he thought he could do these exercises and made a plan that fitted in with his current routine, so that he did not have to find time to do his exercises. For example he suggested he could do his posture exercises when he was playing on his Xbox and we decided he could practice his balance exercises i.e. standing on one leg when he was brushing his teeth. Involving the patient in his own treatment plan and schedule for exercises was done with the aim to motivate the patient. Alongside this I made a plan with the patient to start a course of hydrotherapy weekly for six weeks. Hydrotherapy is known to be a good form of pain relief because of the stimulation of the thermo and mechanoreceptors and suppression of the SNS. For this patient in particular I felt it was appropriate to start with hydrotherapy because one of the patient's main goals was to be able to participate in swimming lessons as he had enjoyed them when he was younger. The water would also allow global strengthening within an environment where his joints were under less stress due to the reduction of gravity and buoyancy support of the

water. The hydrotherapy sessions for patient X were focussed on stretches, core stability exercises, balance exercises and overall cardiovascular exercise. When possible the exercises in the pool were made into games to make the session fun but effective.

An important part of the treatment plan was to liaise with the patient's school as this was where patient X spent the majority of his time. I also felt that the school needed to be aware of the patient's diagnosis and therefore be able to encourage the patient appropriately in sport and other school activities. This was discussed with patient X's mother and she felt very positive about keeping in contact with Patient X's school and therefore a copy of the patient's home exercise plan and a summary explaining the findings of the physiotherapy assessment and advice was sent to the school and discussed at his next educational review.

Patient Follow-Up

Following the initial 6 week course of hydrotherapy sessions a review was scheduled to assess effectiveness of the treatment plan. The patient's mother reported that he was very rarely asking for pain relief anymore. This was very positive and meant that we had achieved the first goal set within the time frame. The patient was also demonstrating improved static balance when assessed with the single leg stance test - on initial assessment the patient was able to stand unsupported for 5 seconds on his left leg and 10 seconds on his right when reviewed the patient achieved single leg stands of 20 seconds on each leg. Patient X also demonstrated improved hamstring flexibility. His popliteal angle had gone from 60 degrees to 45 degrees in both legs. The patient himself reported he was unsure there had been a big difference however when the outcome measures above were reassessed and he saw the difference and said he was happy. He had also stuck to doing the home exercise programme daily which was a big improvement on his previous physiotherapy experience.

Patient X's mother reported a big improvement in the attitude of the school towards the patient's diagnosis. She reported this had meant patient X was enjoying school more and participating in more extra-curricular activities than previously. It was decided that the patient needed further physiotherapy sessions to enable him to achieve his other goals but not so frequently. The patient's home exercise programme plan was adjusted slightly to some higher level exercises and the next appointment was made for three weeks time. This was to enable the patient X to take on some of the responsibility of his rehabilitation and hopefully demonstrate continued adherence to his treatment programme.

Attachment 1: The Beighton score is calculated as follows:



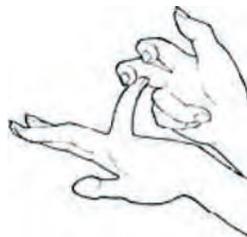
Score one point if you can bend and place your hands flat on the floor without bending your knees.

Score one point for each knee that will bend backwards.



Score one point for each elbow that will bend backwards.

Score one point for each thumb that will bend backwards to touch the forearm.



Score one point for each hand when you can bend the little finger back beyond 90°.

If you are able to perform all of the above manoeuvres then you have a maximum score of 9 points. (Knight and Bird, 2010).

Attachment 2:Subjective Assessment:**History of Presenting Condition:**

Patient X reported being diagnosed with hypermobility syndrome when he was three years of age and at that time and again at 6 years of age the patient reported seeing a physiotherapist who worked with him because he was very 'floppy' and was falling over a lot of the time. Since then the patient had managed well with activities and school but recently since transitioning to secondary school the patient reported gradually slowing down sports and activities due to a number of joint pains, namely lower back, knees and ankles. The patient reported the pain was worse at the end of the day or after any activity. See body chart for full details re. patient's pain including severity, aggravating and easing factors.

Previous Medical History and Birth history:

The patient was born at full term and achieved all his milestones within normal limits, the only problem he had was his instability and regular falls. The patient was diagnosed with dyspraxia at seven years of age. No previous trauma, operations or illnesses of note.

Drug History:

Patient X takes Ibuprofen and Paracetamol as needed.

Investigations:

Patient X reported having an X ray and MRI of his back which showed minor canal stenosis.

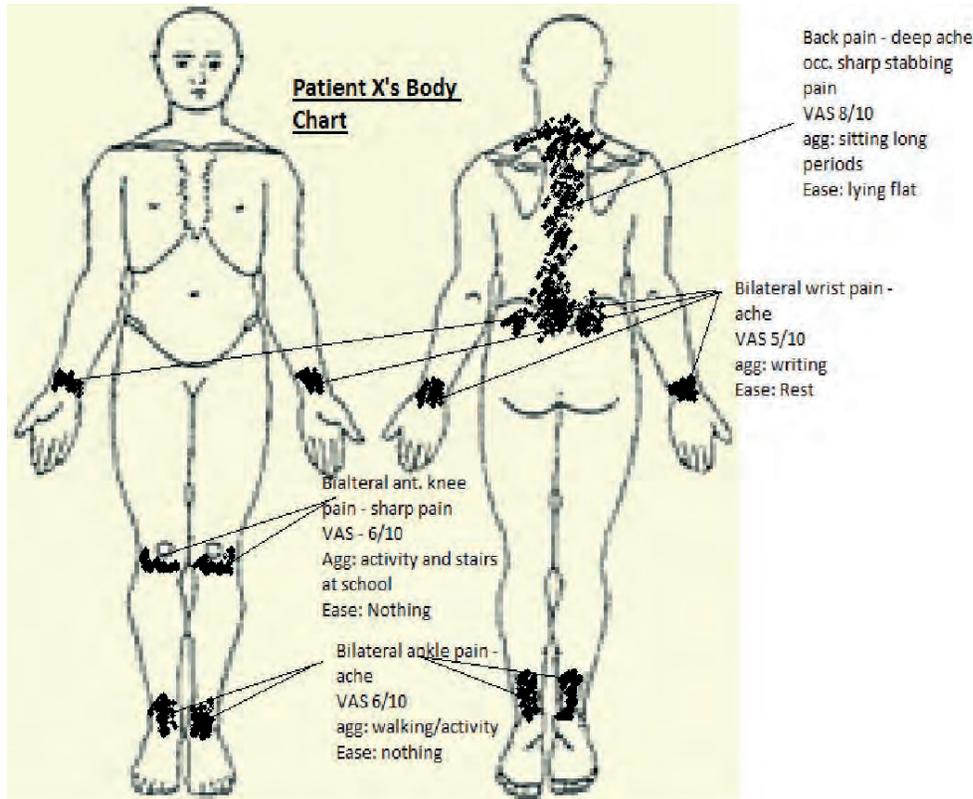
Family History:

Patient X lives with his parents, he is an only child. His mother has fibromyalgia and irritable bowel syndrome and his father has spinal stenosis, hip dysplasia and reports always being 'flexible' in his joints. His father works shifts in a factory and his mother is a full time mother.

Social History:

Patient attends a mainstream academy school and is currently in year 8. The patient reports he enjoys school especially art but finds his pain gets in the way of his learning. The patient does not participate in school sport and has not since he started secondary school due to concerns about his joints. The patient reported he enjoyed his Riding for the Disabled that he did weekly and he also wanted to go swimming but had found it difficult in the past.

Attachment 3:



Attachment 4 – Visual Analogue Scale:

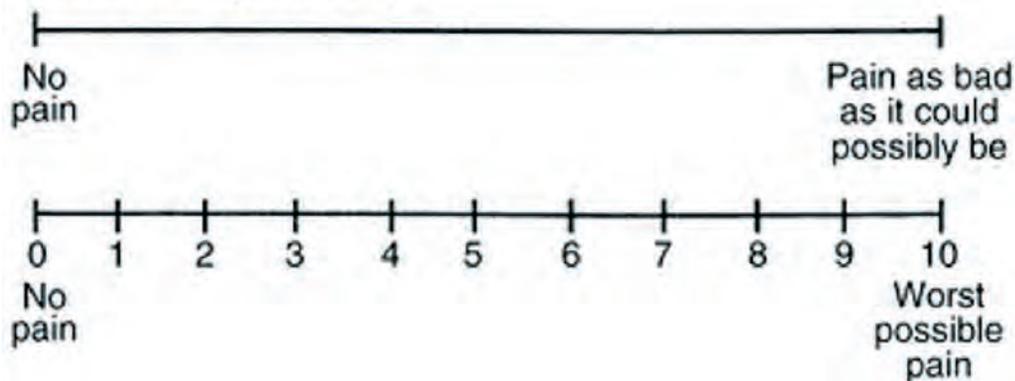
Verbal Numerical Scale

If "0" is "no pain" and "10" is the worst pain you can imagine, where is your pain now? on average? at its worst? at its best?

Word Scale

None Mild Moderate Severe Excruciating

Visual Analogue Scales



(Schofield et al, 2007)

Attachment 5 – Popliteal Angle:



(White et al, 2009)

Attachment 6: Personal Exercise Programme for Patient X

Exercises to be completed every day:



1.
Lying face down.

Bend one knee and hold on to the ankle, pull the ankle towards your bottom until you feel a stretch in your thigh, hold 15 seconds, slowly relax and change legs.

Repeat 5 times, 2 reps



2.
If the other exercise is too hard you can start with this one;
Lying face down.
Put a non elastic piece of material (i.e. dressing gown cord) around your ankle and repeat above exercise using material to help pull ankle towards bottom.



3.
Sit on your bed with one leg straight in front of you with the heel over the edge and the other leg on the floor (as shown).
Bend your upper body forwards keeping your back straight (keep your leg on the bed straight). Hold 15 seconds.
Repeat 5 times, 2 reps on each leg



4.
Stand with your feet together facing a wall, leaning against it with your arms and back straight. Let your body drop towards the wall keeping your heels on the floor. You should feel the stretch in your calves, hold 15 seconds. Repeat 5 times, 2 reps.



5.
Lying on your back with knees bent. Tighten your stomach muscles and slowly lift your bottom of the bed so that your knees are in a straight line with your shoulders, hold 3 seconds then lower slowly. Repeat x 10, 2 reps.



6.
Sitting tall with shoulders in a good position. Slowly slump your lower back, try to feel your pelvis tipping 'like a soup bowl' then slowly sit tall again. Repeat x 10, x 2 reps.

7.
Practise standing on one leg – try and brush your teeth on one leg!
Practise using your wobble board and time how long you can keep your balance



8.
Think about your sitting posture, esp. when on X Box! Ensure you sit on a good chair with back support if you need it.



9.
This is a bad sitting posture!!

Felicity Vann, Band 5 rotational physiotherapist within Dudley Group of Hospitals.

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Introduction to Paediatric Physiotherapy Course: Case study 2

I have selected the following case as I feel the respiratory session with Kath Sharp at the Introduction to Paediatric Physiotherapy Course (IPPC) has had the biggest impact on my clinical practice to date. For confidentiality purposes the child's name has been changed to Holly.

Background/Condition

During an on call shift I attended the Children's Ward to see two patients. I work within the community paediatrics team and both patients listed were known to me from previous hospital admissions and in the community, although not on my own caseload. I had prioritised the patients based on the handover from the nursing staff, as the physiotherapy handover from the previous day reported both children were equally unwell. Holly was with the medical team on the ward round and the other child had just had a period of desaturation with copious secretions, so I selected to see the other child before Holly. While writing the post treatment notes for the first child I was asked to immediately attend to Holly by the ward doctor. The nurse and Holly's Mum were present stating that she was desaturating and appeared to be irritated by retained secretions, the nurse had attempted suction with nil yielded.

PMH

Three year old girl with severe quadriplegic neurological deficit, as yet undiagnosed cause.

Epilepsy – frequent seizure activity.

Microcephaly.

Laryngomalacia and distal bronchomalacia.

Dyskinetic abnormal movements.

PEG fed.

Hearing and visual impairment.

Severe complex global developmental delay - viewed to be at developmental age of 3 months.

Multiple hospital admissions for respiratory infections, including at age 18 months a period of ventilation due to H1N1 virus. Knowing of previous infections is important as reported by Kath Sharp (IPPC 2012) as repeated infections can cause a chronic increase in mucus volume.

Community physiotherapy input with a previous unsuccessful trial of PEP, Holly turned blue with use of the mask and Mum reluctant to try again. Home suction equipment.

Holly is a child with complex needs as per the definition by Dr Rennie on the IPPC in her normal development and disability session. Holly has 7 of the 8 disability categories and all at a severe level: motor, hearing, visual, cognitive, speech and language impairments as well as feeding problems with additional chronic health needs.

HPC

On 7th day of admission for a chest infection. Patient had been receiving IV antibiotics, unknown infection despite blood and sputum cultures taken. At least twice daily physiotherapy input since admission consisting of positioning, percussions, expiratory vibrations and suctioning. Holly was receiving intravenous antibiotics, saline nebulisers and paracetamol as well as her routine medications for epilepsy and excess saliva.

PC/Assessment

- Oxygen Therapy: Holly receiving 5 litres of oxygen by Vapotherm (humidified high flow oxygen therapy) via nasal prongs.
- Observations: SpO₂ fluctuating 90-92%, heart rate 174, temperature 39.4oC, blood pressure 84/46.
- Position: Supine in cot bed with head raised tilt, due to dyskinetic movements sliding down the bed and needing frequent repositioning.
- Therapist Observations: audible airway secretions, child attempting to cough but ineffective effort, continuous dyskinetic movements (normally not continuous) – medical staff unsure if seizure activity or reaction to high temperature, sub costal recession, grunting, irritable and distressed child.
- Palpable secretions mid to lower zones with left side more affected than right.
- Mum upset and anxious.

At this stage I did not auscultate, I felt I had enough information to clinically reason the need for immediate intervention to aid secretion clearance based on dropping oxygen saturations, audible secretions, palpable secretions and child's general distress and signs of increased respiratory effort. As reported by Kath Sharp at the IPPC 'increased secretions leads to increased airway resistance and increased heart rate as infants under 1 year cannot increase their tidal volume to increase their work of breathing' thus 'respiratory failure can happen very quickly'. Although this child is over 1 she is known to have global developmental delay and distal bronchomalacia thus the presentation of her airways are likely to be floppier than would normally be expected of a child of her age and more like a younger infant.

During my assessment Mum was noted to be very anxious and understandably upset. Throughout my assessment and as my treatment session continued I ensure Mum stayed informed of my findings and planned actions. This firstly allowed her to give consent as per Health Rights Information Scotland as Holly is under 16 and unable to understand consent. Secondly as Sheila Milligan stated on the IPPC poor communication can lead to parents feeling vulnerable, having higher levels of stress, feelings of fear and demanding behavior. Holly's Mum was known to the ward and was known to be demanding at times thus good communication was vital to avoid Mum becoming more anxious and upset. During the session Mum was able to settle in her chair and read a magazine so hopefully demonstrating that my communication was effective enough to avoid the negative behaviors raised in Sheila Milligan's talk.

No goals were set with Mum but my short term goals were to improve oxygen saturations to over 94%, clear some of the audible and palpable secretions and reduced the signs of respiratory distress and increased work of breathing.

As stated on the IPPC children have a higher metabolic rate with greater oxygen demand thus saturations, as recommended by Kath Sharp should not be below 94% or as per local protocol. We do not have any guidance locally on lowest recommended saturations but the alarms on this child's saturation monitor were set at 93% by the nursing staff.

My outcome measures would be Holly's vital signs including her SpO₂ and quantity of secretions yielded as well as more subjectively the presence of audible and palpable secretions. Long term goal would be for Holly to return home at the same functional level as upon admission.

Treatment Planning

Positioning: On arrival and during initial assessment Holly was positioned in supine. Positioning directly effects ventilation/perfusion matching and arterial oxygen levels (Hussey 1992). As Holly's saturations were sitting 90-92% the immediate priority was to aid ventilation rather than at this stage secretion clearance. Thus positioning to improve ventilation was important and as the left side was found to be more affected with secretions, Holly was positioned into left side lying. As stated at the IPPC infants and children ventilate non-dependent lung regions (Kath Sharp 2012) thus children with uni-lateral lung disease should be nursed with their good lung uppermost (Hussey 1992).

Manual Techniques: I begun with expiratory vibrations on the left side and then progressed to the right side, on reassessment with my hands I felt the secretions were not being mobilised sufficiently and no cough had been stimulated. My choice to use expiratory vibrations was based on my own clinical experience, having found this to be more effective than percussion at mobilising secretions. Limited research has shown percussions and vibrations to be effective in mobilising retained secretions (Hussey 1992). However as they rarely used as a treatment in themselves but as adjuncts to positioning, breathing exercises and suctioning it is difficult to assess the efficacy (Hussey 1992). The child remained distressed with SpO₂ remaining at 92% and no change to Holly's increased work of breathing. Thus I felt an alternative treatment option was required. I did not feel percussion and shakes would be any more effective as they work in the same way as vibrations, 'by producing a transthoracic pressure wave that shake secretions from the airway, or mobilise secretions by stimulating a cough reflex' (Kath Sharp IPPC 2012). No cough had been stimulated as yet and the secretions were still being retained and causing signs of respiratory distress.

Autogenic Drainage: Prior to attending the IPPC I would not have considered autogenic drainage (AD) for a child under 5 years as this was the guidance from our senior staff that it would not be effective in a child under 5 due to collateral ventilation being less established. Upon attending the IPPC Kath Sharp advised that she uses autogenic drainage in all ages of patients and has found it be effective. Research literature shows in both short and long term trials no significant difference in lung measures between autogenic drainage and postural drainage/percussions but that the patients

showed a preference for autogenic drainage (Kath Sharp IPPC 2012). Agostini and Knowles (2007) also report that there is insufficient quality evidence about which airway clearance technique should be used but that the theory of AD supports its effectiveness in increasing the velocity of air-flow to clear secretions. Patients, such as Holly, who are intolerant and receive little benefit from more forceful expiratory techniques and whom energy conservation and relaxation are desirable are ideal candidates for AD (Agostini and Knowles 2007). In my own clinical experience I have used AD and assisted AD with both adolescents and adults and found it to be effective and well received by patients. For Holly the use of assisted autogenic drainage would be required due to her age and cognitive ability (Van Ginderdeuren 2009). The aim of assisted AD is to increase the expiratory flow velocity and temporarily reduce residual volume in order to mobilise secretions (Kath Sharp IPPC 2012). The explanation on the IPPC of AD with the diagrams displaying the choke point and the importance of getting airflow behind the secretions in order to mobilise clarified the principles of the technique and why it can be effective.

I used assisted AD with Holly during this treatment session and was then able to clear mucoid purulent secretions through nasal pharyngeal suction; this was the first successful clearance of secretions for approximately 2 days. Unfortunately during suctioning Holly desaturated to 85% and heart rate to 188 and required 5 litres of supplementary oxygen via a face mask, with time she her observations improved with saturations to 99%. Holly was less distressed with no audible secretions, some residual palpable secretions on the left lung, no grunting and less sub costal recession. Holly was repositioned into right side lying with the nursing staff to continue nursing in alternate side lying. Although Holly still had secretion retention she was now maintaining her saturations and was drifting into sleep. Holly had slept very little in the last 24 hour period due to her irritability and distress and thus despite there still being secretion retention treatment was stopped for this session. I felt I had met my short term goals of improving oxygen saturations, clearing retained secretions and reducing work of breathing.

Second Treatment Session: I returned to see Holly at lunchtime. A nursing auxiliary was present with Holly. She was now on 6 litres of oxygen via the vapotherm, temperature 39.6°C, SpO₂ 96%, heart rate 184. Dyskinetic movements continue with sub costal recession and general irritability. Holly was in supine with the head up tilt on the cot. Palpable secretions right mid zone with harsh breath sounds throughout on auscultation. As secretion retention remained the presenting complaint and the effectiveness of assisted AD in the earlier session I selected to use this as treatment again. I focused on the right side and again yielded mucoid secretions with nasal pharyngeal suction. During suctioning saturations only dropped to 94% but heart rate rose to 200, although it settled quickly further suctioning was not performed despite secretions remaining due to the distress caused. Normal heart rate for a child of 3 should be between 60-140 (Kenyon and Kenyon 2004). Nursing staff were again advised re nursing in alternate side lying. The use of alternate side lying was advised so no lung region remained dependent for long periods and thus gaining the benefits of both improved ventilation and draining of secretions (Hussey 1992).

Third Treatment Session: Holly's Mum was now present with the nurse and Holly was receiving rectal paracetamol due to a spiked temperature of 40°C. The additional dyskinetic movements were continuing and it was still unclear whether this was seizure activity or a response to the pyrexia. Holly remained extremely distressed with grunting, sub costal recession and extreme irritability. There were audible secretions as well as palpable secretions on both the left and right lung fields. SpO₂ at 94% with a heart rate of 189. Again due to the effectiveness I used assisted AD again with mucoid secretions on suction yielded. Suctioning could only be performed once due to heart rate rising to 210 and Holly becoming extremely distressed. Audible secretions remained and saturations remained at 94%. Holly still displayed many signs of respiratory distress including grunting and sub costal recession (Hough 2001). As well as her irritability she was extremely fatigued. Her inability to tolerate suctioning was of concern to me as she was not stimulating a cough herself and

thus retaining her secretions. As a non specialised hospital with only one paediatric ward and no ability to provide respiratory care higher than the vapotherm for oxygenation and ventilation I had concerns we were reaching our hospitals' limit of being able to care for Holly. The medical staff requested I returned to see Holly for a fourth visit in the evening, and although I agreed this would be appropriate I also felt a full medical review at this stage was necessary. Holly's nurse disagreed with me and appeared insulted I was implying she was not caring adequately for Holly. Despite feeling fairly competent in on call physiotherapy and being static in paediatrics for two years following the IPPC I felt confident now to class myself as a paediatric physiotherapist, thus giving me the confidence to trust my clinical assessment and reasoning that this child with an existing severe complex disability was now severely unwell with a respiratory infection and distress. On the IPPC when discussing the role of the paediatric physiotherapist Elizabeth Gray stated our role is to safeguard the child while using clinical skills and knowledge, communication to be a team member and partner to carers. This formed the basis behind my drive to push for further medical assessment to ensure that Holly was receiving not just the correct physiotherapy input but the best overall care available. As Dawn Moss stated on the IPPC it is everyone's responsibility to ask, this was in reference to the Getting it Right for Every Child (GIRFEC) policy. On reflection the key questions as part of GIRFEC for the named person to ask were relevant to this situation:

- 'What can I do now to help this child?'
- 'What can my organization do to help this child?'
- 'What additional help, if any, may be needed from others?' GIRFEC (2012).

I would answer to the first that physiotherapy has been effective but due to the child fatiguing and the intolerance to suctioning physiotherapy was becoming less effective and not sufficient to help the child. To the second question my organization as mentioned above was reaching its limits of the level of care it could provide. To the third help was needed from a more specialised centre, as was mentioned frequently on the IPPC children are not just miniature adults but a clinical specialty.

I discussed it further with the nurse and agreed we would discuss with the ward doctor. On discussion he agreed the consultant could be contacted, who agreed discussion with the specialised paediatric centre should occur with request for transfer. Holly was transferred that evening.

Conclusion

The benefits I have gained from attending the IPPC are demonstrated in this case study with not only improved knowledge and understanding but an improved confidence in my abilities and my clinical knowledge. The positive influence for my patients and practice is demonstrated with more effective care of Holly with a broader knowledge, understanding, clinical reasoning ability and skills. Since the course I have been able to utilize this in not only this case but in my every day work as a paediatric physiotherapist.

Sarah Mayberry, Community Paediatric Physiotherapist within NHS Forth Valley

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Introduction to Paediatric Physiotherapy Course: Case study 3

Toe walking is a common referral for physiotherapy assessment and review. Although it is considered a normal transient part of the development of gait (Sutherland et al 1980) it can be associated with a number of neurodevelopmental, orthopaedic and psychiatric disorders. Toe walking that continues longer than three months after the onset of independent walking is characterised as persistent and has been associated with developmental delay, language disorders and autism (Barrow et al 2011, Shulman et al 1997, Accardo et al 1989). When toe walking continues beyond the age of three with no recognisable underlying cause it is considered to be idiopathic (Engelbert et al 2011, Sala et al 1999). Barrow et al (2011) reported that in the absence of an underlying motor problem toe walking persists longer in children with autism and can contribute to the development of secondary orthopaedic problems. The following presents the case of a five year old boy with autistic spectrum disorder (ASD) referred to physiotherapy due to concerns regarding his toe walking gait and whether there may be a concurrent underlying organic cause.

Assessment

Assessment was challenging due to the severity of the child's ASD and was therefore staged over several short sessions both at home and the special educational unit that he attended. Subjective information was gathered from the child's mother, teachers, other health care professionals involved in his care and previous physiotherapy notes. His mother reported a normal pregnancy and birth followed by uneventful and expected developmental progress until he was 18 months old. He then began to regress and was subsequently diagnosed with ASD. He was reported to have always walked on his toes and had not received any intervention for this problem. He did not communicate using either verbal or non-verbal language. He was, however, able to follow short commands such as: "heels down" when walking with an adult but needed this to be continually repeated to maintain.

Objectively the child was observed to maintain an equinus posture both in static stance and when mobilising. He had anterior pelvic tilt with a mildly increased lumbar lordosis. His footwear was noted to be moulded into an equinus shape further indicating that this posture was sustained. He was able to fully extend his knees in standing and during gait when on his toes but to bring heels down he flexed at the knees bilaterally and transferred his weight anteriorly increasing hip flexion and lumbar lordosis. This posture compensation suggested tightness of the posterior crural, hamstring and hip flexor muscles. As the child did not tolerate handling well priority was given to gain accurate measurements of the gastrocnemius and soleus muscles particularly as tight heel cords is a well documented problem associated with equinus postures (Barrow et al 2011). Shortening of the hip flexor and hamstring groups was considered likely from the postural assessment and would also be addressed but not objectively measured by goniometry for practical reasons. Passive range of movement of the ankle with knee extension identified bilateral restriction into dorsiflexion attaining plantargrade on the right and -5 degrees on the left. This range increased slightly if the knee was flexed but not to expected ankle joint range. There was therefore soleus involvement in the joint restriction too. On palpation in a resting position the

muscle belly of gastrocnemius was firm. There were no velocity dependent changes in tone. He was able to execute transitions well though when facilitated to stand from a chair with feet plantargrade the movement was with momentum and lead by trunk extension rather than active hip extension. This was noted as it may indicate weakness of the hip extensors. The child had no leg length discrepancy or restriction in range at his hip or knee joints bilaterally.

He had a symmetrical gait pattern with an absent heel strike. He was noted to be able to change direction, accelerate and decelerate and negotiate obstacles with no difficulty demonstrating smooth quality movement, good coordination and balance. The child was able to use both upper limbs appropriately. There was no evident increase in tone or associated movement patterns.

Clinical Findings

There was no clinical indication of a concurrent organic disorder. Barrow et al (2011) made the observation that persistent toe walking in autism may correlate with language disorder more than any other feature of autism. Considering the child has significant language impairment it concurs with available evidence and clinical findings that his toe walking is primarily associated with ASD.

The child had reduced ankle range of movement due to decreased length of the tendo-achilles complex secondary to persistent actively maintained equinus posture and gait.

Although specific hands on assessment of muscle strength and length was limited, observation of functional activities and posture suggested that the child had some muscle power imbalances around the hips/pelvis/trunk secondary to his gait pattern. There were no specific asymmetries detected. Increased plantarflexion forces during the early stages of stance, as in equinus gait, cause a reduction in forces generated by the hip and knee extensors (Sasaki et al 2008, Kerrigan et al 2000). Considering this, it is likely that persistent equinus gait has led to natural weakness of the extensor muscle groups due to decreased demand from a kinesiological perspective.

Setting Treatment Goals

Understanding the underlying cause of toe walking in this child was important for setting a framework for establishing goals and a treatment plan. Very little is understood about the underlying mechanism for toe walking in autism. Speculation has been made that it is related to persistent labyrinthine reflexes, vestibular problems, visuovestibular dysfunction or other sensory processing difficulties (Edelson article accessed 2012, Shulman et al 1997). As toe walking in this child was linked to ASD it was considered that although treatment may influence his gait pattern in the short term it was unlikely to eliminate it. This was therefore not the primary aim of physiotherapy, rather management of the secondary orthopaedic problems that were developing as a consequence of persistent equinus posture. As the child had been referred with the problem of toe walking his carer's expectation was that treatment would stop the toe walking habit. The first goal in managing this case was to explain the clinical findings and the nature of the child's toe walking in order to establish new expectations of the role of physiotherapy in this instance. The child's mother was accepting of the information and open lines of communication were formed as a basis for joint goal setting.

From the clinical findings the following goals were set:

- 1) Short term (6-8 week therapy block) - Improve passive ankle dorsiflexion range of movement measured as increased degrees of range by goniometry.
- 2) Short term (6-8 week therapy block) – Improve strength of hip extensors measured by active hip extension during sit-to-stand with feet plantargrade.
- 3) Long term - Prevent progressive loss of ankle range of movement into dorsiflexion and the development of other foot abnormalities and muscle imbalances along the kinetic chain.

Clinical Reasoning in Treatment Planning

There is very little evidence on the natural progression of toe walking in autism and although tight heel cords has been identified as a secondary problem in this patient group (Barrow et al 2011) there is no research into the types and efficacy of various treatment strategies. In order to be evidence-based in the clinical reasoning of this case, where good randomised controlled trials do not exist in the literature, it was necessary to take a look at the next best external evidence together with the physiotherapists own clinical experience (Sackett et al 1996). It was reasoned that idiopathic toe walkers (ITW) may have more in common with autistic toe walkers as there are no central motor deficits or issues of tone causing the gait pattern and they share identified problems in language development (Barrow et al 2011, Shulman et al 1997, Accardo et al 1989). It was therefore considered appropriate to draw on evidence relating to ITW in developing a treatment strategy.

In healthy children the variation of ankle complex range of movement is wide and mean dorsiflexion with knee extension is measured around 27 degrees (SD 6.6) (Alanen et al 2001, Greene and Heckman 1994). The child in this case therefore has a significant loss of ankle range. As progressive loss of ankle dorsiflexion has been shown in ITW (Sobel et al 1997) intervention is clinically warranted. Passive stretching is used to achieve length changes in muscles. The peak effects of short periods of stretching are not long lasting (Sahrmann 2002) and would unlikely be effective against the long periods of active posturing into equinus. In addition, the child had limited tolerance to having his feet touched and therefore stretching as repeated exercises throughout the day may have caused too much anxiety, burdened his carers and been disruptive to his education. Stretching a shortened muscle should be achieved by prolonged elongation with low loads as this will increase the number of sarcomeres in the muscle fibre thereby improving the overall length of the muscle (Sahrmann 2002). The child did not tolerate orthotics to resist plantarflexion for use with footwear; however, he tolerated Boston night splints. It was hoped that these would help prevent any further loss of dorsiflexion but it was not considered enough to significantly improve the range. Two further treatment options identified in the literature in ITW are Botulinum toxin type A (Botox-A) injections and serial casting. The use of Botox-A appears to normalise EMG patterns during gait in ITW allowing a more normal foot strike pattern and in the absence of contractures has shown favourable results in reducing though not eliminating toe walking (Engstrom et al 2010, Brunt et al 2004). Botox-A is considered a safe treatment modality for use in children with musculoskeletal conditions with no adverse reactions reported in one study (Dahan-Oliel et al 2012). Serial casting improves ankle dorsiflexion, decreases passive resistance to stretch and improves gait parameters in ITW (Fox et al 2006, Brouwer et al 2000). Although these studies are limited due to small convenience samples and subjects of varied age and severity of toe walking, the results provided some evidence to consider these lines of treatment. The child was therefore referred to the Botox-A clinic for assessment and it was there decided to treat him with the aim of reducing the power/activity of the gastrocnemius muscles followed by casting to immobilise the ankle joint in a stretch position. On follow-up at the Botox-A clinic it was decided that the casts would be changed to serially increase the stretch. The risk-benefit relationship of this treatment needed to be carefully considered as it would involve anaesthesia to administer with no definitively predictable outcome. This was explained to the child's mother who agreed with and consented to this line of treatment with full knowledge of the uncertainties.

To address the second goal of improving hip extensor strength the child was encouraged to do activities in high kneeling at home and school. Once wearing casts to fully eliminate plantarflexion a focussed period of hip extensor and core stability exercises was introduced. Included in this programme was exercise and postural management to improve hamstring and hip flexor length as well.

Getting it Right for Every Child

It is also important to place the child's assessment and treatment goals into the context of *Getting it Right for Every Child* and the *National Practice Model* (Scottish Government 2012) as this "provides the foundation for identifying concerns, assessing needs and risks and making plans for children in all sectors". Using the SHANARRI indicators from a physiotherapy point of view the child needs help in the 'Healthy' domain as the orthopaedic problems identified may threaten his future health. For instance he may develop pain in his feet or other joints which may in turn affect his willingness to mobilise. This could impact on how well his carers are able to cope with his care needs as well as his ability to be included in activity at school or the community. The *My World Triangle* (Scottish Government 2010a) is used to gather information to build a holistic view of the child and how social and environmental factors impact on his health. This can be very detailed and it is recommended that information gathering should therefore "be proportionate to the problems". Therefore, it is also relevant to note that the child was from a supportive family but his mother was a lone parent with another child to care for as well. This was important to consider when developing a treatment plan that would rely heavily on carer participation for it to be successful for example if asking the mother to carry out an exercise programme, apply splints every night or attend many appointments. The family also did not have a car and relied on public transport. Where possible, appointments were arranged at home or at school with appropriate feedback. Further, it was anticipated treatment may reduce or limit outdoor mobility for a short time and therefore arrangements were made for a wheelchair device to support his mother/education staff and ensure continued inclusion at school or in the community. Wearing plaster casts would affect bathing and the mother needed to be prepared for this and advice was sought from an occupational therapist.

Furthermore, the child attended a special unit within a mainstream school and was well supported in this environment. Educational staff, allied health professionals and parents worked well together to achieve the best outcomes for the child. Working within the specialist role identified in the AHP Matrix of the Guidance on partnership working between allied health professionals and education (Scottish Government 2010b) the physiotherapist worked with staff to develop expertise in managing the identified needs of the child. This, for example, included training on how to effectively monitor ankle joint range of movement so any new changes could be identified and addressed early. Planning of how treatment such as exercises could be integrated into the child's daily life at home, school and the community was undertaken and those involved in the day-to-day care of the child were encouraged to take responsibility for carrying out the daily treatment with support. Effectiveness of input was measured through objective measures identified in the goals. This information would help inform whether further input was required at the end of the treatment period or whether the child and carers should be prepared for discharge. At the time of writing this outcomes are not known.

Conclusion

Persistent toe walking can lead to secondary orthopaedic problems which may progress over time and therefore early intervention and a management plan is important to prevent possible long term health problems. Goal setting and treatment planning should be done within the context of GIRFEC ensuring a comprehensive and holistic approach that includes the child's whole life context and including measures of effectiveness of any intervention and appropriate discharge planning.

**Louise Myeni, Paediatric Physiotherapist on a career break, but hoping to get back in to work.
Supported by staff within NHS Forth Valley**

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Elastic therapeutic taping in paediatrics

The use of taping has grown dramatically in physiotherapy. Perhaps this has been encouraged by the rainbow colours that were on display on so many of the competitors at the Olympics and more recently at Wimbledon! It would seem, looking at the course adverts, that there are many “styles” of taping; sports, myofascial, therapeutic to name a few.

Training in taping is now easy to access but there are few practitioners who are specialising in paediatrics. How do we know what type of taping to use? Similarly, it is hard to find unbiased information on which of the myriad tapes that are now available is best suited to our needs. Patients can buy tape at places such as “Boots” and are using it to treat themselves, even though the instructions do say “for professional use”.

Personally, I did a two day course led by Esther Du Roi and I found her ideas and experience amazing, educational and helpful and they have worked in many of the patients, adults and children I have treated. Her comments on the tapes to use have also proven extremely invaluable (i.e. don't go for cheap Chinese tapes as the rate of allergic reaction due to chemicals in the glues, is high) However, there are other trainers with other ideas, and I hope at some point to take some other courses to hear other opinions on its use.

As a group of paediatric professionals, perhaps we need to look at how we are using taping, sharing our experiences, our successes and failures, and possibly look at research to give us more evidence as to what we are doing. How does paediatric taping in MSK conditions differ from neurology or other areas of paediatrics? What can we learn from each other?

It may not be useful to suggest a specific group for “tapers” but if people know of any paediatric forums that already exist for discussion perhaps you could share it so we can ensure that as a group, we are promoting best practise and don't give taping a bad name by inappropriate use. Many thanks

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Charcot Marie Tooth Disease: recognising peripheral neuropathies in clinical practise.

Charcot Marie Tooth (CMT) Disease is the most common inherited disorder in the UK affecting 1:2500 people. Many have an adult onset and are therefore not seen in paediatric practise. Some of the common forms have childhood onset but recognising them is not always straight forward.

When they are inherited and a parent has a diagnosis, diagnosing a child is easier, but where there is no family history, where the parent is only very mildly affected or has never been investigated, or in the rarer forms, children's problems may go undiagnosed or they may be misdiagnosed. Some children are referred initially to orthopaedic surgeons, some to paediatricians, but many will be seen at some time by physiotherapists. It may therefore be the physiotherapist who can identify the problems that can lead to a correct diagnosis.

CMT may also be known as Hereditary Motor and Sensory Neuropathy (HMSN). The name CMT was changed to HMSN but changed back to CMT as not all conditions have sensory or marked sensory involvement, and some do not have motor involvement (such as HSAN V, more commonly known as Congenital Insensitivity to Pain)

CMT is classified as axonal or demyelinating. The most common forms that have onset in childhood are CMT1a, CMT1x and CMT2a, where CMT1a and 1x are demyelinating and CMT2a is

axonal. The majority of children you will see in clinical practise have CMT1a and there is often a family history. These children very rarely have sensory involvement.

The presenting features are very variable, even within the same type of CMT or with children in the same family. The most common presenting features are gait changes and foot deformity. The most common foot problem is pes cavus with marked callus formation on the lateral borders and soles of the feet. Not all children, however, have “pes cavus” and some (our data would suggest more boys) have dramatically flat feet.

Weakness is apparent in the dorsiflexors and foot evertors. Foot pain, problems with fitting shoes, falls/tripping and fatigue with walking can all be reported. The feet are often affected asymmetrically. Other features that can be further indicators of CMT are hand weakness, which may not be recognised. This can lead to flat hands with wasting of the muscles of the thenar and hypothenar eminence. This may be reported as fatigue with writing and difficulty with functional activities such as fastening small buttons or unscrewing bottles and jars. Other problems are clicking, painful knees, occasionally dislocating patella in the absence of injury and hip pain, possibly more common in teenagers. Foot slapping, out of proportion to dorsiflexor weakness, may indicate sensory loss. High stepping gait, foot and toe injuries that go unnoticed, or produce little reaction and tripping, can also be indicators of reduced sensation. Some of the older children can have a kyphotic posture. Two of our children have presented in infancy with TA tightness which was treated with surgery.

Diagnostic testing is usually in the first instance by Nerve Conduction Studies (NCS) and genetic testing.

Further information can be found at CMT UK or on the MDC website

Physiotherapy Assessment: When assessing these children it is therefore useful if you suspect a child may have a peripheral neuropathy to look at the following parameters in assessment.

- Power: when assessing power, it is important to look at wrist strength, foot invertors and evertors, as well as dorsiflexion and plantarflexion, and where possible, grip strength. The difficulty with measuring grip strength is having an objective way of measuring it, and knowing the expected norms. Unless weakness is quite marked, smaller changes will not be apparent just by asking the child to squeeze your fingers. Fatigue can be an issue, so they may “let go” sooner than you would expect if you ask them to keep squeezing, but there is little normative data for this!
- Function: balance due to foot weakness or sensory loss can be a problem in CMT and those functions which highlight problems of balance need to be tested. Standing on one leg, balancing with eyes shut, balancing on heels and/or toes, and squatting can highlight difficulty. Hand function may be better evaluated by questioning the parents and children on items such as squeezing a toothpaste tube, opening bottles, doing buttons particularly small ones or jeans waist and fatigue with writing.
- Joint range: TAs may appear tight but this can be misleading in the presence of pes cavus where the tightness of the mid-foot can pull the talus down, elongating the TA. Inversion and eversion of the hind foot from neutral to assess varus or valgus, should be evaluated, even if only by “eye-balling”. In the hand, wrist flexion /extension, ulnar/radial deviation and long finger flexor tightness should be evaluated.
- Gait: assessing walking with and without shoes is needed. Speed, style, foot slapping, toe walking, should all be noted. Foot painting (as shown below)) is a cheap and easy way to evaluate foot problems and gait anomalies including asymmetry.
- Sensory testing: if you suspect sensory involvement in the hands or feet, in the clinical situation you can test fine touch and proprioception. Foot slapping in the absence of, or out of proportion to dorsiflexor weakness, high stepping gait or balance problems, can be indicative of sensory involvement.



Gait analysis any team can perform!



The cavus foot-print



Print showing the



The very flat foot marked callus formation on the lateral border*

If therefore, you are concerned about any of the above parameters, you may want to suggest to the referring Consultant or child's GP that further testing for a peripheral neuropathy would be useful.

(*treatment note; the very flat foot does not need insoles. The problem for these children is the very narrow heel that is not held well in the shoe causing problems with fit and subsequently walking. This can be controlled with a custom made semi-rigid heel-cup)

Further information can be found at www.cmt.org.uk or www.muscular-dystrophy.org

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First Welsh race-running-bike event

Children from South Wales had the opportunity to try out a running bike on the 9th of June, 2013 at the National Indoor Athletics Centre, Cardiff Metropolitan University. The bikes make walking or running possible by supporting the child with 3 large wheels and a slim saddle.



Students from Cardiff University School of Healthcare Studies helped out at the event, which was sponsored by Quest88 and organised by Physiotherapist Gabriela Todd.

Race-running is a competitive sport in Denmark and now also in Sweden. Scotland has already got several running bike clubs. The bikes are expensive and need special surfaces for safe running.

The students said *'everyone we spoke to enjoyed the event'; 'we found them fun and the parents were impressed'* although some found *'the saddles were quite uncomfortable'*.

We will run a similar event again in the autumn. If you are interested in taking part, please e-mail gabrielatodd@btinternet.com or ring 07803 770962.

COURSES

Two-day course on the treatment and management of cerebral palsy

Date: 7th and 8th November 2013

Venue: The Orchard School, Causeway Green Road, Oldbury, Birmingham. B68 8LD

Tutor: Pauline Christmas MSc MCSP, Consultant physiotherapist for the management of spasticity in children

Cost: £235

Details: This two day course will consist of a combination of lectures, videos, practical sessions and patient demonstrations. The approach to treatment will be based on the neurodevelopmental therapy/Bobath approach.

Applications: Please see the APCP website or the events section on the iCSP paediatric, neurology or Bobath networks.

Contact: pmchristmas@googlemail.com

APCP South East Region- MSK Study Afternoon

Date: Tuesday 1st October 2013

Venue: Barcombe Village Hall, Barcombe Mills Road, Barcombe, Lewes. BN8 5BH

Subject and tutor: Adolescent Shoulder Problems- Diagnosis and Treatment. Cath Ellis, ESP upper limb. The Limping Child- Differential Diagnosis and Treatment. Debbie Wilson, Clinical Specialist Paediatrics

Time: 2.00-5.00 (Registration at 1.30 please)

Cost: APCP members £15, non-members £30

Details: Free car parking at the Hall

Applications: Downloadable from APCP or iCSP websites, please return with payment

APCP North East Region- A Practical Gym Ball Study Day

Date: Wednesday 25th September 2013

Venue: Therapy in Praxis, York YO60 7NS

Time: 9.45-4.00 (Registration at 9.30 please)

Cost: APCP members £20, non-members £45 (including cold buffet lunch and refreshments)

Details: Free parking available. Places strictly limited and on first come, first served basis. Anyone wishing to purchase an anti-burst gym ball can do so for an additional £10

Applications: Downloadable from APCP or iCSP websites

Radiology for Paediatric Physiotherapists (RaPP) Lower Limb Course

Date: Monday 11th and Tuesday 12th November 2013

Venue: Radiology Academy, Cotman Centre, Colney Lane, Norwich NR4 7UB

Cost: £160

Details: This two day course is aimed at paediatric physiotherapists with a special interest in musculoskeletal medicine and/or orthopaedics. It will cover basic physics and background information to enable the safe and effective ordering of plain film x-ray images focusing on the lower limb. This will include a systematic approach to the interpretation of normal films to provide a framework for interpretation of images for orthopaedic pathologies.

Applications: Downloadable from APCP and iCSP websites or email simone.philpott@nnuh.nhs.uk for information

COUNTY SPORT PARTNERSHIPS

County Sports Partnerships (CSPs) are local agencies committed to working together to increase participation in sport and physical activity. Partners include: National Governing Bodies of Sport and their clubs; schools; local authorities; leisure facilities; the health sector; and many other sport and non-sporting organisations. CSPs are led by a strategic board supported by a central team of professional staff who provide leadership, co-ordination and structures which allow people and organisations to work more effectively together at a sub-regional level.

CSP Contacts by Region:

North

EFDS Engagement Officer	Tom	Webster	twebster@efds.co.uk 07764 291661	
County	First Name	Surname	Email	Phone Number
<u>Cheshire</u>	Sarah	Tilling	Sarah.Tilling@SportCheshire.org	07720 592784
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Midlands and South West

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Gloucestershire Sports Partnership	Rowland	Clark	rowlandclark@activegloucestershire.org	01242 246134
Herefordshire & Worcestershire	John	Clark	john.clark@worc.ac.uk	01905 542034
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Sport Across Staffordshire & S-O-T	Naomi	Bird	nbird@staffordbc.gov.uk	01785 619585
West of England Sports Partnership	Melonie	Gregory	Melonie.gregory@uwe.ac.uk	01173 286251
Wiltshire & Swindon Sports Partnership	Tasha	Morey	tasha@wiltssport.org	01380 725111

South and East

EFDS Engagement Officer	Jon	Whittingham	jwhittingham@efds.co.uk 07967 573 345
County	First Name	Surname	Email
Active Norfolk	Ellen	Van Lint	ellen.vanlint@activenorfolk.org
Active Surrey	Wendy	Newton	wendy.newton@surreycc.gov.uk
Active Sussex	Sally	Harper	sharper@activesussex.org
Berkshire County Sports Partnership	Justine	Mosley	justine.mosley@berksCSP.co.uk
Bucks & Milton Keynes Sports Partnership	Michaela	Smith	msmith@buckssport.org
Hertfordshire	Shelley	Woods	s.woods4@herts.ac.uk
Kent Sport Leisure & Olympics	Mike	Bishop	mike.bishop@kent.gov.uk
Living Sport - Cambridgeshire & Peterborough	Rebecca	Gilbertson	rebecca.gilbertson@livingsport.co.uk
Oxfordshire Sports Partnership	James	Craggs	Jcraggs@oxford.gov.uk
Pro-Active Central London	Cathy	Carr	carrc3@lsbu.ac.uk
Pro-Active East London	Michelle	Weltman	Michellweltman@yahoo.co.uk
Pro-Active North London	Colin	Smyth	c.smyth@mdx.ac.uk
Pro-Active South London	David	George	David.George@croydon.gov.uk
Pro-Active West London	Jemima	Morris	Jemima.Morris@brunel.ac.uk
Sport Hampshire and IOW	Sophie	Burton	sophie.burton@hants.gov.uk
sportessex	Rebecca	Jones	rebecca.jones@activeessex.org
Suffolk Sport	Terry	Mcentee	terry.mcentee@waveney.gov.uk
team BEDS&LUTON	Will	Hollier	will@teambedsandluton.co.uk

What is Boccia?

Boccia is a disability sport where players aim to propel balls close to a target ball. Two sides compete as individuals, pairs or as a team of three over a set number of ends. Points are accumulated over the course of a match to find a winner.

A ball can be rolled, thrown or kicked. If a player is unable to throw or kick the ball, they can use a ramp. If players are unable to release the ball with their hands, they can use assistive devices – head/hand pointer.

Boccia is a paralympic sport and is particularly suited to players with more severe physical impairment.

Boccia England is the national governing body for the sport in England and delivers competition and participation programmes and we are currently working on increasing the club network across the country.

For more information visit the Boccia England website www.bocciaengland.org.uk or contact the Boccia England office, info@bocciaengland.org.uk, 0115 9678455.





A fantastic action-packed sport that offers not only a great physical workout but a great way to build your confidence, meet new friends and see new places, wheelchair basketball is taking the nation by storm!

A sport for life, many players first play as part of their physical rehabilitation: building their strength, improving their chair skills and hand-eye coordination in a sociable environment.

You don't need to be a wheelchair user to play and people without a disability are also very welcome to play and compete alongside you in The Lord's Taverners Junior League (U15 & U19), Women's League, the British Wheelchair Basketball (BWB) Development League, and National League in Divisions 3-1, so bring your friends and family!

With over 120 teams – including 19 specifically for junior players – having taken part in the 2012/13 season, wheelchair basketball offers a great team sport whether you're looking to play socially or competitively.

Not only this, but with clubs all over the nation, it's easy to find your local team – just enter your postcode into the BWB Club Finder at www.britishwheelchairbasketball.co.uk or call the office on 01509 279900.

To get started, all you need is your gym kit – your club will be more than happy to provide you and your friends with specialised sports chairs.

If you have any questions or would like to find out more, check out the BWB website, Facebook Page (/BritishWheelchairBasketball), Twitter (@BritWheelBall), or give the office a call on 01509 279900



GB U22 v Turkey



The Lord's Taverners National Championships

Leadership
training

Learn new
skills

Join a club
near you!

kidz unlimited

Sign up and
join the most
fun and exciting
network for young
disabled people
in the UK!

Call our team on 0800 151 3350
www.kidz-unlimited.org.uk

Whizz-kidz
move a life forward

Sitting Volleyball

Sitting Volleyball is a fast and exciting team sport, played sat on the floor. At International level it is predominantly played by amputees and people with other physical disabilities however domestically and recreationally it is fantastically inclusive, allowing players with and without a disability to play together at the same time.

Over the last 18 months, over 10,000 young people have experienced sitting volleyball, ranging from inclusive activities in school played with a beach ball, to Julie Rogers, a 13 year old amputee competing for Great Britain at London 2012.

The game is easy to set up and adapt which allows young people with a range of injuries and disabilities to play and is a great way to keep fit and aid with recovery in a fun and sociable way.

For more information as to how you can deliver Sitting Volleyball in your groups or if you have any questions, please visit our website www.volleyballengland.org or contact Daniel Griffin, Sitting Volleyball Development Manager at Volleyball England, at d.griffin@volleyballengland.org or on 01509 22 77 28.



Cerebral Palsy (CP) Sport is the country's leading national charity providing an advisory and delivery service in disability sport. Through a range of disability sports, such as football, swimming, athletics, Boccia, table cricket and adapted sports, we provide sporting opportunities for children, young people and adults to enjoy. We also offer expert, specialist support to parents, support workers, teachers, coaches, physiotherapists, occupational therapists, sport providers and other professionals on how to adapt sports for people with cerebral palsy.

Here are three examples how CP Sport is successfully directly addressing the need for more opportunities for disabled people.

Table Cricket Community League:

In November 2012 CP Sport were successful in securing funding from Sport England's Inclusive Sport Fund. The Table Cricket Community League was one of 44 different projects funded from around the country. The league will give people aged 14+ an opportunity to participate in regular and structured Table Cricket activity. The three year programme will establish 32 County leagues with 128 teams participating in those leagues. There will be regional and national finals established to give the players a pathway to national championship.

CP Sport Football Programme:

CP Sport are continuing to develop football opportunities in new areas of the country. We already have well established CP specific football opportunities in Yorkshire, Newcastle and the Midlands. We will continue to grow and expand these opportunities, by introducing more opportunities to more people such as football for walker users and developing girl's only teams.

Junior Multi Sports Programme

In partnership with Youth Sport Trust, CP Sport is delivering a 3-day bespoke training and adapted sports programme in special and mainstream schools. This inspiring initiative up-skills sports leaders before, under the guidance of CP Sports team of expert coaches, they run a multi sports day and a competitions day for children with a physical disability. The many benefits of this project include:

- **Young people** with a physical disability have the chance to enjoy playing a variety of adapted sports.
- **Young Sports Leaders** learn new skills and gain a qualification.
- **Teachers and volunteers** learn about inclusive sports practices and discover new ways to engage their students in sport. .
- **Students** learn new skills, make new friends and learn about teamwork and leadership.

Swimming Development Programme:

At CP Sport we provide opportunities for anyone with cerebral palsy who wishes to be involved in swimming regardless of age or ability. CP Sport is very proud of the achievements of all the people who have been involved in our charity's swimming programme over the years. Swimming at a grass roots level is our passion and we want to make sure everyone with cerebral palsy who wants to swim gets that opportunity and also has the chance to compete.

Athletics Development Programme:

CP Sport believes everyone with cerebral palsy should have the opportunity to participate in sport. We have a team of dedicated athletics coaches who are here to support, train and offer you great advice. We also provide a range of athletics opportunities starting from a grass root introduction to a senior competitive level for anyone with cerebral palsy regardless of age or ability. CP Sport currently run training days, grand prix events and a single national athletics championships at the end of the season.

Cerebral Palsy (CP) Sport England and Wales will be hosting the CPISRA World Games in Nottingham 7th to 16th August 2015. A multi sport event will attract entries from around the world. You can register your interest in competing or volunteering by registering your interest by emailing: info@cpsport.org

For further information on any of activities above please visit www.cpsport.org

ENGLISH FEDERATION OF DISABILITY SPORT

The English Federation of Disability Sport (EFDS) was established in September 1998 as the umbrella body for disabled people in sport and physical activity throughout England. Their vision is that disabled people are active for life. EFDS champions opportunities for disabled people to enjoy sport, supporting the sport and physical activity sectors to be more inclusive.

By supporting the sport sector and engaging with disability organisations, EFDS are in the best position to support participation at every level. Sport and physical activity should be a meaningful experience, whatever level disabled people choose. EFDS's partnerships across different sectors mean they can share better practices so more inclusive programmes can be offered.

Working with a number of focus National Governing Bodies (NGBs) of sport, EFDS ensure they can maximise their own programme for disabled people. The charity can offer support on disabled people's needs in sport, development, local engagement, disabled children and young people as well as marketing knowledge.

In addition, EFDS works in close partnership with the National Disability Sports Organisations (NDSOs), to collectively support National Governing Bodies of sport (NGBs). This provides NGBs with more support to deliver opportunities for disabled people with specific impairments. The

NDSOs are British Blind Sport, Cerebral Palsy Sport, Dwarf Sports Association, Mencap Sport, Special Olympics GB, UK Deaf Sport and Wheelpower.

EFDS's Inclusive Fitness Initiative (IFI) programme has been established for over ten years, with a national coverage of 400 IFI Mark accredited gym facilities. Now managed in house by EFDS, the IFI Mark remains crucial in addressing inequality in physical activity- to reach inactive populations, raise awareness of the benefits of exercise and create demand. Part of this programme is supported by the Department of Health until 2014. The programme also works with equipment suppliers to improve and provide a wider choice of accessible equipment in gyms.

You can find an Inclusive Fitness gym through the EFDS website. Search on this link:
www.efds.co.uk/inclusive_fitness/ifi_gyms

Disability Sport Events (DSE) is another successful EFDS events programme. The team delivers regional, national and international sports events for disabled people. EFDS's aim through DSE is to increase participation opportunities at every level, providing disabled people with a range of activities to choose from. These can vary from high participation sports like swimming and athletics, to local festivals.

You can find a local or national opportunity in many sports through the EFDS website. Search on this link:
www.efds.co.uk/events

DSE work with many external partners to share events management skills and knowledge . This could be delivery, facility sourcing, welfare and risk assessments, officiating and volunteering. DSE support partners to learn the better practices when delivering a variety of participation opportunities. This programme is self-funded and relies on external funding to continue participation opportunities for disabled people. It has been supported over many years through various funding streams- corporate, trusts and individuals.

To find out more about EFDS visit www.efds.co.uk
Email federation@efds.co.uk
Twitter [@Eng_Dis_Sport](https://twitter.com/Eng_Dis_Sport)



YOUNG ARCHER TARGETS RIO 2016

Harriet Little is a determined and enthusiastic 14 year old young lady, who tragically, at the age of 9 became disabled through an illness that can still not be diagnosed.

As a young child she was extremely sport orientated and dreamed of being part of the Olympic Swimming team. She trained extensively and always had the dream of competing at a high level.



When Harriet was just 9 years old she became severely ill and as a result of this she was left having to use a wheelchair. Harriet feared that she would never be able to represent her country at the Olympics, and feared that she may never compete in sport again. For Harriet adapting to life in a wheelchair was extremely challenging, however the thought of living life without sport was even more difficult for her.

In February 2010 Harriet attended a Junior Sports Camp that was organised by the charity WheelPower, who provide unique opportunities to participate in sport for rehabilitation, recreation and competition for people with a physical disability. The camp was extremely beneficial for Harriet as it allowed her to participate in competitive sport once more. It also gave her the opportunity to try a variety of different sports that she had competed in before. This was the start of Harriet's main recovery as it allowed her to participate again in something that she loved.

From this fantastic event she was talent spotted by Fred Stevens (GB Paralympic Archer) which resulted in Harriet joining an archery club in July 2010. Since then Harriet has trained extensively and has her eyes set on competing in the Paralympics in 2016. As her determination grew she realised she needed more support, so in March 2011 Harriet obtained an individual coach to develop her ability for success further and put her one step closer to obtaining her dream of representing Great Britain.

As part of Harriet's preparation and training she attends the WheelPower sports events regularly. She says: "They have enabled me to make friends and to understand that I am not alone with my disability. It has also taught me that sport is there for everyone".

Through Harriet's own determination she has now been given the opportunity to become a member of the GB Talent Identification Development Squad to prepare for the 2016/2020 Paralympic Games.

In recognition of her hard work, Harriet was nominated to carry the Olympic torch, of which she did in Yarmouth on the Isle of Wight on the 14th July 2012. Harriet enjoyed her once in a lifetime moment and felt it was one more step towards her Paralympic dream.

Harriet's return to sport has made her even more determined to make sure that disabled individuals know that there are sporting opportunities out there for them. She wants to become a sports teacher and specialise in the disability sector. She will be undertaking BTEC Sport at school to start to achieve this ambition. She would also like to become a sports ambassador to support disabled individuals in sport and encourage them to achieve their dreams.

Harriet's mum Helen says; "Harriet would not be where she is today if it hadn't been for WheelPower. They have given her the opportunity to realise her potential and to have confidence to go for her dream, and we cannot thank them enough for the work they have done."

WheelPower

WheelPower-British Wheelchair Sport, the national charity for wheelchair sport provides opportunities, facilities and equipment to enable disabled people to participate in wheelchair sport and lead healthy active lives.

WheelPower manages an annual event programme at Stoke Mandeville Stadium, birthplace of the Paralympic movement which consists of:

- Primary Sports Camps (6-11 year olds, one day have a go event, 2 annually)
- Junior Sports Camps (11-18 year olds, two day residential have a go/coaching event, 3 annually)
- Time to Shine (11-18 year olds, 3 day residential have a go event for Olympic/Paralympic boroughs of London)
- National Junior Games (11-18 year olds, 3 day residential have a go/competition event)
- National Junior Wheelchair Games (11-18 year olds, 2 day have a go/competition event)

Alongside access to these events and general advice on wheelchair sport WheelPower can support you by:

- Providing information on local and national wheelchair sport opportunities.
- Providing advice on sports wheelchairs including funding opportunities.
- Resources on supporting wheelchair users to access sport and physical activity.

A young participant of WheelPower events has stated: "WheelPower has enabled me to make friends and to understand that I am not alone with my disability. It has also taught me that sport is there for everyone".

For more information please get in contact with Steve Snelling, Inclusive Sports Advisor at WheelPower via 01296 395995 or email steve.snelling@wheelpower.org.uk

BECOME A Boccia CLASSIFIER



Do you

- Have a sporting background within boccia, preferably as a coach, and/or a medical background (can include: doctor, occupational therapist, and physiotherapist)?
- Have an interest in boccia and the development of the sport?
- Have the time to commit to attend two Regional Championships and one National Level Competition per season?
- Have good communication skills?
- Have a willingness to undertake the necessary training to achieve Nationally Appointed Classifier Status?

If so, you could be a Boccia Classifier!

Classification is the grouping of athletes based on functional ability. The process is designed to include things such as muscle tone, range of movement and co-ordination but it purposely excludes the evaluation of learnt skills and training development of participants for a chosen sport.

Register your interest

If you are interested in becoming a boccia classifier we would be happy to hear from you. Please register your interest by emailing info@bocciaengland.org.uk and a member of staff will be in touch.

For more information on boccia, please visit www.bocciaengland.org.uk

Profiling and Competition Grouping

The Profile System was devised by Dr Christine Meaden M.C.S.P., Ph.D as a result of trying to make the Disability Sport Events classifications sport-specific (then known as the British Sports Association for the Disabled). DSE's Medical and Technical Committee had declared this a priority in 1985. The definitions of the classes were made specific to swimming. An attempt was then made to do the same exercise specific to track events and to field events (different criteria for running as opposed to throwing).



This was repetitious because it was necessary to continually repeat the same description of each type of impairment. If each impairment type was allocated a number or name, the description of the impairment types in a particular competition group would be more concise.

Thus, if each type of impairment is given a number, it would be unnecessary to keep repeating the description of the impairment when creating groups for each sport. It was decided to call each impairment type 'a profile of functional ability'. This concept was described and presented verbally to the Medical and Technical Committee in March 1985.

The first written draft (March 1985) used definitions for each profile. It was updated to contain rough illustrations in October 1985. It seemed much easier and more consistent to use than the previous system, so it was used theoretically when classifying DSE competitors. No further development took place until a presentation was made in October 1987.

At grass roots, or sports club level, this specialisation is impractical and unnecessary when using the Profile System: if the impairment is measured and a profile allocated, the competitor can be categorised for any sport s/he uses chooses. Thus the assessment of a profile type followed by grouping of profiles in a standard way avoids the need for specialist sports knowledge for all assessors.

The categories use stick men for ease of use and since its development, it has been recognised worldwide, as well as in various sports. In 2008, Dr Meaden received the Nationwide Lifetime Achievement Award for her commitment to disabled people in sport- namely devising a system which would be instrumental in grassroots development. She also aided the charity to create a training course for teachers and Physios to learn how to use the system at a local level.

Contact the EFDS Events Team to find out about the courses at events@efds.co.uk

The profile system has been adopted for many Disability Sport Events participation opportunities, and was used for the Paralympic Equestrian in Sydney and Athens. It has also formed the basis for ParaTriathlon and is being used by England and Wales Cricket Board to in their development of a physical impairment league.

Disability Sport Events, with the input of Elizabeth Neale has created a toolkit so many more teachers and coaches can use the system to increase participation at a grassroots level.

http://www.efds.co.uk/resources/profiling_and_competition_grouping/profiling_toolkit_resource

If you would like to learn more about the established system, contact our events team at events@efds.co.uk

'Therapeakers' Sub 24!

Members of the therapy team at Young Epilepsy took team work to a whole new level in June by competing in, and completing, the 3 Peaks Challenge in under 24 hours to raise money for therapy equipment for the school.

The challenge consisted of scaling the highest mountains in Scotland, England and Wales- Ben Nevis, Scarfell Pike and Snowdon - as well as driving between them, in under 24 hours.

The team consisted of speech therapists, OT assistants, a play therapist and a physiotherapist -all working at Young Epilepsy. Despite training hard as individuals and as a team, no one was prepared for the sleep deprivation or extreme conditions on Ben Nevis- snow, ice, gale force winds and -6 degrees...on midsummer's day!

The challenge was awesome, the team amazing and the outcome fantastic- over £5000 raised for therapy equipment to use with the students at Young Epilepsy. Who knows what our next teambuilding exercise will be!

Dinah Mabbutt
Physiotherapist at Young Epilepsy



Project Ability



Project Ability Lead Schools: making a real difference for young SEND people in school sport through the Sainsbury's School Games

Through a range of interventions and activities, Project Ability will support schools to improve and extend their provision for young SEND people to take part in competitive sport. This includes a network of 50 Project Ability Lead Schools from across England that has been established, each selected for their recognised expertise in engaging young disabled people.

In 2012/13 Project Ability Lead Schools are tasked with five key deliverables. These are to:

1. provide termly training, advice and guidance to School Games Organisers (SGO);
2. work proactively with four schools (minimum of two secondary schools) to develop and run innovation projects;
3. sustain young people's participation by continuing to support the development of multi-sport and sport specific club activities;
4. strengthen leadership pathways by delivering a one-day leadership training camp, mentoring 12 people to become inclusive coaches and by embedding inclusive practice within the school sport workforce; and
5. drive the establishment and implementation of more local meaningful competitive opportunities for young SEND people by:
 - supporting 10 schools across four SGO areas to develop intra- and inter-school competitions in 4-6 sports;
 - supporting termly multi-sport activities with their SGO; and
 - championing inclusion on the Local Organising Committee (LOC) for the Sainsbury's School Games

For further information visit
www.yourschoolgames.com and
www.topsportsability.com



Department for
Education



Thanks to the support of my local Project Ability Lead School my knowledge and skills to develop inclusive competitive opportunities in my SGO area has greatly increased. The TOP Sportsability orientation was invaluable, as well as the informal mentoring support.

Naomi Jones
SGO, Harrogate High School



A key priority for British Tennis is to ensure tennis is a sport which is inclusive and accessible to every kind of community. By working in partnership with two Project Ability Schools we are able to utilise their expertise and reach, and develop an inclusive Sainsbury's School Games competition format to enable all young people, particularly those that cannot easily access the traditional format of the game.

Paul Williams
School Tennis Manager, British Tennis



Project Ability is the most valuable asset we have to fulfill our ambitious vision for the Sainsbury's School Games in Lincolnshire. Through Project Ability we can, for the first time, enable a truly inclusive school sport programme to take place engaging with all young people across the county!

Project Ability is in the driving seat of all inclusive practice within the Sainsbury's School Games. It is vital that we use the knowledge and expertise Project Ability has to offer so that we are always creating opportunities for a fresh look at school sport and PE.

Rob Parkin
Chair of Lincolnshire LOC and Headteacher, Sincil Sports College

For further information visit
www.yourschoolgames.com and
www.topsportsability.com

Project Ability

Frequently Asked Questions

What is Project Ability?

Project Ability is a bespoke project within the School Games designed to help drive and increase opportunities for young disabled people. Through a range of interventions and activities, Project Ability will support schools to improve and extend their provision for young disabled students to take part in competitive sport.

They include:

- **Innovation with NGBs** to establish inclusive formats, with tips and advice on how to adapt activities, as well as specific impairment formats.
- **Training for all SGOs** in disability awareness and the planning/delivery of inclusive competitions.
- Equipping all schools to **increase participation** by those young disabled people who need more substantial or significant help through **TOP Sportsability**.
- The **inclusion of disability events** within Level 3 county events.
- **Aspirational Paralympic events** within the Level 4 national competition.
- The establishment of a national network of **50 Project Ability lead schools** which have established expertise in engaging young disabled people.

How is Project Ability different to Project Ability schools?

Project Ability is designed to increase opportunities for young disabled people, and the Project Ability schools are the network of schools who have expertise to help with this.

How do I contact the Project Ability schools?

There is a Project Ability school in each county throughout England. To identify the school in your county, please go to: <http://www.youthsporttrust.org/how-we-can-help/programmes/project-ability.aspx>. To find out the lead contact for a Project Ability school, please email send@youthsporttrust.org with your requirements.

Are they working with all other schools within the county? / is there full county coverage?

The network of Project Ability schools covers each county in England. To identify the school in your county, please go to: <http://www.youthsporttrust.org/how-we-can-help/programmes/project-ability.aspx>. One of the roles of the Project Ability school is to provide Training, Advice and Guidance to SGOs across a county sport partnership area, so all SGOs are provided with YST content and supported in their delivery to local schools/network. Project Ability schools also involve other local schools to help to deliver their Innovation Project, and pick individuals from differing schools to be part of their leadership development.

We need our 'inclusive' format for the school games to be supported at the LOC, how can Project Ability schools help to influence this?

Part of the Project Ability school's role is to be the inclusion champion on the Local Organising Committee to ensure that Level 3 county events are fully inclusive and there is connectivity between the levels of School Games. In areas where this has not yet happened, PA schools should be appointing an inclusion champion from the Project Ability site to sit on the LOC.

What is the role of Project Ability schools in supporting the inclusion agenda of the school games?

The Project Ability school's role is to drive the establishment and implementation of more local competitive opportunities for young SEND people by sustaining partnership working with a minimum of ten schools across four SGO areas in regular competition in 4 – 6 sports at Levels 1 and 2 (and L3 where they qualify). They do this by:

Supporting the School Games Organiser and schools to increase Inter-School (L2) competitive opportunities in 4-6 sports across 10 schools, including but not limited to, one inter-school multi sport festival per term.

Supporting the Teacher Release Post and schools to increase Intra-school (L1) competitive opportunities in 4-6 sports across ten schools.

To be the inclusion champion on the Local Organising Committee to ensure that Level 3 county events are fully inclusive and there is connectivity between the levels of School Games. In areas where this has not yet happened, appoint an inclusion champion from the Project Ability site to sit on the LOC. Be the exemplar for an inclusive year round, intra-school (Level 1) competition programme

Can Project Ability schools lead on the delivery of training?

Project Ability schools deliver YST training/guidance to SGOs through SGO network engagement events. They do this by attending National Project Ability Meetings/Events and equipping all SGOs with YST content and supporting in their delivery to local schools/network.

How are Project Ability schools connecting in with community activity?

The Project Ability school's role is to sustain young people's participation by continuing to support the development of club activities - Multi Sport and Sport Specific Opportunities, within each county sport partnership area. They do this by supporting the SGOs to identify and establish links with "Expert" Clubs to establish pathways from Level 2/3 competition. "Expert" clubs are community managed/based, and provide a high quality environment with expertise to help young disabled people continue to participate and progress in a **sport specific** activity.

What's been the impact of Project Ability to date?

We have a bank of statements from our Project Ability schools, who have shown the impact on individuals, schools and counties.

Here are some quotes from around the country:

Name of PA School: King Alfred's Academy, Oxfordshire

Project Ability IMPACT on Individuals: Our Paralympic Leadership Programme has had a very positive effect on 18 young leaders all with a learning, physical and/or sensory need. Young people representing their school for the first time ever in sport – "I have never ever had a medal for sport before." Competitor in Inter School Goalball Tournament.

Name of PA School: Lord Silkin School, Shropshire

Project Ability IMPACT on Individuals: Signposted to inclusive clubs. More opportunities to compete/attend festivals. 2 young leaders who attended Step into Sport camp really inspired and now working with disability sports groups/competitions.

Name of PA School: Southfields Community College, London

Project Ability IMPACT on Schools: We have been able to build into the teacher training programme for NQTs a training section for TOP Sportsability and have run practical training for them which will enable them to make their practice inclusive in the future.

Name of PA School: Ellesmere College, Leicestershire

Project Ability IMPACT on Schools: Paralympic road show delivered to all School Games Organiser areas to mainstream schools/special schools. 32 secondary and primary schools throughout the county – outcome of around 4250 young people who accessed this by July 2012.

Name of PA School: Valence School, Kent

Project Ability IMPACT on the County: With LOC support and backing, we took over responsibility for running the Boccia and Table Cricket elements of the School Games as separate events. Boccia over 2 days, 2 age groups and 3 disciplines. Table cricket will develop in the same way but over 1 day. In summer 2012, 18 teams entered over 2 days for Boccia, 4 teams entered Table Cricket.

Sainsbury's

Active Kids

For All

Inclusive PE
Training Programme



As part of the Paralympic Legacy we want to ensure that all young people have the opportunity to have a positive experience in PE preparing them to lead healthy lifestyles and encourage life long participation in sport and physical activity

Putting this legacy into action Sainsbury's have invested £1 million into Active Kids for All

Active Kids for All Inclusive PE training

The Sainsbury's Active Kids for All Inclusive PE Project is a training initiative designed to improve the quality of PE provision for young disabled people in mainstream schools in the UK. The training provides a unique workforce development opportunity designed specifically to improve teachers' competence and confidence in providing a fully inclusive and positive PE experiences to young people with a wide range of needs.

Through this initiative free inclusive PE training and resources will be provided to **23,655** teachers, trainee teachers and learning support assistants throughout the UK, over a four year period from 2012 to 2016. It is anticipated that the initiative will directly benefit an estimated **558,870** young people with special educational needs and disabilities (SEND).

What does the training involve?

Theory and practice supporting delegates to have a clearer understanding of the needs of **all** pupils and to be able to use teaching strategies to ensure all pupils are **engaged and make good progress**, both of which are essential in outstanding teaching.

This workshop is designed to help **teachers to embed inclusive practice in their planning, delivery and assessment within the curriculum.**

The course will take approximately 6 hours to complete and is made up of both online and face to face elements. Delegates will be supported to share material with colleagues and will have access to an online portal to support continued professional development.

Who is this course targeted at?

Primarily designed to support mainstream PE teachers in including young disabled people within PE curriculum; however the principles used can be applied to a number of settings and can be of benefit to **ALL** young people.

The training can also be used to support other teaching staff, trainee teachers, classroom assistants, learning support assistants and Special educational needs co-ordinators.





How can you help?

Please promote this training to the young people, parents, schools and networks that you come into contact with and collectively we can make an impact on inclusive provision of PE and school sport.

To book a place, teachers and school staff will need to visit the following site:

www.inclusivepe-eng.co.uk

How do I find out more about the Active Kids for All project?

Please contact federation@efds.co.uk for further information

Notes to editors:

The Active Kids for All Inclusive PE training programme has been developed in partnership with and will be delivered by Disability Sport Northern Ireland, Disability Sport Wales, Scottish Disability Sport, the English Federation of Disability Sport, alongside the Youth Sport Trust and supported by the British Paralympic Association.



Sainsbury's



FAQ's

What is the Active Kids for All Inclusive PE Training programme?

The Sainsbury's Active Kids for All Inclusive PE Project is a training initiative designed to improve the quality of PE provision for young disabled people in mainstream schools in the UK.

Who is this course targeted at?

The course has primarily been designed to support mainstream PE teachers in including young disabled people within PE curriculum; however the principles used can be applied to a number of settings and can be of benefit to **ALL** young people.

The training can also be used to support other teaching staff, trainee teachers, classroom assistants, learning support assistants and Special educational needs co-ordinators.

What does the training involve?

Theory and practice supporting you to have a clearer understanding of the needs of **all** students and to be able to use teaching strategies to ensure all students are **engaged and make good progress**, both of which are essential in outstanding teaching. The course will take approximately 6 hours to complete.

In Northern Ireland, Wales and Scotland the training is made up of three hours of 'theory' delivered in a classroom environment and three hours of 'practical'. After attending the course the candidates will have access to a password protected website which will provide them with additional resources and information.

In England the course is made up of both online and face to face elements, candidates will be supported to share material with colleagues and will be given access to an online portal to support their continued professional development.

How much does it cost?

Free; this training has been sponsored by Sainsbury's

How do I book a place on the training?

Please visit the following site to book your place: [Inclusive PE](#)

Who do I contact for further information?

Please contact the UK Project Co-ordinator Kat Southwell ksouthwell@efds.co.uk / 07967573343



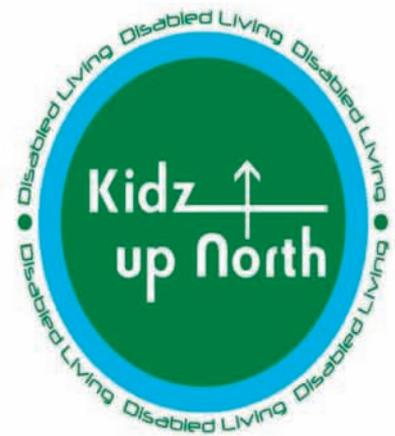
Kidz up North

Thursday, 21st November 2013

EventCity, Barton Dock Road,

Urmston, Manchester

9.30am – 4.30pm



One of the largest, FREE UK exhibitions dedicated to children with disabilities and special needs, their families and the professionals who work with them.

- Over 120 exhibitors offering advice and information on funding, mobility, seating, beds, communication, access, education, toys, transport, style, sensory, sports and leisure and more.....
- Running alongside the event are FREE seminars for parents and professionals. Topics include: Parental Experiences, Sleep Issues, Continence Issues, Moving and Handling, Transition and Legal Advice.



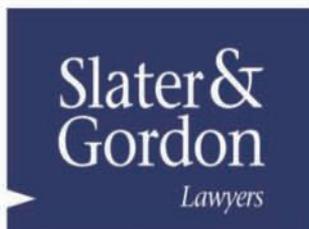
Dates for your Diary

- Kidz in the Middle- 27/03/14
Ricoh Arena, Coventry
- Kidz South – 12/06/14
Rivermead Leisure Complex
Reading
- Kidz Scotland – 11/09/14
Royal Highland Exhibition Centre
Edinburgh

For FREE Visitors Tickets Please

Call: 0161 607 8200

Email: info@disabledliving.co.uk



Proud to sponsor Kidz up North

Kidz is trademark registered to Disabled Living, Manchester
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