

ASSOCIATION OF
PAEDIATRIC
CHARTERED
PHYSIOTHERAPISTS

JOURNAL



DECEMBER 2006

ISSUE
NO. 121

NATIONAL COMMITTEE OFFICERS AND MEMBERS

| | | | |
|------------------------------------|-------------------|--|--|
| CHAIRMAN | Peta Smith | Paediatric Physiotherapy Dept Children's Assessment Centre Kent & Canterbury Hospital Ethelbert Road CANTERBURY CT1 3NG | peta.smith@ekht.nhs.uk |
| VICE-CHAIR/SECRETARY | Laura Wiggins | 26 Braidpark Drive Giffnock GLASGOW G46 6NB | laura.wiggins@ntlworld.com |
| TREASURER | Fiona Down | 3 The Paddocks Woodhurst Cams PE28 3GA | fiona.down@btinternet.com |
| PUBLIC RELATIONS OFFICER | Lindsay Rae | Physiotherapy Dept Birmingham Children's Hospital NHS Trust Steelhouse Lane BIRMINGHAM B4 6NH | lindsay.rae@bch.nhs.uk |
| VICE PUBLIC RELATIONS OFFICER | | | |
| EDUCATION OFFICER | Dawn Pickering | Cardiff University | pickeringdm@Cardiff.ac.uk |
| PUBLICATIONS OFFICER | Lorna Stybelska | Paediatric Physiotherapy Dept Cumberland Infirmary CARLISLE Cumbria CA2 4HY | stybelska@aol.com |
| MEMBERSHIP | Chris Sneade | Physiotherapy Department Child Development Centre Alder Hey Children's Hospital Eaton Road LIVERPOOL L12 2AP | Christine.Sneade@rlc.nhs.uk |
| EDITOR | Terry Pountney | Chailey Heritage Clinical Services North Chailey EAST SUSSEX BN8 4JN | Terry.Pountney@southdowns.nhs.uk |
| RESEARCH | Jeanne Hartley | 36 Cascade Avenue Muswell Hill LONDON N10 3PU | jeannehartley@hotmail.co.uk |
| CIG LIAISON/ DIVERSITY OFFICER | Sue Coombe | Jenny Lind Physiotherapy Dept Norfolk & Norwich University Hospital NHS Trust Colney NORWICH NR4 7UZ | sue.coombe@nnuh.nhs.uk |
| Committee Members | Sarah Crombie | 10a Record Road Emsworth HANTS PO10 7NS | scrombie@srtl.co.uk |
| | Linda Fisher | Sune Start Manager (SEN & Disability) Children Schools & Families Service Hertfordshire County Council County Hall Pegs Lane HERTFORD | linda.fisher@hertscc.gov.uk |
| | Sally Braithwaite | 531 Church Road Yardley BIRMINGHAM B33 8PG | Sally.Braithwaite@btinternet.com |
| Co-opted national committee member | | | |
| PPIMS REP | Carol McKay | Mitchell House School Maruont Holywood Road BELFAST BT4 2GU | mhspphysio@yahoo.com |

apcp.org.uk



| | |
|---|-------------------|
| Editorial | 2 |
| Letters to the Editor | 3 |
| Profile Peta Smith, Chairman APCP | 4 |
| ARTICLES | |
| Mavisbank Project: Use of MOVE and Bobath to facilitate collaborative practice | 5 |
| <i>Susan Horsburgh, Clinical Specialist Physiotherapist; Pearl Heaney, MOVE trainer, MOVErs group co-ordinator</i> | |
| Review Of Service Provision For Children Born With Positional Talipes Within The Ulster Community And Hospital Trust | 10 |
| <i>Felicity Dickson, Superintendent Physiotherapist, Scrabo Children's Centre, Ards Hospital</i> | |
| The Leeds Consensus Statement on Developmental Coordination Disorder (DCD) and its relevance for paediatric physiotherapists | 14 |
| <i>Judith M. Peters MSc; PhD; MCSP. Honorary Clinical Specialist Physiotherapist, Great Ormond Street Hospital for Children, London</i> | |
| <i>Ann Markee MCSP. Senior Community Physiotherapist, Rugby</i> | |
| Conference Proceedings | 18 |
| REGULAR FEATURES | |
| APCP Matters | 29 |
| Research and Education | 35 |
| Regional and Affiliated Groups' Reports | 37 |
| APCP Publications | 41 |
| Book review | 42 |
| Here and There | 43 |
| APCP Research Register | 45 |
| Courses | 51 |
| Regional Representatives | inside back cover |

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

Editorial

Apologies for the late arrival of this issue of the journal. It has been delayed to include some of the conference content and update changes in APCP personnel following the AGM.

The conference was a great success and the Scottish organizing committee deserve a huge thank you for putting together an innovative and diverse programme. Topics ranged across public health, visual problems, neurology, respiratory, musculoskeletal, service, delivery and research. The satellite neo-natal course ran in parallel with the main programme and was well attended. Laila de Groot shared her knowledge and experience with us in the keynote speech and in the neonatal course. Lectures were of a high calibre and expansive giving 'food for thought' not only for clinical practice but also of the increasingly political climate of the NHS. A selection of transcripts and abstracts are included in this issue including the keynote speech.

Next year's conference is planned for November 2007 and will be hosted by the South East region further details can be found in this Journal.

As 2006 draws to a close APCP has made some steady progress in developing competences for paediatric physiotherapists and seen a growing number who are taking masters and higher degrees. These activities all help to improve the evidence base for our clinical practice. The changing climate of the NHS will require us to think critically about the treatment we provide and how it is delivered. Sharing our knowledge is key to achieving better outcomes for children and families, the APCP journal, website and iCSP offer opportunities to do this.

Wishing you all happy and healthy 2007.

Terry Pountney

EDITORIAL BOARD

Terry Pountney – Editor

Terry.Pountney@southdowns.nhs.uk

Peta Smith

peta.smith@ekht.nhs.uk

Lindsay Rae

lindsay.rae@bch.nhs.uk

Alison Gilmour

Alison.gilmour@braidburnedin.sch.uk

Felicity Dickson

Felicity.Dickson@ucht.n-i.nhs.uk

Diane Rogers

rogersd@cardiff.ac.uk

Copy for the
MARCH 2007 JOURNAL

must be with the editor by

1st February 2007

The editorial board reserve the right to edit all material submitted

Letters

Lorna Taylor
Children First Physiotherapy
17 Laurel Crescent
Smalley Village
Derbyshire
DE7 6EJ
(01332) 881665
lorna@childrenfirstphysio.co.uk

Dear All,

We are a small group of paediatric physiotherapists working with children and their families in private practice.

We meet up to six times a year and share information through telephone and email. We would like to invite other physiotherapists working in this field to join us.

Please write / email / telephone. We would like to hear from you.

Yours sincerely

Lorna Taylor

Chris Sneade
Child Development Centre
Alder Hey Children's Hospital
Eaton Road
Liverpool
Christine.Sneade@rlc.nhs.uk

Dear Honorary members,

The Scottish conference welcomed many honorary members at the conference dinner in Glasgow. However, the committee is concerned that not all honorary members on the membership list received an invitation to the dinner.

Please can you let Chris Sneade our new membership secretary know of any changes in your contact details and advise her of any other changes of circumstances.

We wish you all a warm welcome to 2007 APCP conference next November.

Yours sincerely

Terry Pountney
Editor

Profile

Peta Smith, Chairman APCP

What seems like many moons ago now, and disturbingly, as I sit here and actually work out exactly how long, I find it **was** many moons ago, I trained as a physiotherapist at the Oswestry and North Staffordshire School of Physiotherapy qualifying in 1970. Incidentally if there are any of Set 29 out there Sue Edwards and I would love to get in touch with you! But I digress!

For the first 12 months of my career I worked on the paediatric wards of the Robert Jones and Agnes Hunt Orthopaedic Hospital, Oswestry my first foray into the world of Paediatrics. Marriage in 1972 moved me to Telford, and I worked as an out patient physio for two years. The arrival of my first child happily brought a welcome end to this phase of my career and not a day to soon! A break to bring up my two children followed and then in 1983 I discovered my true niche when I became a true paediatric physiotherapist at a Special School in Telford Shropshire. Those were happy days and my interest and skill in the assessment and treatment of children with neuro disability was born and began to develop.



Divorce followed and I eventually met my soul mate John. A happy remarriage in 1989, sadly necessitated me having to leave the friends, colleagues, children and families I had come to know so well and venture out to pastures new in the South Wales countryside. Oh how we all fell in love with South Wales! Working at the Children's Centre, University Hospital of Wales, Cardiff, broadened and matured my knowledge and experience. I was nurtured by Viv Williams et al to develop my skills in the assessment and treatment of very young children, which eventually led me to a specific interest in the infants born prematurely. It was in Cardiff that I was first introduced to the Bobath concept and also dragged along to APCP meetings..... and happily look where that has got me!

5 very happy years later in 1994 my husband's job moved us on to Kent. We arrived in the flat lands of Thanet amongst the smell of cauliflowers rotting in the garden of England, one cold September evening! What had we done? But it did prove to be a very fortunate move for me. I was at last able to indulge myself in my true 'passion' when I was appointed as a neonatal clinical specialist physiotherapist providing an expert opinion, and consultancy to medical staff, paediatric physiotherapists, and other health professionals in this specialist field. The post included developing, coordinating, monitoring the principal of early intervention ensuring a smooth transition of care for neonates and their families on discharge from the NICU into the Community setting.

My professional development was difficult at this time as neonatal physiotherapy was a new and evolving field of practice in the UK. I am grateful to my physiotherapy manager within the PCT, Claire Poole, and the Consultant Paediatricians I worked with in the Hospital's Trust, who supported my development which included travelling abroad in order to access specialist training under the mentorship of Joan Lacey a Physiotherapist from Sydney, who was generously willing to share her wealth of experience and knowledge, and to whom I owe so much.

In 2003 a long held dream was achieved when, along with Allie Carter, we founded the Neonatal clinical interest group affiliated to APCP and I became its first Chair. This group has allowed a forum for promoting neonatal physiotherapy, providing peer support, review and training for physiotherapists interested in working in this field and has given us the opportunity to ensure a national standard of physiotherapeutic care and intervention to the high-risk infants who pass through the Neonatal Units in the UK. I handed over the reins of this post with confidence last year to the capable hands of Adare Brady, a past Chair of APCP. Neonatal physiotherapy will always be my first love and I continue to take a very keen interest in its work and development. I remain on the national committee for this group.

In around 2002 I became South East regional rep for APCP and in 2004 became Vice Chair. So here we are!

I enjoy 'ammie drammies', not as 'a lovey', you understand, but stage management, (the only form of management I wish to indulge in!) I also enjoy fine food and wines especially after a long blustery walk across the Kent Downs!

Finally on behalf of the National Committee I would like to express my sincere thanks to Lesley Smith retiring Chair for all her hard work and commitment to APCP throughout her 2 year term of office. The task in front of me is not too daunting as I am well supported by the national committee who are a dynamic, enthusiastic and experienced bunch and I also look forward very much to working along side Laura Wiggins as the new Vice Chair.

Mavisbank Project: Use of MOVE and Bobath to facilitate collaborative practice

Susan Horsburgh, Clinical Specialist
Physiotherapist; Pearl Heaney, MOVE trainer,
MOVERs group co-ordinator

Introduction

This project was started as a way of improving the outcome for children with complex impairments, within a special school setting. Children are increasingly surviving with complex impairments (Himmelmann et al, 2005) and benefit from multi-disciplinary team working (Mayston, 2000a). Collaborative practice is high on the political agenda (Kerr, 2005) but how do we put this into practice where time and resources are limited.

Twenty four children attend Mavisbank School, with an age range from two to eighteen years. Most of these children present with complex impairments due to cerebral palsy or similar neurological conditions. The children are either level IV or V on the Gross Motor Function Classification System (GMFCS) (Palisano et al, 1997). This is indicative of a high level of impairment, with very little active postural control and poor use of hands. The children are, therefore, dependent on others for all their physical needs and have only limited independent movement on the floor.

The school is divided into four groups; a nursery, two primary age groups and a secondary age group. Each class group has a teacher, instructor and additional support needs assistants. The school also has a healthcare team comprising physiotherapy, occupational therapy, speech and language therapy and nursing input. However, the therapy professionals usually do not attend on the same days and work from different bases. In addition, input from the therapy team members was often given during a class lesson or requests for help taken during a therapy session. In such cases, the giver of information did not have the full attention of the receiver. Information received in this way was frequently not acted upon.

The use of MOVE and the Bobath Concept

Although there was multi-agency working in the school, the practice was not collaborative. The children were discussed in meetings but this was not done on a regular basis and no professionals worked jointly with the children. The staff felt that they

worked in tandem but not together. In addition, targets were set by professionals from each agency in isolation.

Preparation for activity is a fundamental tenet of the Bobath Approach to the treatment of children with cerebral palsy (Bobath & Bobath, 1984, cited in Mayston, 2001). It is essential that the child practices specific movements necessary for a functional goal to enable learning to occur (Mayston, 2000b). Postural tone and patterns of activity are encouraged which will promote that functional goal. Preparation is, therefore, done on an individual basis. For example, if a child has spastic hypertonus, postural tone is raised and patterns of movement are stereotyped with little variety. Emphasis is on a child's own activity, giving him or her opportunities throughout the week to practice, and developing meaningful goals (Mayston, 2000b). Preparation, therefore, needs to be done throughout a child's day before and within their educational activities.

MOVE is an activity based programme which uses the combined knowledge of education, therapy and family to teach children with severe physical impairment the skills of sitting, standing, walking and transferring (Bidabe, 1999). The teaching of these skills is achieved through an approach which focuses on the activities that people are motivated to achieve, rather than what they cannot do. Being able to independently carry out every day, functional skills enables children to make choices for themselves and as a result to enjoy a more inclusive lifestyle at home, at school and out in the community.

The central philosophy of MOVE is that movement is the foundation for learning. A toddler, who is just learning to walk, learns spatial concepts and about the environment around him/her by being able to move about. A child with a disability, who uses a wheelchair and is reliant on others for movement, is not able to do this and therefore his/her opportunities for learning are significantly diminished.

MOVE puts a structure and a framework around the work that is already taking place. It seeks to bring services together and to encourage collaborative working at all levels. In this way, MOVE gives equal worth to the input of every team member and is not a therapy technique that can only be carried out by professionals.

The MOVE approach had been used by the education staff for many years and the physiotherapy team favoured a Bobath approach in therapy. The MOVE approach was combined with principles of the Bobath concept. That is, the classroom staff were taught how to prepare the children for activity by the therapy staff, and, the therapy staff were taught how to observe and use

Mavisbank Project: Use of MOVE and Bobath to facilitate collaborative practice

educational aims to improve the child's function. The principles of both the Bobath concept and MOVE were therefore combined in these groups. Both approaches facilitate collaboration and fit well side by side.

Outcome Measures

As the children have such complex impairments it is difficult to find a useful measure of progress (McCarthy et al, 2002). All the children chosen for the two groups were at level V on the Gross Motor Function Classification System (Palisano et al, 1997). The GMFM (Russell et al, 2002) was used as a reliable and valid tool for measuring change in gross motor skills in children with cerebral palsy and Down Syndrome.

Increasing the repertoire of functional skills is difficult for children who are level V in the GMFCS and as such, quality of life measures may be more appropriate. It is suggested that use of the Paediatric Evaluation and Disability Inventory (PEDI) and GMFM together gives a more complete picture of a child's status and progress (Ketelar et al, 1998). However, concern was raised by the school staff about involving the parents in the early assessments, that no change would be detectable and that this would be yet another initiative which offered false hope. As such only the GMFM was available.

The GMFM was used in two ways. The GMFM-88 (Russell et al, 2002) uses all the original items in the five areas of the scale. All the children could achieve most of the items within the first section of lying and rolling and a few of the children could achieve some of the first items of the sitting section. None of the children achieved any items beyond these first sections. As this detects change only in a small portion of the GMFM, it was decided to subject the results to the GMFM-66 also.

Methodology

The children attending the school mainly have cerebral palsy, congenital neurological impairment of unknown origin, Down's syndrome, and other genetic and neuromuscular impairments. The children with cerebral palsy and Down syndrome can be assessed using the Gross Motor Function Measure (GMFM) (Russell et al, 2002) as this is validated for use with these groups of children. However, it was of interest to analyse change in children with other impairments. For this reason one child was included who had a neuromuscular impairment. Her results are not included in the findings.

The children were chosen and grouped according to their abilities. Two groups of children were chosen for whom the broad aim was to improve their head control. The aim was for children to reach a stage that they could hold their head in midline well enough to reach for a toy while maintaining eye contact on the object. The children were included if they had inadequate head control. This was considered as unable to achieve midline posture or to maintain midline posture for 30 seconds. Children were excluded if they could maintain midline posture but lost control if they tried to use their hands in play even if they could not achieve midline posture. Using these criteria eleven children were initially identified for inclusion. In each group the children had similar problems. The first group of children had problems of extension due to athetosis. They tended to extend strongly pushing back with their heads and were also, therefore, somewhat asymmetrical in posture. The second group had problems of flexion due to either to hypertonus or hypotonus. This group presented with more symmetry.

Children in the groups, therefore, each had an individual programme of preparation although the main aim of the group was similar. For the children who were extending strongly, the aim was for the child to be able to lift their head to the midline and maintain this posture for 30 seconds. Preparation activities were specific for each child and included mobilisation of tight structures and activities to increase trunk co-activation. For example, KB had extreme asymmetry pulling down and back on his left side. His preparation included passive elongation of his left side followed by active use of his abdominal and trunk extensor muscles in a rolling activity. Preparation activities were devised by the physiotherapist and taught to a member of the classroom staff. Following preparation, the group came together for choice making and singing activities. Each child was either supported in a sitting position by a member of classroom or therapy staff or placed in their standing frame.

The GMFM was performed at the start and at the end of the term. The same conditions were used on both occasions. The assessment was carried out in the gym and with two members of the group present.

Group Activities

Members of the teaching staff devised activities which encouraged head lifting. Songs were used which were age appropriate and involved head lifting or maintaining head in midline while the child's arms were moved for them. The speech and language therapist worked with the classroom staff to demonstrate choice making relevant for each child. This included visual tracking and fixation by placing objects appropriately for each child to see

Mavisbank Project: Use of MOVE and Bobath to facilitate collaborative practice

dependent on their visual impairment. Each child was given adequate time to make their choice and the method of choice making was appropriate for each child. This varied from looking at an object, looking from the object to the group leader or key worker and back or gesture (nodding or shaking of the head).

Objects were used as signifiers for songs which involved actions. For example, a brightly coloured roll of cotton was used to signify the nursery song "Wind the Bobbin Up" or a large frog for "Two Little Speckled Frogs". The staff member working with the child would move the child's arms up and out to the side at appropriate points, at a speed that would allow the child to maintain head control. For some of the children the aim would be to look at their key worker during the song, keeping their head and eyes in the middle. The more able child would be watching the group leader moving around the group and would be expected to move their head from side to side without losing control. Many of the children have different levels of visual impairment. Brightly coloured objects, contrasting backgrounds and overall lighting levels were considered to encourage the children to make maximum use of their vision. Two boys were sensitive to bright lights and choice making was enhanced by dimming the lights.

Each group was held for thirty minutes once a week for the term period Easter to Summer. Ten minutes was allowed for preparation activities, ten minutes for group work, and ten minutes for transferring the children at the start, middle, and end of each session.

While the preparation activities are specific to each child and their individual problems, they can be performed by anyone. This type of preparation is routinely taught to parents attending the Bobath Centres. It is also used by a large number of community based therapists not only for teaching parents, but also for teaching nursery and education staff how to handle and position the children for optimum learning.

Results

Nine children participated in the study. Five were diagnosed with cerebral palsy and one with Down Syndrome. Two of the other children have undiagnosed neurological impairment from birth which presents similarly to cerebral palsy and one child has a genetic neuromuscular abnormality and although included in the group her results are not included in the study.

Due to other school activities and half term holiday, several sessions were cancelled and the group therefore ran for nine sessions in total. However, one child became extremely unwell and a second died prior to the start of the project. Of the nine remaining children, two groups were established as described in the methodology.

| Child | GMFM-66 | | GMFM-88 | |
|-------|---------|---------------|---------|---------------|
| | Pre | Post | Pre | Post |
| CS | 23.37 | 24.66* | 10.84 | 9.27** |
| JP | 13.54 | 12.12** | 2.35 | 2.18** |
| CC | 18.01 | 24.66* | 5.98 | 8.49* |
| JS | 8.12 | 12.12* | 1.96 | 2.57* |
| KB | 18.89 | 21.25* | 5.20 | 10.90* |
| RC | 24.66 | 23.77** | 8.82 | 10.51* |
| KF | 4.12 | 13.54* | 0.78 | 2.90* |

Table 1 – pre and post-group results
* = improvement ** = deterioration

The majority of the children showed improvement in either the GMFM-66 or GMFM-88 measures and four of the children improved in both measures (figures in bold). One child showed no improvement in either measure. The mother of this child, however, reported the greatest change in function at home.

Discussion

Russell et al, (2002) have provided information on mean expected improvement in a six month period for children with cerebral palsy of different GMFCS levels related to their age, using both the GMFM-66 and GMFM-88. According to this information, and only considering the children with cerebral palsy (five in total), two of the children deteriorated (**), and each of the others improved equal to or greater than that expected in a six month period for the GMFM-66. Given that this group was run over a three month period the improvement in these three children is beyond expectation. All but one of the children showed improvement in their GMFM-88 scores. Although the improvement was at a level less than expected in a six month period, they achieved equal to or more than 50% towards what would be expected. While these results show an improvement in the child's scores this does not necessarily equate with functional improvements at home.

While the GMFM results showed improvement, as there was no baseline measurement taken prior to changing input it is difficult to quantify exactly how much of this would be expected anyway. In addition, the functional changes were small improvements in quality of control rather than increasing skill level. While this may be more beneficial for the child's parents, they are difficult to measure using a validated and reliable tool. For

Mavisbank Project: Use of MOVE and Bobath to facilitate collaborative practice

example, one of the mothers reported that her child could track her movements around the room. This, she believed, made her son more content, requiring less one to one attention. Use of both the PEDI and GMFM together may have identified these changes. However, many authors advocate the use of Goal Setting as a way of measuring change in children with complex impairments. As such, the group has developed a way of monitoring positive and negative change using SMART goals.

Much of the collaborative work is done by multidisciplinary meeting rather than hands on with children. While this is useful for planning, there is huge scope for miscommunication. For example, physiotherapists describe movement in anatomical terms of flexion and extension and speech and language therapists describe fine motor control of oral movements without description of the gross motor element of the task. Education staff describe function without looking at the control of movement necessary to achieve the task. This therefore makes understanding the child holistically much more difficult for all professionals. In this project, the children were treated within a group, with members from the teaching and therapy staff working together. Working collaboratively in this way was successful because each child had two team members working together with them at any one time. A child's team comprised a member of the class staff and a therapist.

Working collaboratively in this way, allowed the team members to assess, treat and teach children holistically. It allowed classroom staff confidence to effectively continue with therapeutic aims throughout the child's week. At the same time therapy staff could prioritise children who were either showing improvement or deterioration in their abilities. All members of the team gained confidence in questioning the priorities for each child and, as a result, increased respect for each other and each other's role.

This project was started with physiotherapy, speech and language therapy and education input. However, as many of these children have sensory and visual impairments it is important to include occupational therapy input to provide a truly holistic approach. In subsequent groups the occupational therapist has assisted the team in determining the most appropriate activity from a sensory or visual perspective, demonstrating positive approaches to children with hypersensitivity issues and toy placement for children with visual impairment.

This type of collaboration has been very successful

in improving the outcome for the children at this school. It is a model which has been adopted by other schools for a different client group with equal success. Although, time consuming to establish, ultimately this type of team working will maximise the input to the child. It is now possible for professionals to more accurately refer children back for re-assessment. This allows each professional to focus precious therapy time on children who can most benefit from their input at any given instance.

The local guidelines for the partnership agreement (Kerr, 2005) suggests that communication issues can be eased by sharing notes. With this in mind, and to clarify communication within the group, it has been agreed to set joint targets and to keep joint notes. This has been very challenging and time consuming. However, the benefits are that each child has two targets which address their needs from all aspects of educational and therapy. For example:

- Gordon will be able to make a choice between 2 objects by indicating yes or no by tapping with his right arm.
- Gordon will be able to explore his chosen object by eye-hand regard and touch while maintaining his head in midline for 30 seconds.
- Gordon will be able to hold the position of his head when placed in midline for 15 seconds.

Parental involvement has been limited to date. During the first term, the parents started attending the sessions and were able to carry on the activities at weekends and holidays. This resulted in further improvement made by the children, particularly over the extended summer holidays. In addition, while the child, JP, deteriorated in all scores, his mother was most aware of the changes in function at home. This group of children (Level 5 GMFCS) are the most difficult to measure change in. Although the children showed change with the GMFM, none of the validated tools are sensitive enough to analyse the functional change achieved. For this reason, over the next school year, this group is analysing the use of goals as a way of measuring change. Initially this will be mainly done by the group, however, in the future, parents will also be invited to participate in the setting of the targets.

Conclusion

By sharing knowledge on a regular basis three benefits were achieved. Firstly, all staff members felt safe in asking each other questions about their work or showing that they did not understand their role. Secondly, as understanding of each colleague's role increased so too did mutual respect. Thirdly therefore, as mutual respect increased all staff members felt safer in questioning each other. This cycle of respect and questioning resulted in the development of a learning environment where collaboration became stimulating rather than threatening.

Mavisbank Project: Use of MOVE and Bobath to facilitate collaborative practice

References

Bidabe L. (1999) MOVE: Mobility Opportunities Via Education. Bakersfield, CA: Kern County Superintendent of Schools

Himmelmann K, Hagberg G, Beckung E, Hagberg B, Uvebrant P (2005) The changing panorama of cerebral palsy in Sweden. IX. Prevalence and origin in the birth-year period 1995–1998. *Acta Paediatrica* 94(3):287-294

Kerr A (2005) Building a health service fit for the future. *Scottish Executive*

Ketelaar M, Vermeer A, Helders PJ (1998) Functional motor abilities of children with cerebral palsy: a systematic literature review of assessment measures. *Clinical Rehabilitation* 5:369-380

Mayston M (2001) People with cerebral palsy: effects of and perspectives for therapy *Neural Plasticity* 8 (1-2):51-69

Mayston M (2000a) The Bobath concept today. *Synapse* Spring 2001

Mayston M (2000b) Motor learning now needs meaningful goals (letter). *Physiotherapy* 86(9):492-493

McCarthy ML, Silberstein CE, Atkins EA, Harryman SE, Sponseller PD, Hadley-Miller NA (2002) Comparing reliability and validity of pediatric instruments for measuring health and well-being of children with spastic cerebral palsy. *Developmental Medicine and Child Neurology* 44(7):468-76

NHS Lanarkshire Speech and Language Therapy Department, North Lanarkshire Education Department (2005) Guidelines for the partnership agreement

Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B (1997) Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology* 39:214-223

Russell DJ, Rosenbaum PL, Avery LM, Lane M (2002) Gross motor function measure (GMFM-66 & GMFM-88) user's manual *Clinics in Developmental Medicine* No 159 Cambridge University Press

Review Of Service Provision For Children Born With Positional Talipes Within The Ulster Community And Hospital Trust

Felicity Dickson, Superintendent Physiotherapist, Scrabo Children's Centre, Ards Hospital

Introduction

Physiotherapy service delivery for children born with positional talipes within UCHT was historical that all children referred were seen at ward level, reviewed at two weeks of age and then again at three months of age. This was regardless of severity as there were no standardised or validated assessments available. Ongoing work within the orthopaedic service (Ponsetti manipulation and casting) and introduction of TELER outcomes (Le Roux A A 1991) to the paediatric service enabled us to look more objectively at the service we were providing.

Positional talipes as defined by Shepherd (2000) is that there is no bony deformity, but this could occur with time if the foot posture is not corrected and the foot muscles not trained to aid correction. Blakeslee (1997) and Macnicol (1994) also describe positional talipes as part of the structural spectrum where the foot is flexible and there may be malposition of the tarsal bones or a mild degree of talo-navicular subluxation, Blakeslee (1997) also describes this foot as responding well to conservative management and serial casting. Standardised assessment and treatment for positional talipes is not well documented as studies mostly cover structural talipes.

Two forms of positional talipes are seen within the trust. Talipes equinovarus, where the foot is turned down and in, the forefoot showing a position of inversion, supination and adduction and talipes calcaneovalgus where the foot is turned outwards and up, the forefoot showing a position of eversion, pronation and abduction. One in every 1000 babies is born with positional talipes, in 50% both feet are affected and with a male to female ratio of 2:1 (Hicks 2005).

TELER indicators scored 0 to 5, 5 being full and achievable goal were used for this audit. It was decided within the trust that the forefoot indicator was the most appropriate one to analyse, and this described the combined movements of the foot in relation to the Dimeglio et al (1995) classification. This ranged from 0, as per TELER indicator, being

fixed or a structural talipes or stiff/stiff foot, through to full and active correction of the forefoot. Descriptions of the movements were agreed inter house to have an improved consensus of definition and also repeatable scoring. Hence talipes equinovarus forefoot description became inversion, supination and adduction and talipes calcaneovalgus forefoot description became eversion, pronation and abduction.

The reason for assessing all those referred for physiotherapy was to ensure that correct diagnoses were being made and that other problems such as torticollis, neuromuscular disorders and Congenital Dislocation of the Hip (CDH) were picked up. This offered a method of screening some of the population at early stage.

Method

Our aim with the audit and questionnaire was to review the present service, to assess our effectiveness for this client group, to change the service appropriately to provide a more efficient effective service to those identified as requiring it. The review included service users to ensure that our service users were supportive of any changes to the service.

For assessment and outcome purposes, TELER outcomes were reviewed by all the paediatric staff across the acute and community trust. Three acute paediatric physiotherapists and 5 child development paediatric physiotherapists were encouraged to openly discuss the TELER indicators available for positional talipes, three indicators were chosen but for the purpose of the audit it was agreed that the forefoot correction indicator was the most useful and indicative.

TELER Indicator

FOREFOOT CORRECTION

Combined movements of inversion, supination and adduction or eversion, pronation and abduction.

- 0 – Fixed (stiff/stiff)
- 1 – Some passive correction in 1 plane (stiff/soft)
- 2 – Full passive correction in 1 plane (stiff/soft)
- 3 – Full passive correction in 1 plane and 50% other plane (soft)
- 4 – Full passive correction all planes of movement (soft/soft)
- 5 – Full active correction of forefoot

Reviewing current orthopaedic methods of management of structural talipes, the Ponsetti regime was the most common treatment method for this condition within Northern Ireland, and it was agreed that this indicator gave us a better scope of assessment and evaluation (Le Roux A A 1991 and Dimeglio et al 1995).

Review Of Service Provision For Children Born With Positional Talipes Within The Ulster Community And Hospital Trust

Training for all staff and review of assessment and treatment was then implemented to ensure that we were all providing the same treatment, assessing equivalently, advising in the same manner and scoring the agreed indicator equally and consistently. An information leaflet was designed so that all information given to parents was uniform throughout the trust.

With the initial audit 60 children's results were used and these were analysed retrospectively, the children looked at had been born between January and August 2003. At this point all children were given an initial assessment at ward level (average age 2 days), reviewed at the child development centre at two weeks (average age 16 days) and reviewed again at 3 months. Some children did not receive an initial assessment at ward level due to the referral being made at a weekend or on a bank holiday, these children were then seen for initial assessment at the children's centre (average age 13 days).

The outcomes were analysed using the percentage of children scoring between 0 to 5, and the change in these scores at each subsequent assessment, i.e. initial, 2 week review and 3 month review, (computer analyse was not available for this audit).

Following the audit results the service delivery was changed, initial assessment was still given preferably at ward level, but depending upon the initial scores they were not automatically offered a review. Children scoring 2 and below were reviewed but those scoring 3 and above were given an initial assessment, advice and an information leaflet and then discharged.

Changes to the service were then implemented for a year with regular reviews of staff assessment and treatment.

A parent satisfaction questionnaire was subsequently carried out for all children born with positional talipes between January and August 2005. Forty two questionnaires were issued to parents following a live status check and a response of 23 was returned (54.8%). The questionnaire was used to gauge user satisfaction on the information given, the exercises shown, resolution of the positional talipes and overall satisfaction of the service provided. Questionnaires were analysed using the analytical tool SPSS (statistical package for social services).

Results

A random selection of 60 charts for children born with positional talipes between January 2003 and August 2003 was selected for analysis.

Children were identified as having their initial physiotherapy assessment at either the hospital/ward setting or due to holidays at the children's centre.

| | |
|------------------------------------|-----|
| Initial assessment – At ward level | 72% |
| At children's centre | 28% |

The average age of the children depended upon where they had their initial assessment.

The forefoot correction scores were then analysed by percentages.

| | |
|--|---------|
| Assessment scores at ward level – average age 2 days | 0 – 0% |
| | 1 – 5% |
| | 2 – 60% |
| | 3 – 5% |
| | 4 – 28% |
| | 5 – 2% |

| | |
|--|---------|
| Assessment scores at children's centre – average age 13 days | 0 – 0% |
| | 1 – 0% |
| | 2 – 18% |
| | 3 – 0% |
| | 4 – 82% |
| | 5 – 0% |

Initial assessment scores at ward level showed that there is a higher percentage of children with a score of 2 or below (65%) or only full passive movement in one plane of movement. At a later date of initial assessment we see a fall of this score to 18% and evidence of more children resolving to a score 4 or full passive movement in all planes of movement.

Scores for those children whose initial assessment was at ward level were recorded on review at the children's centre 2 weeks later.

| | |
|--|---------|
| Review at 2 weeks at children's centre – average age 16 days | 0 – 0% |
| | 1 – 2% |
| | 2 – 2% |
| | 3 – 10% |
| | 4 – 84% |
| | 5 – 2% |

Comparison of the initial assessment at the children's centre and review at the children's centre shows, when children are around the same age (average 13 days or average 16 days), shows that a score of 2 improves if there is intervention at ward level.

Review Of Service Provision For Children Born With Positional Talipes Within The Ulster Community And Hospital Trust

| | |
|---|---------|
| Review at 3 months at children's centre | 0 – 0% |
| | 1 – 0% |
| | 2 – 0% |
| | 3 – 2% |
| | 4 – 25% |
| | 5 – 73% |

It is a common perception that most positional talipes resolve quickly and these findings would tend to support this.

Outcomes

Following these results we decided to target only those children who on initial assessment scored 2 and below. Those scoring 0 or deemed to be fixed or stiff/stiff (Dimeglio et al 1995) were referred through to orthopaedics, those scoring a 1 were referred to the children's centre for an early review and then a decision made about their ongoing care, those scoring a 2 were referred through for a 3 month review. Those scoring 3 or above were assessed, given advice, an information leaflet and discharged. All parents were advised to contact their health visitor or GP if they continued to be concerned and a referral to the children's centre could be made.

The service was then changed and implemented for a year and the parent satisfaction survey carried out.

The following questions were selected as most relevant to the review and are presented below.

| | | |
|--|----------------|-------|
| 1 – Was positional talipes fully explained | | |
| | fully | 90.1% |
| | partially | 9.1% |
| 2 – Was an information leaflet given | | |
| | yes | 95.2% |
| | no | 4.8% |
| 3 – Was it easy to read | yes | 100% |
| 4 – Was there an opportunity to ask questions | | |
| | yes | 95.5% |
| | no | 4.5% |
| 5 – Were you given details of how to contact the children's centre | | |
| | yes | 50% |
| | no | 50% |
| 6 – Were you shown the exercises | yes | 100% |
| 7 – How confident did you feel | | |
| | very confident | 50% |
| | confident | 50% |
| 8 – Did your baby's foot correct | | |
| | yes | 77.3% |
| | no | 22.7% |

| | | |
|--|----------------|--------|
| 9 – When did your baby's foot correct | | |
| | 1 – 2 weeks | 6.25% |
| | 3 – 4 weeks | 25% |
| | 1 – 2 months | 0% |
| | 2 – 3 months | 18.75% |
| | 3 – 4 months | 37.5% |
| | Other | 12.5% |
| 10 – Were you satisfied with the service | | |
| | very satisfied | 63.6% |
| | satisfied | 36.4% |

The results showed some very positive comments about the service and the overall satisfaction with it.

The information leaflets did not have the child development centre address or contact details on it as parents were advised to go through their GP or health visitor.

Conclusion

The results of the study show that children referred with positional talipes show a trend that the condition resolves usually by 3 months of age or sooner. However input at ward level does appear to have a quicker resolution of the condition.

Changes to the service and analysis by the satisfaction survey, showed that as predicted those children who scored 3 and above resolve by around 3 months of age (87.5%). This has allowed us to target only those children who require direct therapy input, or those children who scored 2 or below, and so we have been able to establish a more efficient effective service for our children.

The main points following both the audit and satisfaction survey are:

- Changes to service delivery for children with positional talipes have continued to provide an effective service.
- Contact details have been placed on the information leaflets allowing parents to contact the child development centre directly.
- The service is more efficient as only those identified as requiring further review are referred but is still able to screen for any associated abnormalities.
- Further work is required to standardise and validate assessment and treatment for positional talipes.

References

- Blakeslee T. Congenital Idiopathic TEV Equinovarus (clubfoot). Current concepts. Clinics in Podiatric Medicine and Surgery 1997 vol 14 part 1
- Dimeglio A, Bensahel H, Souchet P, Bonnet T. Classification of clubfoot. Journal of Pediatric Orthopaedics 1995 vol 4 part B

Review Of Service Provision For Children Born With Positional Talipes Within The Ulster Community And Hospital Trust

Hicks R 2005 Review of Talipes information by Dr Trisha MacNair [bbc.co.uk Health](http://bbc.co.uk/Health)

Laaveg SJ, Ponseti IV. Long term results of congenital clubfoot. The journal of Bone and Joint Surgery 1980 vol 62A part 1

Le Roux A A TELER indicators – CTEV 1991 (registered trademark)

Macnicol M F The surgical management of congenital TEV equinovarus (club foot). Current Orthopaedics 1994

Shepherd R B TEV Equinovarus Physiotherapy in Paediatrics 3rd Edition 2000

The Leeds Consensus Statement on Developmental Coordination Disorder (DCD) and its relevance for paediatric physiotherapists

Judith M. Peters MSc; PhD; MCSP. Honorary Clinical Specialist Physiotherapist, Great Ormond Street Hospital for Children, London*

Ann Markee MCSP. Senior Community Physiotherapist, Rugby.

*Correspondence address:

Dr Judith Peters, 24, Mount View, Mount Avenue, Ealing, London W5 1PR.

We often take for granted the smooth co-ordinated movement skills that we acquire with ease and use automatically without any conscious thought. Such movement competence provides the essential foundation for adaptive function as active sociable human beings. Paediatric physiotherapists however are familiar with a group of children who have abnormal difficulty in acquiring age-appropriate motor skills although the children are bright, have had normal developmental opportunity and display no apparent pathology. Initially identified as the 'clumsy child syndrome' (Editorial, 1962) it was a quarter of a century before this disorder of movement skill was given formal recognition as a distinct clinical condition and gained entry as 'developmental coordination disorder' in official classification manuals (DCD) (APA, 1987; 1994; 2000).

Publications by physiotherapists (including many articles through the Association of Paediatric Chartered Physiotherapists) provide evidence that service delivery for children with DCD has been of concern to UK paediatric physiotherapists over at least the past thirty years (Grimley and McKinley, 1977; Lee and French, 1994; Williams et al 1999; Finlayson, and Rickard 2001; Peters, 2000, 2003). APCP selected DCD as one of three topics for investigation of clinical effectiveness and development of evidence based guidelines (Brownson and Walmsley, 2000). The Chartered Society of Physiotherapy has voiced the needs for this group of children (CSP, 1998) and DCD is currently prioritised as a research topic (CSP, 2002). The recent introduction of network communication via interactivecsp.org.uk reflects the frequency of questions related to DCD. Concern is not only restricted to within the British Isles but paediatric physiotherapists outside UK are focussing attention

on similar issues around DCD and delivery of best evidence-based practice (e.g. Pless and Carlsson 2000; Schoemaker et al 1994, 2005; Van Waelvelde et al 2003). A Cochrane review is in progress examining OT and PT intervention for DCD (Lipson et al 2003). It is important that as paediatric physiotherapists we continue to clarify our definition, diagnostic criteria and understanding of DCD and ensure that we keep up to date with national and international opinion and progress.

For a number of years groups of international researchers from a variety of disciplines across health and education have tried to come to an agreement on what term to apply to a child who displays 'clumsiness' of movement, how to interpret the term and what criteria should be met for a diagnosis to be made. The London (Ontario) Consensus Statement was the result of a multidisciplinary meeting in Canada. (Fox, and Polatjako, 1994). Following this meeting a statement was published (Polatajko, Fox, & Missiuna 1995) reflecting the consensus to adopt the term 'DCD' (used in the 4th edition of the influential diagnostic manual of the American Psychiatric Association – DSM-IV (APA, 1994). This term had also already appeared as the chosen title of a special issue of *Adapted Physical Activity Quarterly* that gathered together 10 research papers addressing aspects of DCD including two by physiotherapists. (Henderson, 1994).

Against this background it is pertinent to draw the attention of APCP members to the recent **Leeds Consensus Statement 2006** (Sugden, 2006) produced following a series of Seminars, on Developmental Coordination Disorder, that took place at Leeds University between 2004-5 in collaboration with the Economic and Social Research Council (ESRC). Forty professionals, experts from across health, psychology, education and sports science, were invited by Professor David Sugden (Principal Investigator) to discuss, analyse, synthesise and gain agreement for a consensus statement regarding the condition of DCD. The seminar series was notable for the effort made to capture a wide range of opinions reflecting the standpoint of researchers in highly academic university environments, experienced clinicians, classroom teachers and representatives linked with charitable organisations (Dyspraxia Foundation, Sensory Integration UK, Dyscovery Trust, National Handwriting Association). From the health professions UK physiotherapists were represented by Anne Markee and Judith Peters who are involved in both clinical practice and research in DCD and have, over the past ten years, regularly participated in DCD conferences worldwide. The seminars also involved physiotherapists from Europe and occupational therapists from UK and Canada. Senior UK consultant paediatricians from Scotland and England and the medical lead at the Dyscovery

The Leeds Consensus Statement on Developmental Coordination Disorder (DCD) and its relevance for paediatric physiotherapists

Centre (Wales) were able to offer expert medical opinion especially on issues related to diagnosis.

What prompted the need for the Leeds seminars and Consensus Statement? Exactly the same reasons that lead APCP to focus on DCD for their drive toward developing clinical guidelines: continuing concern for an unambiguous diagnostic label, need for a standardised evidence-based approach to referral, assessment, intervention and outcome measurement.

Each of the four two-day seminars covered a different aspect of DCD and followed a similar format. International speakers presented key note lectures on an aspect of DCD, supported by presentations by experts on the topic of discussion. Following each presentation multidisciplinary break out groups discussed/argued the theme topic and provided feedback from which summary conclusions were drafted. The topics for the 4 seminars were 1) Concepts and definitions 2) Assessment 3) Characteristics and Comorbidity 4) Intervention. Two months after the final seminar a one day meeting was scheduled in January 2006 to discuss the way forward and plan the preparation of the Consensus Statement which was released six months later (Sugden 2006). This 60 page booklet details the new consensus, summarises the keynote talks and the issues raised by the discussants. We urge paediatric Physiotherapist to read the booklet and consider the various issues especially in relation to their own clinical/research practice in the wider context of current legislation (e.g. Children Act 2004 and National Service Framework (NSF) for Children, Young People and Maternity Services, 2004).

Although there was debate about the term 'DCD', the consensus of the meeting was that it should be maintained particularly as it does not reflect unsubstantiated causation and it is a term that is gaining acceptance throughout many countries. Both 'minimal brain dysfunction' and 'atypical brain development' were considered as unhelpful labels. In the discussions raised by contributors to this series of meetings, it was agreed that the four criteria (ABCD) listed in DSM-IV-TR (2000) provide a useful basis on which to form a diagnosis of DCD. However the group were not satisfied or enthusiastic with the current DSM definition of DCD and a number of clarifications and amendments were proposed. Extracts from the Consensus Statement are quoted in italics in the following section (page numbers refer to DSM-IV entries).

Diagnosis-Criteria A and B

- *Developmental coordination disorder (DCD) is evident when there is a marked impairment in the performance of motor skills. The marked impairment has a significant, negative impact on activities of daily living – such as dressing, feeding, riding a bicycle – and/or on academic achievement such as through poor writing skills. Core aspects of the disorder include difficulties with gross and/or fine motor skills, which may be apparent in locomotion, agility, manual dexterity, complex skills (ball games) and /or balance.*
- *The long-term prognosis of individuals with DCD is variable; a small proportion do appear to improve but more often adolescence and adulthood are characterised by continuing motor difficulties in addition to social and educational problems, medical and psychiatric consequences. The problems experienced are severe and persistent and exist despite appropriate movement experience. As a consequence of these difficulties, and without adequate support and/or specific intervention within the family, school and work environments, an individual with DCD will be placed at a significant disadvantage.*
- *DCD is an idiopathic condition. Its onset is apparent in the early years but would not typically be diagnosed before 5 years of age. It has a varying, but significant impact throughout the lifespan. The difficulties described here as DCD are recognised across culture, race, socio-economic status and gender.*

Diagnosis-Criterion C and D and Co-occurring conditions

- *Criterion C: "The disturbance is not due to a general medical condition (e.g. cerebral palsy, hemiplegia, or muscular dystrophy) and does not meet criteria for a Pervasive Developmental Disorder" p58. DCD does not imply aetiology but is a symptom-based diagnosis. One difficulty with the DSM-IV criteria for diagnosing DCD is the lack of clarity surrounding Criterion C. There are many medical conditions that have a lack of motor control as one 'symptom' among others, and a known condition such as cerebral palsy, hemiplegia or muscular dystrophy should exclude a diagnosis of DCD.*
- *We consider it important to acknowledge that overall, the evidence suggests that DCD is a unique and separate neurodevelopmental disorder which can, and often does, co-occur with one or more other neurodevelopmental disorders. Commonly, these include attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and developmental dyslexia. It is inappropriate to exclude the possibility of a dual diagnosis of DCD and a Pervasive Developmental Disorder, and both should be given if appropriate.*
- *Criterion D concerns the exclusion of individuals with "mental retardation" (p58) when making a diagnosis of DCD. Mental retardation is defined in DSM-IV as*

The Leeds Consensus Statement on Developmental Coordination Disorder (DCD) and its relevance for paediatric physiotherapists

an IQ score below 70 (in the UK the term learning difficulties is used rather than mental retardation). DSM-IV-TR (2000) states that if MR is present, the motor difficulties are in excess of those usually associated with it. Children with a measured, or presumed, IQ below 70 should not be given a diagnosis of DCD, as those children are known to have a higher risk of motor difficulties.

Several key points were recommended by the Leeds group that related to assessment and intervention. The group accepted the diagnostic criteria of DSM-IV as the most suitable set currently available. They recommended the use of an individually administered and culturally appropriate, norm-referenced test of general motor competence. In the absence of definitive prevalence statistics, motor performance at or below the 5th percentile on such a test should be used as a reasonable cut off point for identifying children with significant motor difficulties, in both clinical or research settings. Children with scores falling between the 5th and 15th percentile should be carefully monitored over a period of time until the picture becomes clearer. Paediatric physiotherapists must use standardized measures of motor competence (with documented validity and reliability) if we are to be able to base our assessment reports and intervention on evidence. At present many therapists use only subjective clinical observations which lack reliability and there is no standard cut-off point for identifying movement difficulty outside the normal range.

The group stressed the need to use culturally relevant norms for activities of daily living and highlighted the importance of assessing handwriting as a specific skill that, for so many children with DCD, adversely affects academic achievement. They further emphasized the need for a conventional neurological examination and ideally, also, a measure of general level of intellectual ability. Concern was raised that neither the adverse effect of movement difficulties on social interaction nor the changing impact of motor impairment over time, are sufficiently acknowledged.

Turning to intervention the group reflected many points that underpin good paediatric physiotherapist practice. Intervention approaches should include relevant functional, activities that are meaningful to the child, parents, teachers and others and be based on accurate assessment. The child and other individuals who can contribute (parents, teachers, health professionals etc) should all be

involved. Intervention should be evidence-based and grounded in theories that are applicable to understanding the child with DCD.

An interesting aspect for us as physiotherapists attending the seminars was the opportunity of listening to the contributions from a wide range of separate professions. DCD is perceived rather differently from the educational and medical vantage points. Whereas the PE expert has detailed knowledge of the acquisition of normal motor skills and analysis of tasks in the wider context of education, physiotherapist's expertise lies in analysing movement patterns affecting the musculoskeletal system in the context of normalising functional activity. Non-medical professionals are less aware of the numerous medical conditions that may adversely affect movement leading to lack of coordination or 'clumsiness' in a child. The physiotherapist's role in differential diagnosis of DCD is vital and the Leeds Consensus Statement raises many issues around co-occurring conditions but physiotherapists will find that the document also highlights many relevant issues in other domains.

Finally, it was reassuring to note that the consensus of opinion reflected the current atmosphere of multi-agency working, sharing information, and joined-up service provision with the child and family at the centre of the team. There was a strong move toward function and activities that are part of daily life (practised little and often) and delivery of programmes via a variety of strands other than one-to-one clinic-based intervention. There was emphasis on involving the child's wishes, identifying tasks, choosing priorities, establishing targets for success and the child involved in monitoring his/her own progress. Above all, intervention should be grounded in theories that are based on evidence that the intervention is effective and meet with our aim to deliver consistently high standards of care.

(The Leeds Consensus Statement booklet can be obtained by sending a large stamped address envelope to Dr Amanda Kirby, Discovery Centre, Alltryn Campus, University of Wales, Newport, NP20 5DA plus £2 per copy. Also of interest is the new DCD-UK web site www.dcd-uk.org)

References

American Psychiatric Association 1987 Diagnostic and Statistical Manual of Mental Disorders. DSM III (3rd ed) American Psychiatric Association, Washington, DC

American Psychiatric Association 1994 *Diagnostic and Statistical Manual of Mental Disorders: DSM IV*. (4th ed). American Psychiatric Association, Washington, DC

The Leeds Consensus Statement on Developmental Coordination Disorder (DCD) and its relevance for paediatric physiotherapists

American Psychiatric Association 2000 *Diagnostic and Statistical Manual of Mental Disorders: DSM IV (4th ed.) Text Revision (DSM-IV-TR)*. Arlington VA: American Psychiatric Association.

Chartered Society of Physiotherapy (1998) Annual Report. *Making Strides*. CSP, London.

CSP Research Priorities (2002) *Physiotherapy and Physical Education for children with developmental co-ordination disorder (DCD)*. Topic WHP5: Women's Health and Paediatrics Panel, Research Priorities, Chartered Society of Physiotherapy.

Brownson, J and Walmsley, S 2000 Developmental co-ordination disorder Evidence based summary. *Association of Paediatric Chartered Physiotherapists Journal*, 96: 20-24.

Editorial (1962). Clumsy Children. *British Medical Journal* 296: 1665-1666.

Finlayson, A and Rickard, D (2001) Development of services for children with co-ordination difficulties in Maidstone mainstream schools. *Association of Paediatric Chartered Physiotherapists Journal* 101: 9-16.

Fox, A M and Polatjako, H J (eds) 1994. The London Consensus: A statement from the International Consensus Meeting on Children and Clumsiness; A Disability in Search of a Definition, London, Ontario, Canada.

Grimley, A, & McKinley, I A (1977). The Clumsy Child. *Association of Paediatric Chartered Physiotherapists (APCP)*.

Henderson, S (Ed.) (1994). Special Issue: Developmental Coordination Disorder. *Adapted Physical Activity Quarterly*, 1, 111-114.

Lee, and French, J (1994) *Dyspraxia – A Handbook for Therapists*. Association of Paediatric Chartered Physiotherapists

Lipson A, Edwards P, Logan GS 2003 Occupational therapy and physiotherapy for developmental coordination disorder. (Protocol) The Cochrane Database of Systematic Reviews, Issue I. Art. No.: CD004256. DOI:10.1002/14651858.CD004256

National Service Framework for Children, Young People and Maternity Services (2004)

Peters J M (2000) Developmental coordination disorder: from research to diagnosis and intervention. Report on DCD IV. *Association of Paediatric Chartered Physiotherapists Journal*. 95: 5-8

Peters J M (2003) Report on two international conferences on developmental coordination disorder. *Association of Paediatric Chartered Physiotherapists Journal* 106: 23-25

Pless M & Carlsson M, 2000 Effects of motor skills intervention on DCD: A meta-analysis *Adapted Physical Activity Quarterly*, 17:381-401

Polatajko H J, Fox M, Missiuna C.1995. An international consensus on children with Developmental Coordination Disorder. *Canadian Journal of Occupational Therapy*, 62:3-6

Schoemaker M M, Hijlkema M G J, Kalverboer A F, 1994. Physiotherapy for clumsy children: an evaluation study. *Developmental Medicine and Child Neurology*. 36:143-155

Schoemaker M M & Smits-Engelman BCM, 2005 Neuromotor task training: a new approach to treat children with DCD pp 212-227 in *Children with Developmental Coordination Disorder*. Sugden, D & Chambers, M (Eds.) Whurr Publishers, London

Sugden, D A (Ed) (2006) Leeds Consensus Statement: ESRC Research Seminar Series. Cardiff: Dyscovery Trust.

Van Waelvelde H, De Weerd W, De Cock P, Smits-Engelsman BCM. (2003) Ball Catching. Can it be measured? *Physiotherapy Theory and Practice* 19: 259-67.

Williams, C A, Smith J. & Ainsley L (1999) The effects of a physiotherapy intervention programme on children with developmental co-ordination disorder. *Association of Paediatric Chartered Physiotherapists Journal*; 9:32-40



ASSOCIATION OF PAEDIATRIC CHARTERED PHYSIOTHERAPISTS



APCP CONFERENCE GLASGOW 2006



CONFERENCE PROCEEDINGS



Conference Proceedings

Chaos or development?

Dr. Laila de Groot, Dept of Paediatrics University of Groningen, The Netherlands

The theme of the congress, the slogan so to speak, sounds optimistic: MOVING FORWARD. But apparently the expectations are challenging!

Our profession is being challenged and is even under attack. Scientific evidence is considered meagre and leaves us sometimes desperate and in a state of chaos! But we should not falter.

Chaos is often needed and can be the base for strong healthy development. It is up to us to find a new order in the chaos and to work towards equilibrium and a more evidence based profession. The question is whether it is possible in the human sciences and professions like ours, to set up real controlled studies. To do so one needs big numbers to get a so-called good power analysis. It is pretty hard in our profession to get a coherent group together. No child is identical!

One of the problems we face is the ever-lasting debate about the influence of nature versus nurture; biology and genetics versus environment and social circumstances.

Nature nurture brain

The symbiosis of nature and nurture is all the more important for our profession since it could and should be the core of our actions. In paediatric physiotherapy even more so. Treating children or infants cannot be done without taking into account the ever-changing environment of the child; support and respect from parents and their beliefs is needed and expectations vary with every child. But most important a child is not a constant factor because he or she is a developing individual and could be regarded as a chaotic, dynamic system in itself.

That is why I want to talk about Development. In my opinion the concept of development is the main distinguishing factor between paediatric physiotherapy and other forms of physiotherapy. Furthermore I will also use it as a metaphor when talking about the future of our profession.

A Bushman's child is going to differ from his mom in many ways. The genetic make-up of the Bushman was not prepared for choosing between 20 sorts of ketchup. Slowly but surely the innate and inherited characteristics fit for life in the bush, will change or disappear. It is a reminder that the brain and with it behaviour is not ready made, but grows and

develops. The brain is able to learn, but learning itself is human instinct.

Growth and development are genetically determined but genes are influenced by each other and by environmental factors and changes. In this way individual development is formed and shaped, beginning many million years ago; differences originating in history, culture and circumstances.

Many theories and concepts of human development have been developed and described. Obviously these theories are linked to the knowledge at the time. Nowadays human development is seen as a non-linear process limited by genetic and biological factors, but shaped and altered by experience. Epigenetic imprinting seems possible with time. The genes are the means by which nature expresses itself, as much as they are the means by which nurture expresses itself.

Recent studies (Prof. Dick Swaab, director of the Brain Institute in Amsterdam) claim that the character of the individual is already formed in the womb. So could it be genetic after all? It depends on how we define nurture and nature. In Swaab's studies of identical twins it is proven that the positioning and therewith the optimal or less optimal access to nutrition in the womb makes all the difference for the development of the foetal brain. The access to nutrition and the influence of maternal hormones influences neurogenesis and apoptosis, early cell death. Although apoptosis is strongly ruled by pre-programmed processes, animal experiments have proven that enriched environmental circumstances influence motor behaviour and result in an increased level of cell numbers in adult rats. Thus, the brain is continuously sculptured and formed. Genes and environment are seamless and inseparable.

What has all this to do with our profession? Is it important for us to know these things. How can we optimise or alter (motor) behaviour? Well I am optimistic about that, because a strong hook to hang your hat on is the importance of the motor component in development, which happens to be our expertise.

It is known that already from the 9th week of gestation, foetal movements occur. Studies stemming from our group (Precht, Hanneke de Vries, Gerard Visser). Showed that first small movements like eye movements and haptic mouthing appear, a bit later grosser movements like turning the head and stretches are recorded. Active movement is an absolute necessity for the system to develop and grow normally. Sival et al. proved that foetuses with very little amniotic fluid moved less, this deprivation was still recognisable after birth when looking at the quality of the spontaneous, general movements of these infants.

Thus a very efficient way to study development is to study the motor behaviour of an individual since it can be considered to mirror the ontogeny and timing of brain development.

Can one make the assumption that the motor system is the main important factor for development? This statement is a highly debatable one, since factors like the need to explore, select and remember are innate factors necessary to reach optimal motor function. But I think that one could agree that motor behaviour, which is a term I prefer to use, enables us to communicate with the world around us. The hard part still remains: to explain how the physiological, biological world mediates the psychological part and vice versa.

It was thought that all functions were innate, whilst others said everything was acquired, or development was considered to come about by sheer maturation of biological systems following an evolutionary defined pre-programmed pattern.

Darwin, even without knowing anything about genetics and DNA, already described the theories of natural selection, mutations evolving through variation and habituation to the environment. And I would argue that his theory is not completely different from Bernstein's more modern theory about a dynamic system being formed by affordances, perception and action.

Also the now often disregarded theories of Piaget, Gesell and MacGraw put too much emphasis on the timetable of biological maturation of the brain, but they still hold a lot of truth. Time tables and therewith the so called: "milestones of development" may differ between individual children, but there are limitations. When a child still does not walk free at 24 months, we should be alarmed and the child is entitled to an examination.

Since the possibility to study the unborn child in utero, by means of ultra sound we now know a lot more about early development, its continuity and timetable. We know now as I said before that already at the age of 9 weeks post conception most of the basic motor patterns are present for example, eye movements are already discernable at 16 weeks, while it must be rather dark in the womb. So even with little or no perception, there is action!

Neither intrinsic developmental timetables nor experience can give sufficient explanation for motor development. At every stage motor development is depending on experience and the quality of the stimulus perceived. The perceived information in turn is depending on the right period of brain organisation, the so-called "critical periods of

development". Of course we all know this. It is no use to try to teach a 4-month-old infant to walk, while we also know that a newborn infant "walks" or at least makes stepping movements when supported.

Many studies which tried to enhance or accelerate motor development by a stimulating intervention plan, have shown disappointing results. The so-called milestones of development cannot really be enhanced.

Stepping

Esther Thelen, an American psychologist, tried to explain the fact that this phenomenon disappears at a certain age only to re-appear months later. She argued this was due to the changing biomechanics of the infant, in this case the heavier legs. The late Katalin Bovendeg, at that time a student of mine, repeated her research (Published in *Neuropediatrics* (2000). 31 page 180) by calculating the weight of the legs and the ponderal index of a group of preterm infants, but could not confirm these findings. Esther Thelen also trained the stepping response on a treadmill and in that way could maintain the stepping reaction, but still this did not enhance free walking. It is believed that for this infantile, automatic walking pattern, general pattern generators in the vertebral column are responsible. For the function of free walking far more complicated equilibrium reactions are required. This shows us that many controversies over the origin of human (motor) behaviour have not been solved as yet.

Still it is exactly on this slippery path that paediatric physiotherapists can and should use their expertise. Preventive intervention is a major part of our profession, certainly so in paediatrics. As Andras Peto said, "Catch a fault before it is evident". This is very difficult since there is so much individual variability.

During early infancy each movement is slightly different, each trial is a little different from the one before. By trial and error, selection and memory the sensory motor system is shaped and formed, but always has to be decoded to the morphological changes of the brain and musculo-skeletal limitations. In this way variability in the case of normal development and the lack of it in a damaged brain can be explained. It is the task of the physiotherapist to notice and catch this lack of variability before stereotypy become fixed. By structuring the environment, so by altering the nurture, the perception of the infant will get more or different stimuli this in order to create more variability by using the overflow of neurons available in early development. Once the synapses or circuits are fixed, trial and error processes become limited and result in an unusual performance; be it accelerated or retarded.

Until now I have only been talking about brain damage, but the therapist should also be familiar with the influence of the different (congenital) syndromes, like Down's syndrome and Prader Willy and also know how different diseases interact with the overall development of the child.

Prematurity

As many of you might know my main interest, for the last 30 years or so, has been the prematurely born infant. The fact that the infant is born too early makes it possible to study development outside the womb and to study the influence of the environment on the (motor) behaviour of these infants. It is known from animal research that new neurons and synapses can grow in response to experiences but also lose neurons in response to neglect. This makes the infant born preterm an "experiment in nature" and in my view should be considered as a different biotope. Preterm infants are particularly vulnerable as their immature nervous system is very sensitive to abnormal stimuli, such as abnormal gravity, pain, extreme light and noise. This may result in a higher arousal level, which in turn may have lasting effects on behaviour. Furthermore preterm infants lack movement experience, sometimes due to the necessary sedation, extreme hypotonia or caused by their medical condition. Inappropriate or abnormal stimuli received via proprioception or by vestibular, tactile and visual systems and their mutual integration are of great importance during this period of development. Muscle power dysregulation will influence posture and postural control and therewith hand function and cognitive functions at the later ages. These subtle deviances are often seen in preterm infants who were not obviously neurologically impaired, but more and more evidence has become available showing diffuse disturbances in cerebellum and cerebello-thalamo-cortical pathways. It is very questionable whether these aberrations can be prevented. The infant gets the wrong stimuli at the wrong period of development. Even after correction for gestational age one cannot compare the preterm infant to an infant born fullterm.

So where does this lead the physiotherapist? Our help is often requested when the motor development of these precious infants deviates from the normal. But is it abnormal? We do not have a gold standard for the preterm that has been in the incubator for 3 weeks compared to the ones that were there for much longer periods of time. We do not know the impact of the different medical interventions. In short there is no gold standard for the profile of THE preterm infant. The question is are we dealing with the typical behaviour of a preterm infant, which could be transient or is this

stereotyped (motor) behaviour that requires intervention? A nationwide Dutch follow-up study (POPS) into the overall behaviour of now 19-year-old adolescents born prematurely did not leave us very optimistic. Apart from the known cerebral palsied children, more than 30 % of the adolescents showed problems in the field of neuro-sensory and cognitive functions or coordination. This is twice as much as in the general Dutch population.

Before 12 weeks corrected age it is very hard to assess definite pathology. At this age major transformations take place and it may be the best time to intervene. It should be remembered that the family already under stress does not always welcome intervention after the preterm birth. On the other hand, preventive therapy shows the best results, because of the plasticity and adaptation of the young nervous system. The repertoire of movement may show less variability but is not yet stereotyped. The therapist should try to influence the environment of the infant, council and coach the parents, teaching them to elicit active reactions and responses from their infant and most important: teach them how to wait for the child.

When then a child recovers and develops normally, the question remains: Was this the wonderful therapist's intervention or was it mother nature's own doing??? The theoretical underpinnings of therapies are weak, with little scientific basis. It is hard to give solid evidence, since we are dealing with a non-linear system and there are many variables influencing child development. But there is one thing we can focus on: the motor behaviour of the infant.

So is a Paediatric Physiotherapist needed? The answer is a simple: yes!!! The paediatric physiotherapist is a specialist in the field of motor development, understands how the different subsystems influence each other and how deviations can lead to impairment of function. She or he has knowledge of the overlapping fields of psychology and pedagogy, has specific skills to coach a child and parents and is able to create an environment where functional tasks can be practised and learned. It is of main importance for the physiotherapist to use the right approach at the right time. The most important thing to keep in mind is the time window of development in which the therapy takes place and this need not always be the calendar age of the child but is set by the developmental timetable of each individual child. So far my success story and pep talk!!!

Bears

Now I would like to talk about the bears on the road that I see; actually two big bears!!!, **de beren op de weg**. I want to address and share with you a few of my worries concerning the way our profession is

Conference Proceedings

developing. There are a few things that really worry me.

ICF

Since the publication of the new International Classification of Functioning, Disability and Health, the ICF criteria, the way of thinking about disability has changed considerably. From a medical, physiological way of thinking it was changed and has been succeeded by a view of a so-called minority problem group. The process we physio's are involved in is now no longer called re-habilitation, but habilitation. The aim being: Function and Participation!

In my opinion this way of thinking is OK but should be looked at with great caution. Andra Peto already used the word "function" and "orthofunction". Of course that is what the goal should be. But not when this means a cut back in therapeutic sessions and neglect of restoring normal motor patterns. Distorted adaptive motor patterns should not be considered as an optimal solution for function. It may be a smart way to cut back on the National Health budget, but causes a lot of damage in the long run. At a later age movements will become more restricted, with lesser degrees of freedom.

I argue that when the impaired patient would be left to himself, without the help of a trained therapist this could lead to stereotyped rigid movement patterns and in time to less effective energy use. Extra wear and tear of the musculoskeletal system will be the result.

We should not forget about treating the underlying impairment, the primary deficit, because that is why our help is needed in the first place. Even when the relationship between impairment and the disability of a child is not clear it should be considered together with the development and the environment of the child.

Through the innate drive of a child even an impaired nervous system is capable of learning. Motor learning techniques have demonstrated that special constructed environments assist the brain to adapt beyond the environment where the task is normally learned. It is the expertise of the therapist to find a variety of contexts where a specific task is able to form adaptations and in this way variability of function.

It should be the skill of the paediatric therapist to facilitate a child and his or her environment in a playful and purposeful manner to the best possible motor pattern and try to do so from many different angles, in order to create active variability. Every

child has an innate urge to move and explore in play. I think we paediatric physio's have been or at least should have been giving functional therapy for a long time!!

I said I saw two bears on the road. My second concern is our fanatical desire to measure everything we do. Of course it was high time we started to use protocols in our work. When we want our profession to be taken seriously we need at least consensus of opinion, definitions and documentation. It may be a good idea to get a uniform classification and coding needed for research and useful for political planning of services, but it does not do much good for the individual child. We should not forget to treat!

Consensus with regard to treatment is much harder to get. There is no child like another and there is no therapist like another. And I think that is exactly where our strength lies! From my point of view there should and will be two sorts of therapists in the future: The hands-on therapist and the therapist involved in research. Questions and solutions should come from the shop floor; that is where our skills are practiced. Other therapists should try to put a more scientific base to the profession. Clinical experience is needed before research can start. To plan measurement techniques and research projects seems quite easy from behind your desk. It is far harder to clarify what it is you want to measure and whether it is possible to make your case. This needs a lot of cross-referencing with what is happening on the work floor.

Dia 12. Kind met badwater. (Dutch expression!)

Often the questions we want to get answers to are one bridge too far and this leads to throwing away the child with the bathwater!

In short: Wat wil je weten en wat ga je meten? What do you want to know and what are you measuring? My view is, that this is our Achilles heel and at the same times our strength! We should not let ourselves be too discouraged by criticism about evidence-based results, but likewise we should be critical about ourselves and ask the question what am I doing? And what is the purpose of my treatment and strategy. Challenging???? YES

Conclusion

Now I have come full circle in my talk, because I think the main lead should be the time window in the development of the individual. And by saying that I do not mean the so-called milestones, but the individual timetable of that particular child influenced by that particular disease. This will help us to ask the right questions at the right time and to look for the most suitable measurement or technique. That should be the expertise of the

Conference Proceedings

paediatric physiotherapist. Use nurture via nature to get better function!

Nature via Nurture! Thank you!

References

Bernstein N. Coordination and regulation of movements. New York, Pergamon Press (1967)

Borvendeg K, de Groot L. The stepping response in early infancy. *Neuropaediatrics* (2000) 31 1-6

Edelman GM. Neural Darwinism: Selection and re-entrant signalling in higher brainfunction. *Neuron* (1993) 10 115-25

Groot de L. Chaos, variability and stereotypy in paediatric physiotherapy. *Physical therapy, theory and practice.*(1998) 14 69-74

Hoek vd A, de Groot L. The Peto method. Vrije Universiteit Press, Amsterdam (1992) ISBN 90-5383-153-3.

Mc. Craw MB. The neuromusculair maturation of the human infant. New York, Colombia University Press (1945)

Piaget J. Possibility and necessity. University of Minnesota Press, Minneapolis (1970)

Prechtl HFR. Quality changes of spontaneous movements in fetus and preterm infants are markers for neurological dysfunction. *Early Human Dev.* (1990) 23 151-8

Thelen E, Fisher DM. Newborn stepping; an exploration for a disappearing reflex. *Dev. Psychol.* (1982) 18 760-775

Presentation Outlines

Visual problems following premature birth

Prof. Gordon Dutton, Consultant Ophthalmologist, RSHC, Glasgow

Damage to the eyes due to retinopathy of Prematurity degrades the 'picture' presented to the brain.

Brain damage is now the commonest cause of visual impairment in the developed world, and Prematurity is a major cause. This can be due to periventricular leukomalacia, hydrocephalus due to intraventricular haemorrhage and hypoxic ischaemic encephalopathy.

Damage to the visual area of the brain can also interfere with how the 'picture' is processed and understood. A system which allows the physiotherapist to understand the nature and degree of all the limitations of the damaged visual system needs to be developed.

This paper summaries the main ways in which the visual system is impaired in children with brain damage such as periventricular leukomalacia and hypoxic ischaemic encephalopathy associated with premature birth and suggests the principles which need to be applied to address the issues outlined above.

Physiotherapy in the Paediatric Intensive Care Unit

Elaine Dhouieb, MCSP Assistant Lead
Physiotherapist, RSHC, Edinburgh

Respiratory physiotherapy is a long established part of the management of children in the Intensive Care Unit. This is despite little evidence of benefits. However small numbers, ethical issues of withholding treatment from this complex group of patients and difficulties in identifying robust outcome measures which are totally dependant on physiotherapy intervention, make it unlikely we will ever have gold standard randomised controlled trials.

This presentation will look at the recent evidence and gaps for respiratory physiotherapy in PICU. It will also look at newer modes of management such as High Frequency Oscillatory Ventilation, non invasive ventilation and Mechanical Insufflation Exsufflation, including their role with airway clearance.

Paediatric Intensive Care Medicine and Physiotherapy

Ulf Theiland, Consultant Intensivist, RSHC, Edinburgh

More than 10.000 children in the UK require intensive care treatment per year. The way this care is being delivered has undergone dramatic changes over the last 2 decades. The vast majority of these patients is now looked after in about 30 Paediatric Intensive Care Units (PICUs). This presentation gives an overview of the variety of problems seen in PICUs and the changes in outcome for these critically ill children over time.

The success of PICUs is critically dependent on the functioning of a big multi-disciplinary team. Physiotherapy plays an important part within the care delivered by the PICU team. Evidence-base for intervention by physiotherapists is being discussed together with clinical presentations of PICU patients requiring physiotherapy input.

MOVE: Movement for Learning and Life

Christine Shaw, MOVE Scotland Development Manager

MOVE was designed specifically for children with severe disabilities. It is intended to teach them the functional motor skills needed to sit stand and walk as independently as is possible for them.

MOVE is based on the principle that we have to be able to move in order to learn about our environment, the spatial concepts and cause and effect. These are the skills required to make choices, be naughty and interact with peers, but they are also the skills required as an adult to allow as normal as possible interaction with society and to prevent (or limit) the need to be hoisted.

Mobility therefore is not seen as an add on to the child's timetable, but should underpin all areas of the curriculum and be incorporated into the child's whole day. Therapists, as part of the team around the child, support classroom staff to ensure all opportunities are used to learn and practice mobility skills to support the child's access to their curriculum.

We assume that every child can learn new motor skills if the time and energy is applied to teaching them. In order to expand the possibilities for a child to learn, collaboration between teachers, therapists, support staff and families is vital.

The MOVE framework incorporates joint assessment and child and family oriented goal setting. There is then a team led plan to reduce physical support to allow the child to learn a new motor skill.

Presentation Outlines

MOVE is wide spread throughout Europe but the Scottish model of developing the programme is unique. Local authorities, health, education and social services throughout Scotland are collaboratively funding and committing to MOVE. Steering groups are set up in these authorities to most effectively train the interagency cluster of staff and carers around the child.

A national data base is set up to evaluate the effects of MOVE on each individual child and each authority is developing its own evaluation system.

MOVE supports all education, health and national learning disability strategies towards helping people with disability gain more independence and be more included in their community.

- Ensuring achievement
- Listening to children
- Joint assessment and planning
- Child and family centred goal setting
- Partnership with parents
- Equity of opportunities

Moving Forwards in the management of children with Cerebral Palsy

Margaret Mayston PhD, MCSP, Dept of Physiology, University College London.

The physical management of children with impairments of central nervous system (CNS) origin has evolved over the last century, from the predominantly orthopaedic approach of the early part of the twentieth century, through neurophysiological educational, biomechanical and task – specific approach phases. In most parts of the world there is now a drive to achieve a client or a child / family centered approach, acknowledging the shift from a medical model of management, to one which considers clients and their goals as the central focus. Just as there is no one model for understanding motor control, neither is there one way to approach the management of a child with a neurological movement disorder. To achieve child/family centered management, it is essential to put aside the philosophy approach, and from the determination of a child/family's goals and needs, to provide what is required. This does not mean that the so called named approaches to therapy are no longer relevant; rather these need to be seen in the context of the many options available to meet the needs of each individual. In this talk I will discuss the idea of the 'therapy tool-box' for the management of the child with Cerebral Palsy.

Balance education and movement – getting BEAM into the curriculum

Anne Finlayson, Associate Director for Children's Services for Maidstone Weald PCT
Dianne Rickard, Senior Physiotherapist,
Mainstream Therapy Team, Maidstone, Kent

Increasing numbers of children are being identified with poor motor skills. These children exhibit immaturity of movement, and may demonstrate Dyspraxic tendencies.

BEAM was developed in Maidstone in response to increasing numbers of referrals for Therapy. The result of this increase was a very lengthy wait for a therapy appointment.

A pilot study was undertaken in 1999 to establish the efficacy of a progressive gross motor skills programme, carried out in schools by school staff. Audited results showed significant motor skill improvement in all participants. Initially the Beam programme took the form of a booklet. Subsequently it has been produced as an interactive CD-ROM package. Close working between the Therapists and Education colleagues has led to introduction of BEAM into every Primary School in Maidstone.

Children who fail to progress within the BEAM groups can now be offered prompt Therapy guidance.

The need for an agreed pathway in DMD in light of the evidence base

Marina Morrow, Clinical Specialists in neuromuscular disorders, Yorkhill Division, Glasgow. Marina.m@ntlworld.com

Physiotherapists are being encouraged to utilise current literature when undertaking the assessment, treatment and management of patients within the NHS framework. There are many national policies, guidelines and literature available that discuss clinical governance and best practice. While many of us try to implement these guidelines into our daily practice, there is an emerging body of evidence that discusses the barriers to implementing evidence based practice, the validity of the evidence and the limitations within the current research structure.

With this in mind, physiotherapists can find it difficult to traverse the evidence (whilst filling in the blanks) and this has been a strong implication among members of the neuromuscular physiotherapy group, a special interest group of APCP.

This presentation aims to outline current work based on available literature and expert opinion and illustrate the work to date Duchenne Muscular Dystrophy national pathway. The pathway

Presentation Outlines

discusses stretches, exercises, orthoses, gait, 24-hour postural management, respiratory management, cardiac management, steroid therapy and quality of life issues.

Guidelines for medical surveillance for children with Downs syndrome

Dr Pat Jackson, Consultant Paediatrician,
Community Child Health, Edinburgh

For the past 10 years a group of doctors and nurses with a special interest in the care of people with Down's Syndrome has been meeting. It was agreed that it would be helpful to develop evidence based standards for health surveillance for people with Down's Syndrome (to avoid preventable additional health problems). This is the work that I have pleasure to present at the meeting. The group is now a charitable organisation – The Down's Syndrome Medical Interest Group – and we continue to revise and develop the surveillance guidelines responding to new research and practice. We also support the Down's Syndrome Medical Information Service based at the Children's Centre in Nottingham.

In my talk I will cover the following health surveillance areas where firm recommendations are possible –

1. Thyroid Disorder
2. Cardiac Disease
3. Ophthalmic Problems
4. Hearing Impairment
5. Growth
6. Cervical Spine Instability

As well as presenting the relevant health information I will discuss the process of development of the recommendations as there is a huge job still to be done in developing UK-wide standards for therapeutic input to this group and I hope to hear the views of the meeting on this.

I will also talk about the parent held child record books.

Spot the difference

Over the past few years there has been a wave of new government legislation and guidance influencing services for children in England, Northern Ireland, Scotland and Wales.

'Spot the difference' briefly reviews this legislation and guidance, focusing on the key messages that should affect the development, planning and delivering of services for children and young people. The four presenters, Sarah Crombie, Felicity Dickson, Laura Wiggins and Diane Rogers will represent their country and Linda Fisher will address some of the differences and commonalities of the legislation.

'Spot the Difference' will highlight some of the challenges of re-construing and restructuring how we work and develop services to meet the demands of the legislation and guidance. It may also identify some of the potential solutions !!!

Free Papers

A qualitative exploration into the perspectives of physiotherapy intervention by physiotherapists and adolescents with Duchenne Muscular Dystrophy

Helen Dowden MSc, Superintendent Physiotherapist, East Leeds PCT
 Lisa Salisbury, Physiotherapy Department, Queen Margaret University College, Edinburgh

Introduction

Duchenne Muscular Dystrophy (DMD) is a rare life-limiting genetic condition. The medical profession and families have traditionally viewed physiotherapy as key in the management of DMD. However scarcity of evidence has been recognised (Eagle, 2002, Morrow, 2004). A qualitative study was undertaken to explore the perceptions of non-ambulant adolescents with DMD about their physiotherapy intervention.

Method

A 2 part study was undertaken:

Part 1

A Nominal Group Technique (NGT) was adopted to elicit the views of physiotherapists and assistants (n = 7) recruited from East Leeds PCT, relating to physiotherapy management of adolescents with DMD. They were asked to consider the issues in Table 1

Table 1: Discussion questions for NGT with Physiotherapists and Assistants

| |
|---|
| 1. Benefits of physiotherapy when treating adolescents with DMD. |
| 2. Barriers to physiotherapy when treating adolescents with DMD. |
| 3. Perceived benefits of physiotherapy as viewed by adolescents with DMD. |
| 4. Perceived barriers to physiotherapy as viewed by adolescents with DMD. |

Table 2: Summary of Final Categories from the NGT with Physiotherapists and Assistants

| <i>Benefits</i> | <i>Barriers</i> |
|---|---|
| Physiotherapy Views | |
| Physically more comfortable Someone to Sort Things Out | Manual Handling Insufficient Time |
| Perception of Adolescents Views | |
| Enhance Comfort Enhance Function and Freedom of Movement | Too Hard Consent/ lack of control/ runs into break |

The categories relating to benefits and barriers were summarised (Table 2) and used to develop a topic guide for 2 further focus groups with adolescents with DMD.

Part 2

Focus groups with adolescents using the information from the NGT as a basis for a topic guide.

Two focus groups (n=2 and n=3) were used to elicit the views of adolescents with DMD (12-18 yrs) on their physiotherapy. Ethical approval was obtained from Leeds (West) Research Ethics Committee. The focus groups were audio-taped and qualitative thematic analysis was undertaken from the transcripts.

Results

Two major themes and 7 Sub-themes emerged consistently through the collection and analysis of the data, summarised in Table 3.

Table 3: Emerging Major and Sub-themes

| Major Themes | Sub-Themes |
|--------------|-------------------|
| Physical | Sorting Out |
| | Difficulties |
| | Comfort |
| | Function/Movement |
| Emotional | Manual Handling |
| | Time |
| | Consent/Control |

- It was reported that frequency of passive stretching led to greater comfort, and reduction in sensations of muscular stiffness.
- Frequent use of standing frames was associated with discomfort and pain by both groups of adolescents.
- The adolescents recognised the role of the physiotherapist in training of key school staff to carry out exercise programmes particularly in

Free Papers

mainstream settings. They reported this was important to ensure the feeling of safety during physiotherapy sessions.

Discussion

Due to the paucity of research within the field of physiotherapy, the physiotherapist is often making decisions based on empirical information, anecdotal evidence and clinical experience. Further advances in research within this field of physiotherapy will continue to be a challenge due to ethical dilemmas. Views of the 'users' of services must be sought to identify areas where research can be progressed, as highlighted within this study e.g. effects of standing frames.

Conclusions

The key themes identified in this study highlighted both the positive and negative dimensions of physiotherapy care that have not been previously reported. Of particular interest was their account of the painful experience of standing frames. This in particular warrants further research.

References

- Eagle M., (2002b), report on the Muscular Dystrophy Campaign Workshop: Exercise in Neuromuscular Diseases Newcastle, January 2002, *Neuromuscular Disorders*, 12, pp. 975-983.
- Gibson F., Soanes L., (2000), The Development of Clinical Competencies for use on a Paediatric Oncology Nursing Course using a Nominal Group Technique, *Journal of Clinical Nursing*, 9, pp. 459-469
- Morrow M. (2004). Duchenne Muscular Dystrophy – a biopsychosocial approach. *Physiotherapy*, 90(3), Pages 145-150.

What is the experience of standing in a standing frame for children with cerebral palsy?

Sue Bush MSc MCSP

The presentation discussed the results of interviews with two children with cerebral palsy about their experience of standing in a standing frame. It formed a pilot study for research for a Professional Doctorate.

Physiotherapists believe that standing in a standing support is a valuable activity for children with cerebral palsy who cannot experience aligned standing independently. My initial concerns to research the best way of standing gave way to a desire to find out what children like and dislike about standing in standing frames. There have been very few attempts to discover children's views about any form of physiotherapy.

Child A, an eight year old girl educated at a special school, had positive beliefs about standing, recognised that her hand function improved, but had never been consulted about when she would like to stand. She wanted to have more control of the process.

Child B, a 12 year old, educated in a large mainstream comprehensive secondary school, had little more control but was not bothered by this. Her main concerns centred around being able to stand at the back of the class so that she did not feel everyone was looking at her.

Minutes of the 33rd Annual General Meeting Held on Saturday 11th November 2006, at Crowne Plaza Hotel, Glasgow

The Chairman, Lesley Smith reminded those present that this meeting was for members only. There were 102 members present. The meeting began by observing the one minute silence

1. Apologies

Apologies were received from Jeanne Hartley, Rachael Hufton, Susan Rideout, Liz Hardy, Lesley Katchburian and Kathy Banford

2. Minutes

The minutes of the 32nd Annual General Meeting held at CSP congress, Birmingham, Liverpool were available for members to read and could be requested by members from the secretary. The minutes were approved and signed accordingly

Proposed: Mary Harrison

Seconded: Terry Pountney

3. Matters arising

3.1 Lesley Smith reported that the DCD guideline work was ongoing and the Chairman's report would elaborate

4. Chairman's Report, 2005-2006 Lesley Smith

Welcome to the 33rd Annual General Meeting of The Association of Paediatric Chartered Physiotherapists.

The report this year includes details of planning work undertaken and actions coming from the working weekend, which was held in Belfast in March 06. The pre-planning phase identified areas, topics, policies legislation etc, which required to be addressed. Three working group were identified to cover the diverse aspects of APCP development reflecting the current clinical interest group business.

Working group 1 looked at Constitutional issues both National and Regional and also considered the inclusion of the emerging affiliated sub groups.

The role of APCP is to represent the field of Paediatric Physiotherapy Clinical Practice. The Association requires to demonstrate clear and valid relationship to the core of physiotherapy as described in the CSP charter. Groups reviewed our constitution, which with the formation of the affiliated groups has become even more complex in that it has identified specific clinical areas of paediatric practice requiring our support. Review was also undertaken of the relationships between national and Regional committees and affiliated Group committees emphasising that we are all constituent parts of APCP. The role of the clinical interest group is clearly defined by CSP under the heading of:

- Continuing Professional Development (CPD) and Education
- Influencing/informing
- Promoting Physiotherapy
- Quality Assurance
- Research & Clinical Effectiveness

It was important to consider the Associations objectives and to ensure that they reflect the role of a CIG as described by CSP. Discussion centred round ways of meeting objectives regionally, nationally and for affiliated groups.

The CSP also have criteria for the structure of CIG Groups and their committees and we are required to ensure that we continue to operate within these. The constitution also requires to reflect that of the CSP.

Working group 2 covered the profile of APCP within the emerging but increasingly complex context of how we can improve communication with our membership and also raise our profile in supporting paediatric physiotherapy issues with families and also the media.

A new service launched in 2006 has enabled physiotherapists to share their knowledge and expertise based on their interests irrespective of where they live or work. APCP are partners in the development of interactive

CSP. This service is about physiotherapy, not technology and is easy and intuitive to use. In order to have your voice heard, your needs met and issues debated/discussed, you should if you have not already done so join the network and register on www.interactivecsp.org.uk. Members of APCP who have been trained in the role of moderator manage the network on a day-to-day basis and we need the support of all our membership. Another development following the work of the profile group has been the APCP website going live an important aspect of communication to improve our profile. It is intended to work alongside interactive ICSP as a source of information and contact with APCP and our thanks go to Lindsay Rae, our new Public Relations Officer for concluding this difficult piece of work.

In line with our new website and interactive responsibilities Heather Angilly, links into National Committee on behalf of the moderators.

Working Group 3 started the extensive work to look at the development of a competence framework for paediatric physiotherapists. The use of competences by healthcare workers has been identified as being important to the commissioners of health services. By developing our own professional competence framework we will ensure that we, as providers, meet the standards required not only under the statutory frameworks, but also the standards set by the Chartered Society of Physiotherapy and APCP to ensure consistent high quality standards of care by our members.

APCP is committed to supporting the professional development of its members and sees the development of a Competence Framework for Paediatric Physiotherapists as an essential tool to help members identify, plan and evaluate areas for development. This continuing development (CPD) is also an essential requirement of the Health Professionals Council.

The main aim of this framework will be to guide the practice of physiotherapists in the field of paediatrics. It is expected that the finished document (estimate 2007) will be a working document that will change as new knowledge, skills and innovations emerge.

In awareness that management cannot be separated from clinical practice we are formalising links with PPIMs. Over this period Carole Mackay has attended both the Working Weekend and APCP meetings through out this year.

Early in March Peta Smith and I attended a meeting at Royal College of Paediatrics and Child Health, London. Graham Pope attended as an Allied Health observer from CSP. Agreement was reached that there should be a general sharing of information with distribution of legislation etc to all in order to co-ordinate responses. The volume of legislation and documentation we are requested to comment on is large. Time frames to respond are frequently short and many of the requests require managerial as well as clinical opinion and information. Our ongoing and developing relationship with PPIMS hopefully will secure a sound representative voice on behalf of children and their families if we work together. The Royal College of Paediatric and Health requested APCP send a representative (Dave Threlfall, from PPIMS attended a workshop 'Bringing About Sustainable Improvement in Children's Services' at University of Warwick Campus, Coventry) and will report back to both committees. This workshop was also attended by our Dietetic, Speech and Languages and Occupational Therapy colleagues all of whom have funded posts for representation.

You have had the opportunity in your September Journal to view the breakdown and proposal our treasurer is presenting as the way forward.

In an awareness that the volume of work voluntarily undertaken by APCP executive and committee increases year on, the treasurer has reviewed within the planning cycle what would be required by APCP to employ an administrator. This person would act as the interface between the association and its members and also support the work of the National Committee.

Such an appointment would also allow review of the role of various offices and almost act as a sort of evaluation of the skill mix required on National Committee in response to its rapidly changing function. Fiona Down follows on from me with the Treasurer's report.

2006 had a very difficult start with BACS / IT / Software and producing babies all contributing to the problems.

However the transition of membership secretary from Susan Cleverley to Chris Sneade is now complete.

Chris is our new membership Secretary and she, along with the treasurer, have a modernising agenda in mind which should simplify the system and get 2007 off to a good start and roll out over the following months.

Congratulations and thanks go to Dr Terry Pountney for so capably and seamlessly taking over as Editor of APCP Journal. She requires your ongoing support by way of contributions and copy for 2007.

I wish also to report the progress of 3 affiliated groups:

The Neonatal Group ran the first 3-day course 'The Role of Therapists in Neonatal Care' as a pilot course, 14th - 16th June 2006 at Antrim Hospital Site, Antrim, and Northern Ireland. 17 attended. The content of the programme consisted of respiratory care in neonates, prematurity, pathology and concepts in care of Neurodevelopmental assessment and intervention for premature infants. This course evaluated extremely well with excellent feedback. The group now plan to rotate this course around the UK as 'The Introduction to Paediatrics course', the next one planned will be in Newcastle in February or March 2008. Thanks to Fiona Price for all her hard work in organising the course and Adare Brady for organising the venue. Today the Neonatal Group are holding a satellite study day in parallel with the main conference again an innovation in providing delegates with special interest.

Neuromuscular Special Interest Group have also been busy and had a 2 day working party meeting to outline best practice parameters for the physiotherapy management of Duchenne Muscular Dystrophy. The group have also been establishing links with ACPIN. Dr Michelle Eagle, Marina Morrow and Elaine Scott have had an article regarding the emerging population of adults with NMD accepted for publication in the ACPIN journal Synapse. The Neuromuscular section on the website hope to link with the ACPIN website to assist those with an interest in Neuromuscular disorders. There is a healthy membership at just over 70. A study day and an AGM is planned for the Birmingham Hippodrome for the end of March 2007.

The Critical Care Group held a study day in June at Sheffield Children's Hospital. 'Haematological Considerations for the Acute Respiratory Patient' was the title. The Chairman delivered the annual report and the critical care constitution, which had been developed post the working weekend, was voted in with no objections.

The Botulinum toxin guideline group under the leadership of Lesley Katchburian have continued to meet this year in part to develop a robust guideline but also to link with the Adult Spasticity Management Group. They continue to review the evidence and will have a finished product in 2007.

I wish to acknowledge the grassroots work, which goes on creatively and tirelessly by APCP's Regional Representatives. Again the outcomes from working weekend will have been communicated Country wide along with local opportunity to attend varied, informative and specialised courses. Thank you Regional Reps for all your sterling efforts.

In April 2007 APCP will seek re-recognition as an affiliated group to the CSP. As part of this process we will be asked to evidence our achievements, specific to the roles described for a CIG. Much of the above will go forward as confirmation of work National and Regional specific to our specialist area of clinical practice. Retrospectively undertaken and also look at our Business Plan for the next 2 years.

I wish to acknowledge the sad loss earlier this year of two very special colleagues.

Carole Hurran

Carole was an honorary member of APCP; she had an impressive record contributing to the association and the journal. Her first reports as South West rep appeared in 1991 and in 1994 she was part of the organising committee for the conference held in Bath. Carole was passionate about CPD and contributed via publication on Statutory assessment for children with Special Educational Needs, the Outcomes Measures Pack, Guidance for Good Practice and Manual Handling and by forging links with universities to provide CPD opportunities for Paediatric Physiotherapists. During her years on National APCP committee her marvellous sense of humour lightened many meetings and her presence at annual conferences is and will be greatly missed. APCP today sees many ripples spreading from the work Carole nurtured in the 90's.

Sarah Prior

Sarah's career in paediatrics began at GOSH in 1990 and continued in the community in Brent till 2002. When she became an extended Scope practitioner in Orthopaedics, Sarah was a member of the London branch and served on their committee as PRO and treasurer. She attended National Committee meetings on a number of occasions as alternate London Rep. Bringing enthusiasm, wisdom and willingness to take her share of the work in hand.

Standing down at this year's conference are Adele Leake, Gill Holmes, Ann Martin, Ruth Jacklin, Susan Cleverley and Barbara Haederle.

Thank you all for your prodigious work rate in supporting these offices.

As I also retire this weekend and handover the chair to Peta Smith, I wish to thank all National committee particularly the EXEC team who have supported me over the last 2.5 years and also to extend my best wishes to APCP.

With my thanks and best wishes to APCP.

Adoption of the Chairman's report

Proposed: Christine Shaw

Seconded: Sue Coombe

5. Treasurer's Report 2006 *Fiona Down*

The treasurer's report was published in the September APCP journal.

Fiona Down elaborated on the reasons for the proposed increase in subscription to £40. The largest proportion of this would be to fund the appointment of a paid administrator to support the work of national committee. Lesley Smith commented that this increase would bring APCP in line with subscriptions for other larger CIG's.

Comments from the floor were supportive for the increase but suggested that CSP could offer more support for the CIG's. A member from Birmingham commented that this is proposed at a time of other increasing professional costs for Physiotherapists.

Members were asked to vote by a show of hands to support the proposed increase and the proposal was adopted with no votes against.

Adoption of the Treasurer's report

Proposed: Sally Braithwaite

Seconded: Lesley Smith

6. Adoption of the Auditors

The Nicklin Partnership was formally adopted

Proposed: Fiona Down

Seconded: Sue Coombe

7. PRO's Report *Lindsay Rae*

When I took over the role of PRO one year ago the main issue at that time was the APCP website. Gill Holmes the outgoing PRO worked hard to set the foundations for this and I would like to thank her. The website is now launched and accessible as a source of information for our members, other professionals and the general public. It is still in its early days and we are still working to develop this further. I am always interested to receive any suggestions from our members.

Over the past year we have also seen the development of interactiveCSP. This is well used by Paediatric Physiotherapists and is a good forum for discussion.

Another important aspect of the PRO role is to promote the profession within the media and raise our public profile. So often we read in the media what others have to say about issues that are important to us as Paediatric Physiotherapists. Earlier this year Peta Smith did a fantastic job both locally and nationally to successfully promote 'Tummy Time' for babies. Due to her hard work we were able to have an opportunity as a professional body to emphasise the importance of positioning to the general public.

Within the Association there is a wealth of knowledge and experience. As Paediatric Physiotherapists we are not good at selling ourselves, although informally we hear many stories of good practise etc.

I hope that over the next year we can be more pro-active in promoting our profession. If you do have any burning issues, any suggestions or you have something positive to contribute, please contact me.

8. Research Officer's Report Jeanne Hartley

The report was read by Laura Wiggins

Greetings from Kabul!

First of all my apologies for not being here to give this report in person but I do promise you that it is not a deliberate ploy to avoid the AGM yet again – the swap to November means that it coincides with another professional commitment for which I hope will be thought as a reasonable excuse for my absence.

I have had quite a busy year as Research Officer. There have been a lot of enquiries for help and advice and of course there are always people needing the help of the membership in filling in questionnaires and telephone surveys. It is gratifying that students are thinking about paediatric issues when it comes to their final projects and it is thanks to those kind people on the help list who fill in yet another questionnaire and send it back! I know some of you think that you seem to be the most popular person on the list as another questionnaire drops through your letter box – I do try to keep it as a random choice when I send things out but sometimes I am asked to find people who work, for example, in the community or live only in Wales, or both, so you get chosen – yet again. Being asked to post out 100 questionnaires means that probably only 10 of you on the list manage not to have yet another thing through the post to fill in! Please remember it is not only students that the list is compiled for – if you need to find someone else with the same research or professional interests as you then the list may be helpful. That said, please, if you already haven't, consider filling in the form that is always in the Journal to register your research interests and also you do have the choice to state whether or not you are happy to help others. Only four people have registered this year – surely APCP members can do better than that!

Research Bursaries:

Following the call for applicants for the latest round of Research Bursaries I am delighted to report that APCP will be giving financial support to the following projects:

- An investigation into constraint induced therapy for children with congenital hemiplegia.
- Optimising the management of children with cerebral palsy in mainstream school.
- Funding has also been allocated to a group who are working towards the development of guidelines for assisted standing – a huge subject but it would be great to have evidence to back up (or disprove) this contentious issue. I, for one, would like to put my hand on my heart, when asked by a parent or another physio, that little Jimmy needs to use his standing frame for n hours n times a week – or not! I think it also has a bit of a link to the managing CP children in mainstream school study.

Many congratulations to the successful applicants. I hope to keep you all up to date with their progress, from time to time.

Securing finance to help with research projects can be almost as challenging as getting your proposal through ethics! I hope you will all approve of the idea that a small proportion of your annual subscription will be used to support paediatric physiotherapists in their research. Without an evidence base to establish the effectiveness (or not) of our interventions there will be little hope for our profession in the long term.

Being Research Officer is an honour and a responsibility I don't take lightly. It also means that (despite cutting back on my professional life) I still need to be busy and involved with projects – even to the extent of getting back into the NHS for some part time research! I now have the luxury of working with projects and being paid to do them – without having to fit around a day to day clinical caseload. I know that this is a real luxury so try hacking into my (very mild) guilt trip and don't hang back from asking for help and advice should you need it. If I can't answer your query I know a man or two who can!

I would like to finish with wishing luck to those of you involved in research and to those of you with such good ideas and questions to make 2007 the year that you really try to find the answers!

I do hope you all have a very enjoyable conference in Glasgow – I am very sorry not to be there too!

9. Education Liaison Officer's Report Adele Leake

The Education officers report will be published in the December journal. Adele detailed the work of the education committee during the year and proposed projects for 2007. Adele is standing down as education officer and will be replaced by Dawn Pickering.

10. Honorary Member

The committee received a nomination for Mary Harrison for her contribution to paediatric physiotherapy and to the development of APCP. The citation was read by Barbara Haederle and will be published in full in the APCP journal. Members were asked to agree the nomination by a show of hands which was carried unanimously.

Mary thanked the association and accepted the nomination.

11. Election of Committee Members.

A notice of committee vacancies was published in the September 2006 APCP journal. The secretary received one nomination. Dawn Pickering was proposed by Adele Leake and seconded by Linda Fisher and is elected to national committee.

12. AOCB

11.1 Di Coggings wished members to acknowledge the contribution made by Terry Pountney to the Paediatric physiotherapy MSc module, Edinburgh and congratulated her for her work and commitment in helping to establish this module.

13. Date, time and place of next AGM

The next AGM will be held in November 2007, the date and time to be confirmed and published in the APCP journal.

The meeting closed at 1.50pm.

HONORARY MEMBERSHIP OF THE ASSOCIATION OF PAEDIATRIC CHARTERED PHYSIOTHERAPISTS

Mary Harrison

Mary was nominated for her contribution to the APCP and the Physiotherapy Profession.

Mary has served 8 years on the APCP National Committee. During this time she was CIG Liaison Officer and NE Rep. She gave considerable contribution to the iCSP steering group and was a moderator at the pilot launch. From there she went on to help develop the APCP web site together with Di Coggings and Gill Holmes.

Her work with the development of the Orthotics guidelines has been innovative.

In 1994 she started the Botulinum Toxin pilot study and went on to further research at St. James' Hospital in Leeds. In 1998 she travelled to Cyprus with Dr. Ted Roussounis and his team to set up an assessment and treatment clinic with the Red Cross.

Her interest in Neonates took her to Helsinki in 1998 where she presented a paper on positioning. She has a long history of working with mums and babies including baby massage with the ex neonates. She has lectured on the road shows with BLISS.

Mary has been working in the medico legal field since 1989 and is employed as an expert witness in this capacity.

Since her retirement from the NHS in 2001 she has continued her medico legal work and also helps locally as a volunteer with the RDA.

Barbara Haederle

RESEARCH

It is strange to be sitting here writing a report for the December Journal when the leaves are still on the trees and the sun is shining – and to wish you all a very happy Christmas and an excellent New Year. One of my resolutions for next year is to finally (after much nagging and quite a lot of guilt on my part) write up my MSc project for publication. How sad that statement is – it's really an admission of failure to carry out this year's promise! As I am very much a 'last possible minute' person I hope to be able to report that I was published in June but flying pigs and all that may be too much of a diversion. May all your research projects prosper in 2007 – there is an obligation to disseminate your findings so do keep this Journal in mind as this is probably the best forum for reaching the maximum number of paediatric physiotherapists in this country.

Research Bursaries:

I am delighted to report that as well as helping with funding for an investigation into constraint induced therapy, APCP will also be further supporting an project into 'optimising the management of children with cerebral palsy in mainstream school'. I am sure that this will meet your approval as it is a very newsworthy subject at the moment. Funding has also been allocated to a group who are working towards the development of guidelines for assisted standing – a huge subject but it would be great to have evidence to back up (or disprove) this contentious issue. I, for one, would like to put my hand on my heart, when asked by a parent or another physio, that little Jimmy needs to use his standing frame for n hours n times a week – or not! I think it also has a bit of a link to the managing CP children in mainstream school study.

Many congratulations to the successful applicants. I hope to keep you all up to date with their progress, from time to time.

A question of validity!

I thought you might like to hear about a recent experience of mine which really made me rethink things about questionnaires. I have used questionnaire surveys for both my BSc top up and my MSc so rate myself pretty competent in ensuring that such surveys are valid.

I am that sad person who likes have the definition of things in my mind so I looked in my Polgar and Thomas (my well thumbed edition) to discover that:

- *Questionnaire* – a means of collecting data from people where they provide written responses to a set of questions, either in their own words or by selecting predefined answers

- *Validity* – the extent to which a test measures what it is intended to measure.

So with these definitions firmly in mind I am working with TAG (The Arthrogyrosis Group) to find out what life is like for adults with the condition. Most textbooks concentrate on the effects of arthrogyrosis and treatment in childhood and there is very little written about adulthood. With this in mind I worked on a questionnaire of what I thought were important issues – like physical function, surgery, pain, occupation, psychosocial issues etc and took it along to the TAG conference in Coventry in September to present at a workshop for adults with arthrogyrosis.

So I put my questionnaire up on the screen in front of 17 adults with arthrogyrosis and a torrent of advice and criticism came pouring out from the delegates who poo poed my attempts, which on reflection were looking at things from a very clinical and physio perspective! My idea of validity (face and all) was certainly NOT theirs. Luckily I had taken a tape recorder so that I do have a very good record of opinion and ideas that will help me produce a better measure. What staggered me was I had gone there thinking that this survey would inform parents of children with arthrogyrosis and professionals working with such children of what could be expected in adulthood. However my lovely, opinionated audience were much more interested in whether the problems they were encountering as adults were common amongst their group – be it physical or psychosocial or work place related. One of the most striking things was that, for some of them, this was the first time they been in such a large group and I am sure they will all have much to say when I pilot the questionnaire with them early next year. I was very lucky to have this experience – unnerving though it was – as it has certainly made me much more aware of the need to discuss things, if possible, beforehand. Something my advertising husband has done frequently before the launch of a new product or advertising campaign. I should have listened to him a little more.

I will let you know how things go. Other cautionary tales gratefully received!

Courses and sources of funding:

It is very frustrating to be sending such information in to the editor a month before this Journal is published – and with a three month gap between Journals – as often news about funding applications means that you would have approximately 2 days to get your application in to whoever after the Journal hits your doormat.

If you have not signed into interactive CSP yet please do so – this is perhaps the best place to keep up to date with what is available as well as lots of interesting courses.

Research and Education

So to pick out two things from the research site:

- The Physiotherapy Research Society are running a day entitled 'Focus on Clinical Research' on 28th March 2007 in Cardiff. There is a call for abstracts – deadline 15th December 2006 – and a £100 prize for the best! Further information on www.prs-uk.org
- Research for Patient Benefit – lots of money available – possibly up to £250,000 for a 36 month project!
Further information on www.nih-ccf.org.uk

The ARC Educational Travel/Training Bursary (ETTB) has now been replaced by two separate forms of funding – AHP Educational **Travel** Awards and AHP Educational **Training** Bursaries. The next submission deadline will be of no use to you as it's December 4th for the training bursaries but the Educational Travel Awards have no deadlines but need to be submitted at least 2 months in advance of a planned meeting or visit. Money could help with the cost of presenting a paper at a national or international meeting or help you visit a centre to study. For further information contact the Research and Education Dept of the Arthritis and Rheumatism Council (01246 541115) or www.arc.org.uk

Happy Christmas
Jeanne Hartley
Research Officer

EDUCATION

This has been a very busy year for the education committee, where significant developmental work has been undertaken. I would like to thank the committee for their continued work over the year.

The highlights of the year have been;
APCP accreditation of CPD courses for paediatric physiotherapists. A rigorous quality assurance system is now in place for courses being run for paediatric physiotherapists. The course aims, learning objectives, outline and speaker CVs are reviewed by the accreditation panel. The panel reviews the quality of the course in terms of clarity of objectives, transparency of information, teaching strategies and speaker suitability. Once approved a course is then able to use the APCP name and logo as part of its advertising and certification procedures. This may then help physiotherapists to make informed decisions regarding time and financial costs in planning their CPD and in seeking support from their line manager.

Questionnaire to Physiotherapy Assistants. It was acknowledged by all on the committee and by the membership that physiotherapy assistants form an integral and valuable part of the physiotherapy provision in Paediatrics. Therefore, the APCP feels some responsibility to support assistants in their CPD. The questionnaire regarding Assistant CPD was sent out earlier in the year and had a good response rate. In light of the findings from this questionnaire an assistant course is being run in February 2007. (See the advert in this journal)

Courses. Several courses have been run this year or are in the final stages of organisation for 2007. These include; Advanced course in the management of Cerebral Palsy – Belfast October 2006, Introduction to Paediatrics – London May 2007, PhysioFirst-Issues in Paediatric Physiotherapy – various dates 2007.

Collaboration. The committee is involved in collaboration with other CIG groups via the CIG liaison officer and through direct communication with the Education officers of other CIG groups. This has resulted in fruitful discussions around overall support for CSP members ongoing CPD and collaboration on joint events. In addition, I am currently sitting on the CPD panel at the CSP, thereby able to inform discussion around professional standards of CPD and collaboration with the HPC.

Tutor support. We are always seeking new speakers for our courses or new ideas for courses that would be appropriate for the APCP. In order to facilitate new speakers, a tutor support pack has been developed which helps to outline the nature of the APCP's work and ethos for teaching and learning. This pack helps to support new speakers and feeds into a mentoring system where new speakers are supported by established speakers. If you would like to become involved in teaching for the APCP please feel free to get in touch. If you know of someone in your department who you feel would be a good resource for the APCP, please encourage them to get in touch.

I have now served the full term of office as education officer and therefore this is my last report. I would like to thank the committee for their work and friendship over the last 6 years. I hope I have been able to make a positive impact on the CPD of our membership. The role of Education officer will now be taken up by Dawn Pickering and I wish her every success.

Adele Leake
Education Liaison Officer

Regional and Affiliated Groups Reports

SOUTH WEST

Well summer is well and truly gone now and that cold wet stuff keeps falling from the sky. What a great year for golf it has been (for me). Those who know the slightest thing about the game will know that all players have handicaps which denote how much worse they are than the professionals. Thus a handicap of 36 (mine) means that if I play Tiger Woods (some chance) I would have 2 extra shots per hole than him to score the same points. I was fortunate enough to win the ladies summer singles knockout (the smile is only just fading) at my club beating some very skilled players with some seriously low handicaps. The point being, that if I can achieve the outcome I did, then anyone can achieve whatever they put their minds to. Funny how we tell our families this but don't necessarily apply it to our own lives.

A study day was arranged by Fiona Osmond at Salisbury District Hospital entitled "24 hour Postural Management, How to get it going" led by Ginny Humphreys from Vranck House School and Centre, Exeter and was much enjoyed by all who attended. I'm sure we all now appreciate the importance of implementing 24 hour postural support for the long term development and maintenance of our children with complex needs from whatever cause. Ginny outlined

- current evidence for 24 hour postural management,
- local integrated care pathways,
- training for carers.

The region's AGM was well attended on 14th November 2006. Liz Cunningham stood down and Kelly Graham was elected as a new member of the regional Committee. Many thanks to Liz for all the work she has put in to the South-West Region, and welcome on board to Kelly.

Following the AGM members were asked if there were any courses they would like to see run in the region. One member asked for a course on Orthotics and we will do our best to accommodate. If any other members have requests please feel free to e-mail me with your ideas and we will try to accommodate these too.

Have a great Christmas and New Year.

LYNDA NEW

SCOTLAND

The planning and organisation of Conference 2006 in Glasgow is going well. I hope members studied all the conference information in the June Journal and will take the opportunity to support APCP by not only attending, but also contributing papers and poster presentation. Applications are coming in steadily. Paediatric physiotherapy service managers, regional representatives, and the chairs of the affiliated groups have all been sent a conference information pack and Lindsay Rae our Public Relations Officer is also going to post all the conference information on our website. Take advantage of the early bird rates and send off your application form before you go off on your summer holidays. See you in Glasgow.

Post Note 17th November 2006

APCP Conference 2006 in Glasgow has now taken place. On behalf of the Scottish Organising Committee (Alison, Janet Parkinson, Lyn Campbell, Chris Shaw, Gillian Ferguson, Julie Burslem, Arlene Smillie, Catherine Masters, Katie Kinch, Serene Lim, Nicki Barret, Hilary Cruikshank and Laura Wiggins), thank you to all of you who attended and helped to make Conference successful. We are delighted that we have had such positive feedback. To those of you who wrote, phoned or e-mailed a special "thank you." We are looking forward to meeting up again next year at Conference 2007.

ALISON GILMOUR

NORTH EAST

Please join me in congratulating Mary Harrison on her recent acceptance of Honorary Membership of the APCP at Conference. She has worked tirelessly pursuing various projects for the CIOG over the years and we are proud to have been associated with her. Congratulations Mary.

Our DCD course will have passed by the time you read this but the next one is waiting in the wings...it will be in the Spring and focus on **home based neonatal care**. We are looking forward to a presentation from an Orthotist working in the area of plagiocephaly and using "Starband" helmets. Details have yet to be finalised but will be posted in iCSP when they are. Our AGM will also be held on the day.

In the Autumn we hope to focus on **sport for disabled children**, looking at what is available and developments as a result of "Every Child Matters".

If you have any suggestions of topics you would like to see included in the programme please let the committee know. We are here for you!

Regional and Affiliated Groups Reports

I hope you have by now discovered the APCP website which can be accessed by clicking on the wording under the APCP logo on iCSP or directly via www.apcp.org.uk

As we rush ahead to Christmas let's take time to stop and ponder its real meaning.

HEATHER ANGILLEY

LONDON

London has had a very busy few months, we had very good response to our evening lectures on Update on Cystic Fibrosis and Myofascial release. Both had excellent reviews. We also had our Day course with Elaine Owen on Update in AFO's and gait which those of you who attended felt was a brilliant follow up from her previous work and a taster for those who hadn't been before.

The AGM was also on that day and the committee would like to thank all of you who managed to attend. At the meeting we sadly reported the recent death of our lovely colleague and friend Sarah Prior who had been ill for the last year. Sarah was a long standing committee member and Treasurer we will all miss her tremendously.

We had one retiring member Nikki Bennett who has given so much time and support over the years, we hope we shall see her at meetings and thanked her for everything she has done for APCP.

We welcomed 2 new committee members: Kerry Barrow, Geraint Jones. Thanks you in anticipation. We are very grateful to Val Jennings for taking on the role as Treasurer.

Those of us who attended APCP conference in Glasgow were treated with a very high standard of lectures, hospitality and organisation. Thank you Scotland for organising such a successful event, we hope you have recovered. Angelique Mulders went with her free place courtesy of London APCP. She seemed to be enjoying herself whenever I saw her and would, I'm sure, encourage other members to consider applying for next year. As it is closer to home, near Gatwick, there are no excuses.

We hope you all continue to support the course programme and let us know of any future topics we can consider. Don't forget if you want to lecture or know of someone you think would be good for us to invite, please get in touch.

Finally please don't forget to check your membership details for 2007 and encourage your

colleagues to join so we can continue to be a strong force within the CSP.

Happy Holidays and best wishes for a stress free and productive 2007.

STEPHANIE CAWKER

TRENT

We are planning to run a course on **15 March 2007** on respiratory issues called **Breathe easy at home**. Speakers will address a variety of topics including the management of neuromuscular conditions.

We plan to hold our AGM during the lunch break and also provide you with the opportunity to chat and exchange ideas.

The venue is Loughborough hospital which is close to motorway links and is central to our region. Please put the date in your diary and do plan to join us.

For more information see the flier in this journal or contact Claire Hill on Claire.wagstaff@talk21.com

JENNY SAUNDERS

WEST MIDLANDS

We ran our AGM in May this year during a study day on Plagiocephaly and Torticollis. Both were very well attended, from within the region and further afield and we had very good feedback. We are now planning to run a study day "on the ball" by Joanne Elphinstone in May 2007 which will be subsidised to bring the delegates' cost down and is limited to 20 people. The venue and date will be advertised in iCSP and any keen applicants can contact me with your telephone number / email and I will let you know as soon as the date is confirmed. A future suggested course is on standardising plastering techniques in Cerebral Palsy.

Please contact me if you have any ideas for future courses and suggestions on doing study days, evening lectures, term time, or during holidays etc. and where you would like courses to be run. I recently had some information on the distribution of our members within the West Midlands and would value your thoughts on how we include all members. If any areas would like to run a course and need support from the local APCP then please contact me.

Nationally APCP (Education Committee) are organising another Introduction to Paediatrics course held in London and a new Assistants course in Nottingham on 28/02/07, contact me or look in the Journal for more information.

HELEN BAYLISS

Regional and Affiliated Groups Reports

SOUTH EAST

This is my first report to you as APCP South East Representative. I have worked on the regional APCP committee for over three and half years and have been the regional treasurer for two and a half years. Obviously I will be passing on that role to another local committee member – more news on that in my next report.

I would like to take this opportunity to thank Ann Martin, retiring regional representative for all her dedication and hard work both on a national and regional level over a good many years – her amazing organisational skills and her bright pink fliers(!) will be greatly missed. We will also miss her very imaginative study day titles! Thank you Ann.

Since Ann's last report we hosted a very successful study day titled 'London 2012 – Are you Ready' (one of Ann's titles!). This was held at the rather lavish venue of Dorton House School and covered a variety of issues with regards to disability sports. This day was organised by Judith Robinson and Janine Grainge, both of whom have since retired from the local committee.

Judith served on the committee for three and a half years and so I would like to thank her for her dedication to the committee over that time. Janine has been on the committee for a shorter period of time, but is off to experience working as a physiotherapist in Australia for a year. We wish her luck with her travels and look forward to welcoming her back on the committee when she returns.

We held our local annual general meeting at Bluewater Shopping Centre again this year and cocktails and canapés followed the meeting. We were treated to a very interesting lecture on developing the role of an Extended Scope Practitioner in paediatric orthopaedic and neurology settings, which fuelled a lot of discussion. Sadly the attendance at this meeting was very limited and it was disappointing not to see more members. However we were very pleased to welcome several new members onto both the regional and conference organising committees, following this meeting. Thank you to all of you who volunteered, we look forward to working with you.

That leads me on to mention next year's APCP conference. As you have probably gathered, it is the turn of APCP SE Region to host conference 2007 and lots of work has already been done by the organising committee to make this a successful and enjoyable event. The title of the conference is 'Everybody Matters; Theory and Practice' and it is going to be

held at the Copthorne Hotel Resort Effingham Park, near Gatwick. The hotel has excellent conference and spa facilities, a nine hole golf course(!) and was chosen for its excellent transport links. It is going to be held over the weekend 9-11 November 2007 and I really look forward to seeing you there.

I hope that you all have a wonderfully happy Christmas.

LUCY ERASMUS

WALES

It has been a busy start to the autumn season for the APCP in Wales.

On September 21st we held a successful joint research evening with the Department of Physiotherapy Education, Cardiff University. A number of very brave new graduates presented their BSc research dissertations to an audience of paediatric physiotherapists from the region. The presenters had all looked at issues related to children and young people for their research projects, and their findings were very interesting and thought provoking. Many thanks to paediatric lecturers Dawn Pickering, Lyn Horrocks and especially Geraldine Hastings, who organised the session and introduced the event. It was the first time such an event had been undertaken but I am sure it won't be the last.

I also need to remind members in Wales of a couple of study days that you need to keep in mind.

1. February 27th 2007 there will be a "Care Aims Course" organised by the Post Graduate Office at TY Dewi Sant, Cardiff University. Anyone who would like to attend please contact Lesley Weston.
2. The AGM of the APCP in Wales is provisionally booked for the 14th March 2007. We will be sending out flyers in plenty of time and contacting members by e-mail.

Finally many thanks to all members who contributed to the work around the Staffing Ratio Tool and the All Wales Questionnaire. We hope to be able to report back in the Spring on progress.

DIANE ROGERS

NORTH WEST

Another year has gone by so I'll reflect on the year as I presented in the Chair and Regional Representatives Reports at our recent AGM. The AGM for the North West Region took place on Saturday 14th October in Warrington. It was attended by 45 members of the Association, which represents about 25% of the Regional Membership so meant we had a quorum for the meeting.

Regional and Affiliated Groups Reports

Local committee has met 5 times since last year's AGM. Throughout the year we co-opted 3 members to committee who were formally voted in at the AGM – they are Alison Hacking, Siobhan Goldstaw and Lisa Paul, we also welcomed Chris Wardle to committee on the day. As a committee we appointed officers, Nicola Henderson takes over as secretary and Alison Hacking as chair. I would like to thank all the committee members for their hard work in the past year and for their future commitment.

Last year we ran 2 courses the 2 day muscle strengthening and developmental orthopaedics, and there was to be a follow up hydrotherapy day on October 26th. We also granted 4 bursaries to members who applied to the committee. We plan to continue with this practice for appropriate requests.

As regional representative I attended 3 national committee meetings and have now served as regional representative for 3 years. I would remind members that I am there to represent your views and ask that if you have anything you wish to raise with national committee please let me know.

Over the next year we are in the planning stages for study days for the next years. Topics to be considered are a cycling course in September 2007, a Ventilation/neuromuscular day for April time and a possible follow up to the muscle strengthening in the summer time. Any further suggestions would be gratefully received.

So I'll say goodbye for this year. Hope you all have a Merry Christmas and a Happy New Year. Thank you all for your continued support

ELAINE LLOYD

NEONATAL SPECIAL INTEREST GROUP

The committee last met in Newcastle on the 10th of October. This was to plan and discuss our projects for the next year. Future plans include; Glasgow – first satellite group at APCP conference. This promises to be another fantastic opportunity to meet and network with your fellow professionals as well as an extremely high calibre of speakers.

AGM and Study Day towards the end of September in 2007 probably in London.

A similar course to the one which ran in Belfast to run in Newcastle in Feb/March 2008.

Due to the high level of interest and discussion surrounding the management of positional talipes we plan to compile a document looking at when to treat or not?

Hopefully you will all have seen the front page article in the recent Frontline which has helped to further raise our profile. Thank you to all who had input into this!

As there have been recent changes to the committee I felt it would be useful to update you on the current membership:

Chair – Adare Brady (also to carry out APCP Liaison Officer after Conference in November)

Secretary – Hilary Cruickshank

Membership – Sian Howells

Treasurer – Pat Dulson replacing Jenny Poole
Research and Education – Anna Mayhew
and Fiona Price

Multiprofessional Liaison Officer – Sally Jary

Committee Members – Peta Smith, Allie Carter,

Jenny Poole, Barbara Haederle and Helen Robinson

BARBARA HAEDERLE

NEUROMUSCULAR SPECIAL INTEREST GROUP

The last quarter has been a busy one for the Neuromuscular Group. We have had a very constructive 2-day working party meeting to outline best-practice parameters for the physiotherapy management of Duchenne muscular dystrophy. The charity Muscular Dystrophy Campaign supported the meeting. A more detailed report has been included in the Journal. Work is ongoing to refine and write up our recommendations.

The group has been making links with ACPIN – Dr Michelle Eagle, Marina Morrow and Elaine Scott have had an article regarding the emerging population of adults with NMD accepted for publication in the ACPIN journal Synapse.

The group has a section on the APCP website and hopes to look at possible links with the ACPIN website for those with an interest in NMDs. Membership currently stands at just over 70.

The NM Group chair Marina Morrow and Dr Douglas Wilcox are respectively giving presentations re: Physiotherapy in NMD and the genetic implications of the disease at the National Conference in Glasgow in November. The group will be holding a committee meeting at conference to review this year's activity and plan future activity.

A study day and AGM meeting is planned at the Birmingham Hippodrome at the end of March 2007. As the group will be 2 years old in May 2007 officers on the committee are due for re-election and this will need to be voted on at the AGM.

GILL HOLMES

APPLICATION FORM FOR A.P.C.P. PUBLICATIONS

| | |
|--|--------------------|
| 2005 | |
| Paediatric Outcome Measurement | £20.00 |
| 2003 | |
| Special Educational Needs Code of Practice 2001 | |
| Guidance for Paediatric Physiotherapists | £10.00 |
| 2002 | |
| Paediatric Physiotherapy Guidance for Good Practice | £5.00 |
| Obstetric Brachial Plexus Palsy A guide to physiotherapy management | £10.00 |
| Hip Dislocation in Children with Cerebral Palsy A guide to physiotherapy management | £7.50 |
| Evidence Based Practice | |
| • Management of Obstetric Brachial Plexus Palsy | £3.00 |
| • Hip Subluxation and Dislocation in Children with Cerebral Palsy | £3.00 |
| OR | £5.00 for the pair |
| Paediatric Manual Handling – Guidelines for Paediatric Physiotherapists | £10.00 |
| Human Postural Reactions – Lessons from Purdon Martin by Dr J Foley | £5.00 |
| Baby Massage | £1.50 |
| The Children Act 1989 “A synopsis for Physiotherapists” | £1.00 |

POSTAGE AND PACKAGING INCLUDED IN THE PRICE WITH ALL THE ABOVE.

**FOR MORE THAN 10 COPIES OR FOR POSTING OUTSIDE THE UK –
POSTAGE UPON REQUEST.**

**TERMS: CASH WITH ORDERS ** CHEQUES & POSTAL ORDERS MADE PAYABLE TO:
A.P.C.P. PUBLICATIONS AND INCLUDED WITH THE ORDER PLEASE.**

**SEND ORDER WITH PAYMENT TO :
LORNA STYBELSKA, PAEDIATRIC PHYSIOTHERAPY DEPARTMENT,
CUMBERLAND INFIRMARY, CARLISLE, CUMBRIA CA2 7HY.
WORK TEL: 01228 814739
e-mail: stybelskal@aol.com**

Name and Address for Delivery:

.....

.....

Wheelchair Provision for Children and Adults with Muscular Dystrophy and other Neuromuscular Conditions

The Best Practice Guidelines outlining wheelchair provision for children and adults with a neuromuscular condition were published in June 2006. These guidelines are primarily a resource for healthcare professionals involved in the assessment and provision of wheelchairs and special seating for this client group. The guidelines are also relevant to any healthcare professional working with clients with a neuromuscular disorder as delayed development is discussed as well as the psychological and emotional challenges facing many of these clients and their families.

The guidelines encompass mobility and special seating for babies, children, teenagers and adults. In particular difficulties relating to mobility, experienced by parents when caring for a child with a neuromuscular condition are amongst the areas highlighted within this comprehensive document. This educational resource details developmental differences whilst offering suggestions to help clinicians manage these differences in order to promote independence and enable young children to reach their developmental targets where possible.

Powered mobility and its impact on cognitive function is explored as well as the principles of seating, assessment procedures, planning for different environments and an explanation of the more common neuromuscular conditions. Manual ability including the use of high performance wheelchairs is also featured.

Managing progressive conditions can be difficult for clinicians in this field as functional ability is constantly changing requiring a change in prescription as well as a change in how the client will operate their new chair with weakened muscles, progressive contractures, postural instability and emotional features associated with the loss of function. This resource received excellent reviews at its UK launch earlier this year and is now available for general distribution.

Copies of this resource can be ordered from Muscular Dystrophy Campaign,
7-11 Prescott Place, London SW4 6BS.
Tel: 020 7720 8055
Email: info@muscular-dystrophy.org
Web: www.muscular-dystrophy.org

Although the book is free there is a charge of £3 for postage and packing.

Marina Morrow

Chairperson of the Neuromuscular Physiotherapy Group

Here and There

THE NEUROMUSCULAR PHYSIOTHERAPY GROUP

Background:

The Neuromuscular Physiotherapy Special Interest Group was formed to address an increasing need for physiotherapists working with these rare conditions to share expertise and information, as well as identify areas of research where the evidence base is poor. The group aims to support therapists to address these areas in a rapidly evolving specialist area of medicine. The Neuromuscular SIG currently has a membership of over 70 physiotherapists and allied health professionals from across the UK and from both paediatric and adult services. The need for standardised national standards of care for the physiotherapy management of Duchenne muscular dystrophy (DMD), a severe life-limiting form of muscular dystrophy, was identified at the Neuromuscular Group Annual General Meeting in March 2006.

An 'expert' steering group was established to lead the development of the standards of care. Professionals were sought from all parts of the U.K. to ensure that approaches from around the country were analysed and incorporated as appropriate. This group consists of senior physiotherapists who are either clinical specialists in the field or who have a substantial involvement with neuromuscular disorders in the community.

Workshop Meeting:

In October 2006 a two day workshop was arranged at the Peace Children's Centre in Watford to establish feedback from the literature review/evidence and to develop standards of care. Prior to the meeting key topics relating to physiotherapy management of DMD were identified and each member of the group undertook a comprehensive, systematic review of the existing evidence on a specific topic. These topics include respiratory management, exercise and stretching, orthotics, 24 hour postural management, education, wheelchairs and seating, scoliosis management, pain management, cardiac care and palliative care.

Using the National Institute for Clinical Excellence (NICE) guidelines for categorising literature, all group members formulated an evidence table which also detailed key search words and databases used.

This has proved to be an excellent meeting with all therapists inputting experience and agreeing on areas where gaps in the literature exist. Dr Michelle Eagle, physiotherapy consultant, Jennie Sheehan and Marina Morrow, physiotherapy clinical specialists, headed up the groups. This initial

substantive body of work will be developed and refined throughout November. Standards will be reviewed for consistency in language and presentation and it is hoped to gain final consensus and approval in December. Dissemination via appropriate academic and professional forums will be planned following this.



Members of the Standards Development Group:
Back - Meredith James, Jennie Sheehan, Andrea Grace, Michelle Eagle, Lesley Wotherspoon, Marina Morrow
Front - Lindsey Pallant, Elaine Scott, Karen Woollard, Jane Freebody

Thanks to Muscular Dystrophy Campaign for their support of this meeting.

THE ROLE OF THERAPISTS IN NEONATAL CARE

14 - 16 June 2006
Antrim Area Hospital

A three day Neonatal care course was held in Northern Ireland (Antrim Area Hospital) from the 14th to 16th June 2006. This was the first such course organised by the Neonatal Care Group, a sub-group of the APCP, with plans hopefully to hold similar courses in other areas of the country.

As a participant, I found the course extremely informative, both at a theoretical and a practical level. In fact there was so much information, I feel it would have merited a full five days – although I realise that work commitments can make attendance at a longer course difficult for many therapists.

Each day focused on a different aspect of care of the neonate, logically following the usual timing of therapeutic interventions. Day One looked at Respiratory Care in Neonates and covered topics such as Lung Development; Conditions encountered in NICU; Respiratory assessment; and Indications, Precautions and Contraindications for treatment. These lectures were then very well consolidated by a practical session using case studies.



Course organisers
and participants



The second morning of the course required full attention and concentration with in-depth lectures on Embryology relating to Brain and Lung Development; Brain injury in preterm infants; Development of Muscle Tone; and Preterm Development and Behaviour – followed by a related group work session.

The morning concluded with an insightful interview with a parent of a very preterm infant.

The afternoon sessions included lectures/group work on the Importance of Careful Positioning for Preterm Infants; the Multidisciplinary Team and Getting Involved; and a review of the parental interview.

Day Three was an action packed day for the participants with lots of group work with a very malleable “baby”.

It commenced with lectures on Criteria for Assessment and the Principles involved in

Assessment with an overview of some of the assessment tools available. The rest of the day was then devoted to group work problem and answer sessions associated with the NICU baby, the SCBU baby preparing for home and the first few months at home. Videos were used to enhance assessment skills.

The very high standard of the course overall was reflected in the course evaluation results with 100% of participants rating every lecture as either Highly Relevant or Fairly Relevant.

In summary I would definitely recommend this course to anyone working with preterm infants, including those in Community Paediatrics, as it helps give a deeper understanding of the eventful course which may be led by the baby and its family until eventual discharge from hospital to community care.

Adare Brady

THE APCP RESEARCH GROUP REGISTER

If you would like to be a member of the APCP research group, please fill in the form below and return it to **Jeanne Hartley, Research Officer, 36 Cascade Ave., Muswell Hill, London N10 3PU**. This information will be used to inform you of research study days and help us to learn more about our members' research interests.

Name

Contact
Address

Post Code

Tel. No.

Fax No.

E-Mail:

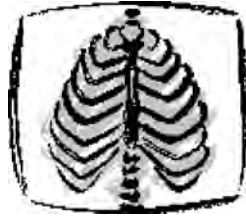
What are your research interests?

Are you undertaking any type of research project large or small? **YES?NO**

If yes please give a brief summary . . .

Would you be happy for other physiotherapists with similar research interests to be put in touch with you? **YES/NO**

Thank you for completing this form.



Are you a Physiotherapist working on Paediatric Intensive Care or Paediatric respiratory wards?

Would you like to receive additional peer support?

Would you like to be part of a CIG specific to physiotherapists in paediatric respiratory care?

Would you like to have the opportunity to attend regular study days specific to your area of work?

The Critical Care Group is affiliated to the APCP which is free for APCP members.

Once registered you will receive notification of courses at discounted rates, minutes of committee meetings and have the opportunity to sit on special interest sub groups such as NIV and BAL.

**To become a member or for more information please fill
in the accompanying membership form and return to:**

Mel Lindley (APCP CCG Secretary)
Physio Department
E Floor, Stephenson Wing
Sheffield Children's Hospital
Western Bank
Sheffield S10 2TH

Tel: 0114 271 7000 bleep 100
Email: melanie.lindley@sch.nhs.uk

APCP CRITICAL CARE GROUP MEMBERSHIP FORM

Please complete and return this form if you wish to be registered with the Critical Care Group in addition to APCP for 2007.

If you are an existing member of this group please still complete and return this form to ensure our records are up to date.

We would like to know a bit more than just your name so we can have a comprehensive database.

Your details will be confidential and will not be disclosed to any other parties.

However, your membership number will be verified with the APCP.



Subscription year: 2007

| | |
|--|--|
| Name | |
| Designation / Title & Grade | |
| Place of work | |
| Work Address | |
| Contact address (if different) | |
| Work telephone No | |
| Other telephone No | |
| e-mail | |
| CSP No | |
| APCP No | |
| Intensive Care Unit: No of beds | |
| Type and size of wards covered | |
| No physios for area | |
| Speciality within unit | |
| Areas of interest | |
| Participating in any research or audit? (if so please give details) | |
| Do you take students / electives? | |
| Would you be prepared to give talks about area of interest? | |

**Please return to: Mel Lindley, Physio Department, E Floor Stephenson Wing,
Sheffield Children's Hospital, Western Bank, Sheffield, S10 2TH**



EVERYBODY MATTERS
Theory and Practice

A DATE FOR YOUR DIARIES . . .

APCP CONFERENCE
2007

HOSTED BY APCP SOUTH EAST REGION

**TO BE HELD AT THE COPTHORNE HOTEL,
EFFINGHAM PARK, GATWICK**

9 - 11 NOVEMBER 2007

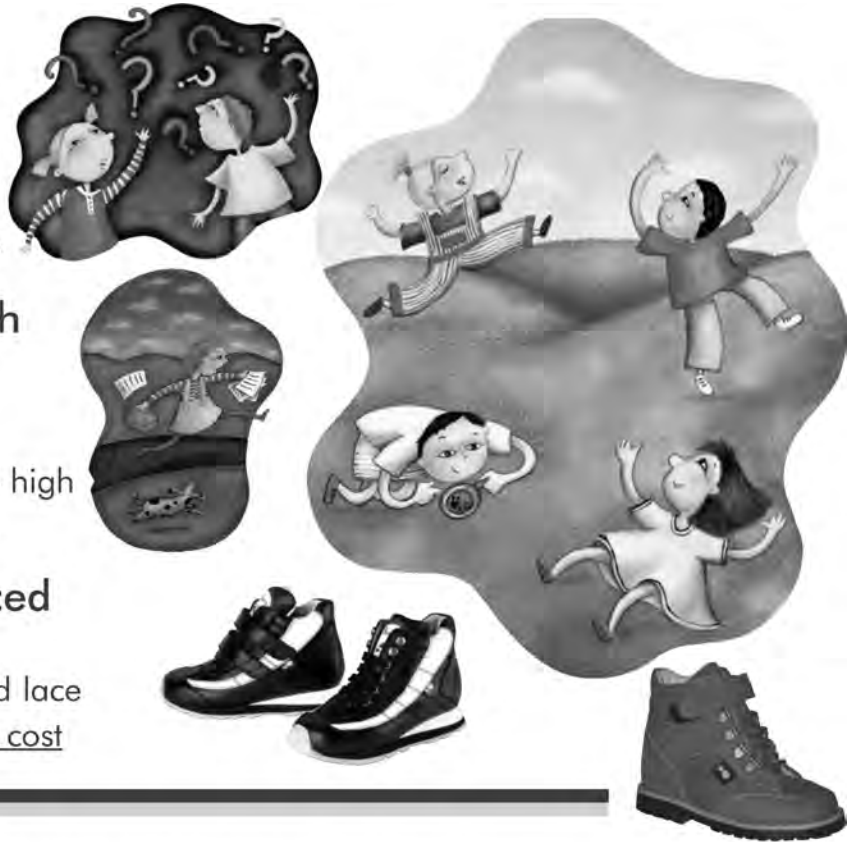
FitzKidz

therapeutic footwear
for children and young adults

48 hour shoe despatch
for all ex-stock styles

excellent quality
standard range - over splint - high
stability and anti varus boots

very competitively priced
standard range from £60
optional velcro/lace/hook and lace
fastening ex-stock at no extra cost



ORTHOEUROPE

Mill Lane, Alton, Hampshire GU34 2PX - t: 01420 83294 f: 01420 80068
e: sales@ortho-europe.co.uk www.ortho-europe.co.uk



Thursday, 15th March 2007

9.30am—5.00pm

**Rivermead Leisure Complex,
Richfield Avenue,
Reading,
RG1 8EQ**

One of the only UK exhibitions totally dedicated to disabled children, their families, and the professionals who work with them.

Entry is free

Information on mobility, seating, beds, communication, access, education, toys, transport, style, sensory, sports and leisure; a programme of free seminars and discussions for parents and professionals; family fun and meet Easter Bunny.

Entry to the exhibition is Free. For free tickets call organisers Disabled Living, Manchester:-

☎ 0870 777 4714

💻 info@disabledliving.co.uk



For updates visit www.disabledliving.co.uk

Contact:- Disabled Living, Redbank House, 4 St Chad's Street, Cheetham, Manchester, M8 8QA

Kidz South is a Trademark registered to Disabled Living, Manchester



Trent APCP Presents.....

“BREATHE EASY AT HOME”

Management of Respiratory Compromise in the Community

15th March 2007

Programme to include.....

Basic update on respiratory physiology (including positioning to facilitate ventilation, age related physiology, deformity and scoliosis)

Informative Investigations – What to do next

Management of respiratory conditions in the community

Non invasive ventilation (basics and in community)

Lunch – to include AGM

Tea/Coffee

Cost £25 members, £30 non members

For more information please contact
Claire Hill at claire.wagstaff@talk21.com

Assistants course Neurodevelopmental Physiotherapy

Course Aim.

To develop an understanding or the clinical reasoning supporting the use of common Physiotherapy techniques in the treatment of children with Neurodevelopmental problems.

Learning outcomes.

By the end of this course assistants will;

- Have an increased awareness of normal development, including social, emotional and physical development.
- Have discussed the rationale behind common treatment strategies implemented by Physiotherapists working with this group of children.
- Begin to evaluate their role in achieving optimum results from physiotherapy intervention strategies.

Course structure.

This is a one day course.

The morning will predominantly be presentations outlining;

- The scope of practice of the assistant, professional oversight and delegation based on the CSP guidelines.
- Normal development and engagement strategies.

The afternoon will be case study based and involved group work, practical work and discussion around common pathologies and common interventions. This will also include discussion around evaluation and monitoring of the relative success of these interventions.

Date - 28th February 2007

Venue - Nottingham "Touchbase" www.letstouchbase.co.uk

Cost = £30 (tea/coffee and lunch included)

For further information & booking please contact:

Adele Leake at School of Health & Social Care, Collegiate Campus, Sheffield Hallam University, Sheffield S10 2BT or [email a.c.leake@shu.ac.uk](mailto:a.c.leake@shu.ac.uk) or

Dawn Pickering at pickeringdm@Cardiff.ac.uk

REGIONAL & SUB-GROUP REPRESENTATIVES

EAST ANGLIA

Priya Jackson
Children Centre
Southend Hospital
Westcliff on Sea
ESSEX
SS0 0RY
priyajackson@southend.nhs.uk

LONDON

Stephanie Cawker
The Wolfson Centre
Mecklenburgh Square
LONDON
WC1N 2AP
cawkes@gosh.nhs.uk

SCOTLAND

Alison Gilmour
Physiotherapy Dept
Braidburn School
107 Oxbgangs Rd North
EDINBURGH
EH14 1ED
Alison.gilmour@braidburnedin.sch.uk

SOUTH WEST

Lynda New
Physiotherapy Dept
Milestone School
Lonford Lane
GLOUCESTER GL2 9EU
Lynda.New@glos.nhs.uk

SOUTH EAST

Lucy Erasmus
Mary Sheridan Wing
Children's Assessment Centre
Kent & Canterbury Hospital
Ethelbert Road
CANTERBURY, Kent CT1 3NG
lucy.erasmus@ekht.nhs.uk

WALES

Diane Rogers
Head of Children's Physiotherapy
Room 386
Paediatrics North Corridor
UHW CF14 4XW
diane.rogers@cardiffandvale.wale.nhs.uk

NORTH WEST

Elaine Lloyd
Physiotherapy Dept
Booth Hall Children's Hospital
Charlston Rd Blackley
MANCHESTER
M9 7AA
elainea.lloyd@cmmc.nhs.uk

TRENT

Suzanne Lawrence
Children's Physiotherapy
Specialist Community Child
Health Services
Bridge Park Plaza
Bridge Park Road
Thrumaston,
LEICESTER, LE4 8PQ
suzanne.lawrence@cnwlpct.nhs.uk

NORTHERN IRELAND

Felicity Dickson
Scrabo Children's Centre
Ards Community Hospital
Church Street
NEWTONARDS
felicity.dickson@ucht.n-i.nhs.uk

WEST MIDLANDS

Helen Bayliss
Paediatric Therapy
Sandwell PCT
The Crest, All Saints Way
WEST BROMWICH
helen.bayliss2@nhs.net

NORTH EAST

Heather Angilley
5 Ridgeway
GUISELEY
LS20 8JA
hangilley@aol.com

OVERSEAS

Public Relations
Officer

NEONATAL CARE GROUP

Barbara Haederle
Paediatric Therapy Unit
Pontefract General Infirmary
PONTEFRACT
Barbara.haederle@midyorks.nhs.uk

CRITICAL CARE GROUP

Mel Lindley
Physiotherapy Dept
Stephenson Wing
Sheffield Children's Hospital
Western Bank
SHEFFIELD
S10 2TH
melanie.lindley@sch.nhs.uk

NEUROMUSCULAR GROUP

Gill Holmes
Gait Laboratory
Alder Hey Children's Hospital
Eaton Road
LIVERPOOL, L12 2AP
Gill.Holmes@rlc.nhs.uk

apcp.org.uk

In this issue :

**Mavisbank Project: Use of MOVE and Bobath
to facilitate collaborative practice**

**Review Of Service Provision For Children Born
With Positional Talipes Within The Ulster
Community And Hospital Trust**

**The Leeds Consensus Statement on Developmental
Coordination Disorder (DCD) and its relevance for
paediatric physiotherapists**

Conference Proceedings

