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Welcome to the August edition of the APCP Newsletter. As I sit writing this, the great summer of sport has fizzled out, England have not done well with the cricket, football or tennis and it remains to be seen if the weather has deserted us as well!

Nevertheless, you will find some interesting articles in this edition, including several sports related items as I firmly believe, as physiotherapists, we must be encouraging our young clients to try and engage in some sort of sport and all the health, social and inclusive benefits it entails. I hope you agree with me and find these articles useful for ideas and inspiration.

We’re very excited about APCP Conference this year as for the first time we are joining with our Occupational Therapy colleagues for a joint event. Details are enclosed and I hope you will all consider joining us north of the Wall this year for a full two days of quality professional development.

We also have some vacancies on National Committee and you will find details herein, as well as National Committee can I also ask all of you to consider joining your local Regional Committee. We’re a friendly bunch, I’m sure some might feel they’re not qualified enough or not top of their field but that really doesn’t matter. We need people who are committed to their chosen career, have ideas to share and can help with organising study days, sourcing speakers and even making tea and cakes!

Many thanks as always to everyone who has sent me items to print, I cannot do this newsletter without you, and I hope those that have perhaps never considered writing for publication will be encouraged to try. This is not an academic journal, we have lots of different article types and writing styles and for that reason I don’t heavily edit items as I think the diversity is what makes it interesting.

Please consider writing for the newsletter; a case study, news on fund raising, secondments, course reviews, charities or sources of funding you have found helpful, please share for the benefit of all of us.

Kerry McGarrity  
Editor

The Editorial Board does not necessarily agree with opinions expressed in articles and correspondence, and does not necessarily endorse courses or equipment advertised
APCP Annual Conference 2014

In Cahoots

21st & 22nd November 2014

The Surgeon’s Hall, Edinburgh

APCP and CYPF (paediatric OTs) will be joining forces on the Friday to present a joint PT/OT programme

Parallel programmes on the Saturday organised by the APCP Scottish Region and by APCP PPIMS Group

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

PRINCIPAL SPONSORS
Working Together in Early Intervention

The impact of occupational therapy and physiotherapy working together for better outcomes for children and young people

Friday, 21st November 2014

08.15-09.00 Registration
09.00-09.10 Opening of joint APCP / CYPF Annual Conference 2014
  Liz Grey – Chair of APCP Scottish Committee and National Vice-Chair
09.10-09.30 Keynote Address: Children & Young People's AHPs - taking our next steps!
  Jane Reid - AHP National Lead for Children & Young People at The Scottish Government
09.30-10.15 Working together to get it right for every child – how health policy has been implemented in Scotland
  Dr Kate McKay – Senior Medical Officer, Scottish Government
10.15-10.45 Break and exhibition
10.45-11.30 Researching together – inter-professional perspectives on research into postural care training for parents and teachers
  Eve Hutton - Head Occupational Therapist in Child Health, Buckland Hospital, Dover & Sarah Crombie - Professional Lead Physiotherapist, Chailey Heritage Clinical Services, East Sussex
11.30-12.00 The practical psychology of families and diagnosis
  Dr Chris Wiles – Consultant Clinical Psychologist and Head of Service Rowan Centre Child and Adolescent Mental Health Services, NHS Grampian
12.00-12.30 Free Paper Presentations
12.30-13.30 Lunch and exhibition
13.30-14.15 Multi-disciplinary team working within the neonatal setting and the importance of anticipatory care / early intervention
  Betty Hutchon - Head Occupational Therapist, Royal Free Hospital; Consultant Neurodevelopmental Therapist North Central London Perinatal Network; and Honorary Lecturer Institute of Child Health University College London
14.15-15.00 Obstetric Brachial Plexus Palsy
  i) Neurobiology of Obstetric Brachial Plexus Injury, and rationale for early nerve surgery
     Professor Andrew Hart – Consultant Plastic and Hand Surgeon, Scottish Brachial Plexus Service
  ii) The importance of early physiotherapy intervention for Obstetric Brachial Plexus Palsy
     Heather Farish – Team Lead Paediatric Physiotherapist, Royal Hospital for Sick Children, Glasgow
  iii) The role of the occupational therapist for Obstetric Brachial Plexus Palsy
     Nicola Hart – Specialist Occupational Therapist, Royal Hospital for Sick Children, Glasgow
15.00-15.30 Break and exhibition
15.30-16.15 The CHAS model of palliative care – working in partnership with you to ensure palliative care is introduced at the right time
  Sue Hogg - Director of Care, Children’s Hospice Association Scotland
16.15-16.45 Supporting parents of disabled children to acknowledge, adjust and adapt
  Shirley Young – Parent, Trainer and Consultant
16.45-17.00 Plenary session

* This programme may be subject to change – see apcp.csp.org.uk for up-to-date information about the conference programme and trade exhibitors.
## Working Together to Advance Practice

The impact of physiotherapists sharing knowledge and skills to advance clinical practice*

**Saturday, 22nd November 2014**

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<tr>
<th>Time</th>
<th>Session</th>
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<tr>
<td>08.30-08.50</td>
<td><strong>Registration</strong></td>
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<tr>
<td>08.50-09.00</td>
<td>Welcome and opening of programme</td>
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<td>Sue Irving – APCP Scottish Committee</td>
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<td>09.00-09.45</td>
<td>The History and Launch of the Cerebral Palsy Integrated Pathway Scotland (CPIPS)</td>
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<td>James Robb – Honorary Senior Lecturer, School of Medicine, University of St Andrews</td>
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<td>09.45-10.15</td>
<td><strong>CPUP to CPIP – The Physiotherapy Experience</strong></td>
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<td>Susan Quinn - Highly Specialist Paediatric Physiotherapist, NHS Lanarkshire &amp; Lesley Harper – Senior Physiotherapist, Royal Hospital for Sick Children, Edinburgh</td>
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<td>10.15-10.45</td>
<td>Early Intervention in Gait</td>
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<td>Dr Barry Meadows - Head of Neurobiomechanics, Westmarc, Southern General Hospital, Glasgow &amp; Nicola Tennant – Advanced Practitioner in Gait and Neurobiomechanics, NHS Greater Glasgow &amp; Clyde</td>
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<td>10.45-11.15</td>
<td>Break and exhibition</td>
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<td>11.15-11.30</td>
<td>‘Physio banishes the hip-hop blues’</td>
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<td>Sally Wilkinson – Neonatal Hip Screening Lead, NHS Lothian</td>
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<td>11.30-11.45</td>
<td>Running a Physiotherapy Led Clubfoot Service</td>
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<td>Sarah Patterson - Orthopaedic Extended Scope Physiotherapist, Royal Hospital for Sick Children, Edinburgh</td>
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<td>11.45-12.15</td>
<td>APCP AGM (APCP members only)</td>
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<td>12.15-13.15</td>
<td>Lunch and exhibition</td>
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<td>13.15-13.45</td>
<td>Free Paper Presentations</td>
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<td>13.45-14.15</td>
<td>Community Respiratory Care</td>
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<td>Kath Sharpe</td>
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<td>14.15-14.30</td>
<td>Rapid Response – Community Paediatric Respiratory Physiotherapy</td>
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<td>Zoe Johnstone – Clinical Specialist Physiotherapist, Royal Hospital for Sick Children, Edinburgh</td>
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<td>14.30-14.45</td>
<td>Management of Focal Spasticity in Children with Neurodisability</td>
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<td>Katie Kinch – Clinical Specialist Paediatric Physiotherapist, NHS Fife</td>
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<tr>
<td>14.45-15.15</td>
<td>Break and exhibition</td>
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<tr>
<td>15.15-16.00</td>
<td>Selective Doral Rhizotomy – The Scottish Perspective</td>
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<td></td>
<td>Heather Read – Consultant Paediatric Orthopaedic Surgeon, Yorkhill Hospital, Glasgow &amp; Laura Wiggins – Principal Physiotherapist, Intensive Treatment Team/ Neurodisability, NHS Greater Glasgow &amp; Clyde</td>
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<td>16.00-16.45</td>
<td>Race-running</td>
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<td>Gavin Drysdale &amp; Hannah Dines – World Champion Athletes with Gabriela Todd &amp; Liz Bryant</td>
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* This programme may be subject to change – see apcp.csp.org.uk for up-to-date information about the conference programme and trade exhibitors.
In Cahoots

Working Together Reform, Develop & Communicate

APCP Paediatric Physiotherapists in Management Support Group*

Saturday, 22nd November 2014

08.30-08.50 Registration
08.50-09.00 Welcome and opening of PPIMS parallel programme
                      Juliet Goodban – Chair, APCP PPIMS Group
09.00-09.45 SEND Reforms and the Implications for Therapy Services
                      Anne Gardner – Senior Development Officer for Health, Council for Disabled Children
09.45-10.30 Expert Evidence for Disability Tribunals
                      Jessica Burns - Regional Tribunal Judge, Scotland
10.30-11.00 Break and exhibition
11.00-11.45 Service Developments - ‘It’s in our hands’
                      Chris Hawley – Team Lead, Children’s Physiotherapy, Suffolk Community Healthcare
11.45-12.15 APCP AGM (APCP members only)
12.15-13.15 Lunch and exhibition
13.15-14.45 Courageous Conversations
                      Jamie Ripman & Philippa Williams - Practive
14.45-15.15 Break and exhibition
15.15-16.00 Using the tools
                      Speaker to be confirmed
16.00-16.45 Social Media
                      Rob Ledger-Head of Online Communication CSP
16.45 – 17.00 Close of PPIMS Parallel Programme
                      Juliet Goodban – Chair, APCP PPIMS Group

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

CLOSING DATE FOR APPLICATIONS: Friday, 31st October 2014

Delegate rates from:
£95.00 (£180.00 for both days)

Download application forms from:
http://apcp.csp.org.uk/annual-conference
or contact: va@apcp.org.uk

ANNUAL CONFERENCE DINNER – £40.00
Friday, 21st November 2014 – 7.30pm til late
Carlton Hotel, Bridge North, Edinburgh, EH1 1SD

Please join us for this year’s annual conference dinner with a Scottish flavour!
ASSOCIATION OF PAEDIATRIC CHARTERED PHYSIOTHERAPISTS
41st ANNUAL GENERAL MEETING
SATURDAY 22 NOVEMBER 2014
11.45

THE SURGEONS HALL
NICHOLSON STREET
EDINBURGH

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

A survey of APCP members was conducted this year to collate information to identify the training and resources that members feel would be most beneficial to support them in working with children and young people with neurodisabilities.

For the purposes of this survey, neurodisabilities are defined as congenital and acquired long-term conditions that are attributed to impairment of the central nervous system, e.g. cerebral palsy, acquired brain injury and spinal cord injury. This is the same definition that is proposed to define the role and remit of the new APCP Neurodisability Group, to keep it distinct from the role and remit of the existing Neuromuscular Group.

The APCP Neuromuscular Group focuses on work with children who have acquired and genetic conditions affecting the function of muscles, either directly as a muscle disease or caused by disorders of the peripheral nerves, motor neurons in the spinal cord or the neuromuscular junctions which supply them, e.g. muscular dystrophies, spinal muscular atrophy, congenital myopathies, hereditary neuropathies and congenital myasthenic syndromes.

Survey responses

391 responses were received. The current APCP membership is 2100 members and so this represents 18.6% of current APCP membership.

Respondents were asked to identify which Region of the UK they work in.

Respondents’ workplaces / services

Respondents were asked to describe the type of service/s they work in. Respondents were able to select more than 1 type of service if applicable.

‘Other’ includes:
- children’s hospices (1)
- schools (12)
- council services (1)
- physiotherapy education – BSc / MSc (1)
- medico-legal (1)

Respondents’ clinical caseloads – age groups treated

Respondents were also asked to identify the age groups that they work with.

Respondents’ clinical caseloads – percentage neurodisabilities

Respondents were then asked to indicate the percentage of their caseload that have neurodisabilities.
Respondents were then asked to estimate the proportion of their caseload with neurodisabilities, which fall into the following categories (below):

Note: Despite the definition of neurodisability given at the beginning of the survey, a significant number (10%) of respondents identified neuromuscular disorders as a type of neurodisability, which for the purposes of this survey and the remit and scope of the APCP Neurodisability Group they are not. It must therefore be assumed that some respondents will have included their neuromuscular patients when indicating the proportion of their caseload that have neurodisabilities.

‘Other’ neurodisability conditions recorded include:
- genetic / rare syndromes (10%)
- spina bifida (3%)
- motor / developmental delay (3%)
- epilepsy (1%)

Dyspraxia, tuberous sclerosis, viral conditions, dystonia, ataxia, hereditary spastic diplegia were also mentioned.

Training Opportunities

Respondents were asked about their preferences for training events in terms of format and topics.
‘Other’ types of training opportunities mentioned:
- advanced clinical skills,
- complex case study based training,
- practical workshops,
- video conferencing,
- online clinical networking.

One respondent also commented that ALL training should be evidence-based with accredited outcome measures.

‘Other’ specific topics mentioned:
- core strengthening
- Vojta and other alternative therapies
- serial casting (2)
- recent research in CP management (3)
- night time postural management
- post op progressive programmes,
- changes in muscle physiology after long term use of Botulinum Toxin
- targeted training
- pain management for non-communicative children
- setting smart goals
- management of persistent poor head control
- role of ESP
- family centered care
Other Resources

Respondent were asked to identify the types of publications and resources that they would most value.

Please see the report about the new Neurodisability Group under the special group pages.
Primary Camps are a great way to introduce disabled children to sport in a safe, friendly and completely inclusive environment. There are a wide range of sports on offer for participants to take part in.

Who?
Primary Sports Camps are open to children with physical or mild sensory impairments between the ages of 6 to 11. We also welcome entry forms from young people who would not traditionally fit within ‘disability sport classification’ such as dyspraxia, epilepsy or form of internal organ dysfunction or absence.

Where?
Nechells Community Sports Centre, Rupert Street, Birmingham, B7 5DT

Interested?
If you are interested in attending the event please get in contact with Stewart Jeeves via stewart.jeeves@wheelpower.org.uk

WheelPower
Stoke Mandeville Stadium, Gottmann Road, Stoke Mandeville, Buckinghamshire, HP21 9PP

@wheelchairsport
@wheelpower
T: 01296 395995
W: www.wheelpower.org.uk

Registered charity number: 265498

Transforming lives through sport
EAST ANGLIA

The East Anglia APCP region would like to welcome Roberta Wakely and Harriet Hewitt who have joined our committee in the last 3 months.

Roberta has quickly got organised with trying to arrange a respiratory update course, which is likely to be held September/October 2014. Otherwise the committee is planning other courses for later in the year. Should anyone else be interested in joining the committee we still would welcome more members. Please email me

Simone Hipperson
simone.hipperson@nnuh.nhs.uk

LONDON

I am writing this off the back of a very successful evening lecture, with Victoria Knox, on the GMFM. We had a full house with almost 80 delegates, thank you all for supporting us in such numbers and for missing the football. However I am pretty confident the lecture was better than the football!

We have been a little quiet for the past few months, but rest assured we have lots of exciting things up our sleeves. Over the next few months we have evening lectures on; dystonia, lycra for scoliosis and a lecture on orthotics planned, as well as a 1/2 day on CP in the early months of next year.

After our baby boom we are now welcoming Lynn and Anne back to the team so we will have a full house, more energy and lots of enthusiasm. Please keep up the amazing attendance and let us know what you would like to hear.

Big attendances mean we can afford to send a London APCP member to conference most years. This year we are able to offer this in such numbers and will be advertising this in the next few weeks, so keep your eyes peeled... We normally do this as names in a hat and all we ask in return, is a short report for the newsletter on how you enjoyed conference, good deal I’d say! Good luck!

Sinead Barkey
barkes@gosh.nhs.uk

NORTH WEST

In early February we held an evening on the HCPC audit in preparation for the letters which were to come through some people’s doors. From the discussions that evening it’s certainly clear that the region have been carrying a wide range of CPD activities. Hopefully those who attended will have had a few more ideas of what they could do if selected to submit their CPD log and a selection of activities as supporting evidence.

The evening in February also helped highlight that there are people who contact the VA to book a place on courses at short notice. We will always do our best to accommodate people wherever possible and appreciate that sometimes it does take a bit longer to get childcare and approval of leave from work. However if people say they will be attending we then include them in the numbers for any refreshments at the venue, and this then costs the region when people later decide not to come after all. As we try to keep costs low for our members, it would be appreciated if people helped us by paying in advance, and in the event that they are unable to attend, they get in touch to inform us.

In October we will be hosting a day of Outcome Measures with Virginia Knox, in Newcastle. Places
are limited and payment will be required to secure your place along with your booking form (£50 members/£70 non-members). Please check out the website for further information and the booking form.

The region have also been busy with the planning for next year’s conference, and are currently in the process of contacting speakers and coming up with plans to keep you entertained. We hope to see as many of you as possible when the conference returns to our region. As we will be losing some of our committee at the conference, it would be great to hear from any regional members who would like to join us.

As always we are looking for venues which we can use for courses so if there is somewhere near you that’s suitable please get in touch.

Helen Chamberlain
helen.chamberlain@humber.nhs.uk

SCOTLAND

Well things are really hotting up here in Scotland – OK so maybe not with the weather (but hopefully), but with the final planning for the joint OT/Physio Conference on Friday 21st & Saturday 22nd November 2014. This has been a long-term project for the Scottish committee, but along with our paediatric OT colleagues and PPIMS, we really hope that we are going to have a top quality packed 2-day programme to offer.

Just to remind you, the conference is this year entitled ‘In Cahoots – Working together in Early Intervention’. There will be lots of information coming to APCP members, with full information, details of the programme and application forms on the APCP website in due course. Please tell your non-APCP member colleagues about it – it’s a fantastic opportunity for Scottish therapists to access two days excellent CPD, without having to travel south of the border, and we want to encourage as many local therapists to attend as possible.

It is also worth remembering that the APCP Neonatal group are also holding a joint therapy conference with OT Neonatal therapists in Edinburgh on Thursday 20th November, looking at infant mental health. So potentially there are 3 days of training available. Places on these conferences are limited, so please don’t miss out and book early and take advantage of the early bird reductions.

Thanks to those of you who showed an interest in becoming members of the new neuro-disability group. National Committee were delighted with the number of people who nominated themselves, and the successful candidates should be available to see on the website by the time this newsletter drops through your door. Thanks also if you were one of the hundreds of therapists who responded to the questionnaire asking about the type of help you would like from this group – the information gathered will be used to direct this committee as they start work together.

All of you should have received a copy of the CPIPS training DVD either via your local Committee member or through the post. If there are any of you who have not yet received your copy, then please contact Nicola Tennant (nicolatennant@nhs.net). Additional copies will be available to purchase at Conference.

Training and study days will be resuming in 2015, so as always, a reminder that we work hard to meet the needs of the Scottish membership by providing training which you want. The only way we can do this is if you let us know what you want! Please get in touch with your local Committee member, or feel free to email me or our training organiser Rachel Mackenzie-Smith (rmackenzie-smith@nhs.net). On a similar theme, we are always looking for articles for publish in this newsletter from local therapists. So if you would be interested in writing a piece, then please contact me for more details. We would welcome all sorts of articles from interesting projects or initiatives that you have been involved with, to course evaluations. If you think other therapists would be interested in hearing about it, then we would be interested in hearing from you!

Finally, we are delighted to welcome some new wee additions to the Scottish Committee. Firstly congratulations goes out to Barry Johnston and his wife Rosa who had a baby girl Libby earlier in the year. Secondly, Gillian Taylor and partner Dave welcomed the early arrival of their son Calum in May. Congratulations to all our new parents!

On behalf of the Scottish Committee, we wish you all a great summer – enjoy the Commonwealth Games if you have been fortunate enough to get tickets to attend; hopefully we will all survive the referendum vote, then we look forward to welcoming and meeting many of you at the conference in Edinburgh in November!

Kirsteen Grieve
kirsteengrieve@gmail.com
SOUTH EAST REGION

The SE region has been busy as usual and we have held two more study events since the last newsletter. In February, on a day when the wind howled and the rain didn’t stop, and with severe weather warnings being broadcast on the radio, we had 30 people bravely turn up for a study afternoon on Epilepsy and its management. The venue was the National Centre for Young People with Epilepsy in Lingfield, this is usually a beautiful and tranquil rural environment, but on the day of our course the surrounding roads were barely passable due to heavy floods and a danger of falling trees, in spite of this nearly everyone managed to safely negotiate their way there. Once people had arrived they were welcomed by the very friendly physio team from NCYPE, and Emma Tingley who is a speech and language therapist who is responsible for their research and education programme. We had a very interesting afternoon on epilepsy and its medical and surgical management, and a case study presented by Dinah Mabbutt, Lead Physiotherapist.

Our second study day of the year was held in June, the weather conditions were much kinder, the sun shone on the lovely Sussex countryside on our way to Chailey Heritage, here we were kindly hosted by Sarah Crombie, Lead Physiotherapist and her team. The study day was on Outcome Measures for children with cerebral palsy and the tutor for the day was Virginia Knox, Consultant Physiotherapist and Bobath Tutor from the Bobath Centre in London. This was a mixture of theory, case studies, videos and workshops and the balance made for a stimulating day.

We are planning a respiratory study afternoon for the autumn. This will be advertised via the APCP website and will be on respiratory care in the community.

Also we are planning on giving away a free place at APCP conference in November and all you need to do is email me to have your name put into the draw, this is available to any member in the SE Region. The winner will have to write an article for the newsletter, but this should not be too onerous!

Please continue to email me with any suggestions for topics for study days and/or any (free) venues – preferably with good parking!

We are pleased to report that we had an excellent study evening in Warwick to update community physios on the latest developments in respiratory care. It was led by Wendy Browne, Advanced Respiratory Physiotherapist from Birmingham Children’s Hospital, who gave an interesting and informative presentation, which generated much discussion amongst delegates. A good number of people attended and gave much positive feedback about the event.

Our next event is to take the format of a forum to promote information sharing, networking and discussion. The theme is ‘Clamping down on Contractures’ and we already have experienced speakers lined up to address the complex issues of spasticity and neuromuscular related contractures. We will also have different company reps in attendance to provide information on relevant products, and to sponsor lunch! We will shortly be sending out a questionnaire to gather information relating to current practice, which will be presented on the day. It would be really helpful if you could complete this survey even if you do not plan to attend, so that we can get as broad scope as possible of responses. It will really not take very long to fill in, and will provide some really valuable information. The forum will take place at Birmingham Vernon Sea Cadet Unit, Osler Street, Birmingham, B16 9EU, on Thursday 2nd October 2014, from 11am - 5pm, for the bargain basement cost of only £10 for APCP members. We hope to see you there! We will also be holding our AGM as part of that event, so please do be in touch if you are

Katherine Heffernan  Katherine.heffernan@glos-care.nhs.uk

SOUTH WEST

This year has been significantly quieter for the committee, after the last year planning Conference. We will have had our AGM in July, at which time several of our committee were standing down. I hope we will have recruited some new committee members especially from the north or west of the region. The following areas have not had representation for a while including Swindon, Bath, Bristol, Somerset, Devon and Cornwall.

Being part of the regional committee is an excellent opportunity to meet colleagues from the region, and we welcome new members with varying levels of experience and varying clinical fields.

Each edition of the newsletter has the capacity for two articles of interest from each region. We would welcome your articles from across the South West, please let me know if you would like to submit an article.

Nicola Burnett  nicola@burnettfamily05.wanadoo.co.uk

WEST MIDLANDS

We are pleased to report that we have an excellent study evening in Warwick to update community physios on the latest developments in respiratory care. It was led by Wendy Browne, Advanced Respiratory Physiotherapist from Birmingham Children’s Hospital, who gave an interesting and informative presentation, which generated much discussion amongst delegates. A good number of people attended and gave much positive feedback about the event.

Our next event is to take the format of a forum to promote information sharing, networking and discussion. The theme is ‘Clamping down on Contractures’ and we already have experienced speakers lined up to address the complex issues of spasticity and neuromuscular related contractures. We will also have different company reps in attendance to provide information on relevant products, and to sponsor lunch! We will shortly be sending out a questionnaire to gather information relating to current practice, which will be presented on the day. It would be really helpful if you could complete this survey even if you do not plan to attend, so that we can get as broad scope as possible of responses. It will really not take very long to fill in, and will provide some really valuable information. The forum will take place at Birmingham Vernon Sea Cadet Unit, Osler Street, Birmingham, B16 9EU, on Thursday 2nd October 2014, from 11am - 5pm, for the bargain basement cost of only £10 for APCP members. We hope to see you there! We will also be holding our AGM as part of that event, so please do be in touch if you are
interested in joining the committee to help with planning and running future events.

Please don’t forget that you can apply to us for bursaries to support you with the cost of courses, and not just those organised by APCP. We are always interested to hear from people if you have ideas for subjects, speakers and venues for future course. We look forward to hearing from you! 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

Cyfarch o Gymru! Greetings from Wales! The APCP Welsh committee continues to be very active and a driven bunch of individuals. We have had a busy year and much more will be coming soon. In March we held our second Motivational Interviewing evening at Bobath Cymru which was well attended. Our AGM was held this year at Llandough Hospital and we had a fabulous afternoon with a CPD session focusing on ‘Smart Start’ a DCD program from Australia which is running in North Wales. We all ‘wiggled our bodies like jelly’ and had fun session with music and dance. We also had feedback from Kirsty Foster a Physiotherapist who was selected to have a free place for APCP Conference 2013. Sadly 6 members from the committee stepped down. We said a sad farewell and big thank you to Davina Isaac, Gaynor Bull, Rebecca Randell, Jodie Pasztor, Vicky Stevenson and Helen Evans (Chair).

Alison Hobbs was elected our new chair at the AGM and we have just recruited lots of new committee members to represent the NHS Trusts across South and Mid Wales. We have yet to recruit from North Wales but are always interested to hear from anyone who would like to be involved. We are holding our next regional committee meeting on the 5th August in Caerphilly.

On the 7th and 8th of June we held the Elaine Owen 2 day Paediatric Gait Analysis & Orthotic Management Course at Nevill Hall Children’s Centre in Abergavenny. Welsh APCP members were able to complete this course at a very reasonable cost and we had excellent feedback. We had 20 Paediatric Physiotherapists and 2 Orthotists that attended.

We are hoping to run an evening CPD event in December. We are always looking for volunteers to speak and share knowledge. If you have any requests on topics or study days you would like us to host or if you would like to get involved please do contact us.

Wales will be hosting APCP Introduction to Paediatric Physiotherapy Course in the spring so please keep a look out on the website for further information coming soon.

And finally…….

Julie Harvey an inspirational Paediatric Physiotherapy Manager at Neath Port Talbot Children’s Centre has been awarded an MBE. This was for her tireless charitable work for disabled children and services to healthcare. Julie is an amazing clinician who I have had the privilege to work with, she always places the child and family first and will always go the extra mile. Julie also founded ‘Ice Cool Kids’ this fantastic charity raises money to enable skiing for groups of special needs children and their families.

Louise Leach
louise.leach@wales.nhs.uk

NORTHERN IRELAND

In February this year Kay McLorn, physiotherapist from Blackstone Physiotherapy Clinic provided an interactive evening on Paediatric Pilates based on her own ‘Kidstone’ programme. Kay took over 40 physiotherapists on an imaginary journey through a toy shop as we pretended to be various toys using dynamic stabilisation activity. The evening was thoroughly enjoyed and provided plenty of treatment ideas.

In April Dr Brona McDowell, clinical specialist physiotherapist based at the NI Gait Analysis Laboratory at Musgrave Park Hospital, presented an update on Gait Analysis. Lee Humphreys, physiotherapist also based at the Gait Analysis Laboratory, presented the protocol around SDR at Oswestry including patient selection criteria, surgical technique and pre and post-operative assessment. The presentations and discussion were very helpful as referrals from NI for SDR will go to Oswestry with support from the NI Gait Analysis Lab.

In May APCP (NI) were able to part subsidise two consecutive 2 day Paediatric Therapeutic Taping courses with Esther De Ru. These were held at the Regional Beeches Education Centre. Esther presented current evidence and indications for
treatment using a variety of techniques. The practical sessions included application of a various tapes and participants headed home looking much more colourful than when they arrived! The course was very stimulating and provided another useful treatment technique to our repertoire.

The programme content for the new academic year will be finalised in July 2014 and members will be kept informed of topics to be covered with times and venues. Dates for your diary include: 25/09/14, 19/11/14, 26/02/15 and 22/04/15.

Please contact the committee with any topics you would like to be included in our programme. We aim to provide up to date clinical information as well as giving members the opportunity to network and exchange ideas. New committee members would be very welcome with an opportunity for election at our next AGM in February 2015.

Sheila McNeill
sheila.mcneill@belfasttrust.hscni.net

TRENT

The Trent Region Committee has been busy planning the Introduction to Paediatric Physiotherapy (ITPP) Course we are hosting on the 5th -7th of September. It promises to be an excellent course with contributions from both experienced ITPP speakers and new local specialists.

In May we also held our second evening lecture. Nicola Rutter, Community Respiratory Physiotherapist gave an interesting and informative talk on the innovative service she works for, providing Respiratory Physiotherapy and a Rapid Response service to children and young people with complex needs and life limiting conditions. This service has been extremely successful in the Nottinghamshire area in reducing hospital admissions for these children and providing families and carers with better support to meet their changing respiratory needs. It was great to hear how well the service is going.

The next evening lecture is planned for October 14th. It will be on Gait Analysis and will be held in Derby at the Gait lab with Helen Evans. This should be a great evening and we hope that the Trent Region members will come and take part.

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

The neonatal group have been very busy over the last few months.

The Neonatal Business Case Template has been launched and should be available on the APCP website. Thanks to Adare Brady for all her time and hard work on putting together this very useful tool. Hopefully it will result in a lot more contracted hours and less ad hoc services in neonatal units across the UK.

We have run another very successful LAPI course (see separate report). There was also the LAPI update day which I attended and really enjoyed, although the first thing we were asked to do was a formative assessment, no pressure! It was a great opportunity to network, share, ideas as well as problems and to pick Adare and Peta’s brains. One of the most exciting things to come out the LAPI week in Edinburgh is the creation of a national database where we can compare outcomes against predicted outcomes.

There is also an advanced day in neonatal respiratory care running at the beginning of July which will see the launch of the Respiratory Competence Framework. I am sure the day will go well and create a great deal of discussion. Thank you to Nicky Hawkes for all her organizing and providing the venue and to Fiona Price and Christa Ronan for allowing us to launch the Framework at this day.

Not wanting to be slouches about conferences and course we have jumped on the band wagon with the APCP ‘In Cahoots’ conference this year and will be running our own joint Neonatal Study Day in November focusing on infant mental health full details of the day can be found below. We hope to confirm speakers soon and have a more structured program very shortly.

Lastly the neonatal committee is sad to say goodbye to Jenny Martin who has left her post in London and has stepped down from the committee, thank you for all your help and good sense we will miss your laugh at conference. Also we say goodbye to Nicky Hawkes who is leaving physiotherapy to concentrate on her personal colour matching business. So we know where to go if we want to be more colour coordinated.

Hilary Cruickshank
Neonatal Group

PPIMS

PPIMs committee and Fiona Moore as VA met on 12th May to discuss the agreed proposal to move towards regional networks and representation on a national PPIMs committee. The constitution was reviewed and reconsidered in light of the response to the member’s survey already taken in autumn 2013. The use of the website and separate space allocation for PPIMS was also discussed and opinion of the national committee will be sought.

Fiona is to draw up a plan for the regional network meetings for rolling out to ensure that APCP membership is recognised within these support groups as well as local networking.

The rest of the meeting was dominated by the APCP National Conference parallel programme development, and I hope you will agree that the programme looks interesting and useful. There are a number of other offers of shared learning we discussed as being an opportunity for study days to be offered next year. We fielded the idea that a study day in May 2015 would have a variety of topics scheduled with presentation for members on shared practise ideas, potentially to be held near Stansted in response to the member survey regarding location of meeting.

Juliet Goodban
PPIMs

COMMUNITY RESPIRATORY GROUP

The community respiratory special interest group has now established a committee of the following people- Leanne Turner, Annika Shepherd, Zoe Johnstone, Emma Graham, Hilary Brewis & Rachel Carew.
We have recently conducted an online survey which you have maybe seen and we would like to thank all who have completed this for us, as the response was excellent. We are in the middle of writing this information up to be published in the near future. This has really helped us to focus on the main aims and objectives of the group.

We are currently working on collating some information around suction for the community and if anyone has any information or would like to contribute to this piece of work please feel free to contact us through the national secretary.

Leanne Turner
Community Respiratory Group

NEUROMUSCULAR GROUP

The next neuromuscular study day is now going to be in Bristol around February....watch this space.
We will be looking at the possibility of a 2 day, "intermediate level" course for the speciality groups.
We are still working on competencies but it is a big job.
MDC are advocating disseminating neuromuscular services in a hub and spoke model. This has advantages particularly for families, but disadvantages of “diluting” expertise which further makes competencies essential.
As a group, we will be putting more information onto the website so please let us know what you want to see.
Members interested in becoming part of the organising group, please let us know

Marion Main
Neuromuscular Group

NEW- NEURODISABILITY GROUP

In March this year, APCP put out a call to members for nominations to a new Neurodisability Specialist Group. We were overwhelmed by the response and received over 30 expressions of interest with most areas of the UK represented and a good spread of clinical experience.

All nominees were invited to attend a meeting at the CSP headquarters on Friday, 23rd May 2014.

The meeting opened with Sam Old presenting a brief overview of APCP and the aims and objectives of the APCP Specialist Groups and how they fit within the structure and objectives of the Association.

The Neurodisability Group will focus on work with children who have congenital and acquired long-term conditions that are attributed to impairment of the central nervous system, e.g. cerebral palsy, acquired brain injury and spinal cord injury.

This definition is intended to distinguish the remit of the Neurodisability Group from that of the existing Neuromuscular Group which focuses on work with children who have acquired and genetic conditions affecting the function of muscles, either directly as a muscle disease or caused by disorders of the peripheral nerves, motor neurons in the spinal cord or the neuromuscular junctions which supply them, e.g. muscular dystrophies, spinal muscular atrophy, congenital myopathies, hereditary neuropathies and congenital myasthenic syndromes.

The meeting then looked at the result of the recent Neurodisability Group survey of members – a summary of which can be seen at the end of this report. This survey was designed to help identify the priorities for the groups as informed by the membership and initiated some interesting discussions around the use of outcome measures in Neurodisability; the pros and cons of trying to standardize assessment and treatment; and the need to look at developing a more standardized pathway to becoming a paediatric physiotherapist.

The meeting then split into working groups where further discussions focusing on the potential role of the group with regards to:

- Acquired Brain Injury and Spinal Cord Injury;
- development of an intermediate level course on cerebral palsy;
- updating APCP resources relating to management of hip in children and young people with neurodisabilities;
• development of resources relating to the use of outcome measures.

It had been decided that it was important that a formal committee was elected at this meeting to ensure that the group would start to move forward independently before the end of the year. Unfortunately this meant that those who had been unable to attend were excluded from this process and also that not all those keen to be involved could be elected. Details of the new Neurodisability Group Committee can be found on the APCP website. The group will, however, attempt to utilize the enthusiasm and knowledge of all those who nominated themselves to take forward specific projects over the next few years.

A committee was elected at this meeting to represent the APCP regions and specialist clinical areas within Neurodisability. The only region that is not represented at present is Northern Ireland.

• Suzanne Carter - Pinderfields Hospital, Wakefield
• Sarah Crombie - Chailey Heritage Clinical Services
• Renee Daelmans - Bobath Children’s Therapy Centre, Wales
• Alison Fletcher - Nottingham Children’s Hospital
• Kirsten Hart - National Spinal Injury Centre, Stoke Mandeville
• Katie Kinch - NHS Fife
• Annie Levis - Cumbria University
• Claire Marcoft - Newcastle upon Tyne Hospitals NHS Trust
• Jennifer McLaughlin - Independent Practitioner
• Anita Patel - Evelina London Children’s Hospital
• Claire Tripathi - Sheffield Children’s Hospital
• Susie Turner - Evelina London Children’s Hospital
• Elizabeth Wright - Birmingham Children’s Hospital
• David Young - Addenbrooke’s Hospital

The new Neurodisability Group Committee will meet next in the autumn to discuss an action plan for the next 1-2 years.

MSK GROUP

• The committee had its AGM in June.
• The group seeks to offer training and guidance to paediatric physiotherapists who are interested in Orthopaedics, Rheumatology and musculoskeletal conditions affecting children (birth to skeletal maturity).
• A new two day “APCP Advanced Paediatric Musculoskeletal and Orthopaedic” course aimed at those physiotherapists who have already completed the “APCP Introduction to Paediatric Physiotherapy” is being developed. The meeting is likely to be held in spring 2015. For those who are interested, please contact vicky.easton@nnuh.nhs.uk
• The group are currently reviewing the evidence for diagnosis and treatment of Osgood Schlatters disease. A new patient leaflet and guideline for use by therapists is being produced.
• In June the third radiology seminar for Paediatric Physiotherapists (The RaPP course) took place in Norwich. One of the delegates wrote a review printed later in this newsletter

Further RAPP courses are planned and will be advertised via the CSP/APCP website

Vicky Easton
MSK Rep
Hello!

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One of the key aims of the British Academy of Childhood Disability (BACD) Strategic Research Group is to encourage and assist families, young people and clinicians to identify the research priorities for children and young people affected by neuro-disability.

The James Lind Alliance (JLA) brings patients, carers and clinicians together in specific conditions to identify and prioritise the top 10 ‘unanswered questions’, about the effects of treatments that they agree are most important. The top 10 ‘unanswered questions’ are then perceived as a priority for research. The JLA calls this sort of activity a ‘Priority Setting Partnership’.

A proposal by the Strategic Research Group for a Childhood Disability Research Priority Setting Partnership was considered by the BACD Executive Committee in spring 2012. BACD have allocated a small resource from the Paul Polani Fund to run a Childhood Disability Research PSP, following the JLA methods and focusing on ‘neuro-disability’ held in June 2014.

The aim of the Childhood Disability Research Priority Setting Partnership was to identify unanswered questions about the effectiveness of interventions for children and young people with neuro-disability from patient, carer and clinical perspectives. Then, to prioritise the questions that young people, parent carers and clinicians agree as most important as research topics.

Suggestions were gathered in an open survey, aggregated and framed as research questions, then checked against existing systematic reviews of research evidence to ensure they were unanswered. The topics were initially prioritised in a vote with stakeholders, and subsequently discussed at a workshop attended by young people, parent carers and various clinicians.

The uncertainties raised and prioritised are the outcome of a systematic and transparent process that includes stakeholders that have often not had a say in setting the research agenda. The Top 10 shared priorities for research, and other topics identified, are a resource to inform government and charitable agencies that commission and fund research.

Neuro-disability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and or neuromuscular system and create functional limitations. A specific diagnosis may or may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include disturbances of movement, cognition, hearing and vision, communication, emotion and behaviour.

There was an expectation that, if shown to be effective in research, the intervention could be expected to benefit the health and wellbeing of children with neuro-disability within 3-5 years of the results to demonstrate effectiveness.

The Steering Group included a young adult, two parent carers, a paediatrician, a charity representative, a researcher, and was chaired by a JLA advisor.

Lesley and Sue represented APCP at this meeting to choose 10 top priorities for research from a short list of 25. This list had been prioritised from an original list of 53 topics gathered from an open survey by a vote of stakeholders, including APCP.

The workshop was attended by young people, parent carers and clinicians. There were also observers from NIHR. The process of choosing the priorities was interesting as it involved championing one’s own choices while considering others priorities and inevitably meant that everyone had to compromise! The field of neuro-disability encompasses a wide range of conditions and it was obvious in discussions that our perspective is only one among many. What matters to a physiotherapist is not necessarily important to a young man with autism.

Please see the list below for the research priorities.

Sue Bush
APCP Research Officer
### The Top 10 ‘shared priority’ research questions

<table>
<thead>
<tr>
<th>Rank</th>
<th>Research question indicative of topics suggested in survey</th>
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<tbody>
<tr>
<td>1</td>
<td>Does the timing and intensity of therapies (e.g. physical, occupational and speech and language therapy, ‘early intervention’, providing information etc.) alter the effectiveness of therapies for infants and young children with neurodisability, including those without specific diagnosis? What is the appropriate age of onset / strategies / dosage / direction of therapy interventions?</td>
</tr>
<tr>
<td>2</td>
<td>To improve communication for children and young people with neurodisability: (a) what is the best way to select the most appropriate communication strategies? And (b) how to encourage staff/carers to use these strategies to enable communication?</td>
</tr>
<tr>
<td>3</td>
<td>Are child-centred strategies to improve children’s (i.e. peers) attitudes towards disability (e.g. buddy or Circle of Friends etc.) effective to improve inclusion and participation within educational, social and community settings?</td>
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<tr>
<td>4</td>
<td>Does appropriate provision of wheelchairs to enable independent mobility for very young children improve their self-efficacy?</td>
</tr>
<tr>
<td>5</td>
<td>Are counselling/psychological strategies (e.g. talking therapies) effective to promote the mental health of children and young people with neurodisability?</td>
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<tr>
<td>6</td>
<td>What is the (long term) comparative safety and effectiveness of medical and surgical spasticity management techniques (Botulinum neurotoxin A (BoNT-A), Selective Dorsal Rhizotomy (SDR), Intrathecal Baclofen (ITB), orally administered medicines) in children and young people with neurodisability?</td>
</tr>
<tr>
<td>7</td>
<td>Does a structured training programme, medicines and/or surgery speed up the achievement of continence (either/or faecal or urinary) for children and young people with neurodisability?</td>
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<tr>
<td>8</td>
<td>What strategies are effective to improve engagement in physical activity (to improve fitness, reduce obesity etc.) for children and young people with neurodisability?</td>
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<tr>
<td>9</td>
<td>Which school characteristics (e.g. policies, attitudes of staff etc.) are most effective to promote inclusion of children and young people with neurodisability in education and after-school clubs?</td>
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<tr>
<td>10</td>
<td>What is the long term safety, effectiveness and sustainability of behavioural strategies and/or drugs (e.g. melatonin) to manage sleep disturbance in children and young people with neurodisability (outcomes include time to onset, duration, and reducing impact on family)?</td>
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**Other research questions considered at the priority setting workshop in ranked order**

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<tr>
<th>Rank</th>
<th>Research question</th>
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<tbody>
<tr>
<td>11</td>
<td>What is the safety and effectiveness of drugs compared to talking therapies (e.g. Cognitive Behavioural Therapy) to treat anxiety in children and young people with Autistic Spectrum Disorders?</td>
</tr>
<tr>
<td>12</td>
<td>Are any types of physical therapy (e.g. Bobath, Neuro-Developmental Therapy, conductive education, hydrotherapy, constraint, strength-training etc.) more or less effective to promote motor functioning in children and young people with neurodisability (e.g. cerebral palsy, acquired brain injury)?</td>
</tr>
<tr>
<td>13</td>
<td>Are sensory processing/integration therapeutic programmes effective in improving behaviour and/or increasing play/participation for children and young people with neurodisability?</td>
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<tr>
<td>14</td>
<td>Are behavioural and sensory interventions (e.g. early intensive behavioural intervention, EarlyBird, encouraging socialisation with peers etc.) effective in managing symptoms of Autistic Spectrum Disorder?</td>
</tr>
<tr>
<td>15</td>
<td>Are postural management programmes (using standing frames and sleep systems etc.) effective and cost effective to prevent deformity (hip and/or spine) and improve function in children and young people with neurodisability? What is the incidence of adverse effects e.g. pain, sleep problems etc.?</td>
</tr>
<tr>
<td>16</td>
<td>Are child-focused strategies (e.g. one-to-one or group social and skills training) effective to improve confidence, self-esteem and promote participation in recreation and leisure activities for children and young people with neurodisability?</td>
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<td>Question</td>
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<tr>
<td>17 Do cross-sector interventions (e.g. key workers, named contacts to promote integrated health, social care, education) improve school attendance, reduce admissions, and parents’ satisfaction and experience of care for children and young people with neurodisability?</td>
<td></td>
</tr>
<tr>
<td>18 Does promoting public positive attitudes towards disability improve participation in recreation and leisure activities for children and young people with neurodisability?</td>
<td></td>
</tr>
<tr>
<td>19 Are dietary modifications/restrictions (e.g. gluten, casein, dairy, meat etc.) effective in managing symptoms of Autistic Spectrum Disorder?</td>
<td></td>
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<tr>
<td>20 Are oro-motor treatment strategies (e.g. oral motor exercises, sensory stimulation, sensorimotor activities etc.) effective to improve eating and drinking or speech for children and young people with neurodisability? Are there identifiable subgroups that benefit more from the strategies?</td>
<td></td>
</tr>
<tr>
<td>21 Are any designs of orthoses (e.g. Lycra, kinesiotaping, plastic etc.) more or less effective to promote functioning and prevent deformity for children and young people with neurodisability?</td>
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<tr>
<td>22 Are interventions to improve consistency of approach between health and education agencies (e.g. keyworkers) effective to improve behavioural problems in children with Autistic Spectrum Disorder (ASD)?</td>
<td></td>
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<tr>
<td>23 What is the long term safety and effectiveness of drugs used in seizure management, especially in terms of adverse effects on learning, psychosis, anxiety, anger and rage?</td>
<td></td>
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<tr>
<td>24 Does using instrumented gait analysis improve decision-making about treatments compared to clinical assessment alone for children and young people with cerebral palsy?</td>
<td></td>
</tr>
<tr>
<td>25 Do massage-based therapies improve functioning and wellbeing for children and young people with neurodisability?</td>
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**APCP Journal Report**

We published our last edition in May 2014 and are now working hard on the November edition. We are due to meet on the 2nd July to discuss the papers for inclusion in this edition and look forward to producing another varied journal.

We are planning a neonatal special edition in May 2015 and are working with Peta Smith and Adare Brady for this edition. The deadline for submissions is January 1st 2015. We are still interested in receiving articles and papers on other topics, so please continue to send these in to us.

**ALL submissions should be sent to the va@apcp.org.uk**

We are looking for more people to peer review papers to reduce the pressure on the editorial board. If you know of anyone who has some research experience and is used to reading and critiquing academic papers, please let me know. We are also still looking for someone with experience in respiratory paediatrics to join the editorial board.

Cate Naylor  
Journal Editor  
cate@naylor.org.uk

**Call for Abstracts**

A large number of members submitted abstracts for the 2013 conference. This is the call for abstracts for 2014. The closing date is 1st July and we appreciate it takes time and is quite difficult to write a good abstract. Don’t forget that the research and education committee are there to help you, although do make contact early if you would like some support or guidance.

In early July the research and education committee will review all the abstracts submitted and decide which ones to offer as poster presentations and which as free paper slots for the 2014 APCP conference.

Jo Brook  
Education Officer
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APCP West Midlands

‘Clamping Down on Contractures’
A forum with speakers including
Pauline Christmas, Consultant Physiotherapist for the Management of Spasticity in Children
Heather McMurchie, Paediatric Neuromuscular Physiotherapist

Will also include
feedback from current practice questionnaire, to be completed prior to the event
West Midlands APCP Annual General Meeting

Thursday 2nd October 2014
11am – 5pm
BIRMINGHAM VERNON SEA CADET UNIT
Osler Street, Birmingham, B16 9EU
Parking is free, refreshments and lunch will be provided
Cost: APCP members £10 / Non-members £15
Please register and pay online at va@apcp.org.uk
Your place will only be secured once payment has been received

Learning Outcomes
• To develop an understanding of the different types of patients presenting with lower limb contractures and the different methodologies used to address them
• Increased awareness of current evidence-based practice
• Increased awareness of orthotic and pharmaceutical adjunct
• An opportunity to review and share current practice
Here and There

RaPP (Radiology for Paediatric Physiotherapists)

In June the third radiology seminar for Paediatric Physiotherapists (The RaPP course) took place in Norwich. One of the delegates wrote the following review:-

The course was aimed at physiotherapists with a special interest in musculoskeletal medicine and/or orthopaedics and covered the basic physics and background information to enable safe and effective ordering of plain film X rays. It focused on the lower limb reviewing common conditions and problems that can occur. The course showed us how to use a systematic approach to review x-rays. It was led by two paediatric orthopaedic consultants supported by members the multi-disciplinary team that work closely with them.

The course format was good with concise informative lectures and lots of group work reviewing x-rays in a fit for purpose room. A lot of the work on the course was done in small groups. This worked well as it allowed us to practice using our new skills with advice from experienced medical staff, physiotherapists and a senior radiologist. A number of these were available at all times so there was always someone to ask for help. It also allowed the clinicians there to have long and thorough discussions with the students as needed. I felt the informal group work was excellent and gave us good opportunity to discuss the x rays and the different management techniques used by the surgical team and also reinforced the importance of physiotherapy support with these conditions. Discussing the different professional’s experience of treating common conditions also provided useful information of what has worked well.

Overall I think the course was really useful to get the essential knowledge and skills of how to review lower limb x-rays and will give me more confidence when doing this with my local orthopaedic colleagues. I feel I have taken away a lot of useful information that will help me in my day to day practice. The course was organised and well run, the staff were friendly and approachable and lunch was excellent too. I understand the group plan to run further courses and I hope to attend as I feel this will continue to develop and maintain my skills in this area.

Sarah Bacon (Paediatric Physiotherapist)

Association of Paediatric Chartered Physiotherapists

INTRODUCTION TO PAEDIATRIC PHYSIOTHERAPY

3 day course for physiotherapists and physiotherapy assistants

Topics include

- Key legislation
- Working with children and families
- Neurodisability
- Neuromuscular disorders
- Respiratory conditions
- Musculoskeletal conditions

5th–7th September 2014

Hilton East Midlands Airport Hotel

Further information and booking at:

http://apcp.esp.org.uk/network-events/apcp-introduction-paediatric-physiotherapy

va@apcp.org.uk
Here and There

Lacey Assessment of Preterm Infants 4-day Course, Edinburgh 2014

Scotland played host to the LAPI 4-day course this year with the generous and most welcoming help of the neonatal team at the Royal Infirmary, Edinburgh.

We would, firstly, like to pay credit to our wonderful tutors, Adare Brady and Peta Smith, who delivered the course with expert skill. Joan Lacey, who sadly passed away in April last year, spent the majority of her working life dedicated to the establishment and progression of a tool that has furthered our understanding, assessment and treatment of preterm infants. Adare and Peta conducted our learning in an utterly professional manner; however, it was the passion and respect with which they spoke that will stay with us long after we return from Scotland.

To fully understand the assessment tool, and its use within the neonatal nursery setting, deeper understanding of the preterm infant and their development is needed. One of the major strengths of this course is the tutors’ ability to teach the intricacies of the assessment itself, as well as the fundamental, underlying knowledge that makes its practitioners successful in continuing the work that Joan worked so tirelessly to perfect throughout her career.

During the 4-day course, there was ample opportunity for delegate participation and discussion to enhance learning and, it is here, that we would like to extend our sincere and heartfelt thanks to Hilary Cruickshank of the physiotherapy team at RIE. Opportunities were given to consolidate classroom learning through observations on the neonatal unit and multiple video examples, with the consent of the infants’ parents. Unfortunately, hands-on experience was limited by factors outside the control of the tutors and host, however, practical application was emphasised through teaching and delegates were not at a disadvantage by the completion of the course.

Adare and Peta’s patience, enthusiasm and, seemingly, endless amount knowledge is a testament to their dedication in carrying on the work started by Joan all those years ago. We thank you, again, and hope we can collaborate with you in the years to come.

Lucy, Charlee and Mick.

Lucy Llewellyn-Stanton (North Middlesex University Hospital, London)
Charlotte Laid (John Radcliffe Hospital, Oxford)
Michael Coates (North Middlesex University Hospital, London)

Delegates from the LAPI course 2014

Attendees at the LAPI update course 2014
Back row left to right - Claire Marcroft, Charlotte Xanthidis, Sheila Bryson, Hilary Cruickshank
Front row - Pat Dulson, Jo Bax, Ali Currie, Gill Ford, Julia Devonport
## CP Sport Calendar of Events

<table>
<thead>
<tr>
<th>Day</th>
<th>Date</th>
<th>Event</th>
<th>Venue</th>
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<tr>
<td><strong>2014</strong></td>
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<td><strong>August</strong></td>
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<tr>
<td>Sat onwards</td>
<td>2-10</td>
<td>IWAS World Junior Championships</td>
<td>Stoke Mandeville</td>
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<td>Thurs onwards</td>
<td>14-24</td>
<td>European Athletics Championships</td>
<td>Swansea</td>
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<td>Sat</td>
<td>16</td>
<td>Swimming Development Gala</td>
<td>Newport, Wales</td>
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<td>Sun</td>
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<td>CP Football Kickstart Day</td>
<td>Staffs</td>
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<td>Sun</td>
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<td>CP Football Kick-Off</td>
<td>St. George's Park, Burton on Trent</td>
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<td>Swimstart Development Day</td>
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<td>Sat-Sun</td>
<td>23-24</td>
<td>Bowls Open Pairs</td>
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<td>Sun</td>
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<td>Athletics Grand Prix</td>
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<td>Swimming Development Gala</td>
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<td>Great North Run</td>
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<td>Sat</td>
<td>20</td>
<td>National Athletics Championships</td>
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<td>Mon - Fri</td>
<td>22-26</td>
<td>National Junior Games</td>
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<td>Sat</td>
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<td>Swimming Development Gala</td>
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<td>Swimming Development Gala</td>
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<td>Development Swimming Gala</td>
<td>Hayward's Heath</td>
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<td>12</td>
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<td>Swimming Training Weekend</td>
<td>Nottingham</td>
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<td>16</td>
<td>Development Swimming Gala</td>
<td>Leek</td>
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<td>Sat-Sun</td>
<td>22-23</td>
<td>Bowls - Masters competition</td>
<td>Nottingham</td>
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<td>Sun</td>
<td>7</td>
<td>National Table Cricket Community League Final</td>
<td>Trent Bridge, Nottingham</td>
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<td>Sun</td>
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<td>National Swimming Championships (TBC)</td>
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<td><strong>April</strong></td>
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<td>London Marathon</td>
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<td><strong>August</strong></td>
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<tr>
<td>Fri onwards</td>
<td>7-16</td>
<td>CP-ISRA World Games</td>
<td>Nottingham</td>
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Key
- General
- Fundraising
- Football
- Swimming
- Multi Sports
- Athletics
- Bowls
- Table Cricket
- World Games

For further information about CP Sport events please contact:
CP Sport, Unit 5 Heathcoat Building, Nottingham Science Park, University Boulevard, Nottingham NG7 2QJ
Tel. 0115 925 7027

Please note all events and venues may be subject to change
Updated 1 July 2014

Up and coming WheelPower Events taking place at Stoke Mandeville Stadium Aylesbury unless stated:

National Junior Games – 22nd-25th September (11-18 year olds, 3 day residential multi-sport/competition event)
Primary Sports Camp – 18th October, Birmingham (6-11 year olds, one day multi-sport event)
Junior Sports Camp – 9th-10th November (11-18 year olds, two day residential multi-sport/coaching event)
In2 Sport – 29th-30th November (18+, two day residential multi-sport/coaching event)

For more information visit www.wheelpower.org.uk or get in contact via info@wheelpower.org.uk or 01296 395995.
Paracanoe

Canoe sprint is a sport where athletes race each-other in specially designed boats. Paracanoe started in 2009 when the first world championships were held in August in Halifax, Nova Scotia, Canada. There were 27 athletes and 7 federations. One of these athletes was trained in Newark by Coach and Paediatric Physiotherapist Julie Gray. Julie works for Nottinghamshire healthcare and has done for the last 25 years alongside volunteer coaching and running her own canoe club-4A’s (Adventure Activities for All Abilities).

Julie trained as a Medical Classifier in February 2009, at a workshop held in Paris by the Canoeing 4 All committee, which runs Paracanoe for the International Canoe Federation (ICF). Classifiers, both medical and technical, are needed in order for the Paracanoe events to take place as all of the athletes need to be classified according to their functional ability in order for the races to be fair.

Julie did her first official international classifications of athletes, at The World Canoe Sprint Championships in Halifax.

The following year the ICF applied for Paracanoe to become part of the Paralympics.

Being one of the First International Medical Classifiers and with her many years of experience in coaching canoe sprint athletes, Julie was asked to be the ICF Head of Classification. In February 2010 she attended her first IPC Heads of Classification meeting in Bonn.

In August 2010 the world championships were held in Poznan, Poland. Julie was responsible for the organisation of the classification programme and was one of the tutors on the classification course to teach new classifiers. Great Britain won it’s first Paracanoe medal, a bronze. This was an extra achievement for Julie, as the athlete was trained at her club in Newark. As Julie was responsible for the organisation of the event she needed the assistance of another physiotherapist and Sarah Bacon, also a Paediatric Physiotherapist for Nottinghamshire NHS trust, volunteered to help.

In December 2010 Paracanoe was accepted into the Paralympics by the International Paralympic Committee (IPC). From that point the competition, and the structure supporting it, has grown rapidly in preparation for the Paralympics in Rio 2016.

In 2011 the world championships were held in Szeged, Hungary. Julie organised the classification programme, supervised the classifiers and taught classification to a new set of classifiers. Sarah also attended again to assist her. Later in the year Julie also went to the Asian CanoeKayak championships in Tehran to teach the classification process, and to increase the spread of classifiers around the world.

In 2011 Paracanoe was added to the European Canoe Association (ECA) calendar, and the first European Paracanoe championships were held in Belgrade, Serbia. This competition has quickly grown to the second largest competition of the racing year, and further events were held in Croatia (2012) and Portugal (2013). This year the Europeans will be in Brandenburg, Germany.

The European championships have been Julie’s chance to maintain her own classifying skills, seeing up to 20 athletes in a couple of days. At these events Julie also organises the Paracanoe race schedule and assists with medal ceremonies. Without this work the events could not take place.

At the beginning of 2012 Julie was invited onto the Canoeing 4 All committee in an advisory capacity, as over half of the committees work now involves Paracanoe.

The world championships were held in Poznan early in 2012, as everyone’s main focus was on the Olympics and Paralympics in London. Both Julie and Sarah attended this event to ensure the classification process was completed.

As Julie was then in the UK for the summer she took the opportunity to give the children and young people, who train with her at 4A’s, the chance to watch the international canoe sprint athletes perform in
the Olympics. She took the club to Eton Dorney to watch Ed McKeever win gold in the 200m sprint kayak (the same distance as the Paracanoeists race).

Julie also attended the IPC’s (International Paralympic Committee’s) education course, during the London Paralympic games, along with representatives from Sochi and Rio. This aims to give future Paralympic organisers an insight into how the games are run. This gave her opportunity to see all of the “back room” stuff, and none of the action. But she did see the closing ceremony and this was fantastic!

In 2013 the World Championships were in Duisburg, Germany. This year marked a huge milestone for Paracanoe, as for the first time there were over 100 athletes in the competition, from 28 federations. Instead of straight finals, there were heats in the most popular events. In the Men’s LTA class (these are the athletes with the least functional impairment), the 40 second barrier was broached for the first time by current World Champion Tom Kierey from Germany.

In 2014 the event calendar continues to grow with World Cup events being added for the first time. The first was a small event in Milan. The Italians were testing out the venue in preparation for the world championships next year, as this will be the first qualifying event for Rio. Sarah attended this event in Julie’s absence taking responsibility for the medical classification of the athletes with the support of the technical classification team. Followed by the World Cup in Szeged where there were over 40 athletes attending from 13 federations. The Head Technical Classifier, Diego Doga, and Julie, worked closely with the Hungarian organising committee to complete the classifications, schedule the races, and get all the information to the federations at the Team Leaders meeting.

As the calendar grows, so does the work load for the Classifiers. They all work voluntarily, and have to take annual leave to attend most of the events. The benefits are that they are developing a network of friends and colleagues around the world. Their Facebook contacts include people in USA, Canada, Brazil, France, Italy, Germany, Kazakhstan, Japan, Australia, Slovenia, Poland, Ukraine ……

Julie’s statement of what she does …

For myself, as well as heading up the classification team at the World Championships where I tutor the classification course, and working as a classifier, both Nationally for GB and Internationally for the ICF and the ECA, I also attend the yearly Canoeing 4 All committee meeting, and the yearly IPC Heads of Classification meetings. I also handle many skype calls and e mails from classifiers wishing to get advice on athletes in their federation.

In addition to that, the ICF is now involved in a Research project into classification, as the IPC demand proof that the classification system is valid and places the athletes in the correct categories. Although I am not directly involved with the research, I have been assisting with the analysis of the results, and the practical application of those results to future classification. I am about to attend a 3 day research meeting at the ICF headquarters in Lausanne with the researchers from Sweden and Brazil, the Chair of the C4All committee and the Head Technical classifier.

The IPC also insist on sport specific classification, which means that our classification has had to evolve from where we started, as we used a system which was developed for Adaptive Rowing. The vast majority of that evolution has come via myself, and I have been able to use my physiotherapy skills to make changes to the testing process, to enable us to analyse the balance and movement patterns needed for kayaking, and which makes our classification process more relevant to the sport.

Sarah’s statement

Since volunteering to work with Julie and the International Canoe Federation I have had the opportunity to work with athletes with a range of abilities, meeting people from different countries, cultures and backgrounds. I feel it has enhanced my physiotherapy skills and shown me how important sport is in aiding rehabilitation and maintaining the fitness of people with a range of abilities. I am keen to continue my involvement with the group and the further development of the classification process to ensure that the process is as fair and inclusive as possible. Without Julie and her team the Paracanoe events could not happen.
“Petra running bikes: a novel exercise/sporting activity for children with cerebral palsy”

Children with cerebral palsy who are unable to walk independently are prone to lower limb muscle weakness which contributes to pain, deformity and functional loss. As a result of these motor difficulties the children are less physically active than their unimpaired peers and subsequently at greater risk of developing secondary conditions such as osteoporosis.

There are limited modes of exercise for non-ambulant children and young people with cerebral palsy. We wanted to find an activity that would be fun and feasible for the children to participate in which may increase their physical fitness and improve their quality of life. Many children have “walkers” which support them in walking but these are often bulky and heavy to manoeuvre.

A novel mobility device, the Petra running bike has been designed in Denmark for outdoor use for children and adults with mobility and balance disorders by Connie Hansen (occupational therapist and paralympian). The Petra running bike consists of a 3 wheeled frame with handlebars, saddle and trunk support. As opposed to a pedalling system the user sits on the saddle and propels themselves forward by contact with his/her feet on the ground. The running-bikes unique design, with various postural support accessories, offers children with cerebral palsy the potential to take part in physical activity, as well as giving them freedom of movement and independence.

The advantage of the running bikes are that they are readily available commercially (Quest88 Ltd) and require minimal instruction or adaptation.

From the initial construction of the first Petra race runner in 1989, race running has flourished as a sport (www.racerunning.org). It is an international disability sport in which children and adults compete with running bikes on athletics tracks in events ranging from 40m to 3000m. In 2011 race running was introduced to IWAS games and included in the 1st European Paralympic Committee Youth Games in 2012. It is hoped that race running will become a Paralympic sport.

The pilot study

We are currently undertaking a pilot study investigating whether the running bikes are a feasible and enjoyable mode of exercise for non-ambulant children with cerebral palsy. This study has been funded by Sparks, the children’s medical research charity.

We have 15 non-ambulant children (4-12 years) who are trialling the running bikes in two specialist schools, 3 times a week for 12 weeks. Each school has been provided with 4 Petra running bikes, and additional items of postural support including body supports; gripping aids and leg separator plates.

So far the physiotherapists have been very positive with their feedback. The running bikes roll freely enabling the children to propel themselves by their own efforts. Despite the severity of their disability the children have generally loved using the running bikes and demonstrated improved ability to propel them as time increased.

As well as investigating if the running bikes are fun and acceptable for these children, we are also measuring other objective outcome measures, including changes in ability to use the running bike; gross motor function; quality of life and bone health status according to calcaneal ultrasound. The results of each of these will be analysed at the time of completion of the pilot study.

For further information contact:

Liz Bryant  PhD
Senior Research Fellow, Chailey Heritage Clinical Services, Sussex Community NHS Trust
Email: liz.bryant@nhs.net
Tel: 01825 722112 ext 7796
Introducing RaceRunner

RaceRunner is a new sport in England being piloted by Cerebral Palsy (CP) Sport. It is for children, young people and adults who cannot functionally run and rely on sports aids for mobility and balance.

RaceRunner is a three wheeled frame where the athlete is supported by a saddle and body plate. The athlete propels against the frame using their feet, and steers using the mobility within their hands and/or arms. People with physical disabilities in other countries already participate in Race Runner – including Scotland.

RaceRunner was invented in Denmark in the 1980s, the sport received international recognition in the mid 1990’s.

RaceRunner is known to have amazing benefits for the athlete:

- Freedom of movement and independence that athletes may not have experienced before
- A rehabilitation/physiotherapy aid – including walking gait
- A training aid for other physical activities, improving the cardio vascular system and muscle strengthening

Reference: Presentation to delegates at the European Paralympic Committee Youth Games in Brno, Czech Republic in 2012. Given by Craig Carscadden, CPISRA Development Officer and International Race Runner classifier.

RaceRunner can currently be enjoyed at CP Sport’s Athletics Training Days and Grand Prix Events allowing athletes with moderate and profound disabilities a chance to enjoy sport. It’s suitable for all levels of ability from the age of 10 upwards.

We hope to extend our RaceRunner programme into our Junior Sportstart days where children from 5 upwards can enjoy a variety of different sports from Polybat and Table Cricket to Adapted Sports Hall Athletics and Boccia. We want to see more children enjoying more sports, more often.

The CP Sport RaceRunner programme is supported by Quest 88. Their mission is to identify and develop new technologies which assist people in their physical development, rehabilitation and their daily living.

Current events:

- 24 August 2014 Athletics Grand Prix Competition - Gateshead
- 20 September 2014 Athletics Grand Prix National Championships - Grantham

2015 dates to be announced shortly

CP Sport will also offer a coaching programme which will lead to the number of people 14+ engaging in sport and physical activity, providing us with new insight and knowledge to develop Race Runner further in the future. We’ll have more information available on this soon.

If you’d like to find out more about RaceRunner, then please get in touch at info@cpsport.org or visit our website to register for one or more of our athletics training days and competitions.
**Introduction**

It is highly unlikely that any of you will need an introduction to hemiplegia as you probably regularly treat a number of children with the condition, but here’s how we describe it at HemiHelp:

Hemiplegia is a neurological condition caused by damage to the brain. In 80% of cases it happens before or around the time of birth and is known as congenital hemiplegia. Parents will usually only become aware of their child’s hemiplegia gradually during his or her infancy as they display developmental delays or ‘one-sidedness.’ Some children acquire the condition (acquired hemiplegia) later in childhood following a stroke, a virus or infection such as meningitis or head trauma.

The effects are like a stroke and it leads to weakness and lack of control on one side of the body. However, the physical severity will vary from one person to the next. In one child this may be very obvious; he or she may have little or no use of one hand and may limp severely. In another child it will be slight and only show when attempting specific physical activities. Most children have additional diagnoses such as epilepsy, visual impairment, speech difficulties, perceptual problems, specific learning difficulties or emotional and behavioural problems.

**The role of the physiotherapist in the treatment of hemiplegia**

**Part of a multi-disciplinary team**

The physiotherapist will form part of a multi-disciplinary team that will also include some or all of the following professionals: paediatricians, occupational therapists, speech and language therapists, teachers, nursing specialists, psychologists and orthotists. It is really important that there is good communication between the different parties as they often need to work closely. For example, together with the occupational therapist and orthotist, the physiotherapist will often advise on, assess and tweak specific pieces of equipment such as casts and splints. It is also helpful for school teaching staff to understand the importance of orthoses in treating children’s movement and to be able to help with their management. In the same vein, if teachers and learning support assistants liaise with the treatment team and are aware of the therapies the child is receiving, they can incorporate the interventions advised by the therapists into daily activities with the child.

**Key aims of physiotherapy**

In most cases, the first person to work with a child diagnosed with hemiplegia will be a paediatric physiotherapist and they are often the professional lead on goal-setting and planning for motor ability.

The physiotherapist’s main aims in the treatment of children with hemiplegia are to:

- Give the child the best possible function on the affected side.
- Minimise secondary deformity at the level of muscles and tendons by targeted strengthening and stretching, promoting activity and balance.

As with most things, there are ‘trends’ within the field of physiotherapy. Whereas twenty years ago, the emphasis was on strengthening, this shifted to stretching ten years ago. Nowadays, the general consensus is that a balanced approach of strengthening, stretching, selectivity, and motor fluidity, focused on goal-orientated activity is optimal.
Exercise programmes can be used to target specific muscle groups and stretching can be helped by pulses (several short spells) of serial plaster casting across joints or splinting. Sometimes, together with the occupational therapist there will be a focus on the treatment of reduced sensation, hypersensitivity and visuospatial difficulties.

Many therapists use specific approaches to therapy. One of the most common is neurodevelopmental therapy – the Bobath approach – whereby the therapist tries to modify muscle tone and repeat typical patterns of movement so that the brain learns these patterns and the child begins to use these movements automatically. A similar adaptative approach is used in other widely used techniques, such as Vojta therapy or conductive education, as championed by the Peto Institute in Budapest. Plasticity within the nervous system is encouraged in all such therapeutic approaches by patterning of movements. The principles have broad acceptance and although there has been an increasing number of studies of these therapies the evidence base to support their benefit is not robust.

According to physiotherapist, Lulu Johnson, “the most important thing as a physio is to try to establish a connection with the child, make an effort to truly engage with them and you will be astounded at the progress that they make!”

**Parent involvement**

It is important to train and support parents so that they can also work with their child to stimulate the affected side of the child as much as possible at home. As physiotherapist Amanda Valentin says “the goal is to make the child as independent as possible and to teach him to integrate his affected side with the rest of his body. To encourage ‘two-sidedness’, Amanda says “it is crucial to treat the child as early as possible because the plasticity of the brain is much more important during early development. The plasticity is what gives us the possibility to learn and adapt our movements, our abilities and our knowledge through environmental interactions and stimulations induced by learning. As a result, the more exposed we are at an early age to stimulations, the easier it is to learn and adapt to our surroundings. Consequently, a child will be more likely to benefit from an early treatment.”

**HemiHelp services to support the physiotherapist**

**Who is HemiHelp?**

HemiHelp is a charity that was set up by a small group of parents in 1990. It has grown into a national organisation that has a membership of over 4,000 families and professionals from all over the UK and beyond. We provide information and support, run events for children and families and promote the rights and well-being of children and young people with hemiplegia.

**Free professional membership**

Membership to HemiHelp is free for professionals and allows access to a range of resources. These include regularly updated information sheets, email updates and an extremely popular quarterly magazine which covers a broad range of topics relating to hemiplegia, including articles by medical experts as well as families of children with hemiplegia.

Lulu Johnson says “I find that the HemiHelp Magazine offers great insight to me as a physiotherapist from the child and their family’s perspective as to what living with hemiplegia entails. As a paediatric physiotherapist I treat children with a variety of conditions, and to have access to a magazine that focuses entirely on hemiplegia, with input from so many different people who work with and are affected by hemiplegia, is very beneficial to my ongoing learning and development as a physiotherapist! Thank you for this great publication.”
As a professional member you will also have access to all the information and support services we offer families, including a helpline staffed by parent volunteers, a home-visiting service, a network of local groups, regular parents’ conferences, children’s fun days and a range of workshops.

**Professionals’ conferences**

HemiHelp also holds conferences for professionals that bring together leading practitioners in the field to share learning and present the latest research and practice. As well as gaining information and knowledge that can improve your skills, attendees also qualify for CPD points.

A physiotherapist who attended one of our recent conferences commented “It has been very valuable to learn more about new developments in managing hemiplegia. Also, I learnt some new things about visual-spatial difficulties which I am going to use to adapt and hopefully improve my treatment techniques.”

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**Our next Professionals Conference ‘Developments in the Management of Hemiplegia’ is being held on 18th September 2014 at Resource for London, 356 Holloway Road, N7 6PA.**

This event will be chaired by Sam Old, Chairman of APCP and will include a range of presentations, a few by leading specialists in paediatric physiotherapy. For details of the full programme and to book your place, please visit the website www.hemihelp.org.uk

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**Try It Days**

HemiHelp tries to promote physical activity for children with hemiplegia by holding ‘Try It’ days across the country. These are sports and activity days that give children a chance to meet other children with the condition and to try out new, exciting activities in a safe, comfortable environment. Past activities at Try It days have included fencing, badminton, roller-skating, swimming, karate and trampolining. As well as giving the children the chance to explore new interests which they then often take up, the activities help them to develop other physical and mental skills, for example improved hand-eye co-ordination, balance and flexibility.

**Contact us**

www.hemihelp.org.uk

If you would like more information about anything discussed in this article, please email Neelam Dongha, neelam@hemihelp.org.uk

To become a professional member (FREE) of HemiHelp or if you would like us to send you some information leaflets to distribute to families with hemiplegia, please email support@hemihelp.org.uk

If you are interested in attending our next professionals’ conference in London this September, please email Samantha Lee, sam@hemihelp.org.uk or book via the website at www.hemihelp.org.uk/about_us/what_we_do/events/professionals_conference_london

We look forward to hearing from you or meeting you at one of our events!

Reference: The Hemiplegia Handbook by Dr Charlie Fairhurst and Liz Barnes
Safety and Feasibility of sputum induction in Pre-school children with Cystic Fibrosis, Wheeze and Recurrent Cough. – a pilot study.

Background

In August 2013, I spent an amazing 3 weeks on an MSc placement with Nic Collins and her paediatric physiotherapy team at the Royal Brompton Hospital. This year, I was given the fantastic opportunity to return to London on a 3 month secondment from rural Dumfries and Galloway to complete a pilot study for the Paediatric Department at The Brompton. The purpose of the study was to assess how well sputum induction is tolerated in pre-school children with Cystic Fibrosis, wheeze and recurrent cough and how it is accepted by the child and family, whilst also comparing the samples obtained from cough/oropharangeal swab, sputum induction and bronchoalveolar lavage if bronchoscopy was clinically indicated.

Results

No adverse effects were seen during the procedure and 28/31 (90%) patients tolerated the whole hypertonic saline nebuliser to varying degrees. 2 patients expectorated independently and the remaining 29 patients all received oropharangeal suction to obtain a sample. 17 growths, including both bacterial and viral were detected in 14 patients. Of this number, 2 were identified from pre-induction cough swab, 1 identified from post induction swab and 14 growths were identified from oropharangeal suction samples. Some macrophages were identified from cytology which demonstrates lower airway sampling was successful.

The results of this pilot show that it is safe and feasible to carry out sputum inductions in pre-school children and that samples obtained can identify infection and inflammation that cannot be provided by a cough swab. More data is required from patients going for bronchoscopy, especially to allow comparison of cytology results. One of the clinical fellows based at The Brompton is continuing this part of the research in the short term.

The Future

Clinically, the results have prompted consideration of sputum induction prior to bronchoscopy in pre-school patients at The Brompton. The CF team is also considering how to fund this as a service due to the comparison of results from induced sputum and suction compared to cough swab alone. The results of this pilot are to be submitted as an abstract and the data will also be used to write my MSc dissertation for MSc in Advanced Paediatric Physiotherapy next academic year. More data including collection of longitudinal data is required and following the positive results from this pilot study, a larger study is going to be completed at The Brompton in the future.

Karen Robson
Paediatric Physiotherapy, Dumfries

With acknowledgement to NHS Education for Scotland’s AHP Careers Fellowship scheme for funding support

“99 Ways to Skin a Cat”
A review from an exploratory fact finding trip to several independent centres in the UK

Emma Cameron, Clinical Lead Paediatric Physiotherapy, Northern Health and Social Care Trust, Northern Ireland
Ruth Clarke, Team Lead Paediatric Physiotherapy, Northern Health and Social Care Trust, Northern Ireland

With welcome contributions from The Footsteps Centre, The Movement Centre and The National Institute for Conductive Education.
In recent years there are a growing number of private methods of therapy offered to children with neurological deficits. With the advent of the World Wide Web and social networking sites families have information at their fingertips. In the Northern Health and Social Care Trust (NHSCT) Northern Ireland, we as a paediatric physiotherapy department have been finding that as families have this information at their disposal they have been seeking other treatment methods such as conductive education and spider therapy. In an effort to further our knowledge of these methods as a department and support our communication and collaboration with therapists offering private methods of treatment we got the support of the physiotherapy manager in the NHSCT to carry out a ‘scoping’ trip. Two members of our department, myself and Ruth Clarke undertook the trip over a three day period in March 2014.

The aim of the scoping trip was as follows:

- To gain a wider understanding of available therapy options for families of children with long term conditions.
- To understand their background, philosophy and application.
- To inform practice and communication with private practitioners.
- To establish if any therapies may enhance NHSCT paediatric physiotherapy services.

Fiona Moore, virtual administrator of the APCP, enquired on our behalf anyone who could help to locate a possible area in which we could explore as many therapies as possible. Juliet Goodban, Paediatric Occupational Therapy and Physiotherapy Lead, Wyre Forest responded with several suggestions for the Midlands area.

The itinerary was then set: Day 1: Footsteps Centre, Oxford: Incorporating spider therapy. Day 2: Conductive Education National Centre Birmingham. Day 3: The Movement Centre in Oswestry, offering and researching targeted therapy. I would like to highlight here that we were welcomed by everyone at every centre. The staff were always transparent about their services and willing to let us ask, observe and ask some more. The children were incredible and the families were also very open and honest with us! Thank you!

It would be unwise of me to go through all that we saw and discussed. We are also not going to provide our own insight on each of the centres that we saw. Those centres have been asked to submit their version of their service so you can explore that further for yourself and through their online media; http://footstepscentre.com/; www.the-movement-centre.co.uk; http://www.conductive-education.org.uk/. However what we would like to do is outline some of the lessons we learnt through the experience.

Building relationships with practitioners in the private centres the families using our services go to is essential. These centres are under demand from families with children with long term neurological conditions. The demand is there as families endeavour to ensure they ‘are doing all they can’. Paediatric physiotherapy departments cannot supply a limitless amount of therapeutic intervention. Therefore as a profession we need to be open and facilitate families exploring these alternatives to ensure they are accessing ones that have trained practitioners, who fulfil professional requirements, who goal set with families and evaluate practice. In being open and not defensive we may hope to maintain our professional relationships with those families through their child’s journey in our service.

The new therapies brought over by overseas therapists even if not research based have a lot to offer. We found the therapies we observed were simple, practical and certainly all had something to offer. As a profession we should explore them and research them to establish if they can add value to our service and enhance outcomes for children. Certain genres have been the mainstay of our treatment approaches for decades and those genres need to be challenged alongside other developments to ensure the best fit for each child.

The centres we visited all have to sell their services to families to ensure business and then repeat business. As a result when we talked to them their discussions were all about the child and family and the benefit of the therapy for them. We also need to ‘sell’ our services to families more. To have conversations were we outline what we are offering, why and to what benefit. Collaborative goal setting offers this regular opportunity. As a profession offering an ‘eclectic’ approach we have a lot of tools at our disposal. I wonder if we do enough to share that with families? With the professional challenges ahead it also reminds us that we have to constantly ensure the child and family are at the heart of everything we do.
The trip also offered us the opportunity to meet other therapy team managers and discuss areas of service provision in order to compare, give thought and benchmark. To this end we would like to thank Jennifer Cahill from Oxfordshire integrated therapy services and Juliet Goodban from Wyre integrated services for giving up their time to answer all our questions and sharing their practice.

As the Melanie Brown, Head of the National Centre for Conductive Education rightly observed ‘there are 99 ways to skin a cat’ and most therapies for this group of children have something to offer. Parents want to explore options, we should help them by offering more diverse treatment options and by helping them work out the centres that are best equipped to meet the needs of their child.

**Contribution by The Movement Centre**

Targeted Training was developed to assist children with the learning of trunk control. With the use of specially designed equipment the child is treated in the upright position from the onset. An initial assessment indicates where the child’s trunk control is poor and support is given just below this point on the trunk to simplify the learning. Activities done in the stander strengthen the trunk above the support and this process continues gradually downwards in a segment-by-segment progression, training the control. A course of therapy takes 9 months from the date of equipment supply. The therapy is delivered by the family or physiotherapist daily, at home or at school for half an hour. Children who benefit from Targeted Training are those with cerebral palsy and other neurological conditions which impact on movement, balance and posture control.

Further information can be found on our website or Facebook page.

**Contribution by The Footsteps Therapy Centre.**

The Footsteps therapy programme combines traditional mat exercises with the use of the ‘Spider’. The programme is individually tailored to the diverse needs of each child, ensuring that all children get the most out of the course. The dual focus of the programme is designed to impact on the physical, cognitive and developmental capabilities of disabled children. Developed in Poland, the ‘Spider’ enables therapists to carry out a full course of exercises in any chosen position. ‘Spider’ therapy focuses on the development of fundamental movements such as reaching, grasping and holding. The child can achieve the correct body positions for crawling, sitting, kneeling, one-legged kneeling and standing, as well as maintaining and changing between positions independently. The Footsteps therapy programme is run throughout the year in blocks of three weeks, enabling the Centre to deliver 17 intensive blocks of therapy a year to over 160 children. The majority of children who attend come for two or more sessions a year.

**Contribution from the National Institute for Conductive Education**

Conductive Education (CE) originates from the work of the Hungarian physician András Pető in the 1940s. CE is more easily understood when considered as an approach of teaching and learning rather than as a medical or therapeutic intervention. The underlying principle is that the person with a neurological motor disorder needs to *learn* how to perform the actions which do not develop automatically due to the damage to the central nervous system or have been impaired as a consequence of an acquired neurological condition. CE as an approach can be beneficial for children with cerebral palsy and related motor disorders and adults with Parkinson’s, stroke, MS and acquired brain injury.

CE can now be seen to have a base in current scientific thinking around the brain, learning and rehabilitation. Popular science shows that people, irrespective of their age or disability, have the potential to learn and develop skills once thought impossible. However there is still little knowledge on how this can be achieved in a systematic way. CE has the main aim of creating active, independent learners, people who are able to transfer learnt motor skills into everyday life. Alongside the physical benefits CE focuses on transforming the personality of the learner; developing a desire to achieve, confidence, and an ability to problem-solve everyday life skills. In order to achieve this Pető integrated medical and educational knowledge and created a ‘new’ professional – the conductor. Whilst it is recognised that CE has been in the UK since the 1980s the integration of areas of education, health and social care are still seen as problematic and revolutionary in 2011.
The National Institute of Conductive Education

The Institute was formed in 1987 to provide a full range of services for children and adults who may benefit from CE. Currently we offer: parent and child groups for children aged 0-3yrs; nursery provision for children aged 3 – 5yrs; full time and part time schooling for children aged 5 – 11yrs and sessional placements for children and adults across the life span. We also house The Conductive College which provides BA Hons training for new conductors; post-graduate training for existing professionals and assistant training courses.

Potential benefits

Children and adults are ‘led’ into developing a range of everyday motor skills to improve their independence. Alongside this parents and participants frequently report an increase in confidence, motivation, social skills/communication. All of these skills enable the person to be more fully included in society at a level which reflects their ability rather than their disability.

Further information: www.conductive-education.org.uk

Dr Melanie R Brown: CEO/Director of Services.

Ruth Clarke (team lead paediatric physio) Dr Melanie Brown from the CE Institute and Dr Emma Cameron (clinical lead paediatric physio)
Music therapy research steps onto world stage

London will become the centre of international music therapy research this week at the inaugural meeting of MANDARI, a pioneering research collaboration for Music and the Neuro-Developmentally At-Risk Infant.

Leading music therapists and neuro-scientists from around the world will meet with composers, parents and other stakeholders at Goldsmiths University of London to develop a music therapy research agenda for fragile infants.

MANDARI has been established by a small group of neo-natal intensive care specialists headed by Australian music therapy researcher and clinician, Dr Helen Shoemark.

Dr Shoemark, from Australia’s world-renowned Murdoch Childrens Research Institute (MCRI) in Melbourne, has created MANDARI over the past year with a core group of British and American collaborators.

MANDARI Core Group members include neuro-scientist Dr Lauren Stewart from Goldsmiths, researcher and clinician Dr Deanna Hanson-Abromeit from the University of Kansas, and leading British music therapy researchers.

Dr Shoemark said music was used with babies in neo-natal intensive care units (NICUs) as a multisensory tool to trigger the senses of hearing, feeling, balance and movement.

“Music can support development outcomes such as self-regulation, feeding and transitions from the sleep to wake cycle,” she said.

“MANDARI combines these clinical applications of music therapy with the latest research in the area to help give a better start in life to our most fragile little citizens.

“British music therapy is building a research agenda on long clinical experience, while Europe, Australia and the USA lead the global research into music therapy for fragile infants.

“The UK is the ideal place to bring together the world’s foremost researchers and clinicians to create powerful international research collaborations.”

MANDARI will include a professional development seminar to outline the latest research-based clinical music therapy practices for fragile hospitalised infants, while the workshop will set future research priorities.

MANDARI interviews:

Dr Helen Shoemark

& Dr Lauren Stewart 020 7919 7195 0044 7545 173 755 l.stewart@gold.ac.uk

Media contact:

Grace Watts, British Association for Music Therapy 020 7837 6100 pr@bamt.org
News release

Issued by the English Federation of Disability Sport

Physiotherapists use sport and exercise to benefit young disabled people

A new report released by the English Federation of Disability Sport aims to understand sport and physical activity as a therapy choice for young disabled people. The report, in partnership with the Association of Paediatric Chartered Physiotherapists, Cerebral Palsy Sport and WheelPower, explores the paediatric physiotherapist’s role and their experiences in supporting more disabled people to be active for life.

The Association of Paediatric Chartered Physiotherapists (APCP) is one of the CSP’s largest Professional Networks with a membership of approximately 2000 paediatric UK physiotherapists and a growing number from overseas. Their work means they have first-hand knowledge of young disabled people as well as sport and exercise’s use in physiotherapy. Working alongside Cerebral Palsy Sport and WheelPower, the English Federation of Disability Sport (EFDS) put together a series of questions for APCP’s members to find out more. The findings provide more insight, which will support programme development and engagement specifically with young disabled people.

Results include a baseline understanding of the value they place on sport and physical activity as a therapy choice. They also determine an understanding of the type of training they receive when they recommend or provide sport and physical activity for young disabled people.

Among the findings, the report showed:

• Almost all physiotherapists (99 per cent) surveyed currently use sport and physical activity as a therapy choice- for at least some, if not all young disabled people.
• 3 in 4 (75 per cent) physiotherapists said that during their assessment of young disabled people, they take into account their current level of involvement in sport or physical activity.
• Almost half (45 percent) of the physiotherapists felt the social integration and associated social skills sport and physical activity can help develop were most important.
• Around 1 in 3 physiotherapists felt that the health and fitness benefits, impact on confidence and self-esteem, and fun and enjoyment of taking part were all important reasons to encourage participation.
• Physiotherapists feel that sport and physical activity complement standard treatment and offer potential lifelong benefits that individuals can manage themselves.

Despite these positive views on sport and physical activity, findings show there are numerous barriers, which prevent physiotherapists from using them as part of their work.

Less than 2 in 10 (18 per cent) of those surveyed have received any training in how to incorporate sport and physical activity into treatment plans.

Physiotherapists are frustrated that their knowledge and awareness of suitable and relevant opportunities for people with different impairments restrict them, in addition to being unaware of local provision that they can refer young disabled people to.

Barry Horne, Chief Executive for EFDS, said:

“This report shows that professionals, such as physiotherapists, play an important role in encouraging some disabled people to take part in sport and physical activity. We are delighted to share the findings and hope the report can be used to help make the necessary improvements and build on the insight within it.”
Evidence has shown that many disabled people come in to contact with a physiotherapist or linked therapist in their daily living. Those disabled people who require physiotherapy often have long-term regular contact with the same physiotherapists from childhood, which can lead to strong and trusting relationships. Therefore, their advice could prove more influential over short and long-term periods.

A representative from the National APCP Committee said:

“We hope to be able to increase the number of young disabled people taking part in sport across the UK and facilitate the training required so that sports coaches as well as teachers can mainstream their participation.”

More information is available on our website www.efds.co.uk

For further information, please contact:

Sarah Marl, Marketing and Communications Manager. Email smarl@efds.co.uk. Mobile: 07764 291671
Emma Spring, Research and Insight Manager. Email espring@efds.co.uk. Mobile: 07817 787542
For more information on EFDS please visit our website: www.efds.co.uk
Find us on Twitter @Eng_Dis_Sport, Facebook and LinkedIn

The English Federation of Disability Sport (EFDS) has a vision that disabled people are active for life. EFDS is the national body dedicated to disabled people in sport and physical activity throughout England.

- Advice and insight on sport and physical activity for disabled people.
- Guidance on improving engagement with disabled people in sport and physical activity. Partners include National Governing Bodies of sport, National Disability Sport Organisations, education networks, as well as local county sports partnerships, local authorities, disability charities and other third sector organisations.
- Support for policy makers and partners on inclusive provision to improve the range and quality of opportunities for disabled people.
- Actively raising the profile of all disabled sports women and men, as well as increasing the opportunities available for disabled people to participate at all levels.
- Help in developing and rolling out national programmes, such as Sainsbury’s Active Kids for All Inclusive PE training.
- Expertise through the Disability Sport Events programme on managing and delivering participation opportunities for disabled people.
- Management of the Inclusive Fitness Initiative (IFI) to increase participation in physical activity. The work includes a national coverage of 400 IFI Mark accredited gym facilities.
- Fundraising to provide more opportunities through EFDS and attracting additional funds to sport for disabled people.
- EFDS receives funding from Sport England as its national partner for disabled people in sport.
Smalley based company wins an award at the UK’s leading training and resources event

Smalley based company, Jolly Back, was last night awarded a prestigious Education Resources Award, in the ‘Supplier of the Year: with less than £1 million annual turnover’ category.

The Education Resources Awards play a key role in identifying and rewarding effective resources and services for use in education. The winning organisations were announced at the Education Resources Awards dinner in at the National Motorcycle Museum in front of a crowd of more than 300 educators and industry leaders.

The judges said of Jolly Back, “Jolly Back represents the best of the UK’s small and innovative education resources supply sector. Their UK manufactured chairs and focus on friendly customer service made Jolly Back stand out from the crowd.”

Caroline Wright, director of BESA, the education sector’s trade association and organisers of the Education Resources Awards, added, “As schools are given increasing freedom to invest in products to suit the specific needs of their students, it is so important to highlight the high quality of resources such as Jolly Back.”

Lorna Taylor of Jolly Back said, “I am immensely pleased and proud to win the ERA Supplier of the Year award and grateful to all Jolly Back customers who provided such positive and supporting testimonials. As a paediatric physiotherapist, I am incredibly passionate about staff and pupil health and injury prevention. The ERA’s have helped highlight the importance of these issues in education and I hope have offered inspiration to others, by showing that as small, innovative, local companies we really can make a difference.”

For further information on the Education Resources Awards, please visit http://www.educationresourcesawards.co.uk/

About BESA

BESA, the British Educational Suppliers Association, is the trade association representing over 300 educational suppliers in the UK, including manufacturers and distributors of equipment, materials, books, consumables, furniture, technology, ICT hardware and digital-content related services to the education market.

With 79 years of experience, BESA offers unparalleled support, research, events and advice on both UK and International markets, and the future of the education supplies industry. BESA is focused on promoting and providing support and advice to their members, the industry and to schools.

BESA has a Code of Practice to which all members must adhere, along with a stringent membership process, both of which assure buyers of a high standard of quality in both product and customer service.

For more information, please visit www.besa.org.uk.
APCP Promotes Paediatric Physiotherapy at Kidz Exhibitions and Primary Care and Public Health Exhibitions

Kidz in the Middle and Kidz South

The Kidz exhibitions, organised by Disabled Living, are the largest exhibitions in the UK that are dedicated to children and young people with disabilities and special needs.

Many of the well-known equipment manufacturers are represented offering advice and information on mobility, seating, beds, accessible vehicles, communication, sensory, bathing, continence, and much more, and thus the Kidz exhibitions provide parents and professionals with a unique opportunity to view and try out a range of products under one roof.

In addition the Kidz exhibitions are a great place to pick up all sorts of helpful information from the array of Voluntary and Support Service Organisations present and from the free seminar programme available to all visitors. A new initiative has been the development of ‘Funding Point’ where information can be obtained on accessing alternative sources of funding for equipment.

APCP has exhibited at Kidz Exhibitions from their early days. The exhibitions provides a great opportunity to promote paediatric physiotherapy to parents and carers and to other healthcare professionals. The most frequently asked question from parents and carers is how to find a private therapist and we are able to direct them to the Physio2U directory with advice about ensuring that the therapist they appoint has appropriate paediatric skills and knowledge and the importance of trying to ensure that the NHS and private therapists involved with their child communicate well with each other.

Exhibiting at Kidz events also gives APCP an opportunity to network with our current members to gain valuable feedback from them, as well as promoting the benefits of membership to paediatric physiotherapists who are not already members! Networking with other exhibitors to promote the activities of the Association is also beneficial in terms of developing links with other organisations supporting children and young people with disabilities and special needs.

Out thanks go to Michelle Bayliss (Chair, APCP West Midlands Region), Laura Allmark  (Acorns Hospice), Donna Sutton (Heart of England NHS Foundation Trust), Shirley Warren (Birmingham Community Health Care Trust), Megha Narayan (Worcestershire Health and Care NHS Trust) and Annette Beman (Warwickshire) who represented APCP at Kidz in the Middle at the Ricoh Centre on Thursday, 27th March 2014.

Michelle reported that: ‘A good time was had by all …. manning the stand gave us all an opportunity to network with each other and with other professionals visiting on the day, to meet parents and families, and to view the other exhibits as well as get in the odd free seminar during the day! We were kept relatively busy throughout the day promoting the APCP parent leaflets. In addition, we managed to encourage some paediatric physiotherapists to become members of APCP - enticing them with the newsletter and journals on show and the fact that we have a good regional network! We got to discuss hot topics such as the new Education and Health Care plans with therapists who were anxious to know if APCP had any plans to publish any form of guidance in the near future. Parents of children that were receiving physiotherapy, and some that were not, came to ask about the Association and were also interested in our parent leaflets’.

An additional ‘thank you’ also goes to Annette Beman who turned out again at Kidz South at the Rivermead Leisure Centre on Thursday, 12th June 2014 to accompany Fiona Moore on the APCP stand. The first Kidz Scotland event will take place take place at the Royal Highland Exhibition Centre, Edinburgh on Thursday, 11th September, with Kidz North taking place on Thursday, 20th November 2014 at EventCity, Manchester. We hope that members attending these events will take time to visit the APCP!
Primary Care and Public Health Exhibition

APCP exhibited for the third time at the Primary Care and Public Health Exhibition at the NEC, Birmingham on 21st – 22nd May 2014.

This event features a multi-streamed conference programme and an extensive trade exhibition geared to all professionals working in primary care, in the community and in public health and offers APCP a very different opportunity to promote the profession to GPs, health visitors, midwives and other professionals working in primary care.

The two days saw us engaging in some interesting discussions around child development and the role of paediatric physiotherapy and gave us the opportunity to signpost visitors to the stand to our range of publications on the APCP website, including the popular parent leaflets.

Thanks go to PPIMS membered who supported me over the two days – Katherine Heffernan, Annette Beman and Anna Evans.

Juliet Goodban
PPIMS Representative

Disabled Living Foundation

Dates announced for Moving & Handling People 2015

The Disabled Living Foundation (DLF) is a national charity. The charity’s mission is to provide impartial advice, information and training on independent living for older and disabled people.

The 21st anniversary of Moving & Handling People will take place on Tuesday 27th and Wednesday 28th January 2015 at a new venue in the City of London. ‘Safeguarding standards, sharing the vision,’ will offer delegates two full days of CPD accredited training based on our trusted formula of a mixture of practical workshops, focus seminars and plenary conference sessions.

Following extensive analysis of delegate feedback the event will be moving to a new more integrated venue and there will be a number of other improvements in format. In January 2015 the event will relocate to Amnesty International’s Human Rights Action Centre facility in Shoreditch in the City of London. The Centre is a modern complex featuring an auditorium, seminar rooms and circulation spaces and is one tube stop away from the previous venue in Islington!
Delegates are invited to come along and discuss the issues and practical problems facing them and their organisation in the workshops and Open Forum that was such a success this year. The practical Open Forum first introduced in 2014 was a great hit with ‘real life situations’ being discussed and peer reviewed by experts and peers alike. On the lead up to the 2015 event we will be asking delegates to submit their most thorny issues or bring them along to the event.

Topics and speakers at the two-day packed training event are expected to education & training, standards & guidance, managing challenging behaviour, legal cases, bariatrics, risk assessment and an exciting new workshop called ‘trial by jury & peers’.

Chris Shaw, Chief Executive of the Disabled Living Foundation was interviewed at the charity’s recently opened Equipment Demonstration Centre in their new offices in Hammersmith. Commenting on the Moving & Handling People event she said, “DLF hears all the time that people get confused about the equipment that will help them live safely and independently. It is vital that professionals charged with supporting people living at home, in care settings as well as in critical care are up to date with the latest best practice and thinking. The beauty of an event like this is that you are sharing the learning experience in both a practical hands-on and getting to grips with the underlying theory at the same time. Two intensive days deal with a range of material and topics and leave delegates feeling energised and up to date.”

Delegate bookings can be made via our dedicated website www.movingandhandlingpeople.co.uk where they will find lots of useful information.

Sponsors of the event can advertise in the extended printed programme or add inserts to the delegates’ bags. Companies that are supplying the equipment for the workshops will also be on hand to handle feedback and queries about the equipment.

Early birds can benefit from a saving by booking before September 30th 2014 and the Disabled Living Foundation is expecting bookings to be made earlier this year as the event has limited places and it will be ‘first come, first served’.
AHP Children & Young People’s Good News Stories- Scotland

It is always a great pleasure to share good news stories of any size; the challenge is generally being told the good news to enable sharing and spread!!!

However, this month we are delighted to share the stories of two national awards received by AHPs working with children and young people. If you or any or your teams have good news stories to share please let us know. It’s great to be able to drop these into conversations with AHP Directors, Health or Education teams, Child Health Commissioners etc. and raise your profile; but it’s also a fantastic way to share good and innovative practice.

Please just drop me an e-mail and let me know of anything happening which may be of interest to your colleagues.

The Neonatal Hip Screening Service

The Neonatal Hip Screening Service based at Simpson’s Centre for Reproductive Health, Royal Infirmary of Edinburgh and Royal Hospital for Sick Children, Edinburgh received recognition from the 2014 Advancing Healthcare Awards in the Northern Ireland maximising resources for success category. The team comprises Sally Wilkinson and Sarah Paterson, both Advanced Physiotherapy Practitioners and Graham Wilkinson, Consultant Paediatric Radiologist.

Babies can be born with a dislocating (unstable) hip which, if undetected at birth, may not be diagnosed until walking age. This condition is known as developmental dysplasia of the hip or DDH. In 2001, in an innovative project by the paediatric services in NHS Lothian, a physiotherapy advanced practitioner replaced an orthopaedic doctor who previously performed the examinations. The remit of the new role was to lead and co-ordinate the neonatal hip screening service ensuring early detection of abnormal hips and effective treatment. Previously there was no formal education programme for medical staff. A teaching package was established and developed with the clinical experience of the lead physiotherapist. Daily supervision and support for all staff who perform the newborn examination, is available on the postnatal ward for difficult cases.
Safe and Effective

Detection rates have improved; the late presentation rate in 2000 and 2001 before the start of the project was approximately 10 children each year who required surgical correction. This has been progressively reduced with no babies presenting late in the last two years. This is comparable to the very best results reported from Europe. The failure rate of babies treated conservatively in harness was four out of 15 in 2000. An average of 45 babies are treated in harness each year. There have been only two harness failures since 2001.

Efficient

The £500,000 savings per year (surgical cost) far exceeds the estimated £100,000 cost of the programme.

The judges were impressed with the excellent therapists working on the project and thought it was a fantastic area of work.

The Haemophilia Society’s “Great Buddy Award”

Jenna Reid, a physiotherapist from Royal Hospital for Sick Children in Edinburgh was presented with a special Buddy Award by BBC TV presenters Dick & Dom, (Richard McCourt and Dominic Wood) World Haemophilia Day (April 17th)

Jenna was nominated by Dr Angela Thomas, Haematology Consultant for the national award, organised by the Haemophilia Society UK and supported by haemophilia care company Novo Nordisk.

The national Buddy Awards recognise the vital support provided by friends, families, carers and teachers of children who have to cope with the everyday challenges that haemophilia and bleeding disorders can involve.

Chief Executive of The Haemophilia Society, Liz Carroll, said: “The lack of public awareness of bleeding disorders means that the families and friends take on a great deal of responsibility for their friends and loved ones, and this often goes unnoticed. The Buddy Awards are a way for people with a bleeding disorder to give a very special thank you to their ‘buddy’ and simultaneously raise awareness of the condition.”

Free powered mobility for children under 5

Wizzybug is a fun first experience of powered mobility for very young children and is available on loan to families free of charge. The Wizzybug was designed and is manufactured by a small charity in Bath called Designability (www.designability.org.uk)

Designability’s engineers and Occupational Therapist Nina Evans linked up with families and expert Occupational Therapists Anne Harris, Jan Nicolson and Eric Lucas to create the Wizzybug, which is now manufactured in Bath.

Reaction to the bright red Wizzybug has been very positive as it is seen as an attractive “first wheels” experience for families.
Clinical evidence has been available since the 1980s that getting mobile has a positive impact on children but there still remains real financial and practical challenges for families and therapists who recognise the need for early independent mobility.

Designability realised that despite interest, this funding gap meant many families were missing out on this valuable pre-school opportunity to benefit from being mobile. The challenges and time taken to fundraise often meant that it was too late for families to choose Wizzybug as an introductory experience.

To counter this and enable timely provision Designability raised funds to set up a charitable loan scheme, open to families in mainland United Kingdom. Children who can benefit can apply for a free Wizzybug. The scheme opened in 2011 and thanks to the generosity of sponsors so far, Designability has loaned Wizzybugs to 131 families. Loans can be as short as 6 months or as long as 30 months. This flexibility means the team at Designability can be responsive to enquiries from children who otherwise would have missed out on this early years opportunity. On return, Designability reconditions the powered wheelchair for another family. Each Wizzybug aims to help at least 3 families.

“We were really lucky to be accepted on to the loan scheme for a Wizzybug for Daisy and she received it the day before her second birthday; what a present! It has opened up her world as she is now able to be mobile at home, in nursery and anywhere that we go, it gives her the legs that other children take for granted.”

Daisy, now approaching her third birthday, fully realises that she will never stand, walk or run like the children in her playgroup, but it does not stop her trying to race around as her friends do, in her own special way.”

Quote from Daisy’s parent

Amazingly Wizzybug has started travelling worldwide….

Designability was delighted to hear from Scott Langmead an Occupational Therapist in Perth, Australia who found out about the Wizzybug and loan scheme and has since used this model of provision to set up loan scheme in Australia using Wizzybugs built in Bath. So far Scott has acquired a fleet of 15 Wizzybugs.

Wizzybug’s worldwide adventure is continuing as a family with a Wizzybug in Israel have been so impressed they have also started importing them!

If you would like to find out more about the Wizzybug Loan Scheme please contact:

Nina Evans, Occupational Therapist
Designability (ninaevans@designability.org.uk)

Designability
www.designability.org.uk
01225 824103
CP Frame Football Development Day 7th June 2014

The day was hosted at St George’s Park, home of the Football Association, and supported by the Football Association and Sport England. In addition guests from Quest88 were in attendance to observe the children in action and offer their feedback in regards to the ‘Frames’ being used by the children.

With 19 children, who are all frame users, in attendance the day provided a fantastic opportunity for CP Sport to observe and gain feedback to support the development of the game. More importantly, the young players ranging from 2.5 years to 14 years old all had the experience of taking part in skills activities and small sided games at the FA’s National Football Development Centre.

Children were also treated to a surprise visit from England legends Terry Butcher and Graeme Le Saux, who dropped in to see what all the excitement was about.

Alison Talbot, Chief Executive at Cerebral Palsy Sport commented “We are very excited to be here today, at St George’s Park, the home of the FA, to work with the children and their families to develop the Frame Walker version of football. A lot of good work has taken place in involving the less ambulant players in our Cerebral Palsy Sport Kickstart Football Days, but we believe that there is a need to add more structure to football for those who use a Frame Walker, ensuring we can provide opportunities for all players to access a game suited to their needs.”

She continued “We’d like to thank everyone who has helped make today possible, including the Football Association, Sport England, all at St George’s Park, our coaches, our volunteers and of course, the team at Cerebral Palsy Sport. We really hope everyone has a great day.’
As part of our development day, we have invited parents, companions and special guests, including our Sporting Ambassador for Football and Paralympian Leon Taylor, to observe the children taking part in a mix of skills, activities and small-sided games to help us to design a game specifically for them.

Leon was a Goalkeeper with the England Cerebral Palsy Football Team from 2003-2011 and competed in international tournaments across Europe and the rest of the world. Leon is delighted to be joining us today, adding “It’s fantastic to be able to get involved in helping develop and grow the Frame Walker Football programme and inspire children and young people with Cerebral Palsy. Watching children get so much both physically and mentally from taking part in sport is so rewarding!”

The future of CP Frame Football is very exciting, with further events currently being planned and plans to present to the FA’s Disability Committee in the hope of forming an endorsed format of the game specifically for frame users.

If you love football and want to learn more about Frame Walker Football and other Cerebral Palsy Sport activities, then please visit our website www.cpsport.org
Moving & Handling People 2015

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Moving & Handling People
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Kidz Scotland 2014
Thursday, 11th September
Royal Highland Exhibition Centre
Edinburgh, EH28 8NB, 9.30am – 4.30pm

One of the largest, FREE UK exhibitions dedicated to children and young adults 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......
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Dates for your Diary
Kidz Up North - Thursday, 20th November 2014
EventCity, Manchester
Kidz in the Middle - Thursday, 19th March 2015
Ricoh Arena, Coventry

For FREE Visitors Tickets
Please Call: 0161 607 8200
Email: info@disabledliving.co.uk
www.kidzscotland.co.uk

Established in 1987, Disabled Living is a charity registered with the Charity Commission for England and Wales. Registered Charity number 246475.

AUGUST 2014