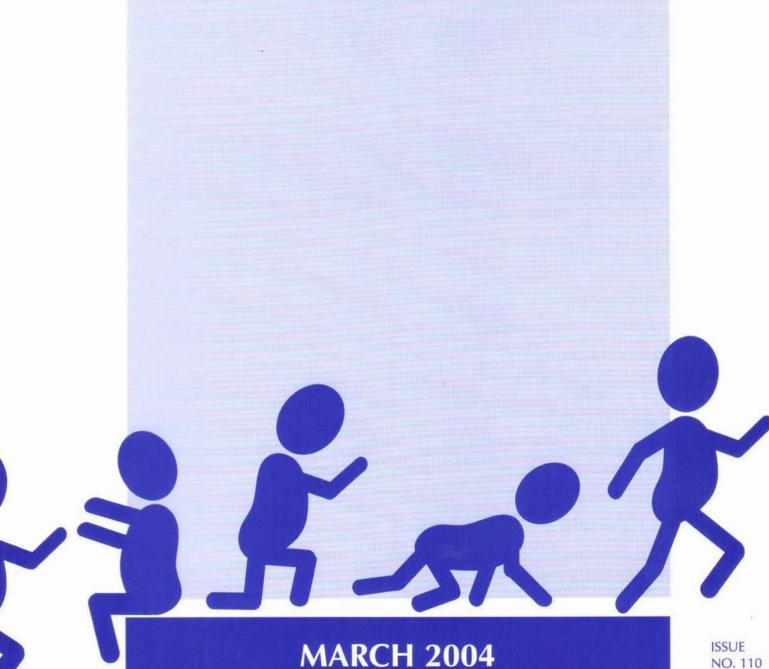
ASSOCIATION OF PAEDIATRIC CHARTERED PHYSIOTHERAPISTS



NO. 110

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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

Firstly, let me take the opportunity, even a little belatedly, to wish you all the very best for your endeavours in 2004.

A big welcome is also extended to those of you who have joined APCP as new members this year. It is important that the association continues to grow and that all its members take an active part, even if this is in a very small way. It is only by sharing and pooling our knowledge and expertise that we will be able to influence the policies that are made by the Strategic Health Authorities, the Department of Health and Central Government amongst many others to ensure that we are able to provide the support and care for the babies, children and adolescents that are in our care and also offer the support that is needed by their families.

It is not possible for physiotherapists to work in isolation any more. The National Committee of APCP recognises that by working with other professionals they will be able to put forward a more comprehensive and wide reaching case for moving national strategies forward in a positive and beneficial way. Closer links are being forged with the Chartered Society of Physiotherapy to ensure that all our members have the support that they feel they need in all areas of their clinical practice and to provide the start of an influential base for all thoughts and ideas.

Our current web site is already out-moded and we are looking seriously at producing an interactive site that can be linked with ICSP to provide an information resource for both our members and our service users. This is all very exciting stuff and will hopefully be ready for us all to access in the very near future. Then we have our new style journal - don't forget that the Editorial Board would like to receive your comments on the changes being made here!

However, the National Committee cannot move these things forward without the help of all of you. You may decide that you are able to take a pro-active part in APCP by taking up a position on a regional or national committee. There are always vacancies for those of you who feel you have something to offer, especially at this time of year. Many of you will feel that you could not, for a variety of reasons, do this. But please make your voice heard. By responding to questionnaires at study days and those sent out by your regional committees you can have your say. Write to the Journal; you can put forward your point of view and seek support from your colleagues. If you wish to write an article or have your research published so much the better, with peer review coming on line, you will be up there with the best. Don't forget to use and contribute to ICSP and to our own web site (details will be announced as soon as possible). Keep your eye open for central publications and draft papers and comment if you can. You are the people who can influence the future of paediatric physiotherapy.

It will be excellent to meet as many of you as possible at National Conference in Liverpool. Try to come along, it will be good fun as well as a learning opportunity and a time for networking and making new friends.

Sally Braithwaite

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Sally Braithwaite - Editor

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LETTERS

Adare Brady Chair APCP 8 Ballyloughan Avenue Ballymena BT43 5HN N Ireland

Dear Sally, Re: Applications for personal bursaries

It has been brought to my attention that some members of APCP are asking the National Committee to fund courses, personal bursaries etc. I would like to remind members that this is the responsibility of the regional committees and not the National Committee. Members should contact their employing authority or regional committee for financial support.

Yours sincerely, Adare Brady

Bernadette Johnson Senior Physiotherapist in Rheumatology Birmingham Children's Hospital. Dear Sally

In response to Clair Culligan's letter (Dec 2003) I felt compelled to write to you regarding the management of children with JIA. Since Clair was a recent attendee on our course, I assume it is my talk to which she is referring. I feel that some of the remarks outlined in her letter have been taken out of context and therefore I would like to take this opportunity to answer some of the questions she raised.

Clair is right when she suggests that there has been a fundamental change in the physio management of JIA. This has occurred over the last few years alongside the advances in medical management. We are fortunate that the majority of children with JIA today, have their disease under better control, with less deformity and loss of function, than was seen five years ago. Because of this therapists can often avoid working on acutely inflamed, painful joints, and in our unit we often wait until post joint injection (or other intervention e.g. IV methyl pred) to fully assess and treat each child. We are fortunate that most of the children in our care have joint injections fairly quickly after diagnosis and so we can afford to wait. However I appreciate this is not the case for all therapists.

With hindsight, I can see that my reference to child abuse was obviously ill thought out as child abuse is the intentional harm of children and I believe that no therapist would intentionally harm a child. However, I also think that we should not cause unnecessary pain to a child and I believe what I said, that to do so would be like child abuse to me (This was a statement of my personal feelings, and one which I did not intend to be taken quite so literally, nor did I intend to imply that parents might accuse therapists of such a deed). But therein lies the problem facing many therapists as to what constitutes necessary pain and what doesn't. In certain situations this is often very clear cut e.g. life or death events, treatment of fractures etc. In the treatment of JIA this is not necessarily the case and as Clair quite rightly points out in her letter, there is perhaps still some variation in practise. There is little in the way of evidence as to which methods of therapy are most effective except anecdote. Like Clair, many of us use our experience to govern our clinical practise. My experience with these children (as well as the experiences of many of my colleagues), has led me to change my approach to practise what I see as a more gentle and equally as effective approach for the majority of these patients. Of course there will always be exceptions to the rule, for example where medical management is not so effective, or late referrals to physio where a deformity has already occurred. Even in these circumstances the locus of control should remain with the child in order to develop and maintain a good therapeutic relationship which will potentially reap greater long term benefits. Some children are prepared to push themselves harder and work into the painful range in order to achieve benefits more quickly, and I agree with Clair that good communication and motivation are important in engaging patients in activities which may cause some discomfort. However if a child or parent refuses to continue with such activities I feel it would be both unfair and unwise to continue to do so, as this

Letters

has implications for issues of consent. I wonder how many therapists tell their patients that there are differing approaches and let them choose which they would prefer!

When treating a child with JIA it is important to remember that it is not all about achieving physical perfection. Psychosocial issues surrounding a chronic illness can have a major impact on these children as well as their families, and therapists can have a major role to play in ensuring their overall well-being. Asking patients and their families to carry out long-term and painful exercises at home can have detrimental consequences, and Carrie Britten has produced some very good research which supports this.

I feel that the role of the therapist working with these children is changing. Although we are there to manage the physical aspects of their disease, there is greater emphasis on psychosocial well-being, as well as having a role to play in health promotion, particularly in encouraging a 'normal' active and healthy lifestyle. If we are to be truly holistic we should embrace these changing roles wholeheartedly.

It was unfortunate that Clair was unable to discuss her concerns with me or my colleagues while attending the course as I'm sure this would have promoted some discussion and debate. However I hope my reply goes some way to answering some of the queries and concerns raised in her letter. If she or any other therapist would like to visit our unit in the future they would be welcome to do so.

Yours sincerely Bernadette Johnson

Dear Sally

Following a recent meeting of the Allied Health Professionals committee of the British Society of Paediatric and Adolescent Rheumatology (BSPAR) I have been asked by the committee to respond to the letter in the December issue.

The committee is multi-disciplinary involving Nurses, Occupational Therapists and Physiotherapists all of whom specialise in Rheumatological conditions in childhood. We have representation from the many specialist Rheumatology units throughout the UK.

I am not sure that we were talking about different techniques but rather in semantics. It is important that we carry out the stretches to the joints and the soft tissues, especially when the joints are active. The child may feel the tight uncomfortable feeling of the stretch, but the joint should not be pushed beyond the tolerance of the child, as this will lead to an increase in muscle spasm. Each child should be assessed as an individual and the treatment plan changed accordingly. When working with an active or painful joint we should use all the techniques and therapeutic modalities available to increase the joint range e.g. hold/relax, contract/relax, hot packs, hydrotherapy.

If a child is in considerable pain and not co-operating with treatment, then the therapist should contact the medics to reassess the disease controlling drugs and pain medication.

Fundamentally, the treatment of the child with JIA must involve the cooperation of the child and the family; as therapists we must be aware of the subject of child abuse and the perception of what is abuse.

HD Murphy, MCSP, Rehabilitation Services Manager with special interest in Paediatric Rheumatology Wexham Park Hospital, Slough In liaison with Sue Maillard, MCSP, Clinical Specialist in Rheumatology Great Ormond Street Hospital, London Samantha Old, MCSP, Clinical Lead Paediatric Physiotherapist Northwick Park Hospital, London Jan Scott, MCSP Birmingham Children's Hospital, Birmingham and Yvonne Rogers, MCSP Senior I Physiotherapist Wexham Park Hospital,

Slough

Letters

Any correspondence Elaine Murphy MCSP Rehabilitation Services Manager Wexham Park Hospital, Slough, Berks SL2 4HL 01753 633532 helen.murphy@hwphtr.nhs.uk It is important that we can assure parents and the child that we are not causing unnecessary pain. This assurance leads to greater commitment from the child and family in the implementation of physiotherapy programme.

As therapists we were disappointed with the results from the question on the CSP interactive website on passively moving joints, especially during the active stage. The experience of the group has found it is important to move the joints passively/actively assisted (if the child is able) to help maintain and increase the joint range of muscle power through the available range of all stages of the disease.

As a group we have put together a booklet for those clinicians not experienced in assessing the child with Juvenile Arthritis. We are hoping for publication in 2004.

HD Murphy, MCSP, In liaison with Sue Maillard, MCSP, Samantha Old, MCSP, Jan Scott, MCSP and Yvonne Rogers, MCSP.

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Dear Mrs Braithwaite

Re: Sleep Systems

In Shropshire we are unable to provide sleep systems for any of our clients, because funding has not been made available.

I would be very grateful to hear from anyone who has been able to secure funding or is in the process of doing so. How did you do it?

We need to be able to give our managers information relating to long term compliance with the equipment and the benefits of its use.

Please let me know if you have any information regarding these areas.

Thank you

Yours sincerely Johanna Saunders

Beverlee Robertson MCSP Paediatric Physiotherapist Physiotherapy Dept., Pinderfields General Hospital, Aberford Road Wakefield WF1 4DG Dear Mrs Braithwaite

I would be pleased if you could publish this letter in the next APCP journal.

I am a paediatric physiotherapist who is soon to begin a 12 month secondment to a local Sure Start programme. I would be grateful to hear from other professionals who are carrying out a similar role to discuss their experiences and possibly arrange a visit to their area. I would also be interested to hear from anyone who knows of any videos available for purchase of child motor development from 0-5 years.

Thank you for your assistance

Best regards Beverlee Robertson MCSP

Letters

Pat Escott and

Dear Sally

Chris Baggett,

Community Physiotherapy

We have a working party looking into the provision of specialised equipment for children with special needs in schools.

West Park Rehabilitation

Hospital

Park Road West Wolverhampton

Does anyone know of protocols for joint funding, maintenance and insurance of equipment between health and education?

WV1 4PW Tel. 01902 444282

We would be grateful to hear details of systems that are in place and working

Fax. 01902 444034

well.

Email: pat.escott@wolvespct.

Thank you for your help.

nhs.uk or

chris.baggett@wolvespct.

Yours sincerely,

nhs.uk

Pat Escott and Chris Baggett

Ian Goddard and Jill Bowerman Senior Paediatric Physiotherapists, Dear Sally

The Children's Centre Nevill Hall Hospital

Please would you print the following letter.

Brecon Road Abergavenny Monmouthshire NP7 7EG

We are Paediatric Physiotherapists who have recently undertaken a study looking at a protocol of treatment for children who have Perthes disease. Currently we are working with an Orthopaedic Consultant whose regime is for children with perthes to go into non-weight bearing broomstick plasters for approximately two years.

Tel: 01873 73 27 12 Fax: 01873 73 27 28 We would be interested to hear from other paediatric physiotherapists involved in the treatment and care of children with perthes disease using these plasters.

Information on any protocol used and your experience of working with such children would be gratefully appreciated.

Looking forward to hearing from you.

Yours sincerely

Jan Goddard and Jill Bowerman

Melanie Arazi, Senior Physiotherapist, The Mary Sheridan Centre for Child Health Wooden Spoon House

Dear Sally

5 Dugard Way Kennington London SE11 4TH

Please can you put the following notice into the APCP Journal.

Tel. 020 7414 1408 email:

We are a paediatric physiotherapy department and are currently looking at producing generic risk assessments for specific tasks, e.g. transfering a child from a wheelchair into a standing frame or onto a wedge. We would be interested to hear whether anyone has already devised such protocols and whether they would be willing to share this information with us.

Yours faithfully, Melanie Arazi

melaniearazi@aol.com

Pam Evans, Senior Paediatric Physiotherapist, Child Development Centre, Portsmouth.

Based on an assignment written for MSc course in the Management of Childhood Disability at the University of Southampton.

Introduction

Multilevel surgery is a subject that arouses strong feelings amongst paediatric practitioners, both in favour of and against its use. It is has been practised since the 1970's in North America and Europe (Norlin and Tkaczuk 1985, Bleck 1987, Gage 1991). It is widely advocated as a better alternative than multiple single surgical procedures. However, there is little evidence to prove its short or long-term efficacy and there is great variation in practice.

There is much anecdotal evidence available, including evidence from children and families, therapists and medical practitioners. Much of this evidence is negative. There have been many papers published by orthopaedic surgeons over the last twenty years, mainly retrospective or prospective studies of small numbers of children, which do not stand up to scrutiny as evidence on which to base future practice.

Multilevel surgery is interpreted as surgical correction of all existing soft tissue and bony deformities in the lower limb in a single session (Bleck 1987, Rang 1990, Gage 1991, Saraph et al 2002,). Occasionally surgery is staged: correction of bony deformities first, then soft tissue surgery a few weeks later. More usually all surgery is carried out under one anaesthetic. This is followed by intensive physiotherapy for up to one year, with provision of necessary orthotics.

Background

Multilevel surgery combines various single interventions, which largely evolved from operations developed for children with poliomyelitis. Graham (1997) explains that the flaccid muscle weakness, muscle inbalance and deformities of poliomyelitis are easily analysed and surgically corrected. Cerebral palsy, being an upper motor neurone disorder, is much more complex and far less predictable in terms of outcomes from surgical intervention. It is difficult to distinguish

between dynamic and fixed contractures of musculotendinous structures and between primary abnormalities and secondary compensations. There is consistency between the gait pattern and clinical examination of a child with poliomyelitis. In contrast, in cerebral palsy, gait patterns and the findings on the examination couch often differ, the 'vertical examination' being much more important than the horizontal. (Graham 1997)

The development of gait analysis laboratories greatly improved the preoperative assessment of children with cerebral palsy, increasing the chances of successful outcomes (Feldkamp 1981, Bleck 1987, Gage 1991, DeLuca et al 1997, Morton 1999, Zwick et al 2001, Saraph et al 2002,). However, gait analysis facilities are not available everywhere and the process is expensive and time consuming. Not all orthopaedic surgeons include gait analysis in presurgical assessment, despite increasing evidence in favour of its use. Some multilevel surgery may be based almost solely on 'horizontal examination' on the couch and without any clear aim for functional outcome.

In "The Role of Orthopaedic Surgery in Cerebral Palsy", Fixsen wrote "unless it can be clearly shown that there is reasonable chance that surgery will improve the patient's function, it should not be attempted in the vain hope that it might do some good". He advocated the use of gait analysis even if only basic recordings could be done. He also emphasised the importance of surgeons working in conjunction with physiotherapists, in order to gain the most accurate pre-operative assessments and best post-operative results. He wrote "surgery will always be palliative and not curative", a reminder that surgery only "seeks to adjust at the periphery for the major disturbance of central control resulting from brain injury". (Fixsen 1989)

Literature search / sources of information

A search for articles on multilevel or single session surgery found only a few on an initial search using Medline and Cinahl. Many of the articles finally used did not have either of these terms in their title or the main body of work and were found via the university library. Reference books on orthopaedic surgery, gait analysis and medical ethics were consulted. Other sources of information include personal communication with surgeons, physiotherapists, and children with cerebral palsy and their parents.

Discussion of the evidence for and against multilevel surgery

The evidence base for multilevel surgery is small and few published trials have shown statistically significant results. The research papers used in this

discussion are very disparate in their aims, techniques used, outcome measures, results and conclusions. It is therefore difficult to compare one piece of research against another, to make generalisations, or to form clear guidelines on the practice of multilevel surgery based on currently available evidence.

Some published research by multiple authors may be part of larger studies, which diminishes the number of independent studies available for comparison still further (Saraph 2000, Saraph 2002, Steinwender 2001, Zwick 2001). Bleck (1987), Rang (1990), and Gage (1991) all provide much information on multilevel surgery but with very little high-level evidence of its efficacy (Sackett et al, 1996). There are some descriptions of retrospective studies but no recently undertaken controlled trials.

Cosgrove (2000) points out that children with cerebral palsy have a wide variety of neurological impairments, degrees of deformity, family circumstances and expectations. He comments, "Although there is an extensive body of literature concerning the outcome of surgical intervention, all the above factors make it very difficult to practise evidence-based medicine". He states that reliable anaesthetic, medical, physiotherapy and orthotic services are essential and quotes Mercer Rang "The decision (to operate) is more important than the incision".

This paper will discuss evidence for and against multilevel surgery within a framework of factors relevant to the management of childhood disability. There is some evidence, of variable quality, on objective aspects of surgery, such as age/stage of development when surgery is undertaken, the importance of the multi-disciplinary team, and outcomes of surgical intervention.

The small amount of evidence available regarding subjective aspects such as attitudes of children and parents, unrealistic expectations, and ethical considerations, is of poor reliability and is largely anecdotal.

1. Timing – the age/stage of development when surgery is performed

There is no agreement on the optimal age or stage of development when multilevel surgery might produce maximal benefit. Bleck (1987) in *Orthopaedic Management in Cerebral Palsy* advised avoidance of the "Birthday Syndrome" as described by Mercer Rang. This occurs, for example, when a child with

equinus has Achilles tendon lengthening in year one, the resultant crouch gait is then corrected by hamstring lengthening the following year and hip flexion contractures are corrected a year later. Each of these procedures entails periods of hospitalisation, immobilisation and rehabilitation. Multilevel surgery avoids the "Birthday Syndrome" and recurrent disruption of the child's and family's life

Rang (1990) recommended an optimal time for surgery at 3 or 4 years of age; to avoid operations for marginal gains in adolescence, and that "Knowing when to stop operating is as important as knowing when to start". Bleck (1987) advised: "surgery should probably not be delayed until skeletal maturity has been reached and adolescent bodyimage and concern is at its height". Surgery in adolescence may be more complex and may trigger a greater incidence of psychological problems: Bleck cites research by Goldkamp in which 17 of 53 adolescent patients with cerebral palsy needed psychiatric help following surgery, although it is not specified who had multilevel surgery and who had single interventions.

Timing of surgery may be crucial for successful outcomes. Bleck (1987) observes that surgery for gait improvement cannot be performed until the child has actually developed a gait pattern that can be measured and, if facilities are available, ideally measured in a laboratory. Mature gait pattern develops by the age of 7 years but by the age of 4 a reasonable idea of the mature pattern can be ascertained and consensus is that much surgical treatment can be accomplished between the ages of 4 and 8, (Bleck, 1987).

Other surgeons do not share this opinion on timing. At Great Ormond Street Hospital for Children, London, single session multilevel surgery is performed between 8 and 10 years (Beneke 2001). The study by Granata, Abel and Damiano on the influence of muscle-tendon lengthening on joint angle velocity in spastic gait, analysed 40 children with cerebral palsy aged between 3.7 and 14.8 years, before and after surgery, against 73 age-matched subjects. Surgery was performed with the aim of improving gait pattern, most being multilevel surgery but some involving single procedures. Many of the subjects far exceeded Rang's and Bleck's optimal age ranges and there was no distinction of age in discussion of results. It was concluded that surgery resulted in improved passive range of movement, modified joint angles and greater stride lengths but that there was no change in hip and knee joint velocities as measured on gait analysis.

Zwick et al (2001) evaluated the propulsive function during gait pre- and post-operatively in 17 children aged between 5.7 and 16.4 years who underwent

single-event multilevel surgery. The subjects were ambulant with diplegic cerebral palsy and were selected using defined inclusion criteria. Gait analyses were interpreted by reference to a group of 12 age-matched children without cerebral palsy. This study was small in number and the authors admitted that the effect of individual surgical procedures as part of multilevel surgery on individual joints was difficult to interpret. The outcome of surgery was that there was a significant increase in stride length and mainly positive changes at the hip and knee in ranges of movements and in power generation patterns. It was not possible to analyse the published results according to age, so no conclusions could be reached on the effects of multilevel surgery at different ages and whether there was an optimal age at which to operate.

Zwick also co-authored three other research papers on multilevel surgery (Saraph et al 2000, Steinwender et al 2001, Saraph et al 2002). The oldest subject was 16.6 years and in none of the studies is it possible to analyse the results according to age, some subjects undergoing surgery before maturation of gait pattern and some when nearing adulthood. Steinwender et al (2001) concluded that although the optimal age for surgery has been quoted to be between 6 and 10 years, that fixed equinus deformities in older children were not amenable to treatment other than surgery.

Lee et al (1992) analysed the pre- and post-operative gait patterns of twenty-three ambulant children with cerebral palsy aged 6 to 17 years. Not all the subjects had multilevel surgery, some having only one or two individual surgical procedures. There was no discussion on optimal age for surgery. The number of children having multilevel surgery was low, so no conclusions could be drawn on the effects of such surgery on the overall management of cerebral palsy.

The age range in Norlin and Tkaczuk's study and five-year follow-up (1985, 1992) was even more disparate, being between 1.5 and 18 years. They recognised that choosing the correct time for the operation is as important as performing the correct operation. Norlin and Tkaczuk commented that normal development of the motor system and gait ability takes place mainly before age 8 to 10 years and that a similar pattern is seen in children with cerebral palsy. They view this as the optimal time for surgery as the correction of the deformity then takes place at such an early stage of development that it is possible to break the patient's former pathological motor pattern. The pre-operative observation period

should be long enough to judge adequately the patient's motor and emotional status and thus facilitate the decision as to which surgical measures are required. Five year follow-up results showed some deterioration in gait, which Norlin and Tkaczuk attributed to the long-term effects of the damaged central nervous system and not to inadequate surgery.

Browne and McManus (1987) investigated 57 diplegic patients, aged from below 5 to over 9 years undergoing multilevel surgery between 1978 and 1985. They concluded that there could be recurrence of contracture to some degree whatever the age at surgery but that none of the subjects needed further surgery. They suggested that by performing surgery on younger patients, the operation was technically easier, and adaptive bone changes due to persistent muscle activity could be prevented. In general there was improvement in gait pattern, and in function and parental satisfaction, (Browne and McManus 1987).

The study by Nene, Evans and Patrick (1993) on changes in the physiological cost index (PCI) after multi-level surgery for spastic diplegia, reviewed 18 patients aged between 8 and 16 years. The published results were not analysed according to age at surgery but the authors concluded that surgery intended to improve the gait pattern should ideally be carried out after motor development has reached a plateau, but before the decompensation which may occur during the adolescent growth spurt. No other studies appear to take into consideration the changes associated with adolescence when there is rapid increase in height and weight, different weight distribution, and alterations to centre of gravity and balance.

There is no clear evidence or consensus of opinion amongst orthopaedic surgeons on the optimal age or stage of development for successful multilevel surgery and the studies discussed above are too diverse to generalize results.

2. Assessment, choice of procedures and surgical technique

There is no consensus of agreement on surgical decision-making based on assessment, or on surgical procedures or techniques used by individual surgeons.

There is increasing evidence that full gait analysis prior to surgery leads to better assessment of the fundamental problems, a more informed choice of operation and better functional outcomes. Bleck (1987), Fixsen (1989), Rang (1990), Gage (1991, 1995), and DeLuca (1996), well-respected surgeons in their field, were early proponents of gait analysis as an assessment tool. Some of the early gait analysis used was primitive in comparison with current

techniques. DeLuca considers three-dimensional gait analysis to be essential in defining all levels of abnormalities and the complex interactions that occur between spastic muscles and the joints they control. He believes it has reduced the cost of care by guiding paediatric orthopaedic surgeons in the selection of specific complex surgery and that post-operatively it allows for the comparison and modification of treatment philosophies as well as facilitating future surgical and orthotic decision-making.

Several studies on multilevel surgery specifically relate to gait analysis as an essential tool and prerequisite to successful outcome (Feldkamp 1981, Lee 1992, DeLuca 1997, Morton 1999, Granata et al 2000, Zwick 2001, Saraph 2002).

The prospective study by DeLuca et al (1997) involved 91 independently ambulant children with cerebral palsy, who were assessed pre-operatively by experienced clinicians, first by clinical examination and video, then with additional inclusion of gait analysis data (joint kinematics, kinetics and EMG). Comparisons were made of the two sets of surgical recommendations and it was found that with gait analysis data, the number of operations was reduced in 52% of cases with an associated reduction in the cost of surgery, not to mention the human impact of an inappropriate surgical decision, (DeLuca 1997). This study emphasises the importance of multilevel surgery being carried out by experienced surgeons, using effective techniques after good assessment, but provides little evidence on its overall benefits.

Other studies looked more specifically at individual techniques or at the effects of combinations of procedures on function post-operatively. Again it is very difficult to generalize the results as the studies are small, look at different specifics, use different criteria and outcome measures, and generally score low on Sackett's levels of evidence (1996).

Rang (1990) points out that there are 12 different operations for equinus. In Saraph et al's study (2002), fixed equinus deformities were corrected by intramuscular gastrosoleus lengthening. Positive (statistically significant) changes were seen in ankle motion and function after multilevel surgery. Saraph et al (2000) also reported on 22 children who had surgery for equinus using the Baumann procedure, i.e. intramuscular gastrosoleus lengthening as part of multilevel surgery. Results were good but provided evidence only on the benefits to foot and ankle from multilevel surgery. The authors acknowledged that function could also be

influenced by the improvement in other joints after multilevel surgery, but only evaluated one component of the multilevel concept. They compare results using the Baumann technique favourably against results using the Vulpius, Strayer and Baker procedures at the musculotendinous junction or Z-lengthening of the Achilles tendon but the majority of published studies on these are not as part of multilevel surgery. Like is not compared with like and the results are not generalisable.

There is also disagreement in the research studies on the efficacy of specific or combined operations at hip and knee, with authors claiming successful outcomes in small numbers of children. Multilevel surgery is so complex and riven with variables, including surgical teams' experience and expertise, and cerebral palsy variants, that comparisons are almost impossible and results may not be reproducible. Rang (1990) sums up the situation, stating that he gave up in frustration after trying to review his results in cerebral palsy because of the many variables and so little hard, trustworthy data.

3. The multidisciplinary team and rehabilitation

Methods of rehabilitation following multilevel surgery vary and may depend on the whim of individual surgeons or be dependent on the availability of local staff and resources. Most of the well-known exponents of multilevel surgery recognize the importance of the multidisciplinary team in assessment prior to surgery and successful rehabilitation afterwards (Bleck 1987, Fixsen 1989, Rang 1990, DeLuca 1996, Gage 2001). The team approach allows for the combined expertise and interaction of the orthopaedic paediatrician, neurologist, physiotherapist, occupational therapist, nurse and social worker, (DeLuca 1996). Not all teams will have all members and some may also include orthotists and technicians.

There is almost no evidence on the efficacy of treatment strategies or on the value of intensive physiotherapy on function or gait re-education after multi-level surgery. It has been suggested (in discussion) that some of the benefit to the child after surgery, in terms of improvements in function and gait, are due in large part to intensive physiotherapy increasing stamina and muscle strength and that benefits may occur in spite of, rather than because of, multilevel surgery.

Harryman (1992) describes physiotherapy management following surgery to the lower limb and could find only one previous report on the subject, by Girolami and Hertz in 1990. There have been few reports since then, other than by Damiano et al on physiotherapy and strength-training in children with spasticity. Harryman advises preoperative assessment should be made in

conjunction with the family, by a professional team who has known the child for some time, so that there can be adequate preparation and adaptation or provision of equipment.

Rehabilitation varies greatly, for example Gage allowing weight-bearing 3 weeks postoperatively but discharge from hospital on day 5 while Great Ormond Street Hospital encourage immediate weight-bearing but hospital admission of 3-4 weeks (Gage 2001, Beneke 2001). Other components of rehabilitation, including the use of orthoses and length of time wearing them, also differ widely but as no evidence was found on the comparative benefits this aspect will not be discussed further.

Differences in rehabilitation techniques and timing further complicate the process of evaluating the pros and cons of multilevel surgery in the management of childhood disability. Even if surgical results were reproducible, it would not be possible to also reproduce the complex variations of rehabilitation and the multi disciplinary team.

4. Attitude of surgeon, child and parents – realistic and unrealistic expectations

Over the last few years, multilevel surgery has achieved a certain glamour, due to media interest with television documentaries and newspaper stories. It could be argued that parents were given false hope that their child with cerebral palsy could be made to walk or to function better if they had multilevel surgery. "Surgery provides a dramatic interlude in the otherwise unchanging pattern of disappointment. Parents may feel that it is worth taking the risk ...", Rang (1990). Thus, some parents are prepared to put their child through the trauma of extensive surgery and up to a year's intensive rehabilitation, with little hope of cure and only some hope of functional improvement.

Anderson (1993) states that in certain cases it is unclear whether surgery is for the benefit of the child, the parent or the surgeon. Parents can feel pressurised into forcing children to undergo treatment for the present or future good, often with no evidence of predicted outcome.

Fixsen (1989) states that surgery will always be palliative rather than curative. A realistic appreciation of this is essential on the part of the patient, parents, therapists and surgeon if disappointment and disillusion are to be avoided. It is important that clear aims and objectives are set out prior to surgery and that expectations are realistic (Bleck 1987, Rang 1990, Gage 2001).

Children and parents need to be prepared for the physical, emotional and psychological impact of multilevel surgery. Fixsen (1989) stated that even well-planned surgery can cause considerable physical and emotional disturbance, and that children used to their preoperative state may find the postoperative one, although technically an improvement, difficult to cope with.

Surgery that is not well-planned creates more problems and anecdotal evidence is common. A physiotherapist (2003, personal communication) described the case of a 15 year old with moderate learning disabilities. She had multilevel surgery at a major hospital without adequate preparation of herself, her parents, the hospital rehabilitation team or the local community multidisciplinary team. She was discharged home after 5 days having had little physiotherapy input in hospital and little hope of intensive therapy at home, without orthotics or equipment, and with no provision of transport to get to and from school. This is not an isolated occurrence.

Parents and children need to be well-motivated to cope with the long period of intensive work necessary post-operatively. They also need an understanding of what multilevel surgery can achieve and what is not going to be altered. Alistair Roderick (1998), who himself had multilevel surgery, said that he would recommend this procedure to other people who would truly benefit and who understand the commitment involved. He stressed that the shock of surgery was extreme.

The attitude of the surgeon can also influence outcomes of multilevel surgery. The surgeon who does not consult the multi-disciplinary team is more likely to make mistakes in choice of patients, choice of procedures and timing and one of the problems in cerebral palsy is that if the wrong operation is done, it is almost impossible to reverse its effects, (Fixsen 1989). In multilevel surgery, wrong decisions can be much more devastating than a failed single procedure, unfortunately, the more muscles that are lengthened at one time, the more risk there is of errors of judgement. Gage (1991), comments that he has personally seen patients in whom the surgeon's enthusiasm to improve ambulation has resulted in the loss of both independent mobility and activities of daily living.

Following his most recent research, Gage (2001) concluded that it would be beneficial to go back and critically study the group of children who did not improve as, from the standpoint of both cost and morbidity, it is important to know who *not* to treat. Orthopaedic surgeons need to choose candidates for multilevel surgery with care and to know when to say "No".

5. Ethical considerations of multilevel surgery

Multilevel surgery has several ethical dimensions. Some parents and children seek it for reasons of cosmetic rather than functional improvement (Rang 1990) and this can be seen to be unethical, particularly if the parents are the prime movers in wanting their child to be "normal". Alderson (1993) argued that the "narrowing notions of normality" add to the emotional problems of disabled children and that not everyone shares the same visions of normality as regards using limbs conventionally and looking like other children. Some teenagers opt to use a wheelchair so that they can behave like their peers, rather than struggle to continue walking independently and would reject multilevel surgery.

It could be argued that multilevel surgery primarily for cosmesis should be viewed in a similar way to other cosmetic surgery and not be available through the British National Health Service.

An uncomfortable ethical consideration in multilevel surgery is the possibility of parents foisting surgery on their child in their own self-interests. Meadow (1991) points out that there are only rare cases of parents fabricating the child's needs for medical treatment.

The ethics of children's consent needs to be considered in multilevel surgery. It is argued that even relatively young children have the ability to understand all the issues, and a right to be included in decision-making, with regard to surgery (Alderson 1993). According to the rule of Gillick competence, a child is capable of consent if they have sufficient understanding and intelligence to understand fully what is proposed and have sufficient discretion to be able to make a wise choice in their own interests, (Alderson 1993).

Sackett (1981) describes the difficulties of distinguishing useful from useless information in clinical journals. Most of the published reviews on multilevel surgery show positive results, even though the numbers of participants may be very small. There is a danger that negative results are either ignored or remain unpublished. Study results may be rejected, regardless of their merit, if they threaten the prestige or livelihood of their audience, (Sackett 1981). In "The Ethics of Ignorance", Smith (1992) points out that only 15% of all medical interventions are truly evidence-based, and that 85% are not.

Chalmers et al (1992) advocate the use of controlled and meta-analysis to help solve disagreements. They suggest that neither the reputations of orthopaedic surgeons nor the interest of their patients are served by acquiescence in strongly held opinions that are unsupported by scientific evidence. DeLuca et al (1997) described the ethical dilemma of providing conclusive evidence on multilevel surgery, for example, the importance of gait analysis in assessment. This issue could only be determined definitively by including a control group in which gait analysis data was collected but not used in surgical decision-making. DeLuca and colleagues believed this would be unethical as such a control group would be deprived of the best available treatment based on best practice. The "gold standard" randomised controlled trial is very much more difficult to set up effectively to test surgical procedures, than to test drugs.

Conclusion

It can be concluded that on the evidence available. there is little to support the notion that multilevel surgery will either enhance the quality of life or improve the functional abilities of children with disabilities. There may be a short-term improvement in gait pattern and a cosmetic effect of improving posture in some children but there is no evidence that these will improve long-term prognosis on the effects of disability into adolescence and adulthood (Feldkamp 1982, Spencer1990). Short-term gains need to be offset against the great expense of surgery in conjunction with gait analysis, the possibly prolonged hospital stay and rehabilitation. The cost to the child and family in terms of pain, effort, possible loss of schooling and disruption to social and family life must be taken into account.

The use of multilevel surgery, even if performed by very experienced specialist surgeons, after accurate pre-operative assessments and followed by optimal rehabilitation, will only benefit a very small number of children. Multilevel surgery has only a small part to play in the management of childhood disability, although for a few children it may be very beneficial: "To get this far has not been at all easy and it took a lot of determination, support and hard work, but there is no way I would go back to how I was...Things can only get better!" (Eleanor Hawkins 1997).

It has been said that multilevel surgery may save money, avoid unnecessary pain and inconvenience, and eliminate the need for more than one postoperative period of rehabilitation, (Gage 1995). There is need for more research including controlled trials to test its efficacy and to formulate guidelines for the practice of multilevel surgery in the future.

References

Alderson P (1993) Children's Consent to Surgery, Open University Press, Buckingham

Beneke D (2001) Management of children undergoing cp surgery, Conference presentation, Nov 2001, Oswestry

Bleck EE (1987) Orthopaedic Management in Cerebral Palsy. Clinics in Developmental Medicine No 99, Mac Keith Press, London

Browne AO, McManus F (1987) One-session surgery for bilateral correction of lower limb deformities in cerebral palsy, *Journal of Pediatric Orthopaedics*, 7: 259-261

Chalmers IG, Collins RE, Dickersin K (1992) Controlled trials and meta-analyses can help resolve disagreements among orthopaedic surgeons (editorial), *Journal of Bone and Joint Surgery*, 74-B, 641-643

Cosgrove A (2000) Orthopaedic surgery in spastic cerebral palsy, In *The Management of Spasticity Associated with the Cerebral Palsies in Children and Adolescents*, (Ed by Neville B, Albright AL), Churchill Communications, New Jersey

DeLuca P (1996) The Musculoskeletal management of children with cerebral palsy, *Pediatric Clinics of North America*, Vol 43, No 5: 1135-1150

DeLuca P, Davis III RB, Ounpuu S, Rose S, Sirkin R (1997) Alterations in surgical decision making in patients with cerebral palsy based on three-dimensional gait analysis, *Journal of Pediatric Orthopaedics*, 17: 608-614

Feldkamp M, (1981) Motion analysis before and after orthopedic operations in cerebral palsy, American Academy for Cerebral Palsy and Developmental Medicine, pub in Orthopaedic Transactions, Vol 5, 193

Feldkamp M (1982) Late results of hip and knee surgery in severely handicapped cerebral palsy patients, Archives of Orthopaedic and Trauma Surgery, 100: 217-224

Fixsen J (1989) The role of orthopaedic surgery in cerebral palsy, *Seminars in Orthopaedics*, Vol 4, No 4: 215-219

Gage JR (1991) Gait analysis in cerebral palsy, Cambridge University Press, New York Gage JR (1995) Gait Analysis: Principles and Applications, Journal of Bone and Joint Surgery, 77-A, No 10, 1607-1623

Gage JR (2001) Outcomes of multilevel surgery in cerebral palsy (Conference presentation on unpublished research), New Mobility Strategies in Cerebral Palsy, Oswestry

Graham HK (1997) The Orthopaedic Management of Cerebral Palsy, In: *A Textbook of Paediatric Orthopaedics*, Ed by NS Broughton. WB Saunders, London

Granata KP, Abel MF, Damiano DL (2000) Joint angular velocity in spastic gait and the influence of muscle-tendon lengthening, *Journal of Bone and Joint Surgery*, 82-A, No 2, 174

Harryman SE (1992) Lower extremity surgery for children with cerebral palsy: Physical therapy management, *Physical Therapy*, 72: 16-24

Hawkins E (1997) Comments on Two Stage Surgery Progress, *British Association of Bobath Trained Therapists*, Newsletter No 28: 37

Lee EH, Goh JCH, Bose K (1992) Value of Gait Analysis in the Assessment of Surgery in Cerebral Palsy, Arch Phys Med Rehabil, 73:642-646

Meadow R (1991) Neurological and Developmental Variants of Munchausen Syndrome by Proxy, Developmental Medicine and Child Neurology, 33: 267-272

Morton R (1999) New surgical interventions for cerebral palsy and the place of gait analysis, *Developmental Medicine & Child Neurology*, 41: 424-428

Nene AV, Evans GA, Patrick JH (1993) Simultaneous multiple operations for spastic diplegia: outcome and functional assessment of walking in 18 patients, *Journal of Bone and Joint Surgery*, 75-B, 488-494

Norlin R, Tkaczuk H (1985) One-session surgery for correction of lower extremity deformities in children with cerebral palsy, *Journal of Pediatric Orthopaedics*, 5: 208-211

Norlin R, Tkaczuk H (1992) One-session surgery on the lower limb in children with cerebral palsy: A five year follow-up, *International Orthopaedics*, 16: 291-293

Rang M et al (1990) Cerebral Palsy, In Lovell and Winter's Paediatric Orthopaedics, 3rd Edn, Ed by Morrissey, JB Lippincott, Philadelphia

Roderick A (1998) Thoughts on Surgery, *British Association of Bobath Trained Therapists*, Newsletter No 30: 8

Sackett DL, Department of Clinical Epistemiology and Biostatistics, McMaster University Health Sciences Centre (1981), How to read clinical journals: V: To distinguish useful from useless or even harmful therapy, CMA Journal, 124: 1156-1162

Sackett DL, Rosenberg WMC, Gray JAM, Haynes RB, Richardson WS (1996) Evidence based medicine: what it is and what it isn't: It's about integrating individual clinical expertise and best external evidence, *British Medical Journal*, 312(7023): 71-72

Saraph V, Zwick E-B, Uitz C, Linhart W, Steinwender G (2000) The Baumann procedure for fixed contracture of the gastrosoleus in cerebral palsy: Evaluation of the ankle after multilevel surgery, *Journal of Bone and Joint Surgery*, Vol 82-B, No 4: 535

Saraph V, Zwick E-B, Zwick G, Steinwender C, Steinwender G, Linhart W (2002) Multilevel surgery in spastic diplegia: Evaluation by physical examination and gait analysis in 25 children, *Journal of Pediatric Orthopaedics*, 22: 150-157

Smith R (1992) The ethics of ignorance, *Journal of Medical Ethics*, 18: 117-118,134

Spencer JD (1990) Mobility of the young adult physically handicapped patient following lower limb surgery in childhood, *Journal of the Royal Society of Medicine*, 83:168-171

Steinwender G, Saraph V, Zwick E-B, Uitz C, Linhart W (2001) Fixed and dynamic equinus in cerebral palsy: Evaluation of ankle function after multilevel surgery, *Journal of Pediatric Orthopaedics*, 21: 102-107

Zwick EB, Saraph V, Linhart W, Steinwender G (2001) Propulsive function during gait in diplegic children: Evaluation after surgery for gait improvement, *Journal of Pediatric Orthopaedics*, 10: 226-233

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Study Aims: To evaluate the satisfaction of disabled children's parents in two children's centres. To enable parents from a wide range of social backgrounds to participate.

Methods: Subjects were parents of 32 disabled children from two children's centres assessed using focus groups and audit questionnaires.

Results: Parents felt they received good medical care and had a good understanding of therapy intervention. They identified the need for advocacy support for the whole family. Parents expressed frustration at poor access to written information and long waiting times for equipment. Parental literacy problems can present difficulties in dealing with information. Services promoted empowerment of parents to make choices.

Conclusion: Focus groups provide a valid method to include socially deprived families. Parents wanted easier access to information appropriate for their literacy level. The role of a professional advocate for the disabled child's family requires further exploration.

INTRODUCTION

In the management of children with a disability, health gain can be difficult to quantify. The main aims are to minimise the effects of a child's disability and to promote maximum independence. An important goal that supports these aims is to support the disabled child's family in understanding and coming to terms with the child's difficulties (Cass and Kugler, 1993). Blum describes the need for parents to experience a negotiative approach from the services they receive and to know that their contribution is as valuable as the professionals; a family centred service is suggested (Blum et al, 1995). Evaluation tools are required to determine the cost effectiveness and quality of service provision, to ensure there is effective, equitable and accessible provision for children with a disability (Stevens and Raftery, 1994). A measure that will include families from socially excluded groups will provide evidence to support the needs of the wider population.

A valid and reliable tool to measure parental satisfaction is the Measure of the Processes of Care (MPOC) Questionnaire (Baine et al 1995, King et al 1997, King et al 1997, King et al 1996). One of the original stages in the construction of the MPOC was the use of focus groups, but the social status of these families was 'well educated'. The MPOC is designed to be self administered by parents but requires a reasonable education standard for compliance. It measures five components of care giving: enabling and partnership; providing general information; providing specific information about the child; coordinated and comprehensive care for the child and family; and respectful and supportive care.

Other questionnaires used have been carried out with parents in social classes I-III (Stallard and Lenton, 1992,1995). This creates a bias to the more educated parents. Milner carried out semi-structured interviews with parents that provided more detailed insights into parental views (Milner et al, 1996), resulting in a disabled children's charter.

The purpose of this study is to ensure that evaluation of services includes families from all social groups to establish their views of the medical, therapy and support services provided for their disabled pre-school child.

Different styles of service provision are well described, with those promoting an empowerment model coming closest to a family centred service (Appleton and Minchom 1991, Spencer 1995). Families want consistency and coordination with services delivered in a way that allows them and their other children to lead an 'ordinary' life. It is suggested that the medical/ expert model is no longer sufficient and that we must start with the quality of each individual family's experience of caring for a disabled child in the community (McConachie, 1997).

SUBJECTS AND SETTING

Two neighbouring Children's Centres in semi-rural parts of South Wales were studied. In the first area, 97% of electoral divisions are amongst the 60% most deprived in Wales. Levels of deprivation were higher than the Welsh average for income, employment, health and education. In the second area, 23% of electoral divisions are amongst the 60% most deprived in Wales. Electoral divisions were generally less deprived than the rest of Wales (National Assembly for Wales, 2000 draft Local Authority profiles).

METHODOLOGY

Sampling was performed by identifying all families with a disabled child aged 2-4 years on 1st May 1998, currently receiving services from the two children's centres. This gave a total of 73 families eligible to take part in the study, 36 from one centre and 37 from the other. A purposive non-random sample of 15 was invited by local therapists to attend a focus group. Those parents who had not attended a focus group were then sent a postal questionnaire to complete, 17/58 replied.

We used Focus Groups because of the low literacy level of some of the parents already known to the team who felt that they would be unable to complete the MPOC questionnaire by themselves. Focus groups were selected as an appropriate tool to generate data from a wide range of parents (Krueger, 1994). The main author facilitated two of the groups in the centre where she was not employed. This was with the assistance of an observer who was a social worker. A retired paediatrician facilitated two groups, with physiotherapy students acting as observers, in the centre where the author was employed. This was to avoid bias as parents may have felt their service would be compromised in some way if they made negative commnets.

The focus group data was combined with an audit questionnaire to provide greater validity. The emphasis reported in this paper, is a measure of the support provided for parents. The standards measured are outlined in Figure 1.

A letter of introduction assured confidentiality and anonymity and verbal consent was obtained. Anonymous family information sheets were also completed to provide a social profile of those who participated.

RESULTS

The prevalence of disability was 34.9 per 100,000 head of population in the first (more deprived) centre and 31.0 in the second centre. The definition that was used for disability was the criteria laid down by the British Association of Community Child Health (BACCH, 2001).

The families who took part had children with a range of disabilities including Down syndrome, Cerebral Palsy, Autism, Epilepsy, Metabolic, Neuromuscular and those with no clear cause for their developmental problems. The frequencies of these are shown in Figure 2.

The focus groups were asked to deal with questions based on parental experiences, involvement and satisfaction with services offered for their children. The topics introduced are outlined in figure 3. The questionnaire was based on the work of Milner but abbreviated from 125 to 23 questions (written permission was sought from Prof. DMB Hall).

THEMES EMERGING FROM FOCUS GROUP DISCUSSIONS

A wide range of experiences are described, parental quotes are printed in italics:

RESPECTFUL AND SUPPORTIVE CARE

Parents described their partners and other parents as providing the most support. A community paediatrician was described as "like talking to a friend". Parents had mixed experiences with accessing services at the children's centres. One parent described the service as easier than accessing his G.P. "We know that help| advice is only a phone call away".

ADVOCACY

There was overwhelming appreciation for all the services available for their children. The Social worker "gave me support after X was born with Down syndrome, stopped me cracking". Parents described the value they found by staff acting as advocates for them particularly when dealing with hospital specialists e.g. Physiotherapist attending Orthopaedic appointments. Some parents felt that they were their child's best advocates.

INFORMATION

The provision of written information varied for different children, the geneticists appearing to provide the most comprehensive information. Where written instructions and pictures had been given for therapy activities, parents had found this helpful.

Some parents felt they had been given too much information too soon, whereas others felt they had not been given enough and considered information had been withheld. Several parents reported finding hospital appointments difficult "Doctors forget that we are human beings who have emotions". Some parents found the invasion of privacy, with many professionals coming into the home, difficult to handle.

One parent described feeling "dull and intimidated" by the Educational Psychology report that she received by post. Some parents wanted more access to written information and did not know where to find this other than the Internet.

Equipment /Resources

The average wait for provision of equipment was around four months but the longest reported time was an eighteen-month wait for a suitable bath aid. Parents described the centre as a focal point "making life much easier".

SERVICE DEVELOPMENTS

In considering ways that services could be improved parents suggested that perhaps a role could be developed for a "multi-skilled therapy assistant" to provide additional support for treatments to be carried out. Parents suggested that an information resource would be beneficial for them to find out about support groups and other voluntary organisations. More respite help including a residential facility was suggested.

AUDIT QUESTIONNAIRE

Responses were obtained from 17 out of 58 giving a 29% response rate. The questions relate to standards and the findings relate to the quality issues for parents.

INFORMATION: 14 parents had received information (as books, leaflets or videos) about their child's condition. 12 parents had received relevant information about support groups and organisations for their child. Contact with another family had been offered for 7 families, but 2 of these had not found it helpful. 9 families had seen an educational psychologist and 4 would like to. The mean age at which parents felt education should be discussed was 30.5 months.

THERAPY: All 17 of the respondents who received therapy understood the purpose of this and what the therapists expected from them. However only 7

were aware of alternative methods of treatment. The length of time families had to wait for equipment ranged from no time to 12 months. The equipment was reviewed by parental request for 10 of these children.

DAY/RESPITE CARE: Respite provision included home sitting and link family, but not all parents knew about their availability. 10 children were attending a day care provision but another 3 were on a waiting list. 3 families were receiving respite and 1 was on a waiting list.

BENEFITS: 16 respondents knew about the Disabled Living Allowance, 12 knew about the Family Fund. 3 parents commented that the Mobility Allowance should be available at a lower age than five.

AREAS FOR IMPROVEMENT: Parents were invited to identify areas of service that could be improved. Respondents identified concern over staff shortages, which meant that children failed to receive certain therapies. Some parents had waited too long for equipment. Earlier diagnosis and more respite provision were areas where services could be improved.

DISCUSSION

Within the current framework of clinical governance it is important to assess the acceptability of services for the pre school disabled child. Whilst the questionnaire gave some useful quantitative information, the poor response rate reduced its value and may have been a marker for possible literacy difficulties, thus emphasising the need to gather information from parents in a different way.

The value of focus groups including families from socio-economically deprived areas was demonstrated. The qualitative data generated enables a richer descriptive component to be expressed that is not achieved with a questionnaire. The dynamics of the focus group enable those less confident or with poor literacy skills to contribute. It worked best where these groups were set up alongside playgroups that the children were attending and where transport had been provided.

Professional Advocate

The descriptions which parents gave of the advocacy role played by staff was an unexpected result. Most therapy staff had not received formal training in counselling or advocacy, but it is a key skill in dealing with distressed parents. It was evident from the parental views expressed that the support they received from staff was as important as the therapy carried out. Flexibility to meet individual family's needs was a strong feature of the services described. High standards were achieved in parental understanding of therapy. Parents felt they

were in control of the appointment times and were able to negotiate their convenience, however the detail of the programmes was left to the professionals involved.

Parents had been concerned about their children not receiving specific therapies. The staffing vacancies reflect the recruitment and retention crisis within the therapy professions in the National Health Service in Britain at the present time.

Information Giving

The way information is given requires further exploration. Hall found that socio-economic factors influenced professionals in terms of their perceived need for parental information and support (Hall S, 1996). However, it is suggested that information exchange is a two way process and that socioeconomic factors do not influence the individual's desire for information (King G et al, 1996). The quality of information that is available to give to parents may be targeted at too high a reading level. The level of literacy of an adult will determine what information they request and are able to comprehend (Chapman and Langridge, 1997). The influence of poverty on parental education standards often limits their understanding of services offered. Many do not take up the services provided. This reinforces Tudor Hart's Inverse Care Law - 'that those most in need of the services do not access them' (Hart TJ, 1971).

Provision of Equipment

The majority of parents had not had undue delay in the provision of equipment. Both children's centres operated a short-term loan facility, whilst social services funded home equipment, but this is often where the delays occurred. The possibility of jointly funded equipment stores has been discussed but no local agreements have yet been reached between Health, Education and Social Services.

Empowerment

Some parents had reported that information was sent to them through the post, which they did not understand. To feel 'dull and intimidated' is not conducive to empowering parents, surely a better way can be found to give information to parents that enables them to better understand their child's needs. The literacy difficulties shown by some of the parents' highlights the need to give greater thought to the way information is given to parents. The lack of available videos to educate parents is perhaps an area to target with resources, to provide greater

choice.

Those parents who participated from wide social backgrounds, were able to describe the benefits of the variety of services available to them. However those parents who did not volunteer to attend a focus group or fill in a questionnaire were underrepresented and it not possible to know if their needs are being met. Although this is a small study similar results are echoed in other studies. The main emphasis in this study is the significance of parental literacy levels in determining the type of information they request and the lack of suitable available material which parents are able to access.

CONCLUSION

As a demonstration of quality assurance, it is essential to include consumer feedback on services for the pre school disabled child. To be effective and inclusive the opportunity to attend a focus group could minimise potential literacy problems.

In order to respond to the improvements suggested by parents suggestion of an information officer and a library facility were explored in a business case. The quality of information available for parents requires further investment from support groups/ drug companies to tailor parents' information needs for specific conditions.

Since the completion of this study, Sure Start have funded an information officer in the authors area, to address the needs of parents and staff. Additionally, a residential respite centre has opened in this area to cater for older children's needs. A National Lottery Grant has recently been awarded to fund a library and an information resource for parents.

References

Appleton PL, Minchom PE (1991). Models of parent partnership and child development centres. Child: Care, Health & Development 17: 27-38

British Association for Community Child Health Child Development and Disability Group. Standards for Child Development Services. A Guide for Commissioners and Providers. Published by the Royal College of Paediatrics and Child Health. July 2000

Baine S, Rosenbaum P, King S (1995). Chronic childhood illnesses: what aspects of care giving do parents value? Child: Care, Health and Development Vol. 21: 5, 291-304.

Blum RW, Suns JC, Patterson J (1995). Adolescents and young people with special needs. In: Social Paediatrics 21: 341-57. Open University Press

Cass HD, Kugler BT (1993). Evaluation and audit in a paediatric disability service. Archives of Disease in Childhood 68: 379-83

Chapman J.A., Langridge J (1997) Physiotherapy health education literature. Physiotherapy Vol. 83, No8: 406-412

Hall S. (1996) An exploration of parental perception of the nature and level of support needed to care for their child with special needs. Journal of Advanced Nursing, 24, 512-521

Hart TJ (1971) The Inverse Care Law. Lancet Feb 27: 405-412

Health Care Needs Assessment (1994) Vol 2. (Ed) A Stevens & J Raftery. Ch. 20 Community Child Health Services, Hall D. Section 2 p 497-529

King GA, King SM, Rosenbaum PL (1996). Interpersonal aspects of care giving and client outcomes: a review of the literature. Ambulatory Child Health 2: 151-160

King GA, Rosenbaum PL, Lung SM (1997). Evaluating family-centred service using a measure of parents' perceptions. Child: Care, Health & Development 23: 47-62

King GA, King SM, Rosenbaum P (1996). How mother and fathers view professional care giving for children with disabilities. Development Medicine & Child Neurology 38: 397-407

Krueger RA (1994). Focus groups: a practical guide for applied research. Sage Publications

McConachie H (1997). Editorial: Organisation of child disability services. Child: Care, Health & Development 231: 3-9

Milner J, Bungay C, Jellinek D, Hall DMB (1996). Needs of disabled children and their families. Archives of Disease in Childhood 75: 399-404

National Assembly for Wales. Draft document. Welsh Index of Multiple Deprivation 2000. Local Authority Profiles.

Spencer N (1995). Progress in Community Child Health. Churchill Livingstone

Spencer N (1996). Poverty and Child Health. Radcliffe Medical Press Stallard P, Lenton S (1992). How satisfied are parents of pre-school children who have special needs with the services they have received? A Consumer Survey. Child: Care, Health & Development 18: 197-205

Stallard P, Hutchinson T (1995). Development and satisfaction with individual programme planning in a disability service. Archives of Disease in Childhood 73: 43-47

Stevens A, Raftery J (Ed.s) (1994) Health Care Needs Assessment Vol.2: Ch.20 Community Child Health Services. Hall DMB p.497-529.

TABLES AND FIGURES

Figure 1 Charter for Disabled Children and their Families

The Standards that were measured in this study are printed in *Italics*.

1. Principles

a) The family should feel that they have been listened to and heard, and that their concerns and aspirations have been taken seriously, and that their responsibility to their child is respected.

b) There should be a prompt response to the first referral (within one week) and the degree of urgency and parental anxiety should be considered when arranging the first appointment.

c) The process of news breaking should follow established guidelines; whichever professional undertakes the task. Where necessary, training should be provided. There should be arrangements for an early follow up appointment or home visit, and telephone support should be made available.

d) The child should receive either regular medical follow up or open access to the consultant in the event of new problems.

e) There should be arrangements for children with complex medical needs to be seen urgently on request. The family should know whom to contact in the event of new problems.

f) The child's future needs (for example, for care in adolescence and adult life, or for terminal care in the case of progressive disease) should be discussed with the parents and the child as soon as possible. There should be planned handover to a relevant, coordinated adult service, in line with the requirements of current legislation.

2. Diagnosis and disability

a) The parents and child should know the correct name, label or description for the child's condition, and its prognosis and functional implications.

b) Investigations should be carried out according to current best professional practice; even if no exact diagnosis can be made, the family should know what tests have been done and what the results mean. If the situation changes, any new investigations should be explained.

c) Every family should receive a written report in language that they can understand or an audiotape of the consultation(s) or both. Their views should be sought and respected regarding the circulation of this report to other professionals. They should have access to professional advice at the time that the report is received, to explain anything that is not clear in the report. Preferably, reports should be delivered, not posted. They should not be posted to arrive when no professional is available.

3. Treatment and therapy

a) If the child takes any medication, the parent should know what, why, for how long and how much. They should have a medication card to summarise complex drug or multiple therapy.

b) The family should know what sort of therapy or teaching that the child is receiving, what is intended to achieve, and how they can help. There should be defined and achievable goals. Parents and the child should understand what system of prioritising need is used by therapists, and the reasons for delays in commencing a treatment programme.

c) The family should know what other methods might be offered by others for treating the child's condition (including both orthodox and controversial therapies, and alternative medicine) and why the team/therapists are not using them for the child; they should be aware that some treatments of dubious efficacy can be disturbing and distressing to children. Families who try other methods should continue to receive support.

4. Information

a) Every family should be offered: full information about the child's condition including implications and prognosis; a meeting with another parent whose child has the same problem; the name and phone number of the organisation for children with this condition.

b) Every family should be offered expert information about the genetic aspects of the child's condition, by either a clinical geneticist or a well-informed paediatrician. This information should not be omitted when the condition is thought to be non-genetic by the professionals.

5. Medical care and support

a) Each child should be offered hearing and vision assessments as appropriate.

b) Every parent should know about day care (day nurseries etc); respite care (short breaks). There should be a range of respite provision and other relevant local support services.

c) Each child should be offered prophylactic dental advice and access to dental specialist services if needed

d) Each parent should know about benefits and the Family Fund.

e) Each child with cerebral palsy associated with a risk of hip dislocation should receive regular orthopaedic checks and hip radiography as appropriate.

f) Each child should be offered a full immunisation programme unless there are recognised contraindications. g) The growth of each child should be monitored.

h) Every parent should know about pre-school educational help (home teachers, Portage etc); their rights under the Education Act. Limitations in resource provision should be explained. There should be an impartial source of advice on services

i) The family should be given all equipment and aids appropriate to the child's needs

j) There should not be undue delays in providing or repairing equipment; if delay is unavoidable, the family should be kept informed.

k) The family should be invited and encouraged to identify other important service needs.

FIGURE 2: DISABILITIES OF CHILDREN WHO PARTICIPATED IN THE STUDY

DISABILITY	QUESTIONNAIRE	FOCUS GROUPS/ INTERVIEWS
DOWN'S SYNDROME	3	5
DEVELOP/DELAY	2	1
CEREBRAL PALSY	7	4
AUTISM		1
EPILEPSY		1
SYNDROME	1	2
METABOLIC		1
NEURO- MUSCULAR	1	1
FAILED TO COMPLETE SHEET	2	
SUB-TOTAL	17	15
TOTAL 32		

FIGURE 3: FOCUS GROUP QUESTIONS

- 1. What in your experiences have been most helpful to you in the services that you have received for your child?
- 2. Can you tell me how you have been or are being helped to adjust to your child's disability?
- 3. How have you found having so many different professionals involved in your child's care?
- 4. Could you describe if you have had any involvement in planning your child's therapy programmes e.g. OT, Speech, Physio, Portage?
- 5. Can you tell me how any written information given to you has enabled you to better understand your child's needs?
- 6. If your child has needed any equipment, how long have you had to wait?
- 7. Do you have any suggestions of how the services that you receive could be improved?

ACKNOWLEDGEMENTS

The Chartered Society of Physiotherapy; Association of Paediatric Chartered Physiotherapists (Welsh Branch); Gwent Healthcare NHS Trust Physiotherapy Service; Llandough Special Children's Centre staff in particular Professor J.R.Sibert, Msc Course Director. A special thanks to the parents who participated to enable us to learn how we can improve our service provision.

Postural Control of Hip and Pelvic Positioning in Seating

Terry Pountney PhD MA MCSP Research Physiotherapist Chailey Heritage Clinical Services

Control of the hip and pelvis is essential when providing postural support for people with a postural disability within a seating system to provide a symmetrical starting position for movement. Seating systems needs to enable function and activity, ensure comfort and reduce tissue trauma and prevent the development of deformity.

Control and stability around the hip and pelvis enables children and adults to achieve improved trunk alignment and stability, upper limb and head control. Instability of the hip and pelvic positions results in either a tendency to slide forward out of the seating system or being able to extend and lose control of their posture.

Although in the short term a slumped posture may appear comfortable for people without postural impairment, over time slumped postures coupled with an inability to change position can cause considerable pain around the hip and pelvis. The tendency to slide forward in the seating system also has implications for pressure against the sacral area of the pelvis and on the ischial tuberosities due to shear forces which are created.

Finally and probably one of the most debilitating aspects of not providing suitable hip and pelvic control, particularly in the younger client, is that without it there is a risk of developing deformity including hip dislocation, spinal curvature and windsweeping of the pelvis. It is recognised that in about 60% of children who have bilateral cerebral palsy and cannot walk independently by 5 years, hip dislocation will occur in one or both hips, and about 70% of them will develop scoliosis. Clearly this is a large number of children and requires attention . Adults with cerebral palsy report high frequency of pain around the hip and pelvis which has been present for many years .

The pelvis and hip complex is difficult to control because of the number of degrees of freedom of movement which are available. Pelvic movement includes pelvic tilt - anterior, neutral or posterior, rotation one side of pelvis further forward than the other, and pelvic obliquity where one side of the pelvis is higher than the other. At the hip joint we have ab and adduction, internal and external rotation, and flexion and extension. Changes in any of these positions can have an impact on the rest of

the body. A total of 12 degrees of freedom. Changes in biomechanical alignment of the hip and pelvic complex can produce a significant impact in posture and movement. Pelvic tilts for instance, can dramatically affect the position of the head, ability to forward reach and arm elevation when the pelvis is resting in the posterior tilt. Posterior tilt also encourages tight hamstrings which are implicated in the development of kyphosis . Pelvic rotation will have a direct impact on the spine causing compensatory rotation and a loss of symmetry. Pelvic obliquity will also have an effect on the spine which will result in either a compensatory scoliosis where spinal curvature is convex towards the raised side or where compensation is not possible, a tendency to lean away from that side and have convexity on the opposing side.

Changes in the position of the hip will impact on load bearing and position of the pelvis and spine. Increased extension of the hip joint will change loadbearing of supporting surface and if used in a 90/90 seating position will cause pressure against the back rest. This may promote a total extension of pattern of movement. If used in a forward lean it will facilitate lumbar extension. Increased hip flexion will increase the load bearing on the ischial tuberosities and move the pelvis into posterior tilt and the spine into a kyphotic position.

Windswept postures of the hip involve combinations of ad and abduction and internal rotation of the hip. If the hip is abducted on one side and adducted on the other there are pelvic rotation and then compensatory changes to load bearing which affect the position of the spine. This also has a long term impact on asymmetrical muscle length across joints.

A number of methods are used in seating systems to control the hip and pelvis and the following few paragraphs will discuss these methods and their efficacy at achieving it. Reid and Rigby (1996) reviewed the literature on various methods of pelvic stabilisation and conclude that there is little research evidence to support one method over another. Since this review a few studies have been undertaken, MacDonald (2003) is currently undertaking a study into pressure & force at the kneeblock and sacral pad, Reid (1996) and Reid et al. (1999) have investigated saddle seating and pelvic stabilisers with a small samples of children with mild to moderate cerebral palsy. Further studies are still needed to evaluate the effects of differing interventions.

This paper will explore three of these methods: a combined pre-ischial bar and sub Anterior Superior Iliac Spine bar combination, the forward tilting seat with either a flat or saddle base and finally a combination of seating components with kneeblocks. There are many configurations of

Postural Control of Hip and Pelvic Positioning in Seating

seating components for the purposes of this paper a few basic components but will be assumed as good practice.

The cushion provides an integral part of the seat and offers a load bearing surface. To prevent obliquity within seating systems it is important that the cushion is flat under the area of the ischial tuberosities. The ramp angle chosen forward of the flattened area will determine the amount of hip flexion and extension which is offered within the seating system. Behind the pelvis, if pelvic control is to be maintained it is important to have a firm sacral pad up to the L5/S1 border. This provides rear pelvic control and accommodates the body dimensions if it is stepped away from the backrest. Firm lateral pelvic support is required to maintain a midline pelvic position. Bearing these aspects in mind we will move on to looking at pre-ischial and sub ASIS bar combinations.

A pre-ischial bar with a firm sacral support may be capable of limiting posterior tilt. In combination with the sub ASIS bar which applies force down and backwards on to the anterior aspect of the pelvis, pelvic tilt and rotation may be capable of being controlled. Without the addition of a sub ASIS bar or a firm pelvic strap then there will be a tendency if an ischial bar is in place for the child to be able to posteriorly tilt their pelvis and slide forward onto the ischial bar. Within this type of system there is no mechanism for controlling the position of the hip in terms of ab and adduction and internal and external rotation. This limits its ability to fully control the wind swept posture.

Seating components used in conjunction with a kneeblock offer the ability to apply pressure through anterior and medial thigh supports to act against the sacrum to control pelvic rotation and tilt. The kneeblock combination with a ramped cushion and sacral pad allows a neutral hip position and can achieve the desired pelvic position.

Forward tilting seats offer a different method of controlling pelvic position via the use of anterior and dropped knee supports. The ability to control posterior pelvic position is limited according to the type of support that is added posteriorly. Saddle type seats will limit hip adduction and possibly encourage neutral pelvic tilt. Control of rotation will be dependent on posterior support. Obliquity can be difficult to control in saddle seating if lateral pelvic control is not applied.

Methods of applying forces sufficient in each method will be explored. For the pre-ischial and sub-ASIS bar combination forces are applied directly to the pelvic surface and may be high over a small area. Through the kneeblock the force is applied via the femur to the pelvis and opposed by a sacral pad. In the forward lean option forces applied through the femur to the hip and pelvis.

What are the indications which we should use for applying proactive pelvic and hip control? The most commonly indicated situation would be where hip and pelvic asymmetry is present, either when the child is static or when they begin to move to take part in activity. Instability in sitting when active is an important indicator for provision of pelvic stability, as this group of children and adults is sometimes overlooked at assessment in static situations. Many individuals can maintain symmetry and stability when still, but once active develop compensatory postural mechanisms. Kyphotic postures are also an indication of lack of pelvic control as these are often an indicator of a persistently posteriorly tilted pelvis and linked with tight hamstrings.

There has been some controversy about the impact of different methods of pelvic and hip control on deformity, particularly knee blocks and hip dislocation. The main factor when considering this is that joints need compression to develop and where a hip is subluxed and not painful then correction of the hip and pelvic position so that the femoral head is centred as well as can be achieved within the seating system may benefit the development of the acetabulum (socket) (Pountney et al 2002). Where the hip and pelvis are not maintained in neutral positions there will be an ongoing increase in muscle imbalance across the joints and bone growth plates . This will lead to poor joint development and alterations in the direction of bone growth. This process of bone modelling is ongoing through life although children are particularly vulnerable. Where there is windsweeping of the pelvis and hip joints the hip which is likely to be affected is the one which is pulled backwards and internally rotated and adducted. In this situation control using a kneeblock system would offer pressure down the unaffected hip to de-rotate the pelvis and bring it into a neutral rotation and tilt. In these situations there is often very little, or no pressure through the affected hip. Pain will be an indicator of whether the application of forces to control the pelvis in a particular way is appropriate. If someone is uncomfortable in a seat it is important to establish the exact cause of the pain which the person is complaining from and when this pain is occurring.

When considering the spine it is important to understand the close relationship between the position of the pelvis which actually acts as the base of the spine and the compensatory mechanisms which are happening above it. Any degree of pelvic

Postural Control of Hip and Pelvic Positioning in Seating

rotation, scoliosis or posterior or anterior tilt which is persistent and excessive may result in rotation, scoliosis or kyphosis of the spine. It is important therefore that the best achievable pelvic position is attained for the best spinal control. In many cases where existing spinal curvatures present a spinal jacket will be needed. In some cases the spinal rotation has become so severe that if the pelvis is placed in a neutral rotation then the trunk would be rotated so that the individual would be looking sideways. In these cases obviously consideration needs to be given to the management of this patient.

For people with existing deformity pelvic and hip control in seating may not alone be capable of preventing or reducing deformity. In these cases it is important to look at the lying position. This provides an opportunity for long, gentle periods of stretch without the effects of gravity to try to balance muscle length across joints over time. With these strategies in place it may be possible over time to improve a person's position in seating as a result of intervention in lying.

In conclusion when considering prescription of pelvic and postural control it is important that a critical analysis is made of the made of the person's posture in terms of their level of ability and their level of deformity. It is essential to reason in a clinical way which of the methods would provide the best form of control for this person and which is the most suitable for their lifestyle. The position required and the impact this may have on their activity should be considered when providing any equipment. It is important to assess the impact of seating on an individual's posture. The secret to achieving good pelvic and hip control both in the short and long term is to prescribe equipment based on a detailed assessment of the clinet's postural needs. Benefits of this will include improved function and reduced deformity.

References:

Arkin, A.M. and J.F. Katz. 1956. The effects of pressure on epiphyseal growth. *Journal of Bone & Joint Surgery* **38-A**:1056-1076.

Lonstein, J. E. 1995. The spine in cerebral palsy. *Current Orthopaedics* **9**:164-177.

MacDonald, R., R. Surtees, et al. (2003). The relationship between pelvic and trunk alignment and force measured through a kneeblock in children with cerebral palsy. International Seating Symposium, Orlando, Florida.

McCarthy, J.J. and R.R Betz. 2000. The Relationship Between Tight Hamstrings and Lumber Hypolordosis in children with Cerebral Palsy. *Spine* 25 (2):211.

Pope, P. M., C. E. Bowes and E. Booth. 1994. Postural control in sitting. the Sam system: Evaluation of use over three years. *Developmental Medicine and Child Neurology* 36:241-252.

Pountney, T. E., A. Mandy, E. M. Green and P. Gard. 2002. Management of hip dislocation with postural management. *Child:care, health and development* **28** (2):179-185.

Pountney, T.E., C. M. Mulcahy, S. Clarke and E. M. Green. 2000. *Chailey Approach to Postural Management*. Birmingham: Active Design.

Reid, D. and P. Rigby (1996). "Towards improved anterior pelvic stabilisation devices for paediatric wheelchair users with cerebral palsy." <u>Canadian</u> Journal of Rehabilitation 9(2): 147-158.

Reid, D., P. Rigby, et al. (1999). "Functional impact of a rigid pelvic stabilizer on children with cerebral palsy who use wheelchairs: users' and caregivers' perceptions." Paediatric Rehabilitation 3(3): 101-118.

Reid, D. (1996). "The effects of the saddle seat on seated postural control and upper extremity movement in children with cerebral palsy." Developmental Medicine & Child Neurology 38: 805-815.

Schwartz, L., J.M. Engel and M.P. Jensen. 1999. Pain in Persons with Cerebral Palsy. *Archives of Medical Rehabilitation* 80:1243-1246.

Scrutton, D. and G. Baird. 1997. Surveillance measures of the hips of children with bilateral cerebral palsy. *Archives of Disease in Childhood* **56** (4):381-384.

Wolff, J. 1986. The Law of Bone Remodelling. Berlin: Springer-Verlag.

EARLY SUPPORT PILOT PROGRAMME

Linda Fisher Paediatric Physiotherapist linda.fisher2@essexcc.gov.uk

Do you know anything about this?

The Early Support Pilot Programme (ESPP) is a pan-disability national initiative funded by the DfES to identify and develop good service provision for children with disabilities under three and their families. It supports development in the following areas:

- > Initial assessment of need so that families are supported from the beginning
- Co-ordination/multi agency support so that families receive co-ordinated support through keyworker systems, better sharing of information between agencies, family support plans and family held records
- > Better information and access so that families are presented with the information they need in a way that is appropriate and are involved in planning and delivery of services
- > Improved professional knowledge and skills so that those working with families have the right knowledge and skills
- > Service review and development so that service providers can assess the quality of services in their area and plan development
- Partnership across agencies and geographical boundaries so that access to good services for families does not depend on where they live.

ESPP is developing service provision building on two sets of Government guidance issued in May 2003. These are:

- > Together from the Start Practical guidance for professionals working with disabled children (birth to third birthday) and their families
- > Developing Early Intervention / Support Services for Deaf Children and their Families

ESPP will support service development at local and regional level by producing:

- > A 'toolkit' to support professionals delivering multi agency, family focussed services
- A complementary family 'toolkit' to inform and support families
- > An audit tool to enable services to check the standard of their provision
- > A national monitoring protocol to measure the very early development of deaf children

Currently the programme is in its second phase with nine 'pathfinder' sites across the country. These pathfinder sites are centrally funded to pilot the materials and provide a 'warts and all' story of what exactly is needed at local level to enable co-ordinated services to become a reality for families.

There is On-Line Information available on the ESPP website. This can be accessed through the specially created hyperlinks on the:

DfES SEN website - www.dfes.gov.uk/sen

DH website - www.doh.gov.uk

NCB website- www.ncb.org.uk

Or go directly to www.espp.org.uk

Are any of you working within any of the pathfinder sites? If so, maybe we could network. It is an opportunity to be involved and be influential in developments as well as raising the profile and role of the paediatric physiotherapist within the multi agency arena.

NOTICE

In March 2004 the format of your journal will be changing to an A4 size. It will therefore be necessary to change some aspects of the advertisements and other copy that we publish. The following information will take effect with the publication of the March 2004 edition.

THE APCP JOURNAL

IBSN 1368-7360

GENERAL INFORMATION FOR CONTRIBUTORS (current circulation 2000 approx)

ARTICLES and FEATURES

We are unable to offer any remuneration for articles printed

Articles should be submitted typed, double-spaced on one side of the paper and the pages must be numbered consecutively. Photographs and diagrams are desirable as they add interest to an article and attract the reader. Manuscripts should clearly show the Title, Name(s) of author(s) and an address for correspondence. A small photograph and thumbnail sketch or mini CV of the author(s) is also useful. Detailed information for contribution of articles, including peer review (this will take effect from March 2004) will be freely available in this journal. Please send a printed copy and, if possible a disc in word 6 format.

ADVERTISEMENTS

Study Days and Courses - Free for all APCP regional and national events

All other study days and courses along with recruitment and advertisements placed by any other interested parties will be charged as follows:-

	Size	Courses and Vacancy Advertisements	Other Advertisements
Full Page	170mm x 253mm	£300	£500
Half Page	170mm x 124mm	£175	£300
Quarter Page	124mm x 82mm	£125	£200

Currently a full mailing of the membership with single A4 flyers inserted into each journal will be charged at £500. Costings for larger inserts will need to be negotiated with the editorial board. This mailing will be strictly reserved for the membership to circulate research questionnaires etc and cannot be used to promote product information.

It is preferable that copy for advertisements is submitted complete with typesetting and artwork. The printers will typeset from text if necessary.

COPY DATES

Distribution date

Copy to be with the editor by

The second week of

March 1st February

Inne

1st May

September

1st August

December

1st November

The Editorial Board reserve the right to edit all material submitted

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New Guidelines for 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 that 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.

Other types of Editorial Material

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:

- The title of the article
- The names of the author(s)
- A complete name and address for correspondence
- Up to three relevant professional and academic qualifications for all authors and their current positions
- Any source of funds supporting the work
- The title, date and location of the conference if the paper is an adaptation of a presentation.

All Peer-reviewed Articles

The title page should give:

- The title of the paper
- Up to five key words.
- A structured summary of no more than 300 words explaining the purpose and summarising the key points and conclusions. For research reports this should be under the headings of:
- Background and Purpose
- Methods
- Results of Findings
- Conclusion

Copy should be:

- typed or printed
- double spaced
- on one-sided A4 paper with at least a 1" margin all round
- consecutively numbered
- include the name, qualifications, current position, and contact address of the author(s).

The text should be well organised and written in simple and correct English under appropriate headings. The positions of tables and figures should be indicated.

References

References should be in the Harvard style:

In *text*, cite only the author(s) surname(s) followed by the date of publication, eg (Robinson, 1994) or Robinson (1994). Use a, b, etc, to indicate more than one publication by the same author(s) in the same year (eg 1992a, b). For three or more authors of a cited paper, name the first followed by et al, eg (Smith et al, 1990).

In the reference list, include articles in journals and books alphabetically by author. For citations from journals, give the names and initials of all authors (year of publication), title of the article, <u>full name of the journal</u>, volume number, issue number and first and last page numbers, eg **Brown**, **A**, **Green**, **B** and **Gold**, **C** (2001). 'The value of exercise', Physiotherapy, **87**, 1, 77-79.

Referring to books, give the names and initials of all authors/editors (year of publication), <u>title</u>, publisher, place of publication, and the chapter number or the page number of the citation or both, eg **Gardner**, **M** (2001). The Annotated Alice, Penguin Books, Harmondsworth, Chap 10, page 210.

Tables

Give them an appropriate title and number them consecutively as they are referred to in the text. Use only horizontal lines. Explain all abbreviations in a footnote. Place tables on a separate sheet after the references.

Figures and photographic images

Number them consecutively as they are referred to in the text and place on separate sheets after the tables. List all captions (legends) on a separate sheet.

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.

NOTICE

The 31st Annual General Meeting

of the

Association of Paediatric Chartered Physiotherapists

will be held on

Saturday 1st May 2004

at

The Crown Plaza Hotel, Liverpool

beginning at 11.30 am

All paid up members of the Association are entitled to attend. Voting will be restricted to full members of the Association and a current membership card will be required.

Minutes of the last AGM are available from the Secretary on receipt of a S.A.E.

COMMITTEE VACANCIES

Nominations are invited for two committee vacancies Nominations should be sent to the secretary by 2nd April 2004 together with the names of a proposer and seconder who must be paid up members of the Association

> The retiring committee members are Adare Brady and Julia Graham

At the AGM members will be asked to adopt changes to the APCP constitution. The main areas which have been altered are

Membership Categories

Executive Committee, inclusion of a Diversity officer

The structure of the Regional Committees and the inclusion of Affiliated groups

The timing of the AGM, procedures and the number needed to form a quorum

These changes will be presented in full at the AGM

APCP CONSTITUTION January 2004

1. TITLE

The Title of the Association shall be THE ASSOCIATION OF PAEDIATRIC CHARTERED PHYSIOTHERAPISTS

2. OBJECTIVES

The objectives of the association shall be as follows:

- 1. To provide a forum to promote the exchange of ideas between those interested in paediatrics
- 2. To promote best practise for those working with children and young people
- To promote and facilitate continuous professional development and educational opportunities in paediatric physiotherapy
- To encourage research and development in paediatric physiotherapy and related field to enhance the research base of physiotherapy
- 5. To develop and maintain links with other relevant organisations in the UK and overseas
- 6. To represent paediatric physiotherapy on behalf of the CSP
- 7. To promote paediatric physiotherapy

3. MEMBERSHIP

Membership will consist of:

Full Membership

 Full membership of the Association will be open to physiotherapists who are members of the Chartered Society of Physiotherapy. They will have full voting rights. An annual subscription as authorised by the Association will be paid. Physiotherapists who are not members of the Chartered society of Physiotherapy will be Associate members.

Associate Membership

Associate membership will be open to persons who, in the opinion of the Executive
committee, are suitably qualified professional people working in the field of paediatrics. These
persons will be nominated and seconded by full members of the Association. Associate
members do not hold voting rights. An annual subscription as for full members applies.

Assistant Membership

Physiotherapy Assistant membership will be open to physiotherapy assistants who are paid
members of the Chartered Society of Physiotherapy and working in the field of paediatrics.
The annual subscription will be half of the full subscription as authorised by the association.
These members will have full voting rights. Physiotherapy assistants who are not full
members of the Chartered Society of Physiotherapy have the right to become Associate
members as detailed in Associate membership. Annual subscription will remain at half of full
subscription.

Overseas Membership

 Overseas members are welcome as Full or Associate members with voting rights as appropriate. An annual subscription as for full members applies.

Student Membership

• Student membership will be open to physiotherapy students. The annual subscription will be half that of the full subscription. Student members do not have voting rights.

Honorary Members

• The retiring chairman of the Association will automatically become an Honorary member. Nominations, with proposers, seconders and full details, will be sent to the Honorary Secretary for the national committee meeting three months prior to the Annual General Meeting (A.G.M.) of the Association. The National Committee will then have the sole right to submit the names of the persons thought suitable to the A.G.M. of the Association for possible election, usually by a show of hands. If fulfilling the criteria for full membership Honorary members will retain full voting rights.

4. COMMITTEES

A: National Committee

The National Committee will consist of up to 16 nationally elected full members, one locally elected full member from each APCP approved region, and a representative from each affiliated group. From this group the required officers will be elected. National Committee members will serve for a term of 4 years and will be eligible for re-election for a further term of 4 years only (8 year rule). Members will then only be eligible for re-election to National Committee after a period of 2 years has elapsed.

The National Committee will comprise

Executive Committee

Chair

Vice Chair

Treasurer

Secretary

Diversity Officer

The executive committee officers will manage the day to day affairs of the Association on its behalf and report action to regular National Committee meetings. The Chair will hold office for two years. The Vice Chair will serve for two years as chair elect. All other officers will normally hold office for two years and will be eligible for a further term of two years. They will not then hold any other office within the Association for at least two years. If an executive officer is due to retire from the National Committee (under the eight year rule), they may be co-opted to continue their term of office for one year only.

Elected Officers

Journal Editor

• Public Relations Officer (PRO)

Membership Secretary

Education Liaison Officer

Research Officer

Publications Officer

CIG Liaison Officer

Committee Members (up to four)

Elected officers will normally hold office for two years and will be eligible for a further term of two years.

Regional Representatives

Each Regional Committee will elect a representative to National Committee. In the event of a Regional representative being elected to an executive or elected office, that region will elect a new representative to National Committee. Time served as a regional representative will be included as part of the eight years term of office.

Co-Opted Members

The National Committee will have the right to co-opt members to fulfil specific functions, as it deems necessary. The number of co-opted members will not exceed one-third of the National Committee members. Co-opted membership will be reviewed annually prior to the AGM. Co-opted members will have full voting rights.

Sub Committees

These will be formed as deemed necessary by the National Committee. The Chairman of such committees will be a National Committee member, but other committee members will be members of APCP with appropriate expertise. They will be approved by the National Committee.

Voting

Voting for members of the national Committee will be as follows:

- APCP members seeking election to National Committee will be proposed and seconded in writing to the Honorary Secretary of the Association at least one calendar month before the AGM. If there are more applications than vacancies, posts will then be filled by a paper ballot at the AGM.
- The Regional Representatives will be elected by the Regional Committees and notification must be sent to the Honorary Secretary of the Association
- 3. A Liaison Officer will be elected by the committee of each Affiliated group and notification must be sent to the Honorary Secretary of the Association.
- 4. All executive officers will be elected by the National Committee as necessary during the year
- 5. Co-opted members will be elected by the National Committee as necessary during the year
- 6. Election of Committee members will be based on a single non-transferable vote. Proxies will not be allowed. The Chair will have a casting vote in addition to an original vote

Honorarium

The following National Committee members will receive an annual honorarium the value of which will be agreed by the National Committee and reviewed annually;

Executive committee

- Chair
- Vice chair
- Treasurer

- Secretary
- Diversity officer

Elected officers

- Journal Editor
- PRO
- Membership secretary
- Education officer
- Publications officer
- CIG Liaison officer

B: Regional Committee and Affiliated Groups

The number and location of these shall be at the discretion of the national committee in response to request from the membership. Within each region there will be elected a Regional Committee to consider the local business of the Association in conjunction with the National Committee.

Each Regional Committee/Affiliated group will elect a Chair, Secretary, Treasurer and Regional representative/Liaison officer and any other officers they deem necessary. An A.G.M. will be held prior to the National A.G.M. and reported to the National Committee by the Regional representative/Liaison officer.

5. ANNUAL GENERAL MEETING

The Annual General Meeting (A.G.M.) will normally be held in the last 4 months of the year. Notification of the date, time and venue of the AGM will be made in an appropriate publication not less than three months prior to the meeting.

Reports will be submitted by the Chairman, Treasurer, Research officer, Education Liaison Officer and PRO.

All members of the national committee should be present at the AGM. At least 3 of the five executive committee members must present otherwise the AGM must be postponed and rearranged at the earliest convenient date. If a regional representative is unable to attend the National AGM then a substitute must attend.

6. PROCEDURES

- Minutes will be taken at all meetings of the Association. These records or reports will be made available to all members of the Association on request.
- 2. Admission to the AGM will be by a show of current membership cards
- 3. The Quorum will be one quarter (25%) at meetings of the National Committee. At the AGM the quorum will be 30 members or 5% of the membership excluding the National Committee whichever is smaller at the time.

- 4. A special meeting of the Association may be convened by the Chair, or by a requisition in writing signed by not less than 20% of ordinary members of the Association. Notification by post will take place fourteen days before the meeting. The business at such meetings will be limited to the agenda.
- Items for the agenda of an ordinary meeting of the Association must be submitted in writing to the Honorary Secretary at least one calendar month before the date of the meeting. Provision for any other business may be given.
- 6. The rules of debate at all meetings of the Association will correspond to those of the CSP
- Notice and agenda for all meetings of the Association will be sent in writing to those persons
 eligible to attend by the Honorary Secretary of the Association, at least fourteen days before
 the meeting
- 8. Any amendments to this Constitution must be submitted in writing for consideration at the AGM, and agreed by at least two thirds of the voting members present.
- All Regional and National accounts are required to be submitted for examination by the second week in January each year. A report of the examined annual accounts will be available at regional and national AGM's. The APCP accountants will be adopted at the AGM.

CESSATION

A recommendation for the cessation of the Association will come from the National Committee to the AGM and will only occur if agreed by at least two thirds of the voting members present. Any funds remaining after completion of all accounting procedures will pass to the Chartered Physiotherapists Benevolent Fund.

A recommendation for merger of the Association with another SIG will come from the National Committee to the AGM and will only occur if agreed by at least two thirds of the voting members present. Any accounts remaining after completion of all accounting procedures will pass to the new group.

Nothing in the Constitution, either expressed or implied, will conflict with the Charter and Bye-laws of the Parent Society. No action will be taken by the Association in any matter affecting the general policy of the CSP, without the consent of Council.

NEWS FROM NATIONAL COMMITTEE

There was a meeting of the National Committee on Friday 16th January '04 in Belfast. This was the first session of the Working Weekend and was attended by all committee members. Committee business included

- Collaboration with NAPOT to produce DCD guidelines continues
- Review of papers for the Hips Evidence Based summary will be completed in March
- There was an update on the progress of the three bursary projects
- There have been technical difficulties in managing the APCP website. This had already been identified as an area for discussion at greater depth during the Working Weekend
- Peta Smith and Jeanne Hartley have sent information on Head Moulding to Kay East at the DOH and continue to work with other agencies on this subject.
- Affiliated groups are to have representatives on the National committee.
- APCP are required by CSP to appoint a Diversity officer. This post will be on the executive committee and will incorporate the role of disability discrimination officer.
- Sarah Crombie has agreed to be the link person with the CSP for NICE guidelines. CSP have also suggested a CPD co-ordinator and this is now part of Adele Moore's role as education liaison officer.
- CSP valued the contribution made by APCP to their response to the green paper Every Child Matters.
- Adare Brady has written to CSP to highlight communication issues between CSP and APCP.
- The committee are preparing motions to be considered for submission at ARC which is being held in Newcastle 12-14th May
- Jeanne Hartly continues to represent APCP on the prescribing steering group.

The Advanced C.P. course was well received with approaches being made from physiotherapy managers to run further courses. The Outcome Measures Pack is to be launched at PPIMS meeting in March and at conference in April. There is ongoing discussion around supporting students with research projects.

Peta Smith attended a meeting in Leicester in November with the Critical Care/Respiratory Group to discuss affiliation with APCP. The group hope to hold an inaugural meeting in April and will be affiliated to APCP.

The next national committee meeting will be held on Friday 30th April in Liverpool.

LAURA WIGGINS APCP Secretery

REPORT FROM THE CLINICAL INTEREST /OCCUPATIONAL GROUPS LIAISON COMMITTEE

Just a brief update:

The Clinical Interest / Occupational Groups Liaison Committee meet at the CSP Offices three times a year. This committee is made up of one member from each recognised clinical interest and occupational group. The chair of Professional Practice Committee and chair of Council also attend. It's purpose is to:

- > Contribute a practitioner / clinician perspective to CSP policy and development
- Provide a forum through which CIGs and OGs can debate and influence changes which affect professional practice and service delivery
- > Provide elected members to relevant CSP committees as required
- > Elect four representatives to the Professional Practice Committee
- > Facilitate and enhance two way communication between Clinical Interest and Occupational Groups and all other CSP sub groups

As this group is one of the major ways the CSP can consult with its members, the flow of information including draft copies of future policy documents is important and valued by them. The minutes and accompanying papers from the meeting are distributed to members of the APCP's National Committee for discussion and consultation, feedback, general interest and sharing of information. They are also discussed at the National Committee meetings and actions are identified.

So, what has been happening......

- The CI /OG Information Pack is about to be published. This 'pack' has been well debated and revised following much consultation. It seeks to offer guidance to all CI / OGs on many aspects including details of the roles of the different officers, a model constitution and advice on running study days. It includes a 'what's in it for me' section to promote the advantages of being a CI/OG member.
- The CSP is due to publish its guidance on 'Supporting students with disabilities on clinical placement'. This will certainly be helpful to have as a reference guide for all services who have students on clinical placements.
- There is a CPD Policy Statement which explains what is expected of members, what support needs to be in place and how CPD links to enhanced quality.
- Interactivecsp' is due to be rolled out this year with all the networks in place.
- Currently the CSP are preparing 'A guide to implementing clinical supervision for qualified and associate members'. Its aim is to provide a practical guide to support the implementation of clinical supervision systems. When completed this should be another useful tool.

Just as a final reminder, your regional representatives will have most, if not all, of the current draft papers and the published Guidance and Policy Statements are available from the CSP.

LINDA FISHER

Clinical Interest Group Liaison Officer

Thanks to all those who returned their forms to me. I am still wading through the pile of renewals; we have nearly 2000 members so it is quite a bit of processing and stamp licking.

You will be receiving your new membership cards as quickly as I can get them out. If you haven't received it by the beginning of March then please contact me.

One request, please would you quote your membership number in any communication as this is how the data base is indexed. Your membership number is a 6-figure number followed by letters ie 104768 EA.

Susan Rideout

Membership Secretary

Research and Education

Research support from the APCP

Following a working weekend where it was discussed how the APCP could best support it's members in their research interests, it was decided to alter the focus of research support. We looked at the current needs of our members, who on the whole can now access support within the workplace to develop research skills such as critical appraisal, methodology and statistics. As paediatric physiotherapists we can however, support each other in appropriate project design and in the need for research in any particular area of interest. For this, the APCP are in an ideal position to be able to put members in touch with others who are researching similar fields and to offer mentorship to discuss project ideas. It has therefore been decided that local APCP regions, if they have not been doing so already, will start to organise regular research meetings to provide support to it's local members. We are hoping that this will provide an easier means of support as opposed to a national research meeting as previously proposed. This is the reason we cancelled the research meeting in London in February. Hopefully, local research groups will encourage everyone to hear what research is going on in their region and provide an informal environment to discuss and develop research ideas. It is still felt, however, that there is a need for a national forum for the dissemination of research, and this will be achieved by providing a free paper session at every national APCP conference. We hope that this will be an improved strategy for all.

Call for applications for the APCP research bursary

Good news that we are again able to offer APCP research bursaries. As before, grants will be made in the region of £10,000 to support projects in the paediatric field. Special consideration will be given to the CSP research priorities (for details of this contact the CSP website at www.csp.org.uk). For grant applications forms and information on the grant's terms and conditions, please contact Sarah Crombie on email:scrombie@srtl.co.uk. Closing date for applications is 1 September 2004.

APCP research group database

I have recently started to use email to send information on calls for applications for research funding or relevant conferences coming up, to those on the research group database. This enables me to update those interested on a more regular basis as the Journal only comes out 4 times a year. If you would like to be added to this email list, please fill

out the form at the back of the Journal and remember to include an email contact. I apologise to anyone who has not been on the email list, but have sent in their form. Please do let me know if this is the case. I may not have an up to date email for you.

Information papers available from the CSP

Registering for a research degree

This paper covers a range of issues which need to be considered when deciding whether to register for a research degree.

Research ethics and ethics committees

This paper gives an overview of the main concepts of research ethics and explains a little about the various types of ethical review. This includes research ethics committees and how best to submit any research proposal.

Sources of research funding

This paper provides information on a wide range of potential funders.

SARAH CROMBIE Research officer

Letter from the Chair

Following the call for research proposals in the summer of 2003, the National Committee of APCP awarded three bursaries. These bursaries will be given over the next 18 months and are subject to ethical approval.

This is the opportunity for the membership of APCP to read the 250 word (max.) summary that each applicant submitted to the Executive Committee for 31st August 2003.

Progress reports and findings of the projects will be in future issues of the APCP Journal.

ADARE BRADY Chair APCP **CATHY MAGUIRE**

Senior Paediatric Physiotherapist

Title of Research: Feet First – A New Approach to Paediatric Knee Pain

Brief Summary (max, 250 words)

An innovative type of functional foot orthosis has been designed for the treatment of paediatric knee pain. If proven, the theory that this is based upon will create a new understanding of how each segment of the foot, and its relationship with the others, affects functional stability and influences the rotational pathways critical to effective gait.

The pivotal concept in describing mode of function for this orthosis, is to define the effect that differential metatarsal segmental rigidity has upon subtalar stability and, therefore, tibial rotational control. That is, that ground reaction force, when encountered by a foot describing a predisposing alignment, and prevalent in those with symptomatic knee pain, inevitably leads to sustained and irrecoverable tibial rotation throughout the stance phase of gait. That the rotational pathways described by thigh and pelvis remain largely unchanged by the scenario described, may suggest the likelihood of a patho-mechanical complex.

It is believed that Advanced Rotational Control F.F.Os may offer a solution to this intractable condition.

SARAH CROMBIE

Title of Research: Physiotherapy for Children with Cerebral Palsy attending mainstream schools

Brief Summary (max. 250 words).

Children with cerebral palsy often require on-going physiotherapy when they start school. With the move from a special school system where services were on site, to the intergration of children with special educational needs into mainstream school, physiotherapy services have had to adapt to meet these changes. Physiotherapists can no longer treat every child individually within the school setting, but now work together with schools to attempt to meet the needs of these children. Within the framework of inclusion, there is a need to investigate how physiotherapy for children with cerebral palsy should best be managed. It is necessary to look closely at how physiotherapy and schools can work in collaboration to ensure that the child's physical development continues to be promoted, whilst ensuring the integration into school and home life can be achieved.

In order to achieve this end, it is firstly necessary to explore the current role of those involved with the child's physiotherapy, both in and out of the school setting. The expectations they have of their role and that of others, and the limitations they have found within this present systems, will be investigated. This study aims to identify appropriate and clear roles for physiotherapists and classroom assistance, in order that a more coherent system can be identified for the child and family in the child's physiotherapy management. The findings from this project will inform future work evaluating a system of therapy input, education and collaborative working.

GERALDINE HASTINGS

Clinical Specialist, University Hospital of Wales, Cardiff

Title of Research Project: Ethical, Legal and Professional Issues in Paediatric Physiotherapy: A "Mere Appendage" or Should Children have More Say in Health Care?

Summary of the proposed research project (in 250 words)

This research will explore the ethical, legal and professional values, which underpin paediatric physiotherapy practice. These values will be compared and contrasted with professional practices in relation to the treatment and nontreatment of children, with a particular focus on practice(s) within paediatric physiotherapy. The central preliminary hypothesis is that current practices are out of step with the core values which should underpin these practices. There is evidence of both (so-called) "good" and "bad" practices, with regard to obtaining and respecting both consent and refusal from the child patient. The research will be both theoretical, in analysing the ethical, legal and professional issues relating to paediatric physiotherapy, and empirical, in analysing the practices and perspectives of those physiotherapists working with children. This has contemporary relevance for health care generally, not least in light of concerns expressed as to the information offered to and choices availabe to, patients in the NHS. In addition, the Department of Health has issued new guidance with a view to standardising how consent is obtained within the NHS. The research is therefore particularly timely and of great interest to paediatric physiotherapists working the NHS as they face difficult consent and/or refusal related dilemmas in clinical practice.

NORTHERN IRELAND

Happy New Year to all our Members!

We have had two great evening talks recently and the second with Ruth Graham at the Northern Ireland Children's Hospice proved to be a very popular and interesting evening.

We hope to see you all back for our forthcoming meetings. By the time you read this we should have had an up-date by Jon Pierre from the Bobath Centre. Hopefully those of you doing the Bobath course will have been able to make it along and won't have had too much homework to do!

Our March meeting is to be preceded by the AGM. I would encourage you all to support this. We would welcome any comments or suggestions that you might have on that evening. We are also looking for some volunteers to join the committee. If you would be interested please contact myself or Tina Weston. The AGM will be followed by a talk from Lou Downey on Paediatric Sports Injuries.

We are delighted to be able to fund two of our members to attend the APCP National Conference in Liverpool this year. We look forward to their feedback from this event at a later date. I would encourage you all to think about Conference - maybe some generous managers would be willing to fund this as part of your continuing professional development!

I look forward to seeing you all at the next meeting

ALISON MOUNSTEPHEN

NORTH WEST

Conference in Liverpool is nearly upon us and the organising committee continue to work hard with the challenge of such a demanding undertaking. Things are coming together well and we have had good uptake of bookings. Remember it is still not too late to book though. It promises to be a very stimulating conference.

Don't forget the AGM on 13th March at the postgraduate centre at Warrington District General. You should all have received the flier for your confirmation with your new membership card. We have vacancies on committee and would welcome interest from anyone who would like the challenge of working for the local committee. It involves four

meetings a year plus organising study days for the region. This is your opportunity to influence and be involved in the working of APCP at local and national level.

Membership renewal to mid January stood at 188 so please encourage any colleagues who haven't renewed or who have never joined to do so.

Local committee have also been hard at work organising further study days for the year. There will be a hydrotherapy study day in the October half term. Details of this will be available nearer the time. We are also holding a day for PMLD which is to be held at the Space Centre/Willows CDC, Preston on Thursday 24th June. Details of this can be obtained from Mrs Wendy Gray, Willows CDC, Peddars Lane, Preston, Lancs. PR2 2TR. Phone 01772 401462. Applications will also be available at the AGM.

Looking forward to seeing you all at the AGM and Conference.

ELAINE LLOYD

LONDON

This will be brief as there is not much to report apart from reminding you all that the London Branch AGM will take place on TUESDAY March 9th 2004 (not one of you spotted the deliberate mistakes in the last report in the December Journal so I'm afraid the six week holiday for two to the Seychelles has not been won and, with reluctance, I am afraid that I will have to bite the bullet and jet off to the sun in your stead. Being a Regional Rep has the odd perk as you can see!)

Please do make every effort to attend the AGM as it is your chance to see what the committee has been up to over the past year and gives you a chance to have your say too. We are aware that this branch covers a huge area and seems to be very London based for meetings etc. If you live out of London and would like to be involved please get in touch with Kate Beattie 0202 7405 9200 ext 5144 (not Kate Page as I called her last time – deliberate mistake no:2! Apologies Kate but you'll always be Kate Page to me!) There will be vacancies on the committee (including Regional Rep - see above!) so if you would like to get involved please let us know.

Along with the AGM we have Cate Naylor presenting her research on Constraint Induced Therapy. This will all take place at the Wolfson Centre in Mecklenberg Square, WCI (nearest tube is Russell Square) from 6.00 if you fancy a glass of wine, 6.30 for the AGM and 7pm for Cate's lecture. Cost to you is £5.00 – ring Kate to book you place. You can just turn up on the night as well but letting us know ensures that you get some vino!

This is my last report as I have served my time on the committee but I would like to wish the London Branch all the best for the future. It's been fun!

JEANNE HARTLEY

SOUTH EAST

Little to report this time round.

We have just held a very successful study day on January 22nd at the Post-graduate centre in Brighton. Pilla Pickles entertained and informed us in her own dynamic style on the subject of a multidisciplinary approach to working with children in education, entitled 'No one can have the ball all of the time.' This course was fairly well attended, however, we were rather disappointed at the uptake from our colleagues working in education. Only a very few teachers attended, even though every education department and school throughout the region was invited to attend. We can really recommend Pilla as a speaker. She is easy to listen to, amusing and practical. She offers a wealth of experience in working with children with special educational needs in various settings and was full of very useful hints and suggestions on how to include therapeutic goals into the curriculum. This, along with plenty of ideas on the use and adaptation of cheap and cheerful everyday objects which she has found to work towards helping these children achieve these goals, was invaluable.

Our next big event is the AGM and study day that takes place on 22nd March 2004 in the Function Room at Pembury Hospital, Maidstone. The AGM is to be held at mid day. The day itself opens at 9 am till 4pm. It includes speakers on the subject of respiratory issues in both the community and acute setting and is entitled 'A Breath of Fresh Air.' This is hopefully to include management of the neuromuscular child, long term ventilation and an update of manual techniques. For further information please contact Ann Martin or Nikki Crockford at Charlton School tel 020 8855 2057

Important changes are being planned for the association in the coming year and being actively involved at regional level gives you all a chance to offer your opinions and thoughts on the important decisions being taken. Your expertise in various fields of paediatric physiotherapy, both clinical and managerial, will be of great value to the national committee as they work hard on your behalf to improve and raise the profile of the association. We look forward to your support.

PETA SMITH

NORTH EAST

The committee met in January to finalise details for the study day in March, held at the same time as the AGM. The autumn study day on Saturday 2nd October at Harrogate District Hospital on 'Paediatric Hydrotherapy' has been confirmed and details will be sent out later via flyer and ICSP.

Thank you to those 49 members who returned questionnaires regarding further study days. The answers have been collated and show that a weekday is most popular and that two study days per annum are sufficient, avoiding the summer term. Suggestions for future topics were many with 2/3 titles constantly being requested. These requests will be noted by the committee and arranged if at all possible.

Penny Sherlock, who has served on the committee for the last 7 years, (plus 2 years previous to that on the organising committee for National Conference when last held in Yorkshire) is resigning to concentrate on semi-retirement and more time with her grandchildren. The committee thank her for her hard work, especially whilst being secretary. We shall miss her organisational skills but most of all her friendship and the use of her home on many occasions for meetings.

Looking forward to hopefully meeting with many of you whilst at Conference in Liverpool

MARY HARRISON

SOUTH WEST

There are a few bits and pieces to report for the start of the New Year.

Firstly, is the success of the study days both on integrating disability into PE and also the Botulinum Study day. The PE days were well over subscribed and as a result we will be running them again in the first half of this year with provisional venues being Exeter and Dorchester. There were a lot of education staff on the courses as we opened it up to many disciplines. However it can only serve to improve links and also educate staff about where we are trying to come from! The cost will have to go up this time, however, to meet the running and materials cost but there will be a far greater price difference for APCP members v the rest of the world! Please watch for flyers and frontline ads.

Secondly thanks and well done to Rob Shaw from Poole who coordinated a great study/working day on Botulinum and subsequent management with

Charlie Fairhurst from Chailey as the Key speaker. Thanks also to Shelley Cox who chaired the sessions. From this a series of working parties have formed to look at some issues/standards at a regional level. I will be forwarding this to the National Committee, where we hope to collate all the evidence and act upon it. Please contact Rob if you wish to help and there will be a follow up study/ workshop day on Friday 16 July in Poole.

Finally there is the AGM, which is combined with a learning disability day in Basingstoke on the 20th April. This will be held at Popley Community Centre with registration at 9.30 am. Again, see Frontline and flyers for details. We have some committee vacancies to fill so if you are feeling willing and able! Thank you to Sue Moll who is resigning from the committee and her position as secretary.

RUTH DAVIES

EAST ANGLIA

By the time this edition of the journal reaches you, our AGM and Study Day on 6th March at Addenbrookes will be upon us. All members should have received a programme in the post, and our topics of Targeted Training, and Caseload Weighting will no doubt provide an interesting day.

Your committee are continuing to work on the rest this year's programme. On 19th June we are holding a study day on Torticollis, BPL, and Talipes, at the Ida Darwin Hospital near Cambridge. As soon as arrangements have been finalised, we will send flyers out in the post with application details.

In September/October we will be running a one or two day course on Sensory Integration. Further details will appear in the next issue of the journal.

We would also like to organise a study day on Strength Training for children with cerebral palsy, perhaps early next year.

Don't forget that our website (apcpeastanglia.org.uk) for up to date information on study days, as well as information on our library of books and videos. We do bring the library to all study days, and also bring copies of all APCP publications for information.

I hope to see many of you at the AGM, and please let me know if there are any topics on which you would like us to try to arrange study days, or ideas for additions to the library. My email is coombeloddon@aol.com.

SUE COOMBE

WEST MIDLANDS

We are holding our AGM in March alongside an Orthopaedic Study Day, which we are hoping will be well attended. At that meeting I will be stepping down as Chairperson and the post will be taken by Sheila Clayton. I would like to wish her all the best.

We are in the process of looking at running further Study Days later in the year. Watch this space!

LINDSAY RAE

NEONATAL CLINICAL INTEREST GROUP (Affiliated to the APCP)

As I write this, it seems a very long time ago since we met at St. Michael's Hospital in Bristol on November 7th 2003. This was our 2nd study day but the 1st AGM. It was incredible to realise how much we had achieved in the previous 12 months. This became apparent at the committee meeting held the previous day. Peta Smith our Chair, has worked extremely hard raising the profile of the group and ensuring we are recognised at the early stages of new developments including looking at competency frameworks, where she and the APCP will be representatives.

Allie Carter, Vice chair has met with Bliss and will hopefully be forging some very important links with them with regard to leaflet design and production. There was also a Respiratory Study Day in London in September, which was well attended and the plan is to run similar style courses around the Regions. Ideas for future study days were to run a 2 day Neonatal Conference and the suggested venue was Edinburgh. This hopefully will be toward the end of September or early October and promises to be an exciting event.

The study day in November entitled "Protecting the Newborn Brain" was attended by around 20 delegates, which was a little disappointing compared to the 50 who attended the inaugural meeting. However I think I speak for everyone who was there that it was once again an extremely interesting and beneficial day. The lead speaker was Professor Marianne Thoresen, Professor of Neonatal Neuroscience, Consultant Neonatologist at St. Michael's Hospital and the University of Bristol. We heard a detailed account of her work over the past 10 years which was coming to it's end studying the effects of cooling in asphyxiated babies to reduce the degree of brain damage. This has been a multicentre trial and the results were being presented in

Washington at a conference in early December. It was very exciting to hear how Marianne had tackled this subject which was so dear to her heart as she had previously been a Physiotherapist and felt the only way she could find these answers was to become a Doctor and then carry out her research. Although spellbinding, the presentation sparked some interesting discussion. We all came away reeling and honoured to have shared in the experience!

Apart from the AGM the rest of the day was given over to the design of leaflets. We had some helpful advice from Russ Davidson of the Illustration & Design Department at UBHT on leaflet design. Some workshops followed looking at developing various leaflets including Positioning and developing flexor patterns, Preparation for Discharge from the NNU, possibilities for Parental and/or Professionals Leaflets ie Health Visitors, and the use of Car Seats for Neonates. A working group was set up to look at the various ideas and will be led by Allie Carter.

Regional meetings will continue along the lines of case study presentations, video analysis, peer and clinical review, developing mentor and buddy systems. The committee will meet at the end of March in Manchester to discuss details for the conference later in the year.

Please continue to contact any of us directly, or myself on petenbop@tesco.net, or Nicky on nicola.mcnarry@mail.qmc.uh-trent.nhs.uk

BARBARA HAEDERLE

APPLICATION FORM FOR A.P.C.P. PUBLICATIONS - 2003

New Pu 2003	Special Educational Needs Code of Practice 2001			
	Guidance for Paediatric Physiotherapists£10.00			
2002	Paediatric Physiotherapy Guidance for Good Practice £5.00			
2002	Obstetric Brachial Plexus Palsy A Guide to physiotherapy management£10.00			
2002	Hip Dislocation in Children with Cerebral Palsy A guide to physiotherapy management			
Evidence •	Management of Obstetric Brachial Plexus Palsy£3.00 Hip Subluxation and Dislocation in Children with Cerebral Palsy£3.00 OR£5.00 for the pair			
Paediat	ric Manual Handling – Guidelines for Paediatric Physiotherapists £10.00			
Human	Postural Reactions – Lessons from Purdon Martin by Dr J Foley £5.00			
Tests and Measures Resources Pack (2ndEdition) £3.50				
Baby Massage £1.50				
The Children Act 1989 "A synopsis for Physiotherapists" £1.00				
Guidelines for Calculating Caseloads (not available at present, in process of being updated)				
POSTAGE AND PACKING INCLUDED IN THE PRICE WITH ALL THE ABOVE.				

FOR MORE THAN 10 COPIES OR FOR POSTING TO OUTSIDE UK - POSTAGE UPON REQUEST PLEASE.

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

SEND ORDER WITH PAYMENT TO:

LORNA STYBELSKA, PAEDIATRIC PHYSIOTHERAPY DEPARTMENT, CUMBERLAND INFIRMARY, CARLISLE, CUMBRIA CA2 7HY.

WORK TEL: 01228 814739

	e-mail: stybelskal@aol.com
Name and Address for Delive	у:
************	***************************************

HERE AND THERE

The Bath Institute of Medical Engineering is a design and

development charity closely linked to Bath University.

We are working on a number of design projects to develop new assistive technology. For details of our projects take a look at our website www.bime.org.uk

Responding to local requests, we have made several weighted walkers for young children in the Bath area. The handle is adjustable and the frame has a wide base with a tray. For these prototype versions we have used a tank, in which variable amounts of water can be added to increase or reduce the overall stability of the walker. The proposal is for the walker to be initially very stable but to reduce this stability, by reducing the amount of water in the tank, as confidence in walking increases. Please contact us if you think this would be a useful mobility product or if you have any comment on this project. We are trying to find out if there is sufficient interest in the weighted walker to continue with development work. It is estimated that any end product would be priced under £100. I look forward to hearing your views.

Nina Evans Occupational Therapist Bath Institute of Medical Engineering The Wolfson Centre, Royal United Hospital,

Bath BA13NG

Tel: 10225 824103 Or e mail N.M.Evans@bath.ac.uk



Easy Riders Wheelchair Committee

The Variety Club Children's Charity aims to help sick, disabled and disadvantaged children aged 18 or under, by assisting with grants for specialist equipment they need. One of the ways Variety Club does this is through the Easy Riders Wheelchair Programme. Founded in 1988, Easy Riders have given custom-designed wheelchairs and mobility aids to over 2,400 children who are contending with a wide range of disabilities and whose families are not able to fully fund the cost themselves.

Part funding often takes place between Health Services, the family and various charities such as Variety Club to ensure each child gets the wheelchair they require to improve their independence and mobility.

Each applicant is sent a form for the parents/guardians to complete which needs to be returned with a supporting letter from a Physiotherapist or Occupational Therapist and a copy of the quote for the appropriate wheelchair. Each application is then considered by the Easy Riders Wheelchair Committee.

If you know of any children who are in need of a wheelchair or buggy, please feel free to contact Variety Club to obtain an application form on 020 7428 8100 or print one from the website www.varietyclub.org.uk.

Alternatively email wheelchair@varietyclub.org.uk

CONFERENCE 2004

COME TO CONFERENCE 2004

EVIDENCE INTO PRACTICE



TAKING PLACE ON LIVERPOOL'S WATERFRONT

AT THE CROWNE PLAZA HOTEL

PROGRAMME & APPLICATION FORM ENCLOSED WITH THIS JOURNAL

LIVERPOOL - IS THE EUROPEAN CITY OF CULTURE 2008

ASSOCIATION OF PAEDIATRIC CHARTERED PHYSIOTHERAPISTS CONFERENCE 2004

"Evidence Into Practice"

Crowne Plaza Hotel Liverpool Friday 30th April - Sunday 2nd May



PROGRAMME

	PROGRAMME
Friday 30	
13.00-13.1	5 Opening and welcome
13.15-14.0	0 Keynote Lecture – National Service Framework for Children
	Professor Al Aynsley Green - National Clinical Director for Children
14.00-15.0	0 Muscle strengthening
	Mrs. Gill Holmes - Clinical Specialist Alder Hey Hospital
15.00-15.3	
15.30-16.3	The decision making process for giving botulinum toxin in managing spasticity in
	cerebral palsy
	Ms.Kaat Desloovere - Kinesiologist, Belgium
16.30-17.1	
	Ms. Adele Moore Senior Lecturer in Physiotherapy Sheffield
17.15-18.0	
18.00-19.0	
20100 2710	Sponsored by Allergan (This is now fully subscribed)
	Optional extra 2 - evening seminar - Interventional procedures: ITB and Deep Brain
	stimulation for Dystonia - Sponsored by Medtronic
	Stimmation for Dystonia Sponsorea by Meatione
Saturday	1st May
7.30-8.30.	Optional extra breakfast meeting – Equipment Reissue and Refurbishment –
,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	Sponsored by Jenx
9.00-9.45	Agenda for change
2.00 2.10	Ms.Claire Strickland Previous Chair of Council
9.45-10.15	
2.43-10.13	Ms. Allie Carter Superintendent Paediatric Physiotherapist -
10.15-10.4	
10.45-11.1	
11.15-11.3	
11.30-12.3	
12.30-1.45	
13.45-14.1	
13.45-14.1	
14 15 15 0	Dr. Bill Yoxall Consultant Neonatologist - Liverpool
14.15-15.0	
15.00 15.4	Dr. Lewis Rosenbloom Consultant Paediatric Neurologist - Liverpool
15.00-15.4	
15.40-16.3	O The state of the
16 20 17 0	Mr. Alfie Bass Consultant Orthopaedic Surgeon - Liverpool
16.30-17.0	
17.00.16.0	Mrs. Anna Mayhew Clinical Specialist -Preston
17.00-16.0	Free Papers & Acknowledgment of essay winners
19.15	PRE- DINNER RECEPTION (all invited) & 20.00 - CONFERENCE DINNER (pre-booked)
Sunday 2	nd MAY
9.30-10.15	Exercise in cystic fibrosis
	Ms. Mary Dodd Consultant Physiotherapist - Manchester
10.15-11.0	
	Ms. Diane Rogers Clinical Specialist In Paediatric Cystic Fibrosis and Respiratory Care -
	Cardiff
11.00-11.2	Coffee
11.20-12.0	Advances in neurosurgical techniques for the treatment of intractable epilepsy
	Mr. Paul May Consultant Paediatric Neurosurgeon - Liverpool
12.00	CLOCING ADDRESS

12.00

CLOSING ADDRESS



APCP - LIVERPOOL 2004

EVIDENCE INTO PRACTICE

CONFERENCE APPLICATION FORM

Name
Please tick appropriate boxes
FULL CONFERENCE PACKAGE
The Full Conference Package includes Hotel Accommodation on Friday & Saturday nights at the <i>Crowne Plaza Hotel</i> , all daytime catering, plus entry to all lecture sessions on Friday afternoon, all day Saturday and on Sunday morning plus <i>Overnight B & B based on 2 people sharing accommodation</i> . Single rooms are available at supplement of £30 per room per night.
Please indicate (if known) with whom you wish to share
PLEASE NOTE THAT THE CONFERENCE DINNER & OPTIONAL MEETINGS ARE EXTRA

MARCH 2004 45 A.P.C.P. JOURNAL

A.	Application after 28 December 2003 1 April 2004	– Final clos	sing date:	
1.A	Full Conference Package	Member		Non-member
1000000		£300		£330
	Single room supplement (per night)	£30		
		Friday		Saturday
		9.77		
2.A	Conference Package without Accom		F . I . 6	11 1 2 1 1 2 2 1
	Includes entry to all conference lectur	re sessions	on Friday after	noon, all day Saturday & Sunday
	morning plus all daytime catering.			
		Member		Non-member
		£150		£165
		2100		2100
3.A	Day & Half Day Rates without accord	mmodation	1	
	*		AFTERNOON	
	Includes entry to Friday conference le	ecture sessi	ons plus tea &	coffee
		Member		Non-member
		£40		£45
			- ALL DAY	
	Includes entry to the conference lectu		plus lunch, te	
		Member		Non-member
		£70		£75
		V 12 172 42/2	tonius o	
			MORNING	
	Includes entry to the morning lecture	s and tea & Member	coffee	NI
		£40		Non-member £45
		£40		£45
OPT	ONAL EXTRAS:			
	TED AVAILABILITY: Please tick box &	r include fe	e with your a	polication
	The state of the s	e merade re	ce min your u	Spiretton .
1.	Friday Evening Seminar: Intervention	nal Procedu	ires: Intratheca	l Baclofen and Deep Brain Stimulatio
	for Paediatric Movement Disorders –			
	Price £10		1	
2.	Saturday morning Breakfast Meeting:	Equipmen	nt Re-issue & R	efurbishment – Sponsor Jenx
	Price £10			€1 27.8

CONFERENCE DINNER & ENTERTAINMENT Saturday Evening at the Crowne Plaza Hotel

COE	D 1
LZO	

For help in booking accommodation separately you can contact Mersey Partnership at: www.merseyside.org/apcp.doc

at: www.merseyside.org/apcp.doc
Please send completed application forms and an A4 SAE to:
Christine Sneade MCSP, 26 Mornington Avenue, Crosby, Liverpool L23 0SA
Cheques should be sent with application and made payable to: APCP Conference Account 2004
NAME
ADDRESS (for correspondence)
POST CODE
TEL Number
e-mailFAX Number
PLACE OF WORK
APCP Number & Region
NATIONAL COMMITTEE MEMBER: YES / NO
Do you have any dietary /special requirements YES / NO
Please detail

Cancellations will be refunded up until the closing date but subject to a £20 fee. However, substitute delegates are welcomed as no extra charge.

APCP CONFERENCE 2004



SWEATSHIRT ORDER FORM

Fruit of the Loom raglan sweatshirts 70/30 cotton/polyester printed with APCP Liverpool Conference Logo

Orders must be in by 25th March 2004 to be collected at Conference. Postage will be charged for orders received after this date.

INAME						
ADDRESS	*******					
***********			*** * * * * * * *			
CONTACT TEL						
PRICE PER SHIR'SIZES: S38		L42	XL46			
COLOUR	5	M	L	XL	COST	
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	S	M	L	XL	COST	

SEND ORDER FORM WITH PAYMENT TO: Linda Whitaker, 21, Hague Bar, New Mills, High Peak SK22 3AT

Cheques payable to: APCP Conference Account 2004

APCP 2004 CONFERENCE NEWS





LATE APPLICATIONS:

We have had an excellent response in terms of conference applications, however we still have some places remaining and hence will accept late applications.

OPTIONAL EXTRAS:

FRIDAY:

- We are oversubscribed for the Friday evening seminar on: "The role of the physiotherapist in the management of spasticity following botulinum toxin injections" presented by Lesley Katchburian - Sponsored by Allergan.
 Lesley has agreed to repeat this workshop at 7.30 on the Saturday morning 1st May for applications already received
- 2. We still have some places available on the optional extra 2 evening seminar on Friday "Interventional procedures: intrathecal baclofen and deep brain stimulation for paediatric movement disorders" presented by Dr Roeste Consultant Neurosurgeon Oslo Sponsored by Medtronic

TRADES EXHIBITION: Join us for complementary cheese and wine to accompany the opening of the trades exhibition at 5.15 on Friday afternoon – The event is to opened by Liverpool actor Ricky Tomlinson

FRIDAY MORNING EXTRA:

For those who will be in Liverpool on the morning before conference begins we can offer a tour of the Liverpool Tate gallery at 10 am on Friday morning. The gallery is only a ten minute walk from the Conference Hotel. For more information please contact Juliet Weston on 0151 932 1139.

SATURDAY: We still have some places on the Optional extra breakfast meeting "Equipment re-issue and refurbishment" - sponsored by Jenx

CONFERENCE DINNER: promises to be an exciting evening - we have a range of entertainment including a live band plus other novel entertainment! NB: THERE IS A PRE-DINNER RECEPTION - ALL WELCOME.

TO AVOID DISAPPOINTMENT PLEASE BOOK IN ADVANCE OF CONFERENCE - as we have a very limited facility to book additional places during the Conference - Price £25

PARKING: There are over 150 car parking spaces available at the hotel. This is allocated on a first come first served basis. There is an NCP car park opposite the Crowne Plaza Hotel and next to the Thistle Hotel.

We look forward to seeing you all at Conference!

EILEEN KINLEY

on behalf of the Conference Organising Committee Contact details: 83waterloo@supanet.com

COURSES

Institute of Child Health And Great Ormond Street Hospital for Children NHS Trust UNIVERSITY COLLEGE LONDON

Paediatric Physiotherapy Course

Monday 7 - Friday 11 June 2004 Fee: £475 / £115 (per module)



Intended for all physiotherapists with an interest in paediatrics, primarily Senior II & above, the course is run as five one day modules. The daily programmes will consist of lectures & interactive workshops allowing plenty of opportunity to discuss & share experiences. The course also looks at conditions requiring physiotherapy input at a tertiary centre & considers the interaction between local community services & some of the more complex & long term conditions currently seen in paediatrics.

Advanced Paediatric Rheumatology

Thursday 15 - Friday 16 July 2004

Fee: £270 / £190 (physiotherapists, occupational therapists, nurses & social workers)

This multidisciplinary course provides an update in the diagnosis and multidisciplinary management of children with rheumatological diseases and aims to encourage the development of shared clinical networks in line with the paediatric NSF.

The Courses and Conferences Office

Institute of Child Health, 30 Guilford Street, London WC1N 1EH.

Tel: 020 7905 2135 / 7829 8692 / 7813 8394

Email: Courses@ich.ucl.ac.uk

To apply & for further details on our wider programme of events visit our website.

www.ich.ucl.ac.uk/shortcourses

SEVENTH ANNUAL COURSE IN PHYSIOTHERAPY FOR CHILDREN WITH MOTOR LEARNING DIFFICULTIES INCLUDING DYSPRAXIA

This course is designed for physiotherapists working in paediatrics with some knowledge of Neuro-Developmental Therapy.

It gives an overview of motor learning difficulties including Dyspraxia and covers assessment and treatment planning. The course offers a mix of theory, practical and video observations. Sally's work combines knowledge of Sensory Integration with Neuro-Development Treatment.

This course would appeal to experienced clinicians and those developing their skills in this area.

Tutor: Sally Wright MCSP

Dates: 10th – 14th May 2004

Venue: Chelsea & Westminster Hospital

Fee: £375.00 payable to Chelsea & Westminster

Healthcare NHS Trust Charity

Closing Date: 16th April 2004

For further information please contact Jenny Bassford, Physiotherapy Dept. Chelsea & Westminster Hospital. 369 Fulham Road, London, SW10 9NH. Tel. 020 8846 1608

COURSES



What's new in Targeted Training?

A one-day seminar for therapy staff working with movement disabled children.

Topics will include:

- √ theory of Targeted Training therapy
- ✓ latest research on effectiveness
- experience in the community

Lecture Theatre, Institute of Orthopaedics,

Robert Jones & Agnes Hunt Orthopaedic & District Hospital NHS Trust, Oswestry, Shropshire. SY10 7AG.

Thursday, 15th April 2004. Cost £25.00

For details contact Penny Butler,

The Movement Centre, C/o RJAH Orthopaedic Hospital, Oswestry, Shropshire. SY10 7AG.
Tel: 01691 404248 e-mail: pennybutler@the-movement-centre.co.uk

Sponsored by The Movement Foundation

Royal Free Hospital, London 6th – 9th July 2004

"Prechtl's Method of Qualitative Assessment of General Movements"

Highly reliable technique for the accurate assessment of neurological functioning in young infants

The Qualitative Assessment of General Movements has been shown to be a better predictor of neurological outcome than the traditional neurological examination in high risk infants and this assessment is now being used worldwide.

The training course is designed for Paediatric Neurologists, Neonatalogists, Paediatricians, Physiotherapists, Occupational Therapists and others working in Infant Neurology.

Course Tuition Fee: £425.00 (including lunch)

For application form and further details contact:

Marilyn Dowdye

Child Health Department

Royal Free Hampstead NHS Trust

Pond Street

London NW3 2QG

Tel: 0207 472 6270 Fax: 0207 830 2003

Email: marilyn.dowdye@royalfree.nhs.uk

Royal Free & University College School of Medicine & the GM Trust

VACANCIES

Hammersmith Hospitals NHS Trust

Hammersmith Hospital: Physiotherapy Department Senior 1 Paediatric Physiotherapist (Full time)

We are looking for an experienced and enthusiastic paediatric physiotherapist, to join our team of 5, who wants a hospital based job in our very specialist unit.

Part of the work involves the assessment and treatment of children in the highly regarded neuromuscular service, which has a national and international reputation as a centre of excellence. (Previous experience in neuromuscular work is not essential as full training will be given)

The job also involves leading the service to one of the country's newest and largest neonatal units, and for the babies born in Queen Charlottes Maternity Hospital, which is on site.

We have a small outpatient caseload of neuro-developmental and musculo-skeletal problems.

This is a job for someone who enjoys teaching and wants to take part in high level research which are high priorities in our work. There is a strong commitment to CPD and a very good on-site training department.

For further information or to arrange a visit, please call one of the paediatric physiotherapy team on 020 8383 4734, e-mail: mmain@hhnt.org

Paediatric Physiotherapists £19,657 - £24,644 equivalent to Whitley Senior II Plus Cost of Living Pay Supplement

Portsmouth City
Teaching Primary Care Trust

Portsmouth Paediatric Physiotherapy is a well-established yet flexible and growing department committed to providing quality services to children in the hospital and across the community.

This is a rotational position with opportunities in Acute Paediatrics including neo-natal intensive care, special schools, mainstream schools, outpatients and home visits. As part of our multi-disciplinary and multi-agency team, you will provide services for children with developmental, respiratory, muscular-skeletal and other paediatric conditions. 18 months' to 2 years' postgraduate experience will be essential.

In return, we offer excellent clinical support and are committed to continuing professional development.

We have close links with the University of Southampton both for undergraduate training and further education courses.

For informal enquires and/or to arrange a visit, please contact

Aileen Ledingham, Physiotherapy Manager, tel: 023 9289 4410.

PO4 8LD or telephone us on 023 9289 4403 (24 hour answerphone) or email us at recpct@ports.nhs.uk Please quote reference PC6707. Closing date: 15th April 2004.

An Enhanced Criminal Records Bureau Disclosure will be obtained prior to appointment for posts that involve working with children or vulnerable adults. Further information about the Disclosure scheme can be found at www.disclosure.gov.uk

WE ACTIVELY ENCOURAGE APPLICATIONS FROM ALL SECTIONS OF THE COMMUNITY. WE OPERATE A POLICY OF NO SMOKING FOR EMPLOYEES.

Any personal information you provide will be held on a confidential computerized database in accordance with the Data Protection Act 1998.

To request an application pack, please write to Portsmouth City Primary Care Trust, Human Resources Department, St James' Hospital, Locksway Road, Portsmouth PO4 8LD or telephone us on 023 9289 4403 (24 hour answerphone) or email us at recpct@ports.nhs.uk Please quote reference number PC6707.

Closing date: 15th April 2004.

VACANCIES

JAMES PAGET HEALTHCARE NHS TRUST Room for Individuals

SUPERINTENDENT III PHYSIOTHERAPIST - PAEDIATRICS

Due to the retirement of the current post holder we are looking for a forward thinking, dynamic and experienced Physiotherapist to lead the Paediatric Physiotherapy Team. The Team is based in a lively and friendly Children's Centre as part of the multidisciplinary team dedicated to providing services for local children (0-16 years of age) with a wide variety of special needs. The Team, which consists of experienced Paediatric Physiotherapists, junior rotations, assistant and clerical support, work in a variety of locations including clinics, homes, nurseries, mainstream and special schools and also within the hospital.

You will be managerially responsible for effective deployment and development of the team and will play a lead role within the organisation and development of the Centre, Children's Services and the multi-disciplinary Team. You will work closely in partnership with other Health, Education and Social Services colleagues and further develop inter-agency working.

You will be part of a Tri-Trust Physiotherapy Management Team working to manage and develop Physiotherapy Services in both Acute Trust and PCTs.

Close links have been established with Paediatric Therapists across the county and with specialist centres. Clinical placements are provided for students both from the University of East Anglia and other Universities and you would be required to maintain and further develop these links.

You should have a minimum of 5 years' Paediatric experience with 2-3 years' at Senior I level, with evidence of team leadership and management skills. Paediatric Bobath training is essential. You should also be a car driver with a current licence.

For further information or to arrange an informal visit, please contact the current post holder Jackie Reynolds, Superintendent Paediatric Physiotherapist on (01493) 442322.

For further information for any of these posts or to arrange an informal visit please contact Sarah Small, Manager of Physiotherapy and Occupational Therapy Services on (01493) 452687, James Paget Healthcare NHS Trust, Lowestoft Road, Gorleston, Gt Yarmouth, Norfolk NR31 6LA or email sarah.small@jpaget.nhs.uk

Information pack and application form available from Jill Evans on (01493) 452048, or email jill.evans@jpaget.nhs.uk

We are an Early Implementer for Agenda for Change We are an Equal Opportunities employer The Trust has a No Smoking policy All posts are open to job share

At James Paget, you're not just a number, you're an individual. You can expect all the benefits in working for a 3-star NHS Trust and our commitment to fulfilling your potential. We've got a great team here. Come and join us!

North Herts and Stevenage Primary Care Trust

Physiotherapy Services

SUPERINTENDENT II PHYSIOTHERAPY

Salary:

£28,020 - £30,960 p.a.

Hours:

Full Time

Base:

CDC Stevenage; QE II Welwyn Garden City; Brockett Road, Hoddesdon

Ref:

588IM

We are looking to recruit a highly skilled and motivated Physiotherapist at Superintendent II level to take the lead and manage the Paediatric Service across East and North Hertfordshire. The service is based at the Child Development Centre, Stevenage, Queen Elizabeth II Hospital, Welwyn Garden City and in Hoddesdon and the post holder could be based on any of these sites, but able to commute between sites as necessary.

Applications should possess good management and leadership skills and have a broad range of experience in paediatrics, including learning disabilities. Attendance on the Paediatric Bobath course is essential.

We provide paediatric physiotherapy service in a community setting at various locations throughout East and North Hertfordshire and therefore a car driver/owner is essential.

We offer our staff a wide range of benefits including family friendly policies, Occupational Health Services, excellent pension scheme and NHS shopping discounts. Please visit our website www.nhsinherts.nhs.uk for more information and for other NHS jobs in your area.

For further information and application pack, please contact Sandy Burstow, Physiotherapy Administrator on 01438 781074.

For an application pack please e-mail james.murphy@hr-herts.nhs.uk, write to Hertfordshire HR Shared Service at Charter House, Parkway, Welwyn Garden City, Herts, AL8 6JL or telephone our 24 hour recruitment line 01707 361209.

INDEX OF ARTICLES WHICH HAVE APPEARED IN THE APCP JOURNAL DURING 2002 AND 2003

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Long Term Repeatability Of Bronchodilator Challenge In Clinically Stable Children With Cystic Fibrosis

Diane Rogers and Iolo JM Doull

Cystic Fibrosis – Case Study Sheona Tilling

The Role Of The Physiotherapist On Paediatric Intensive Care Paul Ritson

A Review Of The Efficacy Of Knee-ankle-foot Orthosis In The Management Of Children With Duchenne Muscular Dystrophy Donna Wynne

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Different Research Methods Eva Bower PhD FCSP

Setting Up A Research Project Anna Simpson MCSP

Abstracts from APCP Study Day The Effects of Strength Training for Cerebral Palsy

Jan Morton & Margaret Brownlee

Hippotherapy- Interim Results In The Walking Ability of Children With Cerebral Palsy *Joan Wold*

Case Study - Lisa Hutchens MCSP

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Birte Tornoe

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Ethical Considerations In Paediatric Research Dr Terry Pountney PhD MA MCSP

Case Study
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Hydrotherapy For Long-term Ventilator Assisted Children: An Evidence Based Approach to Guideline Development Jacqui Taylor, Physiotherapy Clinical Specialist

Case Study –Spastic / Dystonic Quadriplegia Susan Irving - Physiotherapist

Cardiovascular Effects Of Using A Prone Standing Frame: A Comparison Of Normal and Profoundly Disabled Children E C Stannard, Pyhsiotherapy Student and Andrew Kerr, Lecturer

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The Impact of Nocturnal Ventilation in Duchenne Muscular Dystrophy On Survival, Symptoms and Quality of Life Michelle Eagle, Research Practioner and Clinical Specialist Paediatric Physiotherapist

Study – Dyspraxia Donna Wilson MCSP

Report on Two International Conferences on Developmental Co-Ordination Disorder Judith M Peters – Clinical Specialist Paediatric Physiotherapist

Development of Interagency Working Practices To Support Children and Young People with Disabilities and Their Families (Re-printed with correct references)

Linda Fisher, Paediatric Physiotherapist

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Conference Presentations
Making the Right Start
Helen Robinson MCSP, Senior Paediatric
Physiotherapist

Strength Training for Children with Cerebral

Dr Margaret J Mayston PhD MCSP, Lecturer University College London

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An Investigation into the Transmission of Gravitational Force During Standing in a Prone Standing Frame

Sue Bush MSc MCSP

Evaluation of Orthosis in the Management o children with Cerebral Palsy Who Walk with Frames

V Yule Phd C Davey PhD MCSP C Quinn MCSPP Honeycomb

Serial Casting

Shelley Cox MCSP Superintendent Physiotherapist

Management of the Long-Term Ventilated Child in the Community

Barbara Noosfeld RGN RSCN PG Dip in HRD

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John Goldsmith and Liz Goldsmith MCSP

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The Use Of Lycra Socks in Peripheral Sensory Deficit

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Author unknown

Habitual Toe Walkers - Questionnaire Results Emma Day MCSP

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Kath Glendenning MCSP Anne Ryan DBO(D) and Jenny Fonseca MSc BSc CHBiol MIBiol

Issues Around Sports Participation In Disabled Children and Injury Prevention In The Young Wheelchair Athlete Leigh Forsyth BSc Hons MCSP SRP

The Use of Ankle Foot Orthosis in the Management of Children with Cerebral Palsy Robert Grieg SB Orthotist / Prosthetist

Arthrogryposis - A Case Study Sam Double MCSP

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 Sarah Crombie, Research Officer, 10a Record Road, Emsworth, PO10 7NS. This information will be used to inform you of reseach study days and help us to learn more about our members' research interest.

Name						
Contact Address						
Post Code						
Tel. No.						
Fax No.						
E-Mail:						
What are y	our resear	ch interests?				
Are you ur If so please	ndertaking give a bri	any type of r ief summary .	esearch pro	oject small o	r large? YES?	NO

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

Thank you for completing this form.

REGIONAL REPRESENTATIVES

EAST ANGLIA

Ms Sue Coombe 32 High Bungay Rd

LODDEN Norfolk NR14 6JT

coombeloddon@aol.com

LONDON

Mrs Jeanne Hartley Physiotherapy Dept Great Ormond St Hospital

LONDON WC1N 32 JH hartlj@gosh.nhs.uk

SCOTLAND

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Alison.gilmour@graysmill.edin.sch.uk

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Mrs Ruth Davies Child Development Unit Musgrove Park Hospital TAUNTON

Somerset TA1 5DA roofyrooster@hotmail.com

SOUTH EAST

Mrs Peta Smith 1 Physiotherapy Dept Mary Sheridan Centre 43 New Dover Rd . CANTERBURY CT1 3AT peta.smith@ekht.nhs.uk

WALES

Mrs Jill Williams Nursery Unit The Hollies Special School Pentwyn CARDIFF

NORTH WEST

Ms Elaine Lloyd Physiotherapy Dept Booth Hall Children's Hospital Charlston Rd Blockley MANCHESTER M9 7AA elainelloyd911@madasafish.com

elainelloyd911@madasafish.com claire.wagstaff@talk21.com

TRENT

Mrs Claire Hill Physiotherapy Dept Sheffield Children's Hospital Western Bank SHEFFIELD S10 2 TH

NORTHERN IRELAND

Mrs Alison Mounstephen
Physiotherapy Dept
Flemming Fulton School
Malone Rd
BELFAST
N Ireland BT197TY

WEST MIDLANDS

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