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RESEARCH	Jeanne Hartley	36 Cascade Avenue Muswell Hill LONDON N10 3PU	<a href="mailto:jeannehartley@hotmail.co.uk">jeannehartley@hotmail.co.uk</a>
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Committee Members	Sarah Crombie	10a Record Road Emsworth HANTS PO10 7NS	<a href="mailto:scrombie@srtl.co.uk">scrombie@srtl.co.uk</a>
	Linda Fisher	Sune Start Manager (SEN & Disability) Children Schools & Families Service Hertfordshire County Council County Hall Pegs Lane HERTFORD	<a href="mailto:linda.fisher@hertscc.gov.uk">linda.fisher@hertscc.gov.uk</a>
	Sally Braithwaite	531 Church Road Yardley BIRMINGHAM B33 8PG	<a href="mailto:Sally.Braithwaite@btinternet.com">Sally.Braithwaite@btinternet.com</a>
Co-opted national committee member			
PPIMS REP	Carol McKay	Mitchell House School Maruont Holywood Road BELFAST BT4 2GU	<a href="mailto:mhspysio@yahoo.com">mhspysio@yahoo.com</a>

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

## Editorial

This first issue of the journal in 2007 comes with growing concerns regarding the NHS, including in some cases diminishing paediatric services. In this climate we need to demonstrate how physiotherapy can improve not only a child's physical health but also their quality of life. We can do this in a number of ways by addressing issues of competency to ensure that those delivering services to children are properly trained and using appropriate interventions. By using our evidence base to choose the most effective interventions to achieve the best outcomes for children and families. Finally we need to work within the legal and political framework. To help with the latter, in conjunction with the CSP we are developing a publication which contains information on legislation and policies which apply to physiotherapists working with children. More detail is available later in this issue, I am sure it will prove a valuable resource.

We are challenged to find ways to deliver our services in different ways and more effectively. This journal is here to disseminate research findings, service delivery, audits and case studies to underpin our clinical work.

Apologies are due to Finola Beattie, Senior Physiotherapist in the Royal Belfast Hospital for Sick Children, who wrote the article on "The role of the therapist in neonatal care" in the last issue as it was wrongly attributed to Adare Brady.

So as Spring approaches and inspiration comes I look forward to receiving your contributions to the journal.

TERRY POUNTNEY

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**Terry Pountney – Editor**

[Terry.Pountney@southdowns.nhs.uk](mailto:Terry.Pountney@southdowns.nhs.uk)

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[Peta.Smith@ekht.nhs.uk](mailto:Peta.Smith@ekht.nhs.uk)

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[lindsay.rae@bch.nhs.uk](mailto:lindsay.rae@bch.nhs.uk)

**Alison Gilmour**

[Alison.gilmour@braidburnedin.sch.uk](mailto:Alison.gilmour@braidburnedin.sch.uk)

**Felicity Dickson**

[Felicity.Dickson@ucht.n-i.nhs.uk](mailto:Felicity.Dickson@ucht.n-i.nhs.uk)

**Diane Rogers**

[rogersd@cardiff.ac.uk](mailto:rogersd@cardiff.ac.uk)

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**JUNE 2007 JOURNAL**

must be with the editor by

**1st MAY 2007**

**The editorial board reserve the right to edit all material submitted**

## Letters

I would like to welcome new members to APCP, and to thank those members who have renewed their membership, either by direct debit or by cheque, so promptly. I am aware there was some confusion for members, as a renewal form was not in the December journal, although was available on the website in the membership section.

Not all APCP members from 2006 have renewed their membership, and I have therefore enclosed a renewal form in this journal. Please pass on to colleagues who may want to join, or to those who have yet to renew.

CHRIS SNEADE  
APCP Membership Secretary

# Application of a Constraint Induced Movement Therapy Group for Children with Hemiplegic Cerebral Palsy in a Public Health Setting (A Pilot Study)

*Khami Hatcher, Paediatric Physiotherapist;  
Maria Boolieris, Paediatric Occupational Therapist  
Child Development Unit, Hawke's Bay District Health  
Board, Hawke's Bay, New Zealand*

## Abstract

Constraint Induced Movement Therapy is an approach that has been used to treat children with Cerebral Palsy Hemiplegia. It involves an intensive course of therapy over a specified timeframe whilst clients wear a constraint on their unaffected hand. This approach to treatment was initially used with the adult stroke population and in most recent years with children.

A Constraint Induced Movement Therapy (CIMT) Group was conducted over a period of two weeks with six children diagnosed with Cerebral Palsy Hemiplegia. However, two subjects were excluded from the study due to not meeting the inclusion criteria.

Subjects were required to wear a ski glove with digits sewn together on their unaffected hand for six hours per day. Subjects attended six sessions that consisted of pregroup assessment, post-group assessment and four mixed physiotherapist/occupational therapy groups of one and a half hours duration each.

A homework programme was also devised for subjects to partake in over the two week period.

Group sessions consisted of activities that focused on sensation, gross and fine motor tasks, bilateral and coordination skills.

All subjects improved in at least 50% of Range of Movements (ROM) tested in various degrees. Implications of this were improved functional ability as reported by subjects and caregivers. It was also noted that 75% of subjects showed improvement in manual dexterity.

These results suggest that CIMT is a viable form of treatment that can be applied in a regular Child Development Unit setting that has limited resources, as an effective form of service provision,

compared with high levels of therapy input that the client population usually experiences.

In order for CIMT to become a more utilised form of intervention, more complex, statistical, randomised, control studies need to be initiated in New Zealand.

## Introduction

Cerebral Palsy has been defined broadly as "... a non-progressive motor impairment syndrome caused by a problem in the developing brain" (Taub, et al 2004). This often results in impaired sensation, decreased strength and coordination. Children with hemiparesis make up a large degree of this population presenting with asymmetry of the upper limb with resulting significant impaired function (Goldstein, 2004).

The main focus of the physiotherapist and occupational therapist with this client group is directed at rehabilitation and management of the impairments and disabilities as a result of Cerebral Palsy. Children are an ideal target population due to their brain plasticity as it is continuing to develop and reorganise itself in the early years (Murray Law, 2005).

One of the more recent treatment techniques continually being investigated is that of Constraint Induced Movement Therapy (CIMT).

CIMT is a family of techniques that have been implemented to increase the amount and quality of function of an affected upper limb. These techniques involve restraint of the intact limb over an extended period, in combination with a large number of repetitions of task specific training of the affected limb (Hakkennes and Keating, 2005).

This approach to treatment originated in the early 1990's with extensive research of nonhuman primates (Taub, 1990).

These studies found that for successful, permanent gains of the affected limb, restraint of the intact limb following injury for an extended period and shaping of the affected limb for consecutive days was the most beneficial form of treatment.

Even though there was much controversy surrounding the ethical nature of these studies, the conclusiveness of the results prompted further studies with human subjects, firstly targeting the adult stroke population.

Over the last twelve years a wealth of studies have meant that CIMT has become common place practice within the adult stroke population. As a result, studies have started to emerge over the last five years as this being an effective approach to treatment with children who have Cerebral Palsy Hemiplegia.

## **Application of a Constraint Induced Movement Therapy Group for Children with Hemiplegic Cerebral Palsy in a Public Health Setting (A Pilot Study)**

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Previous research has led to a conceptual framework surrounding CIMT. The basis of this is the theory of Learned Non Use (LNU) (Taub, 1995).

Children with Hemiplegia notice that they are less successful in their attempts to perform functional tasks, therefore learn not to use it.

This continued under stimulation of their affected side results in chronic learned non use over time, which can lead to neglect, loss of sensation, body awareness coordination and functional ability (Glover et al, 2002).

This is supported by Taub and Crago (1995) in that "... a child may not develop neural pathways involved in movement because of the lack of ability to experience age appropriate sensorimotor stimuli that lead to the development of upper extremity skills".

Therefore this client group is ideal to target with the CIMT approach due to the huge capacity for plasticity in the developing nervous system.

The fundamental principals of CIMT have been found to be:

1. Short treatment duration – 2-3 week period.
2. High intensity – wearing of constraint for 6 hours a day.
3. Massed practice of specific activities.
4. Positive reinforcement.

There is a diverse range of CIMT forms of restraint used in the past to include plaster of paris casting, slings, splints and mittens. The majority of studies have chosen mittens to decrease the potential for psychological distress as well as allowing the performance of bimanual functional tasks to be continued. There has not been any indication in past research to favour one constraint type over another.

The aim of this pilot study was to formally introduce the use of CIMT within a New Zealand setting, as there has been no reported research conducted to date, with children with Cerebral Palsy Hemiplegia. Another main purpose is whether this type of treatment approach i.e. short duration, intensive input for this client group had any implications for better service provision. Therefore is this approach a more viable alternative to the conventional style review treatments (on a weekly, fortnightly basis) that this sector of the Cerebral Palsy sector have historically had, and therefore a better form of providing this population with treatment.

However, the main change to the focus of this pilot study was to determine the effectiveness of CIMT approach to treatment in a regular New Zealand Child Development Unit setting (at grass roots level) with very limited resources, funds and therapy time due to today's strains on worldwide health services. Therefore the appropriate clients for this particular study were children with Cerebral Palsy Hemiplegia on the current therapist caseloads.

### **Method**

A single non-control trial was chosen due to the limited accessibility to a suitable population of children with Hemiplegia that access the Child Development Unit services in this geographical area.

Liaison occurred between the Child Development Unit, Kaitakawaenga and Pacific Island Liaison Officer to ensure cultural sensitivity was maintained throughout this study and running of the groups.

Other considerations for the eligibility criteria selection of suitable subjects for this study were:

1. Geographical Location – be able to access the Child Development Unit over a two week period.
2. Diagnosis – children who had been diagnosed with hemiplegic Cerebral Palsy.
3. Children from the Child Development Unit with Cerebral Palsy, within the age range of 5-16 years, who were currently on therapists' caseloads and experiencing functional difficulties.

Exclusion criteria for subjects for this study were:

1. Children who cannot follow instructions.
2. Children with complex multiple diagnoses.
3. Children under the age of five and above 16 years of age.

It was decided that a convenience sample was used as this was appropriate for the aims of the study. Eight suitable subjects met the inclusion criteria and were invited to participate in the study, however two subjects were unable to attend as travelling / commuting long distances were not a viable option. All six remaining subjects were offered treatment by asking both the caregiver as well as the individual child during their conventional treatment sessions if they would like to take part in the pilot study. It was important to let them know they could decline and would still receive their conventional treatment.

There was no obligation for them to participate in the study and subjects were given all the required information in order to obtain full informed consent. This also provided the foundation in allowing a comfortable situation for caregivers and participants to ask questions or voice concerns.



## **Application of a Constraint Induced Movement Therapy Group for Children with Hemiplegic Cerebral Palsy in a Public Health Setting (A Pilot Study)**

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Out of the six subjects who agreed to participate in the study, one was excluded due to an injury sustained out of the group setting and irregular attendance with the second subject. There were then four participants aged between 6-8 years, three females and one male.

All four participants were children with a right hemiplegia who lived within a suitable geographical location for travelling. Written consent was received from caregivers post Ethical Board approval. All information taken during the study was stored in their personal Child Development Unit notes in a secure locked filing cabinet, where it will be held in accordance with medical file protocol i.e. up to 20 years.

Consent forms, information sheets and reference lists were given to all the subjects' caregivers to read and then give informed consent prior to the group / study commencing.

### **Treatment**

The Paediatric Constraint Induced Movement Therapy Group involved the child's unaffected hand wearing a soft ski glove with the glove fingers sewn together to replicate a mitten.

Ski gloves were specifically chosen for their bright colours to aid with visual prompting and bulky style to decrease functional use of that hand. The potential risk to health and safety, when the participants were wearing their constraint, was considered in many ways. However the risks were felt to be minimal because a ski glove allows maintenance of bimanual tasks, keeping one's balance and still allowing the child to put both hands out if they were to fall or need to save themselves. The ski glove also allows one to maintain a gross functional grip if needed in the dominant hand.

Other constraints were considered, however it was felt that with casting and splinting:

1. It could lead to potential negative psychological effects on the subjects.
2. The cost of casting (the department could not financially fund this).
3. Casting facilities were not available.
4. Restriction on subjects performing bilateral tasks for safety.

Subjects were given pre-assessment appointments at which time they were formally assessed, then

provided with their glove and homework pack. The homework pack included ideas for gross and fine motor activities, range of movement and bilateral tasks, as well as a progress reward chart for both subject and caregiver to monitor gains made, if any.

Subjects were then required to wear the constraint for six hours per day for twelve consecutive days. The six hours per day was so that the glove was worn in one full session, but could be either in the morning or the afternoon. This was also dependent on the child's preference or on when the parents could implement their homework tasks into their daily routine with the glove on.

During this time it was expected that they attend all four of the allocated therapy sessions of ninety minute duration and perform various self selected tasks from the homework pack during the twelve day period. The school holiday period was chosen for two main reasons, one, to limit the child's potential psychological problems. They are not having to concentrate on school as well as therapy, as well as not having to deal with other children's reactions. Also, the holidays were a more convenient time for parents to invest their time and involvement, as the course is time consuming.

### Therapy Sessions

The Child Development Unit Physiotherapist and Occupational Therapist facilitated four, ninety minute therapy sessions. The sessions were broken down into a gross motor segment followed by morning tea then ending with a fine motor segment.

Tasks included bilateral stretching, throwing and rolling of a ball, use of parachute, balloon volleyball, grasping and releasing objects, drawing, in-hand manipulation and a stereognosis activity.

Morning tea was also part of the therapy time, in that subjects were expected to attempt to perform certain gross and fine motor skills during this functional activity, for example, taking the straw off the juice carton, unwrapping this and piercing carton with affected hand, and monitor potential gains.

Certain activities were timed and also repeated throughout the four group sessions to foster motor planning skill acquisition. During the remaining times the child was wearing their constraint they had various homework tasks to complete which included bilateral integration tasks, range of movement exercises and manual dexterity tasks. The homework pack did not include activities or tasks that were completed in the group as we wanted to avoid repetition of a specific task that could potentially skew results on test re-test tasks.

This treatment style is very different from the conventional sessions that this client base were used



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to having, in time and intensity although the types of tasks were common.

### Assessments

For both the pre-assessment and post-assessment sessions, subjects were tested for:

#### Quantitative Data

1. Range of movement.
2. Grip strength (dynamometer measures).
3. Finger strength (dynamometer measures)
4. Bike maze trail (manual dexterity / hand – eye coordination).

Each therapist was designated the same measurement and tests for both the pre and post assessment sessions, aiding inter-rater reliability for test results.

During the actual groups, quantitative measures included:

1. Timing the Quoit activity.
2. Timed activity of turning wooden shapes over.

#### Qualitative Data

1. Modified Barthel Activity of Daily Living Index. A modified Activities of Daily Living check list was given to each of the subjects' caregivers to complete at the pre-assessment session. This was then sent out to the caregivers after the final post assessment session to complete and return to the therapists.
2. Functional gains reported (parental feedback form post groups). The parents wrote down as many functional gains that they had seen over the course of the group and for up to one month after.

These assessments / measuring tools were chosen because of the limited resources and standardised tools available at the Child Development Unit for children with Hemiplegia.

Past research indicates a combination of both qualitative and quantitative tools to be used as perceived functional gains made, if any, are just as important in indicating the effect of Constraint Induced Movement Therapy with this client group.

Due to inaccessibility to standardised assessments, the tools used to measure subjects have had ethical board approval and no statistical interpretation of the tests was undertaken.

### Results

Five children were included in the pre and post assessment sessions except one, as his affected limb was broken and therefore could not be retested. Of the four children who took part in the study 3 were girls, aged between 7 and 9 years. However findings discussed in this article are for the four children who partook in both assessment sessions and attended all group sessions. There was no control group in the study, the children acted as their own control group in this situation.

#### Range of Movement

Pre and post assessment sessions (see table 1). Improvements were indicated in forearm supination, wrist / ulna deviation and thumb opposition in all four subjects.

75% of the group improved on shoulder flexion, internal rotation, elbow flexion, wrist flexion and radial deviation. 50% of subjects improved on shoulder abduction, external rotation and extension of the wrist. Individually, all subjects improved with range of movement (see Figure 1 and Table 2). 75% of subjects had an improvement of 10% or greater in their general range of movement scores.

Table 1 Range of Movement– Pre and Post Constraint Induced Therapy Group

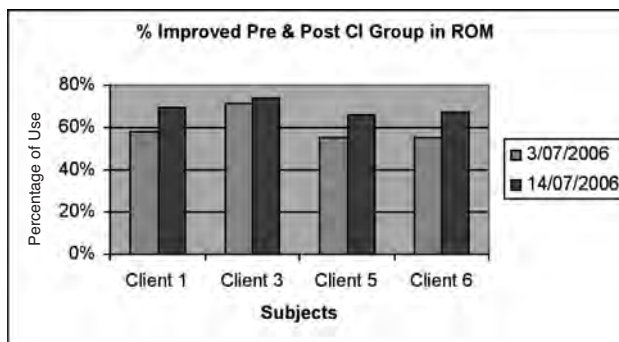
R/L		3/07/2006 Client 1	14/07/2006 Client 1	3/07/2006 Client 3	14/07/2006 Client 3	3/07/2006 Client 5	14/07/2006 Client 5	3/07/2006 Client 6	14/07/2006 Client 6
Shoulder	Extension 0-180	0	* 30	60	60	-25	* 55	20	* 25
	Flexion	170	* 175	180	180	175	* 180	170	* 175
	Adduction 0-180	20	20	55	55	70	70	75	75
	Abduction 0-180	170	* 180	180	180	175	175	90	* 170
	Internal Rotation 0-90	30	* 80	35	* 60	30	* 65	30	* 35
	External Rotation 0-90	80	* 85	90	85	75	* 85	30	30
Elbow	Extension 0-160	5	5	30	10	0	0	30	30
	Flexion 0-160	150	* 160	150	* 165	140	* 160	150	* 170
Forearm	Supination 0-90	20	* 30	10	* 20	5	* 15	0	* 10
	Pronation 0-90	90	90	90	90	90	90	90	90
Wrist	Flexion 0-90	65	* 80	40	* 90	0	* 30	90	90
	Dorsiflexion 0-70	20	* 35	40	* 45	0	* 5	25	25
	Radial Deviation 0-20	5	5	0	* 7	0	* 5	5	* 10
	Ulnar Deviation 0-30	5	* 25	5	* 10	0	* 5	10	* 30
Thumb	Thumb to base 5 <sup>th</sup> digit	Index Finger	Ring Finger	Index Finger	Ring Finger	Index Finger	Ring Finger	Index Finger	Little Finger

Key \* indicates range of movement improvement between pre groups / post group.

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Out of the total fourteen range of movement measures used, the average gain was 8.5/14 measures tested. All subjects improved on seven items. No member lost range of movement in any areas.

**Figure 1 and Table 1 Percentage Improvement Pre and Post Constraint Induced Therapy Programme**



### Grip and Finger Strength

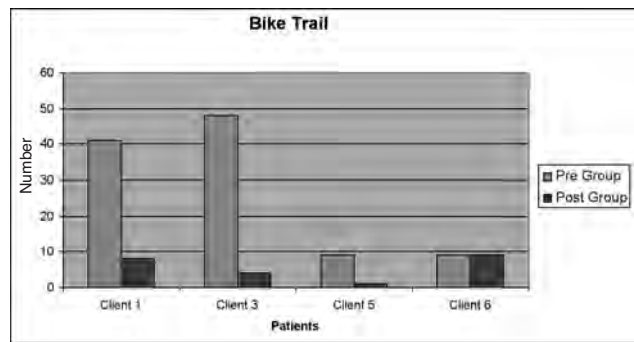
No obvious changes were noted when comparing strength scores in the pre and post assessment sessions, confirming past research findings that significant changes in these are unnoticed. No previous studies have found that grip strength improves during the course of research (Hakkenes and Keating, 2005, Charles et al, 2001).

### Bike Maze Trail

Subjects were asked to draw a continuous line from a starting point to the end. The amount of times a subject's pen/felt was lifted off the page was counted. This was then repeated post group. The larger the number of pen lifts the worse the fine motor control and indicates the poorer dexterity skills.

It was found that three subjects dramatically improved in the amount of times the pen/felt did not leave the page, showing improvement in manual dexterity, fine motor control and functional dexterity. One child had an initial score of 48 lifts off the paper to just four on the re-test, showing remarkable improvement over just four sessions and 12 days of CIMT input. Client number six stayed the same pre assessment and post assessment but this client has a condition that affects vision and this could have played a part in the task being considerably more challenging and may account for the anomaly, see figure 2.

**Figure 2 Number of pen lifts (decreased lifts indicate increased dexterity, fine motor control and accuracy with pen)**



### Modified Barthel Activities of Daily Living Index

The initial feedback form indicated all subjects having difficulty with feeding and certain personal care tasks i.e., brushing hair.

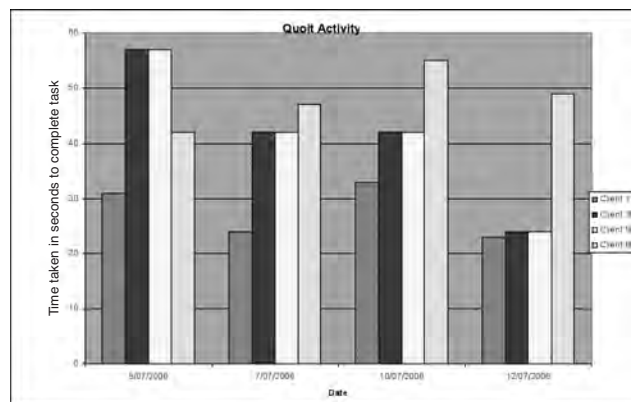
The initial feedback form was then sent out to the four subjects' caregivers one month after the group had finished. All caregivers reported no loss of functional gains made during the groups; within this month timeframe. When comparing the pre and post initial feedback forms, improvements were noted in the areas of cutting food, drinking and dressing. The subjective value of one particular dressing tasks was from a four (full assistance required) to a one (independent). One caregiver even stated that the child attempted to skip with a rope, achieving two skips, whereas prior to the group they were not even able to hold a rope.

Other skills noted were being able to use a glue stick independently, including the manipulation of the lid and brush teeth independently.

### Quoit Activity

It was found that 50% of the group's times gradually improved during each of the four group sessions this activity was undertaken (Figure 3). Many components to the task make it difficult to assess why only 50% improved i.e. it was timed, fine and gross motor combined it involved grip and release and visual perceptual elements. One child has visual problems and the other child who did not improve

**Figure 3 Changes in time of Quoit Activity**



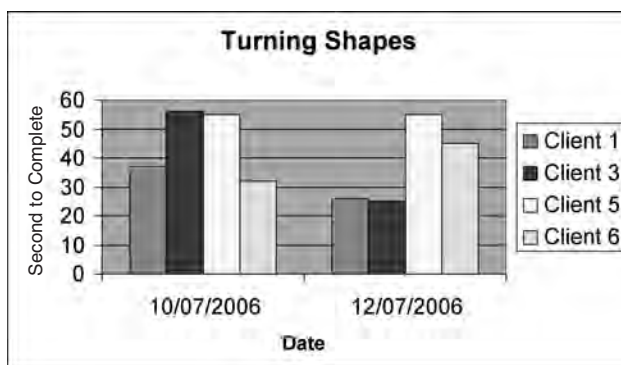
## Application of a Constraint Induced Movement Therapy Group for Children with Hemiplegic Cerebral Palsy in a Public Health Setting (A Pilot Study)

as much as seizure activity and very poor grip release under timed conditions that could account for this.

### Turning Shapes

50% of the subject's times improved with this task that was conducted during the last two group sessions. One subject's time remained unchanged, see figure 4.

**Figure 4 Seconds to complete turning shapes activity**



The first time this task was conducted (during the first group session) all subjects were unsuccessful. The second time the subjects were asked to perform this activity (during group four) they all had at least a 75% success rate. This was a slow activity under non-timed conditions that may have helped with a better success rate.

### Diakokinesis

Subjects were instructed to perform the finger to nose test at the pre and post assessment sessions. Subjects appeared more coordinated and accurate at the post assessment session, being able to touch their nose as opposed to the side of their face at the pre-assessment session. All subjects improved, however this area could be limited by its subjective nature.

### Sensation

Subjects were instructed to close their eyes whilst touched with a pen on the palmar aspect of their affected hand for both the pre and post assessment sessions. 50% of subjects were able to accurately identify where the pen was touching them during the post assessment session, whereas all subjects were unable to identify where the pen was touching them around the second and third fingers during the pre assessment sessions.

### Body Awareness

No obvious impairments were noted during the pre and post assessment sessions in identifying where their affected upper limb was in space in relation to their body. Therefore a change in this area was not expected.

### Discussion

In this pilot study, CIMT was deemed a viable treatment approach in this Child Development Unit setting.

Caregiver "buy in" was gained with ease, as well as the implementation of the home programme and positive reinforcement required for subjects to persevere with the wearing of the constraint.

Both child and caregivers feedback was positive concerning length and intensity of treatment. Although this is subjective in nature, it is important to acknowledge all feedback given by the above persons.

It was found that out of the six subjects initially enrolled in the CIMT pilot study, two were excluded as previously documented, leaving four subjects. This sample size is small, therefore generalisations to the total population are limited, however noticeable gains were observed in range of movement, functional performance and sensory awareness.

The sample size was limited due to the availability of appropriate subjects to partake in this study.

Ranges of Movement (ROM), subjects were tested in fourteen upper limb measurements. All subjects achieved improvement, on average, in eight and a half of the fourteen tested, therefore they improved on 61% of their ROM. Specifically supination, opposition and ulnar deviation were ROM areas improved, therefore the functional gains included better grasp and release of objects, greater accuracy, control and independent performance of fine motor tasks. This can be seen with the Quoit game, turning the shapes game, and the sensory activity.

Comparing the results between the pre and post assessment groups, fine motor control improved in the bike maze trail activity. One subject showed a change from initially lifting their pen/felt forty-eight times off the page to only four times in the final assessment session. The one subject that did not improve, remained the same, however this subject also has a diagnosis of heminopia, which would make any drawing task more challenging. This was also noticed in the other activities that this subject participated in, indicating a need for a clear, single diagnosis of Hemiplegia for children included in study to exclude variables.



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Two out of four subjects improved significantly with the timed Quoit game, demonstrating increased speed and a more effective grasp/release technique. This improvement could be due to the subjects being the older members of the group having a higher level of cognition and greater exposure to competitive timed situations. This posed an increasing question as to selection of age of population to be involved.

This was also mirrored with the turning of shapes activity where the two older subjects improve significantly with their skill performance with this task (Eliasson et al 2003 study two week day camp would concur with this idea).

Regarding a change in subjects' sensation, as previously mentioned, 50% of subjects were able to accurately identify the site when tested on the palmar aspect of the affected hand. These two subjects failed the subtest at the with pre assessment session. These two clients were the older of the sample with no other conflicting medical conditions affecting them except their Hemiplegia.

Interestingly, it was the same subjects who had improved supination as well, that also demonstrated improved sensory awareness.

Is there a correlation between decreased supination and impaired, sensation of the affected hand? This has not been previously documented in past studies and therefore may require further significant consideration in future studies/research, posing an interesting point of discussion for this population.

This highlights the importance of therapy intended to mediate the effects of 'developmental non-use' and needs to be developmentally appropriate (Hart, 2005) which is what appears to have been demonstrated in this pilot study.

As shown in other studies, and predicted by the therapists involved in the study, subjects strength did not change. It can be concluded that strength training is not part of the core CIMT principles, therefore improvement is not likely to be an outcome with this treatment approach (Fedrizzi et al, 2003).

Finally, even though subjective in nature, caregivers were asked to write down any noted functional gains during the post assessment session. Some of the comments were as follows:

1. "More two handed activities ....."
2. "Trying hard to use spoon for eating with right hand ....."
3. "Tries really hard now to use the right hand. So much better at opening drink containers, spreading jam, etc."

Prominent functional gains were increased bilateral activity, increased awareness of the affected limb and improved performance with tasks such as eating, brushing teeth and dressing.

No detrimental effects were noted or observed by caregivers, with all feedback being positive and functionally specific in nature.

This pilot study highlights that with limited resources in a regular Child Developmental Unit setting, CIMT can be put into practice with positive outcomes on both a qualitative and quantitative basis, short term. With future long term outcomes and measures needing to be taken for outcomes to be justified further.

It also appears that this approach to treatment is highly applicable with this particular group and can provide a cost effective, time conscious solution compared with conventional therapy input varying from weekly or a review basis "sessions" for this population, with caregiver feedback also supporting this.

However, this study was a pilot study, which also brings with it certain limitations. As already mentioned the sample size was small, it was not randomised and there was no control group, therefore generalisations made across the hemiplegic population could not be made conclusively. However, the pilot study gave indication and support to suggest that CIMT is an effective treatment option. We acknowledge that further follow up is important to determine significant skill and movement gains are sustained.

Future studies would benefit from larger sample sizes with a greater population to draw from and therefore need to target at a national level with to generalise its findings in combination with long term follow up for true gains to be measured.

Standardised tests/measures were not used in this pilot study as there was no access to these and the cost of purchasing the tools were not a budgeting option. Therefore, future studies need to contain more quantitative rather than qualitative data. "Statistical tests are only one tool to conclusively measure gains and CIMT with children with Cerebral Palsy and could incorporate functional magnetic resonance imaging to further investigate recovery mechanism in this population". (Pierce, 2002).

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An extraneous variable of this study was no caregiver treatment times at home were supervised by the therapists, which led to an inability to determine length of time subjects actually wore their constraint out of group sessions. During this study, the therapists conducting the study attempted to control this by asking caregivers to complete the homework pack, however, this was also reliant on their honesty.

Previous studies such as Eliasson (2003), conducted their CIMT treatment as a two week long camp where they were able to, somewhat, more accurately supervise and monitor subjects. This could also be a future option.

A point of discussion is the two varying arguments between targeting under five year olds and the older age group up to eighteen years.

Hart (2005) argues that "... children under five years have better outcomes as a result of the underlying plasticity changes that are also occurring". However, it has been discussed that with children over the age of five years, they have increased cognitive ability. Therefore they can understand what is being asked of them and work well in competitive group setting, which was seen in this study.

Hart (2005) proposed that "... the potentially greater neuroplasticity in young children suggests that treatment would be more effective in the younger child." Eliasson would argue against this as he found success in the two week (2003) day camp study, which was for children aged thirteen to eighteen years old, which found great success. This may support findings of this study.

However Gordon et al's (2006) research study results indicated that "... the intensive practice associated with CI therapy can improve movement efficiency and environmental functional limitations among a carefully selected sub-group of children with hemiplegic Cerebral Palsy of varying ages and that this efficiency is not age dependent." Further supporting our findings.

### **Conclusion**

This small pilot study showed promising results in determining the effectiveness of CIMT as an appropriate treatment approach. It showed that it was a transferable treatment approach to a Child Development Unit and now that homework packs and constraint method has been trialled and tested,

the group could be easily set up time and time again without a lot of difficulty.

Even though a specific standardised assessment tool was not utilised, the findings still suggest that this approach can be affectively actioned in a community paediatric service that has limited resources, with positive outcomes. This also has large implications for service provision. To optimise outcomes of CIMT input, subjects should ideally be retested at six months using quantitative measures, for conclusive results. The service provisions should then alter accordingly.

In order for CIMT to become a more utilised form of intervention, more complex, statistical, randomised control studies need to be initiated in New Zealand.

### **Acknowledgements**

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# Jalalabad Clubfoot Project - Introducing Ponseti Management Of Clubfoot To Afghanistan

*Jeanne Hartley, Clinical Specialist, Great Ormond Street Children's Hospital, London, UK.*

*Shah Mahmood, Head of Physiotherapy, Sandy Gall's Afghanistan Appeal, Jalalabad, Afghanistan.*

Sandy Gall's Afghanistan Appeal (SGAA), founded by Independent Television News war reporter and journalist, Sandy Gall in 1983, provides physiotherapy, orthotics and prosthetics, mobility aids and wheelchairs as well as health education to people in that country. All these services are provided by Afghan staff, trained and supported by SGAA. Approximately 12,000 patients a year are treated at the main rehabilitation centre in Jalalabad, Nangahar Province, from where SGAA physiotherapists and health educators visit three provinces. Patients include land mine victims and many children and adults with polio, cerebral palsy, clubfoot and other disabilities. Technical help is provided to the Kabul Orthopaedic Organisation (KOO). In 2006 SGAA merged with the Swedish Committee for Afghanistan (SCA) which will supplement SCA's own disability programme in other provinces of the country.

Jeanne Hartley, (JH), has been involved with SGAA since 2003 after a chance meeting early one morning in a hospital corridor with John Fixsen, honorary consultant orthopaedic surgeon at Great Ormond Street. John had just returned from a trip to Afghanistan and a throw away line from JH about how she would love to do something like that resulted in a phone call a few weeks later with an invite to get involved too. Now JH is completely in love with this beautiful country and its people who, despite the ravages of thirty years of war and strife, desperate poverty for many and lack of even basic amenities such as health care, electricity, clean water and good roads are some of the nicest and most dignified people you could meet.

In November 2005, Philip Henman, a consultant orthopaedic surgeon in Newcastle, John Fixsen and JH travelled to Afghanistan with the specific goal of introducing the Ponseti management of clubfoot to Afghan physiotherapists working in clinics in Kabul and in Jalalabad and clinics in nearby provinces.

A year later, in November 2006, Philip, John and JH travelled to Mazar e Sharif, in the north of Afghanistan, where we carried out the same training programme for the physiotherapists and orthotists

employed by SCA as well as orthopaedic surgeons from the city and surrounding areas. Training was also carried out at the clinic run by the International Committee for the Red Cross (ICRC) there and in Kabul.

## Clubfoot in Afghanistan

The prevalence of Clubfoot in Afghanistan is very high, although it is unlikely that the actual incidence in the country is accurately recorded. However it has been recorded at approximately 100,000 infants per year born with clubfoot about 80% of these in developing nations (Global Help 2003). To help put this information into context, JH treated 2 babies in 2006 in the UK using the Ponseti method, whereas the physiotherapists in Jalalabad saw 172 babies and small children in the same period! When I was in Jalalabad in April 2006 JH helped cast 15 feet (11 patients) in one clinic.

In Afghanistan it is not unusual to see adults and older children with untreated clubfoot. Neglected clubfoot is considered to be the most serious cause of physical disability from musculoskeletal birth defects worldwide. In developing countries, for women the human cost is enormous as afflicted females are less likely to marry and more likely to suffer abuse. Children with neglected clubfoot, despite being able to walk, run and play on their deformed feet are condemned to a downward spiral of deformity, disability, dependency and despair. Fewer than 2% of children with disabilities attend school in developing countries – the more difficult it is to walk the less likely a child is to attend school. In adulthood, for those with clubfoot activities such as digging, ploughing, carrying wood and water are unmanageable. For a mother caring for a child with a disability there is less time for other children, for domestic, agricultural and economic activities. There is much poverty and ill health as well as reduced social, educational and employment opportunities affecting the whole family (Global Help 2003).

Dr Ignacio Ponseti developed his method of clubfoot management in the 1960s and long term follow up studies show that feet treated by this inexpensive but effective method are strong, flexible and pain free. Treatment involves a series of plaster casts applied in a precise manner to correct the deformity over a period of weeks, with tentotomy of the Achilles tendon carried out, if needed, during the casting programme. Once the deformity is corrected the position is maintained by the application of foot abduction orthoses (boots and bar) which are worn day and night initially and then at night for a period of several years. It has been very successfully introduced into developing nations where the incidence of clubfoot is high, such as Uganda, Malawi, Gujerat, Tamil Nadhu, where there are few if any orthopaedic surgeons, and



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neglected clubfoot results in disability for the individual, a reduced standard of living for the entire family, and a burden for the community. In 2005 plans were made to introduce the method to Afghanistan. (see figures 1-4)



*Fig 1: This 33 year old man came to the clinic in Mazar e Sharif asking for treatment. He worked as a tailor, was married and had three children. Unfortunately not even extensive surgery in the best of hands, even in the West, was not likely to have been successful and in fact may have increased his problems.*



*Fig 3: Farid is a six year old boy with untreated clubfoot. Despite his deformity he was able to walk and run short distances but was not able to go to school.*



*Fig 2: Abdur-Rahman is eight years old. He wears sloppy, distorted sandals to protect his feet from the unmade roads so that he can get to school.*



*Fig 4: First Ponseti plaster casts for Farid. After several casts he needed surgery to lengthen his Achilles tendons and release the tight medial structures in his feet. However the plaster casting meant that less radical surgical correction was needed. His feet are now flat on the ground.*

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### Introducing the Ponseti method

In 2005, the training was centred in the main rehabilitation centre in Jalalabad, with physiotherapists and orthotists in attendance as well as at KOO in Kabul. The technique was quickly learnt and practiced. It was very useful to be based in the area for several days rather than just being there to teach a session and then leave them to it. This meant that someone from the team was available to help with the casting and supervise hand holds over the next few days. More challenging for the delegates was getting used to assessing the deformity and recording the severity so that treatment progress could be charted. The Pirani score was introduced and a simple assessment sheet was devised to facilitate record keeping (Figure 5). This was initially used with varying degrees of idiosyncrasy and accuracy – further discussion when I visited in April 2006 ironed out any residual problems and there has been a pleasing improvement since then.

To begin with, in Jalalabad the service quickly came under strain as patients began to flock into the city as news of successful treatment spread. People came with their babies and children, not only from the local area but also through the Khyber Pass from the north-west frontier provinces of Pakistan and from Nuristan, a difficult to access province in north-eastern Afghanistan. SGAA health educators also identified new born babies in the villages with clubfoot and encouraged the parents to bring them in for treatment as soon as they could travel. Initially it was difficult as there is no appointment system so patients needing casting had to be fitted in amongst other patients. Eventually it became apparent that the clubfoot service needed to be better organised and clubfoot sessions are now on specific days. The physios in Mazar were warned that they may experience the same 'rush' but will be better prepared as the effects of the new service in Jalalabad was discussed and clubfoot clinics will be held on specific days.

The SGAA clinic in Jalalabad is based within the grounds of the Public Health Hospital. Dr Said Shal is an orthopaedic surgeon in the hospital who will provide a service for paediatric patients. However it is important to realise that facilities within the hospital are basic – although improving slowly – so simple procedures are possible, complex orthopaedic surgery for children is not possible. Dr Said Shal works closely with SGAA physiotherapists and orthotists in an out patient clinic in the Male Clinic. A tenotomy clinic to

complete the clubfoot correction when needed has now been set up there with the post-op plaster being applied by a physiotherapist. Previous plasters applied post-op in theatre had not been well applied and when this concern was raised changes were made. In Mazar orthopaedic surgeons from the city attended the training and John and Philip were able to demonstrate simple tenotomies on some children,



Fig 5: Bilateral clubfoot in a 4 month old girl in Mazar. Ponseti score was 5 bilaterally.



Fig 6: Physiotherapist Kamila, helped by colleague Fatima, apply the first plaster cast.



Figure 7: First plaster completed with some improvement in foot position.

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apply plaster casts in the over corrected position and made sure that the importance of long term splintage following the cast treatment was hammered home (Figures 6 and 7).

In Jalalabad providing the boots and bar to maintain the corrected foot position after the plaster casting became a major work commitment for the orthotists and the leather man initially, but once the first few made had been refined full production could start. Now it is possible for babies to be provided with gold leather boots, red, blue, pink – whatever colour leather is available this week in the Bazaar! Great fun and puts the white boots in the UK firmly back in their place (Figure 8).



Fig 8: Boots and bar applied to maintain corrected position of left club foot.

### Results of the Jalalabad clubfoot project 2005-2006

These results were collated by Shah Mahmood, Head Physiotherapist for the male section in the SGAA clinic in Jalalabad and presented by him at a physiotherapy conference in Nepal in October 2006. Shah Mahmood has also been responsible for the teaching and training of student physiotherapists by SGAA.

#### Demographic information:

Number of patients: 172 of which 132 were male and 40 female  
 Age: 162 patients 0-5 years  
 10 patients 6-10 years  
 Unilateral clubfoot: 92  
 Bilateral clubfoot: 80  
 Previous treatment. 91 patients had been treated with Plaster of Paris (POP) casts  
 62 patients had been given Ankle Foot Orthoses  
 19 patients have had surgery.

#### Initial assessment:

The Pirani score is a reliable and valid method of clinically assessing the amount of deformity present in a club foot. Documenting the amount of deformity allows the treating practitioner to chart progress and also to know when a tenotomy is indicated as well as allowing a meaningful comparison of results. The Pirani scores six clinical signs, three in the hindfoot and three in the midfoot, either 0 (normal), 0.5 (moderately abnormal), or 1 (severely abnormal) (Table 1).

Pirani score	No of Patients n=172
6	34
5.5	30
5	23
4.5	25
4	19
3.5	19
3	22
2.5	8
2	2

Table 1: Review of Pirani score at the start of treatment.

#### Ponseti Treatment:

Above knee POP: 130 patients

Below knee POP: 42 patients children older than three years of age (Table 2)

Weeks of cast treatment	No of patients n=172
2	12
3	42
4	51
5	37
6	17
7	8
8	5

Table 2: No of weeks treatment in Ponseti casts.

#### Outcome of treatment:

152 patients' feet corrected with conservative treatment.

20 patients required Achilles tendon tenotomy to achieve correction. This is less than would be expected with the experience in the UK. There has been some recurrence of heel equinus in a few of those treated conservatively and on reflection perhaps these children should have been referred for tenotomy too.



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### Splintage:

- Boots and bar: 142 patients
- AFO: 18 patients (*older children were provided with AFOs for night wear – we have advised that boots and bar should be used*)
- Dynamic AFO: 9 patients (*not able to discover why these were prescribed but boots and bar are now to be used*)
- KAFO: 2 patients (*who also had fixed flexion at the knee*)
- Orthoprosthesis: 1 patient (*to gain leg length equality*)

### Review findings:

One year on from the introduction of the Ponseti method many babies and young children have benefited from the treatment. There have been a few regressions – this is the nature of clubfoot but is more likely to be the result of not appreciating that tenotomy was required for those feet that had minimal residual equinus. We have now advised that if the Pirani score for the empty heel and/or rigid equinus remains at 1 or just over, even though the foot looks to be in a plantargrade position, then a surgical opinion should be sought.

Provision of the boots and bar is now in the hands of the orthotists and they are apprised of children needing these splints in plenty of time to ensure they are fitted as soon as the casting finishes. The orthotists now have a recall system to review the use of the boots and also to provide bigger sizes as needed. They also have been trained in the Pirani score and refer children back to the physiotherapists if there appears to be any loss of position.

The tenotomy clinic has just started in Jalalabad and it is hoped that the improved application of the post-op cast will improve outcome following surgery (some feet had been cast in a poor position in theatre negating the benefit of surgical release!).

The SCA physiotherapists working in Mazar and surrounding rural areas have the benefit of learning from the experience of setting up a Ponseti service in Jalalabad as well as having support and advice from the SGAA team. Likewise the teams working for ICRC have access to others working in the clubfoot field. I feel an Afghan Clubfoot Group coming on!

### Conclusion

The SGAA/SCA physios and orthotists are to be congratulated on their new service. With the help of the health educators, who visit the villages in rural areas, who hopefully will identify babies with clubfoot quickly, and get treatment started early so that the incidence of neglected clubfoot and the accompanying long term, terrible effects will become a thing of the past.

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[www.sandygallsafghanistanappeal.org](http://www.sandygallsafghanistanappeal.org)

# The changing role of the Paediatric Physiotherapist in the emerging population of adults with Neuromuscular Disorders

*Michelle Eagle PhD, MSc, MCSP, Newcastle Muscle Centre*

*Marina Morrow MSc, MCSP, Yorkhill Division, Glasgow*

*Elaine Scott MPhil, MCSP, Muscular Dystrophy Campaign*

## Introduction

Over the last decade there have been steady advances in technologies that have increased our ability to diagnose and treat people with neuromuscular disorders (NMDs). Improvements in diagnoses have led to a better understanding of the complications associated with individual disorders, which in turn can facilitate the prediction and management of future problems. Understanding the individual disorder is vital, and having this knowledge enables clinicians and families to take advantage of the treatments that are now more readily available and to plan for the future.

Only a decade ago the muscular dystrophies and myopathies were poorly defined conditions with unclear pathology, aetiology, prognosis and treatment options. Today, the number of patients without a precise diagnosis is rapidly declining as new genes and gene products are identified by ever more sophisticated mutation analysis and immunohistochemistry.

This article will briefly describe the most common NMDs and discusses the various treatment options that have made an enormous difference to life expectancy and quality of life in many of these conditions. It will highlight some of the problems faced by paediatric physiotherapists who are continuing to offer care and advice for, what is essentially, an adult population with severe disabilities and will outline the challenges presented to our physiotherapy colleagues working within adult services.

To give some perspective on how these advances have changed prognosis for individuals with NMD, Duchenne muscular dystrophy (DMD) in particular will be discussed. DMD has many complications that are common in other conditions and lessons learnt here can be just as easily applied to other neuromuscular disorders.

## Classification of Neuromuscular Disorders

The term 'neuromuscular disorders' covers a group of conditions, which may affect any part of the neuromuscular system from the lower motor neurone onwards. They may involve the anterior horn cell, the nerve, the neuromuscular junction or the muscle itself. The classification of NMDs can be complex. The following list is **not** exhaustive, but includes some of the more common conditions. An excellent web site is available for reference to these and other neuromuscular conditions at [www.neuro.wustl.edu/neuromuscular/index.html](http://www.neuro.wustl.edu/neuromuscular/index.html)

Over the years the nomenclature used to describe these disorders has changed and continues to change as more precise diagnoses are made. Classification is based on the phenotype, the clinical features of affected individuals together with the identification of the genotype and the genetic and biochemical defects.

As can be seen from the following list, many disorders are still referred to by the original name given to them by the physician who first described them. Duchenne muscular dystrophy, so called after Guillaume Benjamin Amand Duchenne who first published his description of this condition in the 1860s is a typical example. Other disorders are named by their clinical manifestation such as Fascio-scapulo-humeral muscular dystrophy or limb-girdle muscular dystrophy. In the case of the former this has led to a misunderstanding of the condition especially by patients who find increasing problems with lower limb weakness. In the latter case, some limb girdle muscular dystrophies may also have distal involvement and furthermore have been shown not to be a single disorder but a very diverse group of different conditions. Classification and understanding of conditions in this group of disorders is continually evolving.

## Clinical interventions leading to increased longevity:

### *Respiratory Support*

The most significant advance to date has been the use of nocturnal ventilation and other methods of respiratory support. In the 1960s the average life expectancy of children with DMD was 14 years of age. Death was mainly due to respiratory failure (90%) and cardiomyopathy (10%)(1). Due to the development of specialist clinics during the 70s, 80s and 90s the average survival increased to 19 years of age. However the introduction of nocturnal ventilation during the 1990s dramatically improved life expectancy to the mid twenties for those patients ventilated in the 1990s (2;3). Now patients with DMD can be expected to live even longer. In Denmark, where ventilation was introduced during the 1980s, there are many patients in their 30s and

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**Table of conditions**

Name of Condition	Gene symbol (Protein)	Inheritance	Phenotype	Respiratory weakness	Cardiac Complication
Duchenne Muscular Dystrophy DMD	Dystrophin	x-linked 1:3500 live male births	Rapidly progressive muscle weakness. Untreated will die by age 19 years, Associated with learning difficulties and an increased frequency of autistic tendencies though intelligence can be normal. With currently available treatments life expectancy can reach 30+.	Usually require non-invasive ventilation by late teens	Annual cardiac monitoring from 8 to 10 years. Treatment with ACE inhibitors and Beta blockers
Becker MD BMD	Dystrophin	x-linked	A milder and more variable form of DMD with similar complications.	Evidence of respiratory weakness	Requires similar cardiac evaluations and treatment to DMD
Charcot Marie Tooth Disorder CMT Type 1-IV	Multiple disease caused by genes and proteins	Dominantly inherited	Sensory loss in hands and feet Muscle weakness and foot deformities are common.		Risk of cardiac complication but not common
Merosin deficient Congenital MD MDC1A	LAMA2 Lamin alpha 2 chain of merosin	Recessive inheritance	Severe muscle weakness and contractures. Some patients may be able to walk initially but this ability is not sustainable.	Respiratory failure common	Cardiac failure uncommon
Ullrich syndrome UCMD	Coll6A	Recessive inheritance	Characterised by contractures and distal hyper mobility Scoliosis is common. Most lose independent ambulation in childhood.	Respiratory failure common	Cardiac failure uncommon
Emery Dreyfuss MD EDMD	LMNA Lamin A/C	x-linked or dominantly inherited	Contractures are a problem in this type of MD.		Conduction defects of the heart require pacing or implantable defibrillator

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Fascio-Scapulo-Humeral MD	FSHD Unknown protein abnormality	Dominant inheritance	Variable presentation and age of onset although the earlier the diagnosis the greater the severity. Foot drop is common as well as facial and U.L. weakness.	Respiratory failure rare	Cardiac complications rare
Limb girdle MD LDMD Type 1 A-E LGMD Type 2A-J	CAV3 Caveolin CAPN3 Calpain DYSF Dysferlin LGMD2C-F Sarcoglycan FKRP Fukutin related protein	Type 1 Dominant inheritance Type 2 recessive inheritance	Presentation can vary from the teenage years into adulthood. Although limb girdle weakness is characteristic distal involvement may also be present.	May have respiratory weakness	May have cardiac complications
Myopathies	Many diseases with multiple gene and protein abnormalities	Dominant or recessive inheritance	Variable presentation, progression and severity.	May have respiratory weakness	May have cardiac complications
Multicore myopathy	SEPN1 selenoprotein	Recessive inheritance	Distal laxity, proximal and generalised weakness. Spinal rigidity with typical 'side sliding' spinal deformity which develops whilst ambulant. Atrophic phenotype.	Respiratory failure develops whilst ambulant	
Bethlem myopathy	COL6A1- COL6A3	Dominant inheritance	Contractural phenotype. Variable age at onset and disease severity. Slowly progressive.	Occasional respiratory failure	Cardiac involvement uncommon
Myotonic Dystrophy DM1 DM2/PROMM	DMPK Myotonin protein kinase	Dominant inheritance	Congenital type (babies born to affected mothers) is severe with severe learning difficulties and motor delay. Adults have very variable phenotypes with multi-system involvement, cataracts, frontal balding, facial weakness, myotonia, increasing weakness with age.	NIV may be required	Cardiac complications are frequent with sudden death syndrome common



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Spinal Muscular Atrophy Types 1-111 reflect a disease spectrum rather than separate entities	Type I SMN1 Survival motor neurone protein	Recessive inheritance	Type 1 SMA. Very severe, diagnosed in infancy. Increasing respiratory and bulbar weakness leads to death usually around the age of 18 months to 2 years. These children are never able to sit or stand independently.	Some are ventilated invasively	
	Type II SMN1 Survival motor neurone protein	Recessive	Severe muscle weakness. Unable to walk independently but may walk or stand with orthotic intervention. Life expectancy is increasing now that nocturnal ventilation is available. Intelligence is at least normal.	NIV commonly required in early childhood or teenage years but also in later adult life	Occasional cardiac problems
	Type III SMN1 Survival motor neurone protein	Recessive	Walk independently but may lose ambulation in time especially if diagnosed in childhood. Others with milder disease may walk into adulthood.	Respiratory failure may occur in adulthood years after ambulation is lost	Cardiac problems uncommon

40s.(4) All of these older patients have tracheostomy ventilation, which in Denmark is introduced once daytime ventilation is required. Here in the UK, those people with DMD who have had spinal surgery, who use respiratory support at night (and sometimes during the day) are increasingly surviving to 30 years of age. It is thought that the additive impact of ventilation and a stable spine further improve longevity.

The management of respiratory weakness is one example of how the physiotherapist must keep up to date with current literature principally where the use of physiotherapy techniques make a huge difference to life expectancy and quality of life. Those of us working in specialist centres have a particular responsibility to disseminate this knowledge where there is new evidence to support therapeutic interventions. New treatments are still being evaluated to help with the effects of weak inspiration and an ineffective cough. For example the cough assist machine (mechanical in-exsufflator)

provides the therapist and the family with a simple way of managing ineffective coughing (5-10).

The same principles that are used in DMD can also be applied to many other conditions including Spinal muscular atrophy, LGMD 2I, Congenital muscular dystrophy 1A, Sarcoglycan deficiency, Multicore myopathy and Rigid Spine Muscular Dystrophy 1 (RSMD1 or SEPN1).

In the case of people with Multicore myopathy or SEPN1, ventilatory failure occurs whilst they are still ambulant, highlighting the importance of specific understanding of individual conditions. The introduction of ventilation has evolved gradually but there are now published guidelines for respiratory management in DMD and in other neuromuscular disorders (11;12). Regular assessment of respiratory function is recommended with trigger points to stimulate further evaluation and to indicate when ventilation is required. When nocturnal ventilation first began to be used in the

## **The changing role of the Paediatric Physiotherapist in the emerging population of adults with Neuromuscular Disorders**

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management of DMD, most patients were ventilated following an acute emergency admission but now regular assessment and careful monitoring of clinical symptoms can enable the clinician to anticipate the onset of respiratory problems and introduce effective treatment before a crisis occurs (13).

### ***Cardiac Monitoring***

There have also been significant advances in the management of cardiomyopathy. Death from severe progressive cardiomyopathy used to occur around age 16 in boys with DMD. By the age of 18, all young people with DMD are likely to have developed a cardiomyopathy that will progress over time (14). However, the treatment for heart problems has also moved forwards significantly (15). Previously, treatment tended to be given to patients with DMD who were in severe heart failure and exhibiting symptoms such as ankle swelling and shortness of breath. Now, there is a systematic approach to the management of cardiomyopathy. Guidelines have recommended the regular evaluation of cardiac function yearly over the age of 10 and treatment with ACE inhibitors and beta blockers is offered if there is deterioration from one assessment to the next, even within a normal range (16;17). This demonstrates how knowledge of the potential complications can influence management and how today the emphasis is much more about prevention of complications and prophylaxis than crisis management. As with ventilation, lessons have been learnt about the management of cardiomyopathy in other diseases. For example patients with LGMD 2I may experience cardiac failure so these patients also have regular echocardiography. Treatment will be recommended before cardiac failure is debilitating, knowing the diagnosis can pre-empt a crisis by early intervention.

Other NMDs have different cardiac complications. For example patients with myotonic dystrophy may die suddenly. For this reason regular cardiac evaluation is recommended so that should there be evidence of arrhythmia, a pacemaker can be inserted. Similarly, patients with Emery Dreyfuss MD almost inevitably have conduction defects of the heart, which require pacing and possibly implantable defibrillators.

### ***Physiotherapy***

Physiotherapy has a vital role to play in the treatment and management of these conditions throughout every stage of the condition. For growing children with progressive conditions

stretches, passive movements and orthoses when used together can make a difference in the prevention of deformity (18;19). The role of exercise is controversial for both adults and children. Clearly there is a risk of disuse atrophy but also there is concern regarding the effect of exercise particularly resisted or eccentric exercise on fragile muscle membranes although in the mouse at least voluntary exercise was found to be beneficial. (20-23). In FSHD, there is weak evidence for overwork atrophy but more recently moderate exercise has been encouraged (24;25). Individually tailored advice and exercise programmes are required. Respiratory muscle training is another controversial topic. The quality of evidence is generally poor in adult neuromuscular populations but is more robust in DMD. Overall it is thought that stronger muscles are more likely to respond to training and endurance is more likely to improve than strength (26-31). However the long term benefits are uncertain. A Cochrane review is planned on this topic.

Assessment of 24 hour postural management with appropriate intervention taking account of lying, sitting and standing postures is an essential aspect of physiotherapy intervention. Ensuring movement is facilitated using appropriate wheelchair provision for those who are unable to independently alleviate static postures is imperative and the correct advice with regard to when and when not to exercise is a fundamental part of the physiotherapists work. The increased availability of tilt in space and recline wheelchairs has dramatically improved postural management. However our ability to influence funding sources is severely hampered by the lack of quality evidence for benefits. We should learn from this experience and actively promote quality clinical research.

Our expertise is essential in assessment of function, strength and changes over time as well as providers of treatment, advice and support. Our assessment and evaluation skills will become even more important as new treatments are developed and we must evaluate change to determine the outcome of new interventions and treatments. Already physiotherapists are developing new roles as members of international clinical trials teams.

### ***Steroids***

These brief examples give an idea of how longevity has improved in the population of patients currently in adulthood or approaching adulthood. However, daily treatment with corticosteroids has become the gold standard for ambulant patients with DMD (34-36). Steroid treatment (either prednisone or deflazacort) has been shown to prolong ambulation up to age 13 or more (when ambulation is usually lost at a mean age of 9 years), the requirement for spinal surgery is greatly reduced, the heart remains

## **The changing role of the Paediatric Physiotherapist in the emerging population of adults with Neuromuscular Disorders**

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stronger than boys not taking steroids and the FVC is hugely improved so that at age 18 the FVC is 80% of the predicted value for age and height compared with 10-20% for those not treated. The average age for ventilation is around 17-18 years but in those treated with steroids none have yet required ventilation having reached their early 20s (37-39). The population of steroid treated boys in the UK is still young, most are under the age of 11 years, and only recently has it become a widespread treatment but in the future we would expect an even greater population of adults with DMD.

New treatments do not mean that there will be no problems and it is likely that there will be unexpected new problems as we see an emerging population of patients entering a phase of their condition that has never before been experienced.

### **Quality of Life**

Quality of life however must surely be the most important outcome. Medical professionals severely underestimate the quality of life experienced by ventilated people with progressive neuromuscular disease (32). Recently (33) Rahbek reported observations from an adult population of people with DMD which confirmed that quality of life was good but there were some important areas, which could be improved, for example most people did not have paid employment, or experience a good education and most did not have an intimate relationship with a loving partner. This was a cause of concern and regret to the participants in the study. Significant changes in our expectations and improvements in services promoting independence must be sought to improve life long outcomes.

### **The Paediatric Physiotherapy Service**

There is no doubt that medical advances have changed the natural history of the disease progression of many of the neuromuscular disorders and this change has impacted on service provision within the NHS.

In previous years paediatric physicians and physiotherapists have continued to offer their specialist input to the occasional young person who lived beyond the age of eighteen years. Indeed there was a feeling that it would be cruel to transfer them to a service where their condition was unknown and life expectancy beyond a further two or three years was unlikely.

However, over the years, this case load has grown as more young people are surviving. There are still the

same number of new cases each year but the number of deaths is decreasing and the population at the upper end of the paediatric age group is continuing to grow. It is now recognised that there is enough of a population to transfer to adult services where expertise can develop in this new population and indeed many centres have introduced the concept of "transition clinics".

Moving to adult services has become a right of passage and paediatric physiotherapists are now developing the transition process in order to ensure the young person is fully prepared and able to independently access the appropriate service at the correct time.

Adult services can be less well staffed than paediatric and it can be uncomfortable for clinical staff to "let go". However, this is what we must do if we are to promote a good service in the adult sector and work more closely with our colleagues to develop new skills for a new population.

### **The Adult Physiotherapy Service**

For therapists currently working with adults, the neuromuscular adult population is now more clearly defined. It is possible, given a precise diagnosis, to at least have an understanding of what the potential problems might be and to deliver therapeutic interventions to delay or manage those problems. Although there are several potential therapeutic treatments under way, currently none of these offer a complete cure. Management of the physical signs and symptoms of NMDs, as and when they occur, therefore continues to play a key role in the treatment of these conditions. In the future it is likely that the severity of the disorder will be reduced and the progression may slow down. For the paediatric therapist in 10 or 20 years time this may mean a reduced caseload or less intense intervention to the neuromuscular population but for therapists who look after adults it is highly likely that there will be many more patients with NMDs due to improved longevity.

As discussed earlier. The changing pattern of clinical referral to adult services reflects the dramatically improved management of these children that has enabled them to achieve adulthood. This has created a dilemma for those providing children's hospice services as usually a place is offered to children whose life expectancy is not expected to exceed 18 years. Traditionally adult hospice services have not offered the facilities that are needed by young people with chronic and progressive conditions and there are only a few hospices that cater specifically for young adults. This increasing population, which is directly a result of improved medical care, requires both development of new and restructuring of existing services.



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### **Research**

There are several international Phase 1 and Phase 2 trials underway. Currently a trial of myostatin inhibition in adult patients with limb-girdle muscular dystrophies, Becker Muscular Dystrophy and Facioscapulohumeral muscular dystrophy is approaching completion. Several trials are in progress for children with SMA and in DMD there are several trials pending including a Phase 1/2 trial of antisense oligonucleotide therapy and a trial of a compound called PTC 124 which would be applicable for patients with a point mutation. Interestingly this compound is also being tested in patients with Cystic Fibrosis. We wait in anticipation for a cure but at the moment all of these treatments are likely to require repeated treatments and are unlikely to cure but hopefully will significantly reduce the severity of the disease (40-42).

### **Conclusion**

These patients are now expected to live into adulthood, and as therapists we have to prepare for this and develop new networks that can ease the transition into adult services. It may be helpful to prepare ourselves to expect the unexpected, to research the literature for new developments in management and treatment and as physiotherapists we have to help each other across the child/adult boundary. We will have to learn from each other as never before. Many neuromuscular conditions are no longer just childhood disorders. Those of us with an interest in NMDs affecting both children and adults have much to learn in this exciting time (43;44).

Specialist muscle centres have a role to play in the education of professionals who are involved in the treatment and management of NMDs but have a generic caseload. The muscle centres which increasingly provide services for both children and adults can provide a platform for the transition from paediatric to adult services whilst working with charities such as Muscular Dystrophy Campaign to raise awareness of the changing face of neuromuscular disorders. Professionals also have a responsibility to generate evidence and take up research challenges to ensure momentum within the progression of treatment and management strategies is maintained. If this is undertaken within multidisciplinary teams, a multifaceted approach must surely be fostered which can only be beneficial to young people and adults with a neuromuscular disorder. For example, the specialist genetics nurse, care advisors, speech and language therapists, occupational therapists all have important roles to play. No one profession can assume responsibility

for such clinically complex conditions and maintaining strong trans-disciplinary links will continue to encourage an all encompassing approach to treatment and management.

### **The Neuromuscular Physiotherapy Group**

The Neuromuscular Physiotherapy Group is a special interest group of the APCP. The group was formed to address an increasing need for physiotherapists working with these rare conditions to share expertise and information, in an area which is rapidly changing.

For further information, or to join this Group, please contact Elaine Scott, Secretary Tel: 07795 227170 Email: e\_scott@btopenworld.com **OR** Marina Morrow, Chairperson Tel: 0141 774 3428 Email: marina.m@ntlworld.com

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## Organization of Physical Therapists in Paediatrics (IOPTP)

The World Confederation of Physical Therapy (WCPT) is a confederation of 92 national physical therapy associations. Individuals are linked to WCPT through their national associations. They do not have an individual membership category.

The CSP has been a member since 1951.

All Member Organisations are assigned to one of WCPT's five Regions:

Africa,  
Asia,  
Asia  
Western Pacific,  
Europe,  
North American,  
Caribbean  
South America.

WCPT publishes a newsletter, WCPT News, which provides news and information from Member Organisations, Regions and Subgroups. It also includes reports on WCPT initiatives and Executive Committee and General Meeting decisions, and opinion articles on international issues relevant to the profession. WCPT News is published every three months, and is available for download via the WCPT News page.

Further information can be found at the WCPT website <http://www.wcpt.org>

At the end of 2006 APCP was approached by Barbara Connolly a Paediatric Physiotherapist from the Department of Physiotherapy at the University of Tennessee Healthcare Sciences Centre USA. Barbara was the immediate past president of the Paediatric Section of the American Physical Therapy Association.

The members of this group had expressed an interest in establishing a sub-group for paediatrics in the World Confederation for Physical Therapy WCPT.

Requirements to become an established sub-group of WCPT are:

- Have a specific interest and be organized to exchange scientific knowledge and to promote the advancement of physiotherapy.
- Be composed of member organizations or groups recognized by their Member Organization.
- Members of the Group must also be members of the WCPT Member Organization.
- Sub-groups shall comprise at least 10 members representing 3 regions.
- Be approved by WCPT Executive and have their status confirmed at the next succeeding General Meeting.
- Have a governing body composed of physical therapists only.
- Have a Constitution, Articles of Association, and Rules that are not in conflict with WCPT's Articles of Association.

We agreed to take this forward on behalf of APCP. I contacted Phil Gray who signed the consent to be a founder as the representative of the member organization (CSP) and this was returned to Barbara at the end of November 2006. She has thanked us for our support.

Other countries who have also agreed are

Australia  
Cyprus  
Canada



## APCP Matters

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Ireland  
Kenya  
Netherlands  
New Zealand United States of America.

Barbara has proposed to WCPT that the organizational meeting of this new sub-group will be held at the WCPT in Vancouver.

*Our Mission (draft):*

The purpose of the International Organization of Physical Therapist in Paediatrics is to provide a means by which WCPT members having a common interest in the physical therapy problems of children and concerns of their families may meet, confer, and promote these interests.

*The objectives of this organization are:*

1. To foster cooperation between physical therapists practicing in paediatrics throughout the world.
2. To encourage improved standards and consistency of practice in paediatrics care by physical therapists.
3. To advance practice by communication and exchange of information.
4. To encourage scientific research and promote opportunities for the spread of knowledge of new developments in the field of paediatrics.
5. To assist WCPT member countries in the development of recognized Sub-sections in paediatrics.

*The next International WCPT Congress is in 2-6 June 2007, Vancouver, Canada and the overall Congress theme for 2007 is Moving Physical Therapy Forward*

I am sure you will all agree this is an exciting venture and will enable us to network and cooperate with our paediatric colleagues around the world and also to promote the work of APCP. We will keep you informed of progress.

PETA SMITH  
Chairman APCP February 2007

### APCP Affiliated Groups

You should all be aware that in the past 3-4 years APCP has developed 3 new 'Affiliated Groups' – the Neonatal, Neuromuscular and Critical Care.

These groups have been developed to bring together members of APCP working within specific clinical areas and to support members who may be treating a smaller number of children from these groups.

Affiliated Groups aim to utilise the skills and knowledge of specialists within their field:

- to promote the role of paediatric physiotherapists within each clinical area;
- to develop and promote the use of evidence based practice;
- to promote and ensure a national standard of best practice;
- to develop and promote access to continuing professional development opportunities through conferences, course and study days.

In addition the groups provide a forum for clinical networking and peer support.

*Would you like to be part of an affiliated group?*

As a member of APCP you are all able to access any or all the Affiliated Groups - but if you have a particular interest in a specific clinical area why not consider joining the Committee and really getting involved. **All of the existing Affiliated Groups need new Committee Members** - simply contact the representative for the group and find out more (contacts listed on inside back cover).

## APCP Matters

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APCP would also like to encourage the development of more Affiliated Groups for other clinical areas. If you are motivated to see the development of a group to promote your specific area of interest, why not contact the National Committee to discuss your ideas?

### *Development of affiliated groups*

The National Committee will consider any suggestion for a new group and decide whether or not it can be supported. It is suggested that Affiliated Groups are not condition-specific.

National Committee would then try to establish whether there is sufficient interest and commitment from the membership to develop the Group by advertising in the APCP Journal and on iCSP.

If an adequate response is received, APCP will then facilitate a discussion forum for all interested members, where members can discuss their ideas for developing the Group and potentially a Committee could be elected.

If you would like to see the development of a new Affiliated Group contact Laura Wiggins (laura.wiggins@ntlworld.com) to discuss your ideas.

### **APCP Business Administrator**

At last year's AGM, the Membership supported a significant subscription rise to enable APCP to employ a Business Administrator to support the Association's activities. On behalf of National Committee, I would like to thank the Membership for supporting this rise.

We are currently in the process of developing a comprehensive job description and are consulting with a Business Adviser with regard to the type of employment that would be most suitable for the Association, and the best way to go about recruiting someone to the job. It is not possible to give any further details at present, but we should have more information for the next Journal.

My time as Treasurer is now coming to an end and so once the end of year audit is complete, I shall be handing over the cheque book to Lynda New! Lynda has represented the South West Region at National Committee for several years, and I am confident that she will quickly get to grips with the financial aspects of the Association.

FIONA DOWN  
APCP National Treasurer

### **Neonatal Group AGM – Chairman's report 2006**

I am delighted to welcome you all to the neonatal group AGM in Glasgow. I thought I would just remind everyone what the neonatal group APCP constitution actually says, and how that relates to the work taken forward by the committee on your behalf.

1. To promote the role of this specialist area of paediatrics.  
What an excellent article "Hold me now" was in the 20th September edition of Frontline. The article highlighted the findings of the Bliss report on neonatal care across the UK and discussed the speciality of neonatal physiotherapy. I personally would like to thank the contributors from the neonatal committee who responded at extremely short notice to the journalist's tight deadline. It was encouraging to see the group's work promoted and perhaps this is an item for all our managers to read and digest.
2. To provide a forum for clinical networking, peer support, review and information on specific conditions.  
Professional isolation can be a problem for some physiotherapists who have limited time or experience in neonatal care. The links to the neonatal group, the further development of iCSP and the regional neonatal networks are the way forward for neonatal physiotherapists to connect with like-minded professionals.

3. To provide an expert body of skills and knowledge in a specific clinical field of paediatrics.  
This is highlighted by the amount of correspondence received by the committee requesting advice on all areas of neonatal physiotherapy. This includes putting forward the case to have dedicated hours for input to neonatal units. The debates also continue on iCSP.  
I was also asked to represent neonatal physiotherapists on the Forum for Maternity and the Newborn at the Royal Society of Medicine by attending a meeting in London in May. The details can be found in the Sept APCP journal, but it was decided in discussion with the committee that it was not the best use of time or limited resources to become a member of the Forum, and the National Committee of APCP was informed.
4. To develop and promote the use of Evidence Based Practice.  
If you are using iCSP, you will see the ongoing "thread" regarding the treatment of positional talipes, care pathways.  
Denise Hart, Senior Neonatal Physiotherapist, Southampton General Hospital, published an article in the June 06 APCP journal outlining the variability in physiotherapy treatment of talipes equinovarus. The neonatal committee has approached Denise and she has agreed, with 2 other experts in the field, to write an evidence based summary on the treatment, or to be more accurate, the non- treatment of positional talipes. So watch this space.  
The group has also been contacted in relation to producing respiratory guidelines for neonatal physiotherapy but this is in the very early discussion stage at present. We have explored the idea with 3 of the group's respiratory experts and I will be meeting with Di Coggings and Terry Pountney, who led the APCP work on OBPP and Hips evidence based summaries, to see how best to take this forward. I should also highlight the role of neonatal physiotherapists involved in research – Anna Mayhew and Emma Cameron, who were referred to in the Frontline article.
5. To promote and ensure a national standard of best practice by members working in neonatal physiotherapy.  
Peta Smith has been part of a working party from the National Committee of APCP looking at the development of a Competence Framework for paediatric physiotherapists, along with the CSP CPD Adviser Mairead O'Siochru. Representatives of the neonatal group have already been involved with Skills for Health in the production of the competences needed to care for families and their newborn babies. The plan will be to role out the work to the affiliated groups, building on experiences from those who have already developed a competence framework.  
See Sept Journal.
6. To develop and promote access to CPD.  
Here is where I refer to Fiona Price's report in her absence.

### *Education officer's report*

The work of the education officer this year has centred around coordinating the planning and execution of the proposed 3 day course for therapists involved in neonatal care. It was attended by between 12 and 17 physiotherapists and one OT. The course consisted of a respiratory day, a day on prematurity, pathology and philosophies of intervention, and a day on neurological assessment, follow-up and treatment. The course evaluated extremely well and was economically viable. It is proposed by the committee that the course runs approximately every 2 years providing there is an interested party willing to host and organise the event as the teaching and facilitating will be organised by the committee. We plan to run the course in early 2008 in Newcastle. Fliers will be circulated and posted on interactive CSP website after summer 2008.

We are still waiting to hear from APCP committee regarding accreditation for the course and will continue to pursue this.

Finally, I would like to thank all those members of the committee who participated in the organizing and running of the course and particularly to those who prepared teaching sessions.

## APCP Matters

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7 and 8 and 9. To elect a rep to APCP National Committee, to collaborate with APCP, and maintain formal links between APCP and the neonatal group.

Barbara's report will go into the details of this.

The neonatal group is now 4 years old and I think much has been achieved. There are some committee changes to report. Nicky McNarry, former secretary of the group and committee member, has decided to stand down due to family and work commitments.

Jenny Poole, Treasurer, and Barbara Haederle, APCP Liaison Officer, have completed their term of office and will be replaced by Pat Dulson and myself respectively.

I am glad to report both Jenny and Barbara will remain on the committee.

I would like to thank the committee for all their hard work over the last year, which has been done with only one face to face meeting (Oct in Newcastle), especially when changes to our services and the NHS are pushing us to even greater limits.

We continue to need enthusiastic physiotherapists to help the committee take on pieces of work identified as important to improving the standard of care we provide to our vulnerable babies and would encourage all of you to renew your membership of the neonatal group in the New Year. And just to finish, I would like to thank Hilary Cruickshank for all her hard work in putting together the programme for today on our behalf.

Finally, I would like to wish Peta Smith, one of the founder members of the neonatal group APCP, all the best for her new role as chair of APCP and she can count on our support.

ADARE BRADY  
Chair Neonatal Group APCP

FIONA PRICE  
Education Officer

# Research and Education

## RESEARCH

Well, here I am again – blank page staring out at me and the usual ‘what can I talk about’ panic beginning to set in. It has been a very quiet time ‘research wise’ since my last report as I have been travelling, then it was Christmas and New Year, quickly followed by Weightwatchers! Then, it’s time to write my report for this Journal - how time flies.

Perhaps I can fill in a bit of space telling you all how the questionnaire is going. You may remember I had a bit of a sticky time presenting my thoughts to adults with arthrogyrosis in the (vain) hope that the questions I thought important in finding out about life with the condition as an adult were valid. After they had wrung me out, the questionnaire was reformed, using tape recordings of their comments and later sending it out to 6 of the group for piloting and also for their comments. I am now awaiting the definitive list of adult members of TAG (The Arthrogyrosis Group) so that the questionnaire can be rolled out to as many people as possible. I am hoping to present the results at TAG conference in the autumn so I feel quite pleased with myself to be getting things going in January! New Year Resolution 7 – no more last minute stuff!

### Reliability testing:

I am about to start a new part time research job looking at the functional effects of avascular necrosis of the hip (AVN) in children. My remit is to measure range of hip movement and administer questionnaires (and chase their return). First of all my reliability in measuring hip movement has to be tested. This involves measuring hip ranges in 10 patients on two occasions two weeks apart – obviously without having access to the previous measurements. Strangely I feel a little apprehensive about all this – even though I have probably assessed range of movement on almost every day of my working life!

Reliability, as you all know, is the dependability, repeatability or reproducibility of research or a measuring instrument. Hopefully, for me with my shiny new goniometer, there will be minimal error and therefore high intra-rater reliability. However we know that measures of values are confounded with errors. Measurement theory recognises that all scores of human behaviour contain amounts of the variable being measured in addition to the error component. Since my assessment is a test/retest approach there will be one variable to measure with, for which I am hoping, a high intraclass correlation coefficient. Fingers crossed!

### Finding funding:

I have had a couple of enquiries from APCP members about sourcing funding for research – also from students who were required to show such knowledge in their project research proposals. As you know there are from time to time monies offered by APCP to assist in members’ research but this is not available every year and is dependent on funds being on hand and the quality and applicability of the proposal. The CSP also has some funds to assist in research – keep looking on iCSP as I find this to be a great source of information. Then there are some of the ‘medical’ charities such as ARC (the Arthritis and Rheumatism Council) who are very kindly funding my research. Funding can also sometimes be found via companies involved in health care. Smith and Nephew generously funded the Delphi study to formulate physiotherapy guidelines for patients with Ilizarov frames. Some of the drug companies have, I know, helped with physiotherapy research into respiratory conditions and cerebral palsy. The thing is to think laterally and not give up. Often information about sources of funding comes in just after the copy date for the Journal and the application date has come and gone before the next Journal. I do keep information about funding opportunities whilst still current so contact me if you need to.

I also had two queries about whether money was available to help with attending conferences when presenting papers. I know from experience, that being chosen to present a paper involves great expense for your 5 minutes of fame! I could not believe that I had to pay to attend the conference as well as pay air fare and hotel costs. A great expenditure but essential (I think) to raise the profile of paediatric physiotherapy. I was very, very lucky to find funds – many are not so lucky. Again look to the CSP – they have funds to help but again these often have deadlines so you need to keep looking. I was asked to discuss this with the National Committee, which I will do (and get back to the person involved) but I am not confident that APCP would ever have sufficient funds to be able to offer such support in the near future.

### CSP Research Database

Funding for research is currently undergoing major changes, not just funding for research projects and programmes but also funding to develop research capacity. To ensure that the CSP has a complete research picture to support its lobbying and to facilitate networking between researchers we are undertaking a survey of physiotherapists who have experience of undertaking research or who have postgraduate training in research.



## Research and Education

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The information from the questionnaire will be put into a new CSP database of researchers which will facilitate the networking mentioned above and help members contact researchers with expertise in specific research areas. The data will also be analysed and the CSP will produce a report about current physiotherapy research capacity. The report will also aim to identify current barriers to accessing research funding.

If you have any research experience at a postgraduate level and have not already received information about the survey and database please find the time to complete the questionnaire – it is vitally important for the future of physiotherapy research. The questionnaire can be completed online at [www.csp.org.uk/researchdatabase](http://www.csp.org.uk/researchdatabase). The deadline for completion is now Friday 29 June 2007.

If you have any enquiries about the questionnaire or how to complete it contact [researchdatabase@csp.org.uk](mailto:researchdatabase@csp.org.uk)

### Research Meetings:

I thought you might want to know about the following:

- Physiotherapy Research Society Spring Meeting.  
'Focus on Clinical Research'  
Cardiff 28th March 2007 [www.prs-uk.org](http://www.prs-uk.org)  
for details.
- Translating Research into Clinical Reality – a one day national conference.  
Liverpool 18th April 2007 contact:  
[a.stoker@liverpool.ac.uk](mailto:a.stoker@liverpool.ac.uk)
- Third Colloquium of Qualitative Research in Allied Health Professions: Client Focused Care.  
University of East Anglia 3-4 May 2007  
contact: [shortcourse.ahp@uea.ac.uk](mailto:shortcourse.ahp@uea.ac.uk)

Well that's it. Please keep a look out in your e-mail if you are on the Research List as I am busy up-dating it. I'm not sure what can be done if you have moved on and therefore I cannot contact you – if this applies to you and you still want to be on the list please either fill in another form from the back of the Journal or e-mail me.

JEANNE HARTLEY  
Research Officer

## EDUCATION

Let me introduce myself, my name is Dawn Pickering. I have been a member of APCP for 24 years! I worked in Paediatric Physiotherapy both in Cardiff and Caerphilly, enjoying all aspects of both Acute and Community. After completing a Masters Degree in Child Health, I moved into physiotherapy lecturing in Cardiff University in 2002. As well as teaching undergraduate students, I now run a Masters Programme including a Postgraduate Certificate in Paediatric Neurorehabilitation. It's never easy to follow in the footsteps of someone who has developed a role and is well known within APCP. However, having been invited by Adele Leake to join the Education and Research committee last year, I now find myself chairing this and being asked to contribute in various ways for APCP. I am grateful to Adele for the organization of the many files she has passed on to me so that I can maintain some form of continuity as I get to grips with this role. I wish her well in her new venture of motherhood.

The New Year has started with a few pressing issues. Firstly, the CSP are nearing completion of their consultation document relating to Clinical Interest Groups and accreditation for courses outside Higher Education Institutions. The Committee needs to make a fuller comment on this document and our representative Sue Coombe has attended these meetings. In principle, CSP endorsement for our courses will be good. Adele set up a very good system for interested members to apply to the Education and Research committee for accreditation, to date we awarded one course last year. If members are interested in applying to have a course they have designed accredited by APCP, then please email me for the application form, my contact details are given at the end of this report.

Secondly, there are 2 courses being run in the Spring. The first APCP Assistants course is being run on 28th February in Nottingham. Sarah Crombie is going to facilitate this day assisted by Lyn Horrocks. This assistants' course could be run again in different geographical locations. If members could find a cheaper venue for 30 people it would be more cost effective to run.

'Physio First' is an organization for private practitioners and had requested a 'Paediatric day', this is being delivered on 20th April in Nottingham by Jeanne Hartley, APCP's Research officer and Geraldine Hastings. In the information Adele has passed on, I do have some contact details for speakers with their specialties but it would be good to have more across the country. If you consider you could offer to do some occasional lecturing for APCP then please send me your CV and the Education and Research committee can consider your application.

## Research and Education

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We aim to assist in the professional development of our members and the popular 'Introduction to Paediatrics' course did not run last year. A decision was made to offer the course as stand alone days to enable the unemployed graduates to access it more easily. It usually rotates around the country and this year it is the opportunity for London to host it. I hope to be able to make further progress in organizing this over the next few months.

I will endeavour to get to grips with the information passed on from Adele, meanwhile if I overlook something that's a burning training need for you, get in touch and share your idea. The advent of an administrator will make a big difference to this Education officer's role, so I hope in due course to be able to concentrate on course development and delivery rather than organizing them.

DAWN PICKERING  
Education Liaison Officer

## Publication in Progress

### Physiotherapists Working with Children: Information to Guide Good Practice

This tool is designed to ensure physiotherapists have fast access to information addressing every issue surrounding child well-being in the UK. The resource provides web links to the policy documents and legal frameworks which physiotherapists need to be aware of and uses the CSP iCSP networks to provide short write-ups on the key issues.

The tool covers issues spanning the health, educational, social care and voluntary boundaries and includes children from all walks of life, age and level of disability. It is therefore essential reading for any physiotherapist, NHS or independent practitioner to ensure that they are fully cognisant with issues affecting children.

Léonie Dawson  
Professional Adviser  
Chartered Society of Physiotherapy



## Regional and Affiliated Groups Reports

### SOUTH WEST

Well winter went quickly this year didn't it? That could be because we are all working so hard or just because it didn't get that cold. Either way spring is most welcome.

We are planning the year's AGM for Monday 1st October to be held at Salisbury District General Hospital. This study day will relate to the various aspects of Orthotics we use with our paediatric caseloads. Further information will be available in the next issue.

Please contact me if you have any ideas for future courses and suggestions for doing study days, evening lectures, term-time/school holidays. Our region is geographically large and if you would like courses etc in your locality please contact me and we will try to accommodate.

We are still looking for colleagues to join us on the regional committee as committee members. The meetings occur about 4 times a year with a small amount of work for each member to carry out following each. You can become as involved as you wish to. We continue to look for representation for South Devon and Cornwall especially. If interested please get in touch.

LYNDA NEW

### SCOTLAND

Since the National APCP Conference in Glasgow on 11th, 12th and 13th of November 2006, the Scottish Regional Organising Committee have not met face to face. There has been lots of communication by phone and email in order to complete all the post conference business and tie up the loose ends. Unfortunately we had to get back to work too! However the plan is to organise a committee meeting in February to get together and plan a study day for later in the year. Suggestions for that study day are very welcome.

#### Speakers' Expenses

All the conference speakers were sent an expenses form, with the suggestion that the prompt submission of expenses would facilitate prompt payment. Ann Kendal our treasurer reports that the final payment cheques were sent out before Christmas, she is still waiting for two expenses forms to be cashed. Although the final financial report is not quite completed, the conference account shows a profit which will enable us to return "Start Up" conference funding, received from the national treasurer Fiona Down.

#### CDs of the Conference presentations

We are aware that conference delegates who applied and paid for a CD of the conference presentations must be wondering what has happened. Gillian Ferguson our Glasgow based committee member has had the unenviable task of chasing up the audiovisual team at the hotel who undertook to produce them. I am very happy and relieved to report that Gillian was able to collect our ordered CDs this week and they will be posted out pronto!

#### Conference evaluation forms and conference feedback

The Scottish Regional Organising Committee are very grateful to all the delegates who took the time to complete the Conference evaluation forms. They made interesting and informative reading. Julie Burslam, our committee member who represents the North East of Scotland has done a very thorough job in collating all the feedback information from the evaluation forms into a comprehensive report.

There was very positive feedback on the conference organisation, structure and content of the programme, trade exhibition, hotel location, accommodation including the conference facilities and the conference dinner/ceilidh was voted a great success with a record attendance of one hundred and twenty nine covers for dinner. The ceilidh band were excellent at calling the dances to help those of us who were not too sure of the steps!

The feedback about the inadequate catering provided by the hotel for "The Taste of Scotland" on Friday and lunch on Saturday was very helpful, supporting the views of the organising committee and enabled us to achieve a positive outcome with the hotel.

Through out the planning and organising of the National APCP Conference 2006 in Glasgow, the organising committee found the reports from the National APCP Conferences in Liverpool and Swansea very useful. The Scottish Regional Organising Committee will endeavour to complete their report by the Spring and send it to the South East Regional Organising Committee.

The APCP Conference tablecloth is packed in my suitcase to take to the National Committee Meeting in London, on 2nd February. I look forward to handing it over to Lucy Erasmus with all good wishes to the South East Region for a very successful National APCP Conference 2007.

ALISON GILMOUR

### NORTH EAST

As we look forward to longer days and a little more sun and a little less rain we also think about the courses planned for the coming year.

## Regional and Affiliated Groups Reports

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Our next course is about “**Home-based Neonatal Care**”. The course will be held at the school of Life Sciences at Bradford University. We are not yet in a position to give full course details but they will appear on iCSP as soon as they become available and a flyer will be sent to all members. Why not photocopy the flyer for your department. It may encourage new members. Can I encourage you to support the AGM, which will be held during that day and perhaps even offer your time to be on the committee. The AGMs have not been well attended over the past few years and the committee want to be in a position to continue providing good quality study days for you. We cannot do this without your support.

The next course will be in September and entitled “**Sport for All?**” looking at the implications of “Every Child Matters” and how disabled children can access sport, including information on Profiling for DSE events. Again do look out for details on the website.

HEATHER ANGILLEY

### LONDON

STEPHANIE CAWKER

### TRENT

SUZANNE LAWRENCE

### WEST MIDLANDS

We are running a gym ball course, with Joanne Elphinstone as the tutor, in May this year. The provisional date is 24th May 2007 which will be confirmed following our committee meeting which is on 1st Feb and the details will be posted on iCSP. For those who have already emailed me about the course, I will email you with the confirmed details ASAP. If I haven't contacted you by the time the journal is published, please email me again on Helen.bayliss2@nhs.net.

I haven't had any suggestions about study day topics or times e.g. evening lectures, full days, term time, weekend or holidays. Please let me know if you have any suggestions at all!!!

HELEN BAYLISS

### SOUTH EAST

The New Year has seen lots of new faces joining the regional committee, which is very exciting. I would like to take this opportunity to welcome the following people onto the committee: Kerry McGarrity, Roz Florida-James, Jane Forster, Sandra Speller, Mandy Humphries and Emma Williams

who has also taken on the role of treasurer (thank you very much, Emma).

We are currently planning a study day (or two) for the summer considering the role of the physiotherapist in the care of young elite athletes. We are making good progress with the organisation of this event and hope that we will be able to advertise it in the spring, so keep your eyes on iCSP and in this journal.

The conference is continuing to be meticulously planned by a number of very dedicated people living in this area and promises to be a very informative and exciting weekend. The title and theme is 'Everybody's Special; Theory and Practice'; please see the conference advertisement in this journal for more information about some of the speakers. Other advertisements will be posted on iCSP, in Frontline and in this journal, so there will be no excuse for not knowing all about the event! Applications will be welcomed very soon.

Please do not hesitate to contact me or one of the other committee members if you have any suggestions for future study days; we aim to please!

LUCY ERASMUS

### EAST ANGLIA

PRIYA JACKSON

### WALES

Season's greetings to all Welsh members, I hope everyone had the Christmas they wanted and the New Year that they deserve. The Wales committee continues meet regularly and is very active in the region, all due to the hard work of the members, and hopefully 2007 will be as productive for us as last year and we already have some dates for your diaries.

The regional AGM is on Wednesday March 28th at St David's Children's Centre, Cardiff and is in combination with a “Muscle Strengthening in Cerebral Palsy Course” led by Gill Holmes. Flyers for the study day and the AGM have gone out to all members and course application forms need to be in by the 5th of March. The AGM will be held over lunch, starting at 1.00pm and all members are welcome to attend. Nominations for committee vacancies need to be sent to our secretary Wendy Williams at Eveswell Clinic, Newport.

During 2007 we hope to organise a Spinal Surgery study Day and more wheelchair courses for both members and non-members, also last year our combined research meeting with Cardiff University was especially successful and Geraldine Hastings will be organising another meeting in September.

## Regional and Affiliated Groups Reports

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Finally best wishes to all welsh members in 2006 who have either got married, had babies, left for pastures new or moved into the area. In that order I will say either Good Luck, Heaven help you, commiserations and welcome.

DIANE ROGERS

**NORTH WEST**  
ELAINE LLOYD

**NORTHERN IRELAND**  
GEMMA LIPSCOMB

### NEONATAL SPECIAL INTEREST GROUP

As I sit trying to write my report I find it hard to realise that the conference was already almost 3 months ago! What I do remember is the feeling of living in a bubble whilst in Glasgow – and trust me it was not solely due to the alcohol, although there was some alcohol consumed (no names mentioned). For those who were present or have been at conference in the past you will know what I am talking about. You will have been fortunate enough to experience the feeling of being with your fellow professionals, learning and sharing in ideas and developments.

For the Neonatal Group it was a 'first' as we joined in the National APCP Conference Programme. All the hard work of the organising committee was evident as they presented a varied and stimulating programme with something for everyone and also some very topical and specialised topics as well.

For many it was the culmination of a lot of hard work and also the opportunity to meet and hear speakers who have influenced their clinical work over many years. I personally would like to say a really big and heartfelt THANK YOU to the organising committee for all their hard work in putting this fabulous event together.

We were very fortunate to have 2 excellent speakers. Our first, Dr Laila de Groot from Amsterdam who gave presentations on theories of development, assessments and follow up of pre term infants. Our second, Dr Gopi Menon from Edinburgh who was looking at follow up and outcomes of pre terms over the past 10 years. Both were well received and gave us all food for thought to continue in our work with this ever growing and developing area (No pun intended).

I have thoroughly enjoyed my time as Liaison officer for the Neonatal group APCP and am pleased to remain on the committee. I wish Adare Brady all the best as she carries on from here. I would also like to

thank the National Committee for the warm welcome they have given me during my time with them. All the best and thank you for all the hard work you do.

BARBARA HAEDERLE

**CRITICAL CARE SPECIAL INTEREST GROUP**  
MEL LINDLEY

### NEUROMUSCULAR SPECIAL INTEREST GROUP

It was with great pleasure that the Neuromuscular special interest group welcomed Mrs Lesley Smith to their committee meeting in November 2006. This was one of Mrs Smith's last roles as chairperson of the APCP. One of the difficulties in being, what is still perceived as many of the members, to be a 'new group', is coming to terms with the roles, responsibilities and expectations of the APCP in terms of the work required by the committee members. Mrs Smith was able to discuss this with group at length and offer advice and support with the ongoing work of the group and enable this to be dovetailed with the aims and objectives of the APCP.

Sadly, this committee meeting also saw Gill Holmes, our liaison officer stepping down and the committee thanked her for her input into the group's first eighteen months. Elaine Scott, secretary and Marina Morrow, chairperson will continue with the role of liaison officer and share the responsibilities accordingly.

The committee are currently in the midst of final preparations to the APCP neuromuscular special interest group meeting and AGM which runs alongside the annual Muscular Dystrophy Campaign (MDC) symposium on Wednesday 28th March 2007 at the Birmingham Hippodrome. For further details on this course and for information on the MDC symposium please contact Marina Morrow, Chairperson (marina.m@ntlworld.com) or Elaine Scott, secretary (E\_Scott@btopenworld.com).

The special interest group works in partnership with the charity Muscular Dystrophy Campaign and many of you will be aware of the work undertaken by Elaine Scott in her role as co-ordinator of the North Star Clinical Network. This has led to the standardisation of physiotherapy assessments for ambulant children with Duchenne muscular dystrophy. The Network consists of 17 specialist paediatric muscle centres from across the U.K. The special interest group are now pleased to work in conjunction with Dr. Anna Mayhew who is currently undertaking a similar project to standardise the assessment procedures for children and young people with spinal muscular atrophy. Watch this space...

MARINA MORROW



## Tribute to Noreen Hare



*Noreen Hare and one of the scores of teddy bears at the University Hospital children's departments.*

### Noreen Hare 1934 -2006

The work of Noreen Hare will have influenced the approach of many physiotherapists to the treatment and management of people with neurological impairment.

After gaining her physiotherapy diploma with distinction from Guys Hospital in 1956, Noreen joined the staff at the Westminster Hospital, and it was during her rotations there that she was introduced to working with children. She went on to study under Berta Bobath and subsequently became a Bobath tutor. She spent six years working in Montreal, returning to England in 1969 to take up the post of Superintendent Physiotherapist at the Cheyne Centre in London. The Cheyne Centre (now incorporated into the Chelsea and Westminster Hospital) was an internationally recognised centre of excellence providing true multidisciplinary treatment, management and education of children with cerebral palsy. Noreen was also the Centre's Course Director, organising a highly regarded education programme for doctors, therapists and teachers.

Noreen continuously questioned herself and her colleagues, encouraging critical analysis of practice long before the term "clinical reasoning" came into standard use. Her fascination with cerebral palsy and related conditions was matched and complemented by that of Dr. John Foley, the Paediatric Neurologist at the Cheyne Centre for many years. Her time at Cheyne also coincided with the time of the Bobaths at the Bobath Centre, Nancie Finnie at the Charing Cross Hospital, David Scrutton at the Newcomen Centre (Guys Hospital) and Pauline Pope at the Royal Home in Putney, and there were frequent discussions amongst these and other innovative people. They were exciting times! Noreen challenged the established practice of using positive signs (abnormality of tone, release or persistence of reflexes, etc.) as a basis for physical assessment and treatment of cerebral palsy, and instead suggested that analysis of the body's ability to deal with the opposing forces of gravity and the supporting surface provided a more consistent and easily interpreted baseline for therapeutic intervention. She recognised the fundamental importance of learning to accommodate to, and "anchor" through, a base of support as a prerequisite for functional activity, and that



## Tribute to Noreen Hare

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this applied to the lying position as well as to sitting and standing. These ideas were incorporated into her development of the Physical Ability Scale. She established interdisciplinary group sessions, often including parents, based on Conductive Education, with the children grouped according to their levels of ability as identified by the Physical Ability Scale. Her ideas were clear and simple in her own mind and she had the knack of teaching patients, parents and carers to understand the effects of the environment and gravity on the body and therefore to improve their (or their children's) abilities themselves through simple management techniques. It was a puzzle to Noreen that parents and other "lay" people often grasped the basics more easily than therapists did!

In the early eighties, while still at Cheyne, Noreen was part of a multi-disciplinary team helping to set up a Spastics Society in four cities in India. She spent four weeks in each city, advising, lecturing and teaching, and came to love India and the people there. She was particularly proud of her personal association with Mother Teresa.

In 1983, Noreen left Cheyne to take up the post of Superintendent Paediatric Physiotherapist at University Hospital in Nottingham. Her responsibilities included bringing together the children's services across the whole of Nottinghamshire.

In 1986, Noreen presented her ideas to the Physiotherapy Congress in Oxford. In 1990, the Hare Association for Physical Ability was founded in order to disseminate the Hare Approach, to clarify and document the ideas, and to promote research. A HAFFPA web site is currently in the final stages of completion.

Following her retirement in Nottingham in 1992, Noreen carried on expounding her ideas through numerous courses, workshops and in consultancy work. She continued to enjoy singing in local choirs, walking with her beloved dog, Bess, and sketching whilst on her travels.

In 2000, Noreen was awarded with a Fellowship of the Chartered Society of Physiotherapy for her contribution to Paediatric Physiotherapy and, in particular, for her work with children with cerebral palsy.

Noreen was passionate and uninhibited by convention in her work, as she was in all other aspects of her life, as evidenced by her numerous letters to a succession of Prime Ministers! She had an unceasing enthusiasm for the children and their families. She was a brilliant observer of human movement, and a stimulating and inspiring teacher and manager. Working with her was always intriguing, exciting and fun. Her ideas continue to influence the treatment and management of children and adults with motor impairment today. The Physical Ability Scale has been adapted to suit various groups in the field of neurology and will continue to be the foundation of much future work. She has been a good friend and a mentor to many and will be very much missed both personally and professionally.

Noreen had been frail for some time and died on 31st October 2006. The funeral was held at the Church of the Holy Spirit in Nottingham on 14th November 2006, with Noreen's brothers officiating.

**Carolyn Nichols, Pauline Pope, Linda Whitaker**



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# 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.

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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**

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Critical Care Group

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# Writing for the APCP Journal

The aim of the APCP Journal is a forum to disseminate original research, facilitate continuing education for paediatric physiotherapists and provide an opportunity to debate all controversial issues.

Most articles should be no longer than 3,000 words excluding references and abstract. The types of article identified to achieve these aims include:

## Peer reviewed articles

Papers submitted under this section are all reviewed blind.

- *Research Report*

A report which permits examination of the method, argument and analysis of research using any method or design (quantitative, qualitative, single case study or single case design etc).

- *Scholarly paper*

A paper sharing ideas and experience or reviews in a specific area of practice.

- *Audit Report*

A report which contains examination of the method, results, analysis, conclusions and service developments of audit relating to children and physiotherapy, using any method or design.

- *Review Paper*

A critical appraisal of primary source material on a specific topic related to children.

- *Treatment Report/Case Studies*

A report of the treatment of a child or series of children which provides a base line description of established treatments, or a new insight into the techniques or treatment of children with a specific problem.

Case reports should be no longer than 2,000 words.

- *Technical Evaluation*

A description of a mechanical or technical device used in assessment, treatment, management or education to include specifications and summary evaluation.

- *Service Development Report*

A report of changes in service delivery aimed at improving quality.

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- *Abstracts of Theses and Dissertations*

Abstracts from research projects, including those from undergraduate or higher degrees, audits or presentations. They should be up to 300 words and where possible the conventional format: introduction, purpose, method, results, discussion, conclusion.

- *Letters and replies to APCP*

These can be about any issue pertinent to paediatric physiotherapy or APCP. They may relate to material published in the previous issue(s) of the APCP journal. Copies of replies to editor.

- *Book reviews – up to 500 words*

## Preparation of Editorial Material

Copy should be produced in Microsoft Word. Wherever possible diagrams and tables should be produced in electronic form, e.g. Excel, and the software used clearly identified.

The first page should give:

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- Up to three relevant professional and academic qualifications for all authors and their current positions
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The title page should give:

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### Permissions and Ethical Certification

Protection of subjects: Written permission from children, parents or guardians to publish photographs of recognisable individuals must be enclosed with the material, or obscure facial features. For reports of research involving people written confirmation of informed consent is required.

Any paper based on a study of children, families or staff, submitted to the APCP journal, must have received ethical approval and state by which REC committee. If for any reason your study is exempt, you must make a statement with the covering letter explaining why it is not applicable.

The use of names for children is encouraged in case studies for clarity and humanity, but they should not be their real names.

### Submission of Articles

A disk or CD Rom and 2 hard copies of each article should be sent with a covering letter from the principal author stating the type of article being submitted.

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## REGIONAL & SUB-GROUP REPRESENTATIVES

### EAST ANGLIA

Priya Jackson  
Children Centre  
Southend Hospital  
Westcliff on Sea  
ESSEX  
SS0 0RY  
[priyajackson@southend.nhs.uk](mailto:priyajackson@southend.nhs.uk)

### LONDON

Stephanie Cawker  
The Wolfson Centre  
Mecklenburgh Square  
LONDON  
WC1N 2AP  
[cawkes@gosh.nhs.uk](mailto:cawkes@gosh.nhs.uk)

### SCOTLAND

Alison Gilmour  
Physiotherapy Dept  
Braidburn School  
107 Oxbgangs Rd North  
EDINBURGH  
EH14 1ED  
[Alison.gilmour@braidburnedin.sch.uk](mailto:Alison.gilmour@braidburnedin.sch.uk)

### SOUTH WEST

Lynda New  
Physiotherapy Dept  
Milestone School  
Lonford Lane  
GLOUCESTER GL2 9EU  
[Lynda.New@glos.nhs.uk](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto:helen.bayliss2@nhs.net)

### NORTH EAST

Heather Angilley  
5 Ridgeway  
GUISELEY  
LS20 8JA  
[hangilley@aol.com](mailto:hangilley@aol.com)

### OVERSEAS

Public Relations  
Officer

### NEONATAL CARE GROUP

Barbara Haederle  
Paediatric Therapy Unit  
Pontefract General Infirmary  
PONTEFRACT  
[Barbara.haederle@midyorks.nhs.uk](mailto: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](mailto:melanie.lindley@sch.nhs.uk)

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Gait Laboratory  
Alder Hey Children's Hospital  
Eaton Road  
LIVERPOOL, L12 2AP  
[Gill.Holmes@rlc.nhs.uk](mailto:Gill.Holmes@rlc.nhs.uk)

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