ASSOCIATION OF

PAEDIATRIC

CHARTERED PHYSIOTHERAPISTS

NEWSLETTER

Association of Paediatric Chartered Physiotherapists

Newsletter No.67 May 1993

ASPECTS OF MUSCULAR DYSTROPHY

Officers of the Association

EDITORIAL

Jill Brownson - Chairman A.P.C.P.

Looking back through past issues of the APCP Newsletter I came across many Editorials asking for contributions from members. One, in particular, caught my attention because it explained that although not a scientific journal, copies of our Newsletter are kept in the British Library; it also encouraged members to write, inviting material to be offered for discussion, wanting members to have confidence in their practice and to lay themselves open to criticism.

These thoughts and hopes for our publication have persisted throughout the years - each Editorial Board has wanted that from the Newsletter and each Editor has sought to persuade you, the members, to contribute.

Your new Editor has all these hopes too. To support her nomination as Editor she told the National Committee that she wants to see a publication which encourages members' own evaluation of practice, their studies and research, as well as being able to attract articles from other professionals. She wants, not to lose the qualities of a Newsletter but, to re-inforce its development as a publication highly regarded for the quality of its articles.

Members increasingly tell us that they need to include details of published articles and research in their CVs, and that to write 'APCP Newsletter' does not give our publication the merit it deserves.

To mark the coming 21st year of the APCP it is proposed that the Newsletter become known as the APCP Journal and consideration will be given to comparing its format with those of other Clinical Interest Group Journals. The Editorial Board will be grateful to hear members' opinions regarding these proposed changes.

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ORDINARY MEMBERSHIP is open to suitably qualified members of the Chartered Society of Physiotherapy

ASSOCIATE MEMBERSHIP is open to suitably qualified professionals working in the field of paediatrics. New applicants require to be proposed and seconded by full members of the Association.

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Cheques made payable to "APCP' should be sent to :
MEMBERSHIP SECRETARY: Mrs. J. McKinlay,
3 Stanley Gardens, Sanderstead, S. Croydon, Surrey CR2 9AH.

LETTERS TO THE EDITOR

Dear Editor,

My son suffers from Aperts Syndrome. I am trying to do a survey into this condition because very little seems to be known about what to expect of such children.

I have a list of families from the parents support group and I have written to all those families. I have had a good response and many of them are more than willing to take part in a survey.

Unfortunately the list is somewhat out of date. As I wish to contact as many Aperts families as possible, I was wondering if there was a way in which you could help me contact families, who have moved since the list was compiled or who are not on the support group list at all.

Thank you

Mrs. J. Hancock - 17 Henry Road, Chelmsford, Essex CM1 1RG.

Please could members put parents of children with Aperts Syndrome known to them, in touch with Mrs. Hancock. - *Editor*

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To All APCP Members

We have at last moved with the times and purchased a new computer system on which we can store a great deal more information than has so far been possible.

This will of course be subject to the Data Protection Act, and further details of this will be made known to you before we embark fully on what is possible.

Do not be alarmed.

We are not going to ask you to tell us what you wear under your 'uniform'!

You are all familiar already with the Application/Renewal forms that we fill in every year before the start of the new year. It tells us your correspondence address, CSP No., APCP No. (If you are able to find your current card! It is amazing how many folk do not know where that card has gone). And you tell us your work place.

We would like to obtain a little more information so that we can help each other to know what goes on where in the country.

Where can I find someone really interested in SCBU in the North East Region? Or do we know of anyone who works on Vibration Therapy anywhere? And, would anyone be prepared to speak to us about their speciality? Is there a superintendent physiotherapist with a special interest in paediatrics on the island of Mull?

These are just a few examples of what can be done. It would be easy to add to the basic information, and I would be pleased to hear from you just what you would like to know about members in your area.

Of course there are areas of confidentiality which must be respected, and there may be a limit to information because all we can have at the moment is based on Members of APCP, not on Non-members.

There will be more information in the August Newsletter, and a new form to be filled in by all those willing to contribute. You will not have to fill in such detail every year (only if it changes), but you are encouraged to use this facility to further enable us to learn more about each other and especially for our younger therapists to grow in their knowledge of paediatrics.

Watch this space for further information!

Jenny McKinlay - *Membership Secretary*

GENETICS AND MUSCULAR DYSTROPHY

Alan Fryer Consultant Clinical Geneticist Royal Liverpool University Hospital and Royal Liverpool Childrens Hospital, Alder Hey.

The muscular dystrophies are a group of primary muscle disorders characterised by progressive wasting and concomitent muscle weakness. They have to be distinguished from myopathies which are non-progressive and neuropathies where the muscle wasting is secondary. The muscular dystrophies are genetic disorders and the most common one encountered in childhood is Duchenne. I have listed some other muscular dystrophies which may present in childhood in the table below but I will confine this review to a discussion of Duchenne and its milder variant Becker.

TABLE: Some types of muscular dystrophy and their inheritance

Duchenne/Becker *	X-linked recessive	Gene isolated
Myotonic (esp congenital)	Autosomal dominant	Gene isolated
Congenital	Autosomal recessive	Gene unknown
Facioscapulohumeral (FSHD)	Autosomal dominant	Gene mapped
Limb Girdle (LGMD)	Autosomal recessive	Some genes mapped

* *Duchenne and Becker are essentially the same condition as they are due to mutations in the same gene - the mutations in Becker produce a milder disease.*

There have been dramatic advances in our understanding of the genetics of these disorders in recent years with the isolation of some of the genes responsible. Genes are made of DNA, a double-stranded molecule which itself consists of 4 nucleotide bases (Adenine, Thymine, Guanine and Cytosine). The bases are not randomly arranged as an adenine base on one strand will always pair with thymine on the complementary strand and similarly guanine always pairs with cytosine. It is estimated that the human genome consists of 3×10^9 base pairs but only about 10% of the DNA is within genes - the function of much of the remaining DNA is obscure. Most genes code for proteins with a three base sequence coding for a specific amino-acid eg. CTT codes for glutamic acid. Within genes the coding sequences are not continuous - each coding sequence (exon) being separated by non-coding DNA (intron). Exonic sequences make up only about 2% of human DNA - thus most of the DNA in genes is within the introns. When a gene is transcribed into messenger RNA (mRNA) the intronic sequences are spliced out so the mRNA consists of transcribed exons and is hence a much smaller molecule.

Duchenne (DMD) and Becker (BMD)

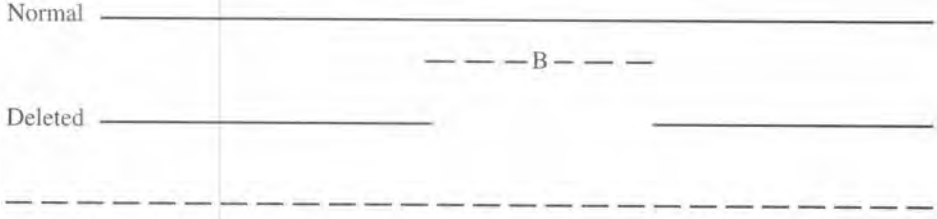
Duchenne affects approximately 1 in 3000 boys and affected males usually require a wheelchair by the age of 12 years and die in their late teens or early twenties. Intellectual retardation is also a feature and in a survey from Newcastle, 24% of affected boys had an I.Q. below 70. Becker is a milder form of the same genetic condition but the Duchenne form is ten times more common.

The gene responsible is carried on the X chromosome. A female with a mutant gene is usually unaffected because of the compensatory effect of the normal gene on her other X. In each of her cells only one X is active but, on average, in 50% of her cells it will be the normal X which will be active. She would however have a 50:50 chance of transmitting the gene to any son she may have and such a son would develop the disease as he lacks a compensatory second X chromosome. In two-thirds of cases of boys with DMD, his mother is a carrier and in one-third of cases the disorder has arisen as a new mutation in the boy.

The gene responsible for Duchenne was isolated in 1988. It is an enormous gene consisting of 2.3 million base pairs (bp) of DNA with about a hundred exons. The mRNA molecule is 14 kilobases long and codes for a large protein which was called dystrophin and was found to be present in skeletal muscle, smooth muscle and brain (neurons). In muscle, it is part of the inner surface of the sarcolemnal membrane but its exact physiological role is still uncertain. The protein has 4 domains - I (amino terminal), II (rod), III and IV (C-terminal).

The gene was isolated at approximately the same time by two laboratories - one in Boston led by Lou Kunkel and one in Toronto led by Ron Worton. Kunkel used DNA from a boy with Duchenne who had a deletion of his X chromosome which was visible under the microscope. It was correctly assumed that this deletion involved part or all of the normal dystrophin gene and was the cause of the disease in this patient. In simple terms he used DNA from this patient and "subtracted" it from DNA from a healthy person where the gene was intact (see figure 1) and by isolating the sequence labelled B in the diagram, he had isolated part of the gene.

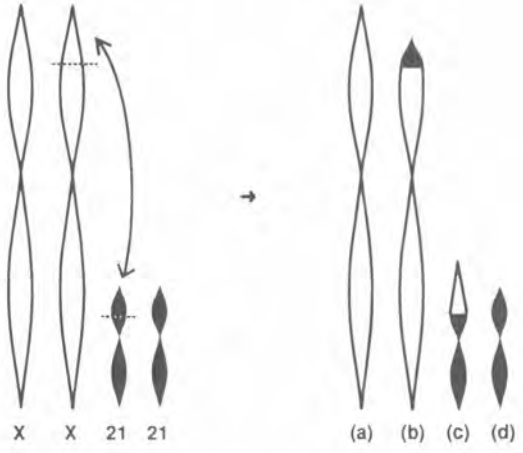
Figure 1: Subtraction method of isolating DMD gene sequences.



A good and simple explanation of the actual techniques used is given in reference 1. Worton also took advantage of a patient with a visible chromosome abnormality. He used DNA from a female patient who had an X; 21 translocation i.e. part of one X chromosome and part of one no. 21 chromosome had exchanged places (figure 2). It was correctly assumed that the cause of the disease in this girl was that the break in the X went right through the DMD gene, disrupting its function. In the case of X-autosome translocations, the normal X is almost always the one which is inactivated and so the active X in each cell will be the one containing the disrupted gene. Worton managed to isolate sequences from the breakpoint and these proved to be within the gene but some way from the sequences which Kunkel isolated. The two groups used standard molecular techniques to isolate the intervening DNA and eventually the entire gene was available.

Fig 2 : X : 21 translocation

Fig 2 : X : 21 Reciprocal translocation



(a) normal X (b) translocated X (c) translocated 21 (d) normal 21

Using DNA from the normal gene it became possible to test DNA from known patients. As a result it is now known that 60-70% of boys with DMD have a large deletion and about 5% have a duplication. The remaining patients must have small deletions or point mutations which are not easily detectable by routine methods.

The main deletion "hot spot" is around exons 43-55, although there are a number of patients with deletions near the 5' end of the gene which tend to be longer and are mostly confined to the region from exon 2 - exon 30. Most studies of patients with the milder BMD have shown an even higher incidence of deletions (over 80% in some series) and over 80% of these deletions begin in intron 44. (This is also the hot spot area for DMD but the 5' end of the deletions is more variable in DMD). Given that the deletions in DMD and BMD are broadly similar, why is BMD milder? As a general rule, it seems that if a deletion alters the reading frame of the genetic code, no dystrophin will be produced and the patient will have DMD. If the deletion does not affect the reading frame, a small but still functional molecule is produced and the patient has BMD (Figure 3). Sometimes even very large deletions can result in mild diseases if the reading frame is intact.

In about 95% of cases this generalisation appears to be correct. The rare cases where frame-shift deletions result in some dystrophin production are the subject of much study and different mechanisms for this have been found or have been suggested.

Figure 3: Hypothetical section of DMD gene

Normal sequence	CTG/ATC/CCG/CGA/TTA/CGG/AAA/AGG/GGG/...
In frame deletion	CTG/ATC/ ——delete ——/AAA/AGG/GGG/...
Frame-shift	CTG/ATC/C [CG/GGA/TTA] CGG/AAA/GGG/..

delete

CTG.ATC/C—CG/GAA/AAG/GGG/G...

In BMD, the position of the deletion can have some influence on the phenotype :- most deletions are in the distal portion of domain II (around exons 45-53) and produce typical BMD. In-frame deletions in domain I tend to produce a severe BMD phenotype or one intermediate between DMD and BMD - perhaps this portion of the protein is important for dystrophin stability. Loss of the most terminal part of domain IV leads to a mild, non-progressive BMD.

These are only gross generalisations and there is considerable clinical variability in patients with similar deletions and protein levels although a muscle biopsy in an affected child which shows the presence of dystrophin in reduced amount or size would tend to indicate BMD and the complete absence of dystrophin would indicate DMD. No clear correlation has emerged between the type of deletion and degree of intellectual retardation.

So far the finding of the gene has not led to treatment but has resulted in better diagnostic ability (by detection of deletion or duplication or altered dystrophin size or levels in muscle biopsy) and better genetic counselling. From a diagnostic viewpoint, it can be difficult to distinguish DMD and BMD from LGMD or mild SMA (spinal muscular atrophy) and this is clearly important from a genetic standpoint as the inheritance patterns are different. With regards to genetic counselling, if a detectable deletion is present, accurate prenatal diagnosis at 10 - 11 weeks of pregnancy can be offered to those family members at high risk. The presence of a deletion also offers a greater prospect of accurate carrier detection for females in the family. In the absence of a deletion or if the affected individuals are deceased, it is frequently possible to use indirect methods i.e. by tracking the X chromosome carrying the mutant gene in the family and provide accurate carrier detection and prenatal testing. Few families these days have to rely on fetal sexing with termination of any male pregnancy as the only means of avoiding having an affected child. The severity of DMD is such that most family members at high risk have opted for prenatal diagnosis when this has been available.

Treatment - The large size of the dystrophin gene and its product and its tissue specificity makes replacement therapy very difficult. It may be however that once more is known of dystrophin function that new strategies will be developed. Injection of the dystrophin gene into muscle cells of the mdx mouse (a mouse model of DMD) has shown that the molecule can achieve its correct localisation in the cell membrane but the levels of dystrophin expression are very low. The alternative approach of injecting normal myoblasts into muscle has not proved successful [2]. Sadly therefore there are no immediate prospects for the cure of this devastating disorder.

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CLINICAL APPLICATION OF STUDIES OF THE CONTRACTILE PROPERTIES OF MUSCLES OF CHILDREN WITH DUCHENNE MUSCULAR DYSTROPHY (DMD)

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Introduction

After years of searching,it is now known that Duchenne and Becker (DMD and BMD) forms of muscular dystrophy result from alterations of a large gene of about 2,000 kb on the short arm of the X-chromosome (1,2). The protein encoded for by this region is called dystrophin and is present in very small amounts in normal muscle. It is absent in DMD and markedly reduced or abnormal in size in BMD. The exact function of dystrophin and its precise role in the resulting necrosis of dystrophic muscle fibres has not yet been determined and it still is not known how the absence of dystrophin leads to the clinical manifestations of DMD(3).

Contractile properties

The mechanisms which cause the symptoms of the disease are not yet understood. Questions concerning the wide variation in the clinical severity and the apparently selective pattern in the muscle involvement, although all muscles lack dystrophin, have not yet been answered (3). It may be that the relationship between electrical and mechanical responses in some instances will provide some insight into the pathophysiological basis for weakness in such patients (4).

Boys with DMD may seem to be unaffected when they are very young but muscle biopsies show that pathological changes of necrosis and regeneration are already present at birth and there is evidence of leakage from the muscle into the serum of enzymes such as creatine kinase (3). About half of the boys are slow to walk and walking may be delayed until 18 months or later (the mean for normal children is about 13 months and 97 percentile is about 17 months). From the early years, there is a gradual progression in disability with associated muscle weakness and increasing difficulty in climbing stairs, getting up from lying, getting off a chair and then in maintaining the ability to walk without assistance (5).

Maximum voluntary strength

In normal children, muscle strength increases with age; Figure 1 shows that this relationship is not maintained in children with DMD. Results from many studies show low values of maximum force output of young boys (4-6 years) and a gradual deterioration with age. Although all muscles become weaker, there is variation in the loss of force. Environmental and other factors may be very important in determining the rate of progression of the disease (5). Questions have been raised as to whether the absence of dystrophin is merely an early trigger in the pathogenesis of the dystrophy with subsequent secondary mechanisms being more important (3).

Time course of contraction

In recent years, a number of studies have compared the contractile characteristics of normal children's muscles with those of boys with DMD and confirmed the mechanical changes and effects of the disease process even in the youngest children (4) Slowing of the time course of

contraction associated (figure 2) with prolonged relaxation times and high resistance to fatigue are consistent features of dystrophic muscles and have been used as evidence of 'immature' characteristics in the muscles of these children (6). We also identified an inability to modify their mechanical responses during fatigue testing (4). This inability may mean that the muscle is biomechanically disadvantaged when exposed to prolonged and sustained activation.

It is thought that dystrophin forms a membrane-skeleton lattice in the muscle plasma membrane and provides integrity to the plasma membrane during repeated cycles of contraction and relaxation (2). Recent work by Minetti et al (1992) suggests that this membrane has a barrel-like array of thick transverse bands interconnected by a finer network that encircles the muscle fibre (7). In their paper, they suggest that these bands mirror components of the contractile apparatus of the muscle fibres and match the sites of attachment of the sarcomeres to the plasma membrane. Dystrophin may be one of the proteins involved in the linkage structures from the extracellular matrix to the contractile myofibrils. It is suggested that the absence of dystrophin may place physical stresses on the myofibril and lead to necrosis (7).

Electrical stimulation

It was Duchenne who first suggested that electrical stimulation of diseased muscle might be beneficial to patients with muscular dystrophy. Recent studies (5,8) have suggested that the progressive loss of strength of muscles of children suffering from DMD can be influenced by chronic low frequency stimulation provided that the stimulation is applied at a time when the children are not yet severely disabled.

Another feature in the disease process of DMD is the early accumulation of connective tissue. The importance of stretch and contractile activity in the prevention of connective tissue accumulation in muscle is well known (9). When a muscle is shorter than optimal length its force output is reduced. The positive effect of stretching in the management of children with DMD is well established. It may be that electrical stimulation provides the degenerating muscle with conditions of increased circulation and improved oxidative metabolism. Increased muscle activity may reduce the rate of proliferation of connective tissue as well as enhancing muscle regeneration.

Conclusion

The recent advances and rapidly expanding understanding of the underlying abnormalities in Duchenne and Becker muscular dystrophies combined with research into the effect of clinical intervention have implications for paediatric physiotherapists engaged in treating children suffering from these progressive neuromuscular diseases.

Acknowledgements

Most of the clinical research into muscle function was undertaken in the Physiotherapy Department of the Hammersmith Hospital. We were grateful for the support of the Medical Research Council and the Muscular Dystrophy Group of Great Britain, to Neen Pain Systems Ltd. and Biomedical Engineering Ltd. for supplying the stimulators and to the families who participated in the studies.

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Legends to Figures

1 Relationship of maximum voluntary contraction (MVC) of quadriceps femoris of normal children (•, n=34) and children with DMD (o, n=15) with age. Lines shown are the regression line and the 95% confidence limits for normals.

2 Time course of contraction of the tibialis anterior muscle of a 5-year-old boy with Duchenne muscular dystrophy (DMD) and that of his normal 8-year-old brother on stimulation for 250ms at 40 Hz. % MVC = % of maximum voluntary contraction, 1/2RT = time to fall to 50% of peak tension (see Scott et al, J of Neurol, Neurosurg & Psychiat 1986; 49: 1427-1434).

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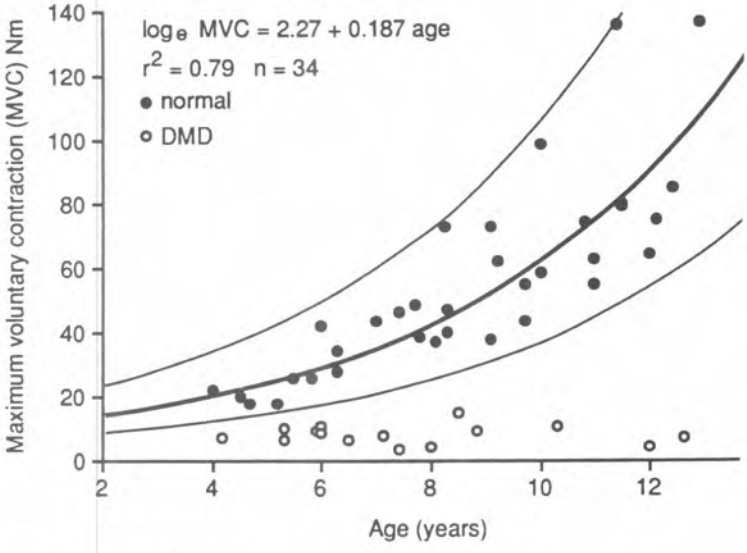
Fig. 1



= 0.5 kg

5 year old boy with Duchenne Muscular Dystrophy. (DMD)

$\frac{1}{2}RT_{40}$ = 165 ms

%MRC = 47 %

Fig. 2

* * * * * *

8 year old normal brother.

$\frac{1}{2}RT_{40}$ = 110 ms

%MRC = 35 %

= 1 kg

* * * * * *

= 250 ms

DUCHENNE MUSCULAR DYSTROPHY: INTERVENTION TO PROLONG AMBULATION

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The development of lower limb contractures in Duchenne Muscular Dystrophy (DMD) is the most important reason for loss of ambulation in this disease other than the intrinsic loss of muscle strength. Marked proximal weakness, with greater early involvement of the extensor groups, leads to secondary postural adjustments necessary to maintain standing equilibrium. This results in typical habitual postures associated with DMD and the subsequent development of chronic fixed contractures of weight-bearing joints.

The management of contractures is one of the major contributions of physiotherapy in muscular dystrophy. The aim is not only to retard contracture progression but more importantly to extend the period of independent ambulation and functional ability. Impairment of mobility caused by contractures compromises the strength of the muscles working across the involved joint or joints. It has been shown that the maximum tension developed by muscles immobilised in shortened positions can be reduced compared with controls (Williams and Goldspink 1978). Thus, in the presence of profound weakness, the maintenance of full range of joint motion is essential for optimal function of muscles.

A sustained programme of splinting and passive stretching in the early stages of Duchenne Muscular Dystrophy can retard the development of lower limb contractures. Scott et al carried out a prospective study on 59 DMD boys (age range 4-12 years) evaluating the effect of below-knee night splints and daily passive stretching on lower limb contractures. This programme, applied systematically, delayed the development of contractures of the achilles tendon and thus delayed the loss of dorsiflexion at the ankles, compared with a control group. A direct relationship was demonstrated between the development of lower limb contractures and loss of ambulation, and the study concluded that independent ambulation could be prolonged for as much as 2 years using passive stretching and night splints. The combination of stretching and splints was found to be more effective than stretching alone. Harris and Cherry examined the effect of a physiotherapy programme on 100 DMD boys which emphasised daily passive stretching of weight-bearing joints. Stair-climbirng ability and independent walking were prolonged by 2 years. These two studies are in agreement concerning the importance and effectiveness of management aimed at minimising lower-limb contractures.

While independently ambulant the provision of AFO's for control of tendo-achilles contracture should be confirmed to night use only. Early, on, absent heel strike is caused by weakness of the ankle dorsiflexors. Later in the disease, gait analysis has shown that an equinus position of the foot is used a a compensatory manouvre to increase knee stability during stance phase. Khodadadeh et al observed that boys with DMD necessarily adopt a dynamic equinus during gait in order to maintain a knee extending moment in the presence of gross quadriceps weakness. AFO's intend to correct the foot position by reducing the equinus during walking, will have biomechanical effects which will destabilise the knee. If there is significant quadriceps weakness the knees will buckle. Thus AFO's used in this way reduce the available compensatory manouvres and can result in premature loss of ambulation.

Following the cessation of independent walking, which occurs in 95% of cases by the age

of 12, the duration of useful ambulation can be prolonged with an immediate programme of percutaneous achilles tenotomy and rehabilitation in lightweight ischial-weight-bearing knee-ankle-foot orthoses. The gains in additional walking time have varied in different centres but on average an extra 2 years of walking can be achieved and may be up to 4 years (Heckmatt et al 1985). This has been shown to both impede the development of lower limb contractures and scoliosis. The additional period of upright mobility afforded by this programme may represent approximately 20% of the child's life span and extends his ability to perform tasks of daily living.

The accurate timing of intervention and prompt provision of orthoses are crucial to the success of prolonging ambulation. The optimal time for the provision of the orthoses is when the child has lost useful walking but is still able to stand or walk a few steps. There is no advantage in providing orthoses earlier than this. Two of the important factors used to predict successful outcome are the absence of severe hip and knee contractures and the percentage of residual muscle strength. Once the child has been wheelchair-bound for even a short time, fixed lower limb deformities and muscle weakness progress rapidly, and therefore any delay in undertaking this programme may compromise a successful outcome.

The development of scoliosis is associated with the loss of independent ambulation, when there is a sharp increase in scoliosis which corresponds with an adolescent growth spurt. If walking can be prolonged beyond 13 years with ischial weight-bearing KAFO's the rate of progression of the curve can be significantly reduced (Rodillo et al 1988). There are two likely reasons for this protective effect of orthoses. During orthotic walking lateral trunk sway demands active control of spinal posture which may avoid deformity through symmetrical challenges placed on weak trunk muscles. Secondly, the lordotic posture encouraged by the posterior ischial-lip of the orthoses is thought to stabilise the spine by locking the lumbar facet joints.

It is increasingly accepted that the quality of life of a child with Duchenne Muscular Dystrophy can be improved, ambulation prolonged, and secondary deformities reduced by the appropriate intervention of a comprehensive management programme.

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THE SUPPLY OF SWIVEL WALKERS TO MUSCULAR DYSTROPHY PATIENTS

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Swivel Walkers have long been used as an effective means of ambulation for patients with acquired or traumatic spinal lesion. (Motloch & Elliot (1984), Edbrooke (1970), Rose & Henshaw (1972), Stallard et al (1978), Butler et al (1982), Farmer et al (1982). Heavily handicapped patients are able to use the device to walk with a high degree of stability, whilst avoiding the need for additional walking aids such as crutches etc.

Many Centres (notably Rocky Bay in Australia, Hebden Green School in England and Ysgol Erwir Delwy in Wales) have recognised the potential for swivel walkers to be used to extend the period during which MD patients can continue to ambulate (Sibert et al (1987) & Evans (1992)). It is appropriate for them to be used when the patient would otherwise be wheelchair bound. Initially standard designs of swivel walker were prescribed, but it became apparent to those responsible for the on-going care of muscular dystrophy boys that they had unique problems which existing types did not effectively address. Analysis of these difficulties made it clear that a swivel walker with new features was required in order to accommodate Muscular Dystrophy patients more comfortably and enable them to walk more easily.

Orthotic Problems of Muscular Dystrophy

A detailed review of Muscular Dystrophy patients showed they had the following particular difficulties in comparison with other groups (primarily paraplegic) using swivel walkers:-

1. A low tolerance to changes in their comfortably established posture.
2. Variability of hip and knee contractures.
3. Sensation in the lower limbs which can cause discomfort at the patient/orthosis interface.
4. A need for hip abduction to promote better hip joint containment. This is frequently a preferred posture - probably due to hip proprioception.
5. Overall weakness, which reduces the potential input of propulsion forces from the upper limbs.
6. Apprehension of unsteady support and excessive step-length.
7. Inability to transfer independently into their orthosis thus requiring physiotherapists or parents to lift heavy, weak patients into the device.

The ORLAU VCG Swivel Walker

Consideration of the identified problems for muscular dystrophy patients indicates that two distinct elements within the general concept of swivel walkers need to be addressed for this group:-

1. Postural support
2. Ambulation Mechanics

A new swivel walker has been developed in response to these difficulties, the design of which has been evolved through discussion with physiotherapists who are committed to this treatment approach for muscular dystrophy boys. The ORLAU VCG Swivel Walker (Stallard et al (1992)) is shown in Fig. 1. It separates out the two elements of postural support and ambulation mechanics in order to permit each to be more effectively provided than earlier designs. The unavoidable consequence of this is more complex setting up procedures and the need for more careful on-going monitoring. It should not, therefore, be assumed that the new design supersedes existing devices. The greater degree of complexity also means that the cost is likely to be higher than other swivel walkers in the same size range, though it should still be less expensive than many HKAFO devices.

Fig. 1

The DRLAU VCG Swivel Walker

Postural Support

The lack of power at hips and knees requires that postural support is provided by 4 location points (at feet, knees, hips and chest) as in conventional swivel walkers (Stallard et al 1986). Additional adjustability for positioning of the feet is incorporated in order to permit careful alignment of posture through variable heel cups.

The postural deformities which the VCG Swivel Walker is designed to accommodate are:-

1. Equinus
2. Knee flexion
3. Hip flexion
4. Hyperlordosis of the spine.

The contractures which cause these deformities tend to develop with the progress of the disease and can also be variable in nature over short time spans. To accommodate these problems the VCG Swivel Walker has:-

1. The facility for insertion of compensatory wedges for equinus.
2. A range of easily adjusted knee pads with sheepskin interfaces.
3. An adjustable sacral band with a Evazote lining for patient comfort.
4. A range of thoracic bands which permit the appropriate compromise between convenience and patient comfort.

The need for adjustability of knee location in order to provide the essential feature of potential contracture correction demands the elimination of the fixed knee bar used in the standard ORLAU Swivel Walker. A fixed knee bar is convenient for patients in that it provides for speedy doff and don. Importantly, it also ensures that the correct knee location identified by the physiotherapist can not be easily changed by the patient or their parents. Clearly this valuable feature can not be incorporated into the VCG design and this places an added burden on the physiotherapist to instruct the patient's non-professional helpers in the appropriate use of the device.

Ambulation Mechanics

Swivel Walker ambulation mechanics (Stallard et al (1986)), (Rose & Henshaw (1972) consists of two linked footplates mounted beneath the baseplate, each one indexing forwards as the patient rocks from side to side.

Walking can be considerably more difficult for MD patients because of their general weakness. Consequently they require even more careful adjustment of ambulation mechanics. Postural sensitivity renders adjustment of these through changes in postural alignment (as is conventional in standard swivel walkers) much more difficult.

The main factors affecting ease of ambulation in a swivel walker are:-

1. Position of C of G relative to the footplate bearing centre in the sagittal plane. Ideally it should be 18-25 mm forward of this.
2. Distance between footplate bearings in the coronal plane. The closer they are the easier it is to ambulate.
3. The step length. If this is too great the next step is more difficult, but when it is too short speed is greatly reduced.

All of these factors have been made more readily available in the VCG Swivel Walker. The baseplate consists of a double plate arrangement which allows the upper part of the swivel walker frame, including the patient, to be moved forwards or backwards on the lower plate which houses the footplates. This enables the orthotists to adjust the patient's centre of gravity about the footplate bearing centres to the optimum position without altering the patient's posture in the swivel walker frame. The footplate bearings are bolted to the lower plate and their relative spacing in the coronal plane is adjustable via a series of additional holes. An adjustable stop arrangement is provided on the footplates so that an appropriate step length can be set individually for each patient.

In order to cope with the apprehension which MD patients have of unsteady support, additional stability is provided by extended footplates.

Conclusion

A clinical trial of the new design was conducted in two centres with experience of using swivel walkers for muscular dystrophy patients. Both reported that it had beneficial effects on patient confidence with commensurate improvements in ambulation performance. Patients extended the length of time in which they used their orthosis and the distance they walked. This was attributed to additional comfort and stability, and greater ease of walking.

It is very important that swivel walkers for Muscular Dystrophy are used within a fully planned treatment regime for individual patients. Appropriate control of clinical supply is vital if the best interests of patients are to be served.

The ORLAU VCG Swivel Walker is now a DH approved orthosis and is routinely available. A contractual requirement is that it must be fitted by an orthotist who has attended the DH approved Swivel Walker Course run by ORLAU. An important aspect of the orthotist training for the ORLAU VCG Swivel Walker is the philosophy of supply within a co-ordinated treatment regime. This is intended to eliminate inappropriate and harmful prescription and it is for this reason that orthotist training is a mandatory condition for supply of the device to the NHS by an orthotic contractor.

Acknowledgements

The author gratefully acknowledges the assistance and support of the physiotherapy staff and patients of the Hebden Green School, Winsford and Ysgol Erwir Delwy, Cardiff. Without their generous assistance the clinical trials which permitted the successful outcome of this orthotic development would not have been possible.

Encouragement from the physiotherapy staff at the Rocky Bay Centre in Australia through video evidence of their experience is also greatly appreciated.

The contribution to the design by:

- Mr. B. Lomas of Consort Engineering (the licensee for the device)

- Mr. J. Henshaw FBIST of Quest 88 Ltd.

is gratefully acknowledged.

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Use of the ORLAU Swivel Walker for the severely handicapped patient. Physiotherapy, 68(10)., 324-326.

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Evans, G.A. (1992). Changes in the management of the child with Duchenne muscular dystrophy. In: Recent Advances in Orthopaedics Ed. A. Catterall, Churchill Livingstone, Edinburgh, No.6.

Once the various elements of a baseline assessment have been correlated then a list of problems can be drawn up. From this, short and long term aims and objectives can be established. This is done following discussion with the student, parents and therapist.

As the therapist has this baseline from which to work he/she can quickly judge levels of degeneration in condition and highlight this fact to all staff involved with the student.

Treatment Programme

Following the assessment a treatment programme is formulated. As with most other establishments we are unable to give daily 'hands on' treatment by physiotherapists, so we look to providing the student with as much therapeutic input throughout the school day as is physically possible, utilising the skills of many other staff within the College.

The day may begin by care staff giving the boys a stretch as they dress them in the morning. Care staff work closely with therapists who train them in the stretching procedures.

In the classroom situation the boys may use standing frames or 'Levo' chairs during their lessons. This enables them to achieve an upright, weightbearing posture for periods of 40 minutes or more. This is ideal in that it helps to maintain spinal alignment which degenerates so quickly when they become wheelchair users. It may also have other beneficial effects such as assisting drainage systems and digestion within the body.

The day may include an individual session with their physiotherapist, a hydrotherapy session or swimming session so that the boys once again get out of their chairs and achieve a change of posture.

Hydrotherapy

The use of hydrotherapy pool is encouraged for all our boys for a multitude of reasons all of which we believe are an integral part of physiotherapy treatment.

- To increase confidence.
- To promote a feeling of freedom.
- The boys are often more active in the water as they can achieve movement and they are usually motivated to participate in activities.
- Exercise in water can be made fun and relaxing.
- The boys often get relief of pain and discomfort, possibly caused by pressure or postural imbalance.
- It is often an excellent opportunity for the boys to talk to you in a fairly private setting. They may be seeking reassurance or have questions about their disability that they need to discuss.
- There are other more obvious reasons for including hydrotherapy in the programme such as stretching exercise, maintenance exercise, increasing circulation, and lung function exercise.

Individual Physiotherapy Sessions

All the boys are encouraged to stay on their feet for as long as is possible. This we achieve by using KAFO's once independent standing is lost, then a range of standing frames or wheelchairs eg. Levo Chairs, that achieve a standing position.

A variety of staff are involved in this process in different situations within the College. The boys may stand in the department, in class or on the house in the evenings whilst watching television.

Flowpulse is also used to help improve circulation and stretch lower limb joints. This is usually applied when the boy comes to the department but some students do have their own units at home too.

The boys can carry out other activities with their upper limbs while the unit is working.

Lung function exercises are also an integral part of the physiotherapy programme with regular chest expansion routines carried out both in the department and in the hydrotherapy pool.

Should any of the students develop chest infections then twenty four hour cover is provided by the physiotherapy staff within the college medical centre.

Physiotherapy treatments include stretches with particular emphasis on the tendo-achilles, ham-strings, hip flexors and ilio-tibial tract of the lower limbs and the elbow and wrist flexors and forearm pronators of the upper limbs.

It is common for boys to develop foot deformities once they become wheelchair users therefore the posture of the feet in the wheelchair is carefully monitored. If the lower limb position is asymmetrical this can be a precipitating factor to a spinal scoliosis which is rapidly progressive therefore care is taken to provide supportive footwear and AFO splinting for both day and night use at an early stage.

Once the boys become wheelchair users on a permanent basis then the spine is closely monitored. It is essential that good postural alignment is maintained. The pointers to highlight are a level pelvis, a firm supportive back cushion (to promote a lumbar lordosis), lateral support where necessary and a seat cushion which prevents abduction of the hips or alternatively wedged side pads.

Pressure care is also considered in seating and when appropriate with selected students we use Roho cushions or Jay cushions.

We have extremely close links with the College Medical Officer and if we are concerned about a progressing scoliosis then we can refer to them and then on to a Consultant.

We have had several boys who have undergone spinal fusions and we have found that it is vital to maintain range of movement in the hips and knees following surgery as this can very quickly be lost.

We do have the facility to provide the boys with spinal bracing but care must be taken not to mask the opportunities for surgery particularly with regard to lung function.

Wheelchair provision is another important element of the physiotherapeutic care of the DMD boy. Once the boy comes off his feet he rapidly requires an electric wheelchair. The

College site is fairly large and boys do have difficulty in propelling themselves around in manual wheelchairs.

There is also a large pyschological element in providing electric mobility as it enables the boy to keep up with his peers in leisure time and allows him to join in games.

At the College we are often asked to carry out assessments for privately purchased electric wheelchairs. The boys find these often more comfortable and 'faster' and cosmetically more acceptable than others more readily available. During these assessments we take into consideration all the factors affecting posture and symmetry that have previously been mentioned.

All the boys are regularly reviewed both internally and by external agencies such as Local Education Authorities. We do also have regular contact with the Doctors and therapists from the co-ordinating hospitals, and reports are sent and received following routine and special appointments.

Parent Partnership

Parents are encouraged to be involved with the whole process of therapeutic input and are invited into the College on a regular basis.

The physiotherapy staff are involved in parent meetings to discuss progress each term.

Therapy staff are also involved in 'Open Days' and training days organised by care staff, for the parents, on the residential units.

The physiotherapy department hold an 'Open Week' each year and invite parents to join the therapists with their son during an individual session. This provides staff with an ideal opportunity to set up realistic holiday programmes for the parents to carry out.

At crucial stages during the progression of their condition the boys seek help from different members of staff within the college, particularly the counselling team. I have only mentioned a few here but readers are reminded that there is a wealth of professional expertise at the college and communication between departments is essential and non-stop, so that the best possible care, medical treatment, therapeutic involvement and education are provided for the boys.

* * * * * * * * * * *

MUSCULAR DYSTROPHY
RESEARCH · COUNSELLING · CARE

Muscular Dystrophy Group of Great Britain and Northern Ireland, Nattrass House, 35 Macaulay Road, London SW4 0QP.

Tel: 071-720 8055. Facsimilie: 071-498 0670

VIDEOS AVAILABLE FOR HIRE OR PURCHASE FROM THE SUPPORT SERVICES DEPARTMENT

1. **THE CHAIN OF INHERITANCE (1987)** *14 minutes*

'The Chain of Inheritance' is intended for a lay audience, and describes the nature of muscular dystrophy and allied neuromuscular diseases, their effects on various children and adults, and the reaction of their relatives. Current research work is described by scientists funded by The Muscular Dystrophy Group.

Available on free loan from Nattrass House

2. **WHY CAN'T HE WALK PROPERLY? (1984)** *13 minutes*

'Why Can't He Walk Properly' is the title of a video produced by Dr. David Gardner-Medwin, Paediatric Neurologist at Newcastle General Hosptial. Intended for professional use only, it explains the early symptoms of Duchenne muscular dystrophy and provides a guide to the health professional in the early recognition of the disease.

Available on free loan.

3. **ONE AMONG MANY (1988)** *14 minutes*

This video is aimed at student nurses, and those nursing patients with muscular dystrophy who are admitted to hospital for an unrelated condition, eg tonsillectomy, fracture. It emphasises the importance of listening to both patient and parents. The video also gives guidelines on correct procedures for lifting and transfers, and suggests ways in which the patient's stay in hospital can be made more comfortable.

Available in VHS video, price £8 or on free loan

ABSTRACTS

Title: The Natural History of Congenital Myotonic Dystrophy - mortality and long term clinical aspects.

Authors: W. Reardon, R. Newcombe, I. Fenton, J. Sibert, P.S. Harper, University of Wales College of Medicine and Institute of Medical Genetics.

Source: Archives of Disease in Childhood 1993
Vol. 68, pp 177-181

Data documenting long term outcomes of patients with this disorder are deficient, as is data on mortality, life expectancy and cause of death.

Myotonic dystrophy in early childhood was first recognised by Vanier, who correctly identified problems starting from birth. This fact has been corroborated by subsequent studies.

Principal clinical features have been defined as:

hypotonia with facial weakness
talipes
neonatal respiratory distress
pharyngeal inco-ordinated with palatal weakness.

Delayed motor development and mental retardation have been observed in approximately two-thirds of patients and the need for special education has been documented often.

Death in the neonatal period is now well recognised, usually due to failure in the establishment of respiration. Development of intensive care management has altered the care of congenitally affected children, but the mortality rate in early infancy remains significant.

Myotonic dystrophy is an autosomal dominant condition, the molecular defect having been traced to an unstable DNA triplet sequence. This fact could offer an explanation for the reason congenital myotonic dystrophy differs clinically from the classic adult form.

In view of the lack of data concerning long term outcomes, follow up data on a cohort of patients was obtained.

Data was obtained on 115 patients born between January 1, 1940 and December 31, 1989, all having been given a diagnosis of cmd during their lifetime. 71 were alive at the time when the study began. 42 were examined personally. 44 had died by the time of survey in 1992.

Tables concerning results in survival time scales, clinical details, delays in motor and mental development and causes of death then ensued.

Discussion

In definite cases of cmd, 25% die within the first 18 months of life, mostly in the neonatal period due to respiratory complications. Very few deaths occur subsequently until late teenage years. Figures suggest half of the subjects survive to their mid-30s, but die before reaching 41 years of age.

Clinical data confirm a significant 18% of obstetric complications in pregnancy.

The presence of CTEU is an important factor in the delay of the onset of walking. However talipes could be a reflection of the more serious muscle weakness.

Death due to cardiac dysrhythmia is a feature of the disease in its congenital form. 3 deaths however were due to accidents during anaesthesia.

Widespread observation of gastro-intestinal symptoms possibly reflect the involvement of the smooth muscle within the bowel resulting in abnormal tone of the anal sphincter muscle. There is a high incidence of positive anal dilation test.

Maternal transmission of the gene was observed in all cases in the study. An apparent excess of grandfathers among the gene transmitters has been recorded in other studies, but not in the study described here.

Title: Effects of inhibitory casts and orthoses on bony alignment of foot and ankle during weightbearing in children with spasticity.

Authors: Nancie R. Ricks

Superintendent Rehabilitation, Children's Hospital, Denver, Colorado

Robert E. Eilert

Clinical Professor Orthopaedic Surgery, University of Colorado, Denver

Source: Development Medicine and Child Neurologh, 1993, Vol. 35, pp 11-16

Introduction

Abnormal alignment of the foot and ankle can effect the balance, gait and ranges of movement of children with spasticity. This abnormal alignment is more noticeable during weight bearing.

Orthopaedic devices can prevent the development of fixed deformities and inhibit spasticity, especially during gait. Other effects include the lessening of abnormally sensitive foot reflexes and the diminution of the influence of hyperactive extensor thrusts. Most studies emphasise the importance of the correct alignment between the subaltar, midtarsal joints and forefoot.

Method

The purpose of this study was to compare the bony alignment during weightbearing in three differing types of orthosis.

27 children with cerebral palsy aged between 2-16 years took part. 11 could walk independently, 9 could walk using support and 7 were only able to stand without support.

Descriptions then follow describing the moulding and fitting of three types of cast, namely:
inhibitory casts static AFOs articulated AFOs.

The children had lateral X-rays taken of their right feet whilst standing on a table, with weight taken equally on each foot. First the orthoses were worn and then removed for a second X-ray.

Angles were measured on the X-rays which included the following:
Calcaneal inclination tibial/calcaneal angle
talar declination talo/calcaneal angle
talo/metatarsal angles.

Result

No significant differences in bony alignment were noted between any of the casts. The only change noted was found in children wearing the articulated AFO in that there was a change in the calcaneal inclination when worn and then taken off.

However, the question remains as to how the orthoses produce their effect.

REPORTS

CLINICAL INTEREST GROUP (C.I.G.) LIAISON COMMITTEE REPORT

Carol F. Foster - A.P.C.P. Representative C.I.G. Liaison Committee

The inaugral meeting of the C.I.G. Liaison Committee was held on the 16th March 1993 in the Founders room at the C.S.P.

The group will send four representatives to the Professional Practice Committee of the C.S.P. and in this way there will be a direct link from members of Clinical Interest Groups to the C.S.P.

The group will meet four times a year, just prior to the PPC meeting, with extra meetings if necessary - a review of the terms of reference will occur annually.

Some of the items discussed at the meeting were -

CIG Capitation fee - capitation money of £1.00 per member per group will be payable to CIG's in the Autumn - each CIG will be required to submit a report on the audited accounts for each financial year - the first one being due at the end of April 1994.

CIG Data Bases - an effort was to be made to encourage all CIG's to purchase compatible software - information is therefore needed on each CIG's present software situation and possible future needs. This information to be sought through Regional Reps.

Care Profiles - After some discussion each member was asked to consult her CIG to identify 6 problems for care profiling which may be common to all CIG's e.g. reduced mobility - any work undertaken in this area will be shared with the Quality Assurance working party and PPC and any other relevant committees at the CSP - IMPORTANT please read briefing paper 15 Patient Focused Care before responding (available from CSP).

Short Course Accreditation and Pace

Ms Gosling, CSP Accreditation Officer in the Education Department gave a clear and informative talk which promoted discussion about accreditation of C.I.G. courses and study days. Ms Gosling stated that she was available to offer advice to groups setting up courses but stressed that CIG's should consult educationalists among their membership as well.

The date of the next meeting is Monday 28th June - I should appreciate any information re CIG data bases and care profiling by Monday 21st June.

This group is an excellent opportunity to feed back information directly through the PPC and then to council - it can only work if I have information to take back from APCP membership. Please make every effort to pass information to me by the above date.

C.S.P. REPRESENTATIVES CONFERENCE REPORT

Jill Brownson - Chairman A.P.C.P.

Last September at the Representative's Conference in Glasgow which was held after the CSP Congress, APCP was represented by Jill Brownson and Michele Lee.

This was the fourth conference of its kind. Delegates for the Conference represented Special Interest Groups, Clinical Interest Groups, Stewards and Branches and were financed by CSP.

The Motions debated covered a wide range of topics such a Professional Practise, Physiotherapy and GPs, Support Workers, Service Management, Education, Industrial Relations, Allowances, Health and Safety, Public relations. All Motions had previously been published in the July issue of the CSP Journal and were subsequently reported on in the November and December issues.

APCP submitted 3 motions, one was lost due to lack of time in its section, one was rejected by conference and one was accepted. The accepted motion was therefore taken to Council for further action.

The Motion stated that:

The CSP should devise a national scale for the recording of Physiotherapy input to patient care in order to enable managers to cost the service and purchasers to make accurate comparisons.

The drafted response from council stated that:

Recording of input is a responsibility of NHS Management rather than the CSP, and will have to reflect local circumstances and policies. A number of Physiotherapy Managers have devised appropriate scales and the CSP will be happy to disseminate examples of good practice.

At this year's Representative's Conference to be held in Belfast, APCP will be represented by Terri Fearn and Elizabeth Harty. Last year's 'lost' motion and others received will be submitted for consideration by CSP - they have to fulfil certain criteria and are scrutinized thoroughly to ensure that they have not previously been heard and that, if carried, they can be acted upon by Council.

If any Members of APCP have an issue that they would like this year's representatives to submit please write to the Hon. Secretary.

The National Committee will be happy to consider any member who would like to represent APCP in this Public Speaking exercise.

COURSES

May 10-14, 1993

INTERDISCIPLINARY TEAM MANAGEMENT OF CHILDREN WITH MULTIPLE DISABILITIES

Apply to: Mrs. M. Price,
Course Secretary
Newcomen Centre
Guy's Hospital
St. Thomas St.
London SE1 9RT

Cost: £150

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3 JUNE 1993

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Contributors to the Conference will include:

Dr. Philip Bairstow	*University of Perth, Western Australia*
Professor Raymond Cochrane	*The University of Birmingham*
Mr. Mel Farrar	*Foxdenton School, Manchester*
Dr. Maria Hari	*Peto Institute, Budapest*
Mr. Andrew Sutton	*Foundation for Conductive Education*

For programme and reservations contact:

Ms. S. Phillips, School of Psychology, The University of Birmingham, Edgbaston, Birmingham, B15 2TT. (Tel: 021-414 4936)

Registration forms returned by 20th May 1993

JUNE 5, 1993

REHABILITATION MANAGEMENT OF CHILDREN WITH ACQUIRED HEAD INJURIES - THE INTERDISCIPLINARY APPROACH.

Venue: Basildon Hospital
Apply to: Jean Offord
East Anglian Branch APCP
"Shoulder Sticks", Northill
Little Baddow
Chelmsford CM3 4TW (Sae please)
Cost: £20 (£25 for non APCP members)

CASTLE PRIORY

JULY 6, 1993 & JULY 14, 1993

INTRODUCTION TO THE USE OF MULTI SENSORY ROOMS

Cost: £48 + £8.40 VAT

JULY 13, 1993

SHERBORNE MOVEMENT METHOD FOR CHILDREN WITH SPECIAL NEEDS

Cost: £48 + £8.40 VAT
Apply to: Castle Priory
Thames Street
Wallingford
Oxfordshire OX10 0HE
Tel: 0491 37551

AUTUMN 1993

MSC IN HEALTH PRACTICE/POST GRADUATE DIPLOMA IN RESPIRATORY CARE OR PAEDIATRIC NEUROLOGY

Details on this modular part-time course from:
Ms J. Mella
Head of School of Physiotherapy
Centre of Health Studies
University College Salford
Frederick Road
Salford M6 6PU

WHAT IS PACE AND HOW CAN IT HELP YOU?

PACE - Physiotherapy Access to Continuing Education - was first launched in 1991 by the Chartered Society of Physiotherapy. It is a practice-based system of continuing education for Chartered and State Registered Physiotherapists.

In implementing the PACE system, the Society aims above all to develop post-registration study on a flexible basis. PACE is intended to meet the needs of all physiotherapists, whether in the public, private or voluntary sector; whether newly-qualified, returning to practice, or changing career direction; whether developing specialist clinical skills, working with a client group, or qualifying as a teacher. The Society believes that by providing a structured programme of post-registration study, and due reward for those who successfully complete it, employers will be more convinced of the significance and value that post-registration study represents to the service, while physiotherapists themselves will be more inclined to pursue it. The individualised learning programme intrinsic to PACE will provide a unique profile of the physiotherapist's background, experience and qualifications.

The PACE structure consists of three categories of learning, practice-based courses, common core courses and experiential or work-based learning.

Practice-based Courses

Practice-based courses are those designed to develop knowledge and skills specific to a branch of physiotherapy practice, or to the treatment of a particular client group. Such courses may either focus upon the development of knowledge and skills discrete to physiotherapy practice, or may promote a multi-professional approach. Many of the courses that previously were validated by the Society have now been accredited within PACE.

Common Core Courses

Changing working environments and the developing role of physiotherapy within health care mean that it is increasingly important for physiotherapists to gain generic skills that transcend professional boundaries. The common core category of learning has been developed within PACE in recognition of this. Courses included within the common core category are likely to be conducted on a multi-disciplinary basis and to fall within the following broad subject areas:

- Communication (including information technology)
- Counselling
- Evaluation of practice
- Health education
- Health studies
- Management
- Research methodology
- Core science areas (eg. advanced anatomy, physiology)
- Teaching

Experiential or Work-based Learning

This refers to learning gained from professional experience, eg:

- unplanned learning through everyday work
- planned, directed learning within normal job responsibilities
- planned learning through additional responsibilities
- planned learning through research projects
- planned learning from line managers and/or colleagues.

Work-based learning may be recorded as it happens, eg. in-service training, every day work, special projects, etc. However, it is the reflection on this learning which is important, and the change it has subsequently made to your practice. The expression of the learning in the form of a case study, report, extended essay, etc. can form the basis of a claim for academic credit.

Credit Accumulation And Transfer Schemes (CATS)

The entire structure of PACE is built around the principle of Credit Accumulation and Transfer, whereby formal courses, together with work-based learning undertaken within PACE, attract an academic credit rating which has UK-wide currency. CATS are very flexible, and this means that as well as studying in the PACE system to further your professional development, it is possible to build up credits from a wide variety of sources towards a range of academic awards.

The Credit Accumulation System provides a ladder of awards, with exit awards at each Level. The individual student progresses from Level to Level, eg. physiotherapists who qualified with a Graduate Diploma exited at Level 2.

With CATS, it is possible to re-enter the system to pursue higher qualifications.

A big advantage of CATS is that it makes it possible for an academic value to be assigned to the learning that takes place outside higher education institutions. This valuation can be accomplished in various ways:

The Range Of Awards Offered Within Pace
BSc(Honours) Physiotherapy Studies

This is the first academic award developed within PACE and is offered by the CSP and the University of Greenwich. The award is aimed at physiotherapists who qualified with a Graduate Diploma and wish to upgrade their qualification to an Honours degree. It consists of a programme of learning which leads to the accumulation of 120 credit points at Level 3. Each programme will be unique, since it will form a coherent educational package that will meet the professional development needs of each applicant. A rationale will be requested which should indicate how the learning categories chosen will serve to enhance the applicant's effectiveness as a physiotherapist.

Fees for the BSc(Honours) Physiotherapy Studies

The registration fee for the degree will be £75. An additional fee of £350 will be charged for undertaking the Research Preparation Unit and for the supervision and assessment of the

Project. Registrants wishing to present experiential learning within their programme of learning will be required to pay a fee determined by the University of Greenwich according to the size of the claim made.

The Diploma in Advanced Physiotherapy Studies

This was the first award introduced within PACE and since it is a professional award from the CSP, it is only open to Chartered Physiotherapists.

Registrants for the Diploma are required to undertake a programme of learning that displays coherence educationally, and serves to meet their particular professional development needs. Although a curriculum of study is not attached to the Diploma, the award does have a structure. Registrants are required to undertake educational activity within three categories of learning:

- practice-based courses
- common core courses
- experiential learning

Experiential Learning Component

The Society has developed guidelines for physiotherapists undertaking the experiential learning component of the Diploma. Advice on how to present a claim for the accreditation of experiential learning in the form of a portfolio will be provided on a distance basis.

Fees for the Diploma in Advanced Physiotherapy Studies

The registration fee for the Diploma is £50. The fee for the presentation of experiential learning will be determined by the participating higher education institution.

Post-Graduate Awards

Work will begin in the coming year 1992/93 to create a post-graduate system of awards. This will enable either Graduate Diploma holders or graduates to embark on postgraduate study through PACE. A Post-Graduate Diploma can be built on to progress to a Master's degree or stand in its own right.

For further information about any of the awards, please contact Julia O'Sullivan, Sally Gosling, or Elaine Venables in the Education Department at the CSP, 14 Bedford Row, London, WC1R 4ED.

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HERE AND THERE

1. CHILDREN IN HOSPITAL

a) Action for Sick Children

This is the campaign name for National Association for the Welfare of Children in Hospital. A charity dedicated to representing the needs of sick children and their families and ensuring that children receive the highest quality care, wherever they are nursed.

The Association holds a unique library which specialises in the emotional and psycho-social care of sick children.

For details of membership contact:-

Action for Sick Children
Argyle House
29-31 Euston Road
London N.W.1 25D

The Editor has a list of publications, available on request.

A review of one publication follows later.

b) Costs Of Visiting Children In Hospital

The two organisations Action for Sick Children and Contact a Family were concerned about the degree of hardship to some families visiting sick children in hospital. They commissioned a research project by Julie Golding.

'A cardinal principle of hospital services for children is complete ease of access to the child by his or her parent. This is not a luxury. It is now generally accepted that the care and comfort of parents for a child is fundamental to the care and treatment of children in hospital.'

With these words the Department of Health (1991) recognised explicitly that parents are an essential part of the health care team. They are also an acknowledgement of the emotional harm caused to children separated from parents in hospital.

The study included a hospital from each Regional Health Authority, covering rural and inner city areas, local district hospitals and regional centres.

Research Findings

- 15% parents considered that they suffered financial stress as a result of visiting. 5.6% went into debt as a result of visiting and 12% had nothing left at the end of the week to cover visiting costs.
- 25.6% of families said they would like to have visited more.
- Families on Income Support did not tend to apply to the Social Fund for help despite having financial difficulties.

- Low income families not on Income Support appeared to manage by 'doing without'.
- Families whose children suffered long-term illness with long or repeated admissions to hospital suffered severe financial hardship. Nine families had to travel over 100 miles to visit.
- If the mother stayed, fathers often had heavy visiting costs. Britain does not have statutory paid leave for parents of sick children.

Proposals

- The cost of one visit per day per family should be granted to all parents on Income Support and Family Credit.
- Parents not on these benefits should be reimbursed their travel costs after the first three days if their costs are higher than average, as calculated by our research.
- Parents should be reimbursed at the hospital where their child is an inpatient. The hospital could then claim the money back from a central fund for visiting costs.
- The Social Fund should no longer deal with such provision.

If you agree, you can help. As parents and professionals, write to your local MPs *now* asking them to support the case for a visiting costs fund.

c) Publications

Care by parents

Jean Cleary has written an important and very readable study of the care-by-parent scheme in Cardiff, showing how parents may take over the responsibility for their children's care in hospital and the effects this has on nurses' roles and attitudes. Detailed comparisons of the quality of everyday life on the ordinary children's wards and the care-by-parent ward reveal that, on the latter, children spent less time alone, were handled by fewer strangers and were discharged home sooner.

Caring for children in hospital: parents and nurses in partnership, Jean Cleary, Scutari Press, 1992, ISBN 1-871364-67-1, £14.50

d) Audit Commission Puts Children First

Much more can be done to improve the quality of care of children in hospital, reveals an Audit Commission report out today*. The report calls for more child and family centred care, specially skilled staff, better use of separate facilities and reduced hospitalisation. The Commission found that in general there is a lack of any co-ordinated approach to hospital care programmes for children.

The Audit Commission recommends six principles which should underline the care of children:

- Child and family-centred care
- Specially skilled staff
- Separate facilities
- Effective treatments
- Appropriate hospitalisation
- Strategic commissioning

Hospitals often fail to implement all these principles. For example, some staff lack the special skills required to care for children. During the day many wards failed to meet the Department of Health's standard of two Registered Sick Children's Nurses on duty at any one time. At night, almost 50% of wards failed to meet the standard on any shift.

The Commission found that the type of hospitals at which a child is treated has a dramatic impact on the outcome of treatment. For instance, survival rates of premature babies receiving intensive care treatment in regional or specialist units were significantly higher than those receiving care in general hospitals, despite the fact that these specialist units were often dealing with sicker children. In addition, the cost of providing these more central, specialist services can be as much as 30% less than general hospitals.

The report has identified ways of overcoming each of these problems:-

- Each child should have a 'named nurse' responsible for their care while in hospital, and parents should be encouraged to be part of the care team.
- Hospitals should establish separate waiting areas and treatment rooms for children's services.
- Parents should be given basic facilities such as somewhere to sleep, sit in privacy and launder their clothes when staying with their children.
- Greater effort should be made to reduce the need for children to be admitted to hospital at all by improving the efficiency of admission and discharge procedures and providing more care at home.
- Health Authorities should ensure that children have access to specialist hospitals, with sub-regional centres being set up if their workload is sufficient.
- Hospitals should produce a management policy with greater emphasis on child and family-centred care.

Many of these improvements can be made at little or no financial cost.
*"Children First: A study of hospital services". HMSO £9.50

2. Children And Pain - by Priscilla Alderson PhD.

This is the first in a new series of family information leaflets produced by Action for Sick Children. It is mostly about pain felt by children in hospital during a short illness or surgery - it does give some guidelines for dealing with long-term pain.

The leaflet describes pain and how to tell when a child is in pain. It gives explanations of some of the terms that may be used when talking about this subject.

It describes pain control without drugs, which parents and people working with the child can use.

Pain control with drugs is also explained giving examples of drugs that may be used and how they can be given.

The leaflet emphasizes the importance of the family recognizing when their child is in pain as they often know the child best. The child should be given honest information and some choices so they can feel some control over what is happening.

A useful chart is printed out for children, who find it difficult to describe their pain or who are too young to say, to indicate how bad their pain is at any one time.

The leaflets are available from: Action for Sick Children, Argyle House, 29-31 Euston Road London NW1 2SD. Tel (071) 833-2041. Cost: £1 each or 10 copies for £7.50.

Jayne Fellows, Senior Occupational Therapist, Sadler Unit, Swindon.
Reprinted from N.A.P.Ot. Newsletter - Autumn 1992.

3. 'Cerebral Palsy Today'

A quarterly update for people interested in cerebral palsy and related conditions.

The research newsletter called 'Cerebral Palsy Today' provides a current and readily accessible source of information on advances in medicine, science and technology related to the treatment, management and care of people with cerebral palsy and associated conditions.

Subscriptions are available from Cerebral Palsy Today at the address below for an annual rate of £10 for institutions and £5 for individuals. Cheques made payable to The Spastics Society or payment by credit card is acceptable.

Contact: Dr.Hilary Katz
THE SPASTICS SOCIETY, 16 Fitzroy Square, London W1P 5HQ

4 a) Evaluation Of Conductive Education

A report is to be published on 24th May, 1993 which will contain details of the first ever systematic evaluation of Conductive Education in Britain. The research, which was sponsored by the Department for Education, was carried out at the Birmingham Institute for Conductive Education and at several Special Schools in the Greater Manchester area.

The project was undertaken by a team of psychologists from Birmingham University, and it aimed to answer four questions about Conductive Education;

1. To what extent was the form of Conductive Education developed in Birmingham an accurate replica of that established at the Peto Institute?
2. Is it possible to make explicit the principles upon which Conductive Education operates, and generate hypotheses as to which of these principles may be crucial to its effective implementation?
3. What is the effectiveness of Conductive Education for children with cerebral palsy in the Birmingham Institute, compared to the effectiveness of some alternative British programmes?
4. What is the range of applicability of Conductive Education in Britain?

A Conference will be held at the University on 3rd June, 1993 at which the research team will present the Report's findings on each of these four questions, and leading international experts on Conductive Education will give their views of the research methodology employed and the extent to which they consider the findings are valid indicators of the success or otherwise of Conductive Education in Britain.

b) Conductive education research to be published

A leaked account of the research findings in the Sunday Times last month indicated that there was no benefit to be gained by parents taking their children to the Peto Institute in Hungary. If the research actually shows this when it is released on 24 May at a press conference, there may well be a great deal of media interest.

If the research does show that conductive education is no more beneficial than physiotherapy and a multidisciplinary approach, the CSP will be able to comment positively. Any comment you make should stress the need now to secure more public funding for paediatric physiotherapy services in Britain. That is what we will be doing nationally.

5. Following a letter from Mrs. M.C. Thurston M.C.S.P., regarding physiotherapists' responsibilities towards families with cerebral palsied children who seek alternative treatment, the National Committee replied that

"The current position is that we have an obligation to continue supporting parents, maintaining contact and advising on the provision of equipment which is a Health Service responsibility. One should use one's professional judgement when considering individual circumstances."

6. **"The Children Act 1989 - A Synopsis For Paediatric Physiotherapists."**

Published by The Association of Paediatric Chartered Physiotherapists.

A guide to the Children Act 1989, written for Physiotherapists, but valuable to many professionals and others working with children, and young people.

This booklet is aimed to explain the purposes of the Act, to highlight its key points and to simplify the legal terminology. It has the advantage of being written at a time when some of the effects of the Act are only now becoming apparent.

Price £2.50 available from:-
APCP Publications,
c/o The Childrens' Hospital, Ladywood Middleway.
Ladywood, Birmingham.
A.P.C.P. members will receive a free copy.

7. **Primary Ciliary Dyskinesia (PCD) Family Support Group**

Contact Address: Carol Polak
67 Evendons Lane
Wokingham
Berks
RG11 4AD

A MOTHER'S OBSERVATION:-

Middle Lobe - Is Your Physio Effective?

Alex, my 5 year old with PCD seems to have been keeping his lungs remarkably free of infection with twice daily chest physiotherapy. So some months ago, I took him for his ventilation scan with a light heart expecting nothing abnormal to show up. Wrong! Despite having a neurotic physio-mum the Left-Middle lobe showed less air going in and out. As Alex has Situs Inversus and Dextrocardia, his Middle Lobe is on his Left side. For most people their Middle lobe is on their Right side.

I realised that I had been doing his physio religiously but missing out the postural drainage position for the area which frequently needs particular help to keep clear. The more I speak to PCD adults and children the more I hear that there seems quite frequently to be problems with the Middle lobe, whichever side it is on for you!

Therefore may I suggest that you make sure your physio shows you how to do this particular area efficiently, as part of the physio routine. Hopefully it might help to prevent problems occurring there in the future.

REGIONAL REPORTS

South West: **Mrs. Carole Hurran, 23, Bayswater Ave., Westbury Park, Bristol.**

A big **Thank You** to everybody who helped organise this years Conference at Bath University. An enormous amount of work went on behind the scenes to make it happen, and a great deal of time was spent by the committee beforehand in planning and preparation. We hope everyone enjoyed it and is encouraged to come next year to Chester
(Please book early!)

The AGM for the South West Region will be held on:
Friday 11th June at the CDC, Scott Hosptial, Plymouth
This will be at mid day during a study day given by Sophie Levitt. More details in the regional newsletter.
We hope to be able to reform the regional committee with some new members from further down the South West.

South East: **Terri Fearn, Woodland Close, Peacehaven, E. Sussex. BN10 7SF.**

London: **Rowenna Hughes - 87 Norbury Hill, London SW16 3RU**
The Committee has been meeting regularly to organise study days and to keep "up to date" with changes that are happening across London in the various services. We are sorry to lose Marion Main who resigned in January from the Chair on the Committee. We would like to thank her for her many years of hard work.
January '93 - An excellent A.G.M. and study day was held on 16th January at Northwick Park Hospital. It was well attended and encouraging to see professionals from other areas of work. The topic was "Gait Analysis". Mark Rossiter and Sally Patterson were the Speakers.
March - As requested at the previous course, we repeated the "Inhibitory Casting Day" at Hammersmith Hospital for 16 members. It was run by Di Coggins and Roz Boyd. Again it was successful and members are keen to attend study days and learn special skills. Study day is being planned for June and a Halliwick Day in September. If you have any requests for study days please contact any of the Committee Members.

East Anglia: **Jackie Reynolds, Lark Cottage, School Lane, Cratfield, Nr. Halesworth, Suffolk. IP19 0BN.**
A Study Day and AGM were held at Moulsham Grange in Chelmsford on March 10, 1993. An introduction to Sensory Integration was given by Sue Keam from SIUK with an opportunity to explore the well equipped SI room at the Centre. Sue Chillingworth talked about her work at Great Ormond Street with babies with HIV. The afternoon was well attended and thirty one people were present at the AGM. The branch are running a day course on Rehabilitation of children with acquired Head Injuries on June 5, 1993 at Basildon Hospital. The team from the National Paediatric Head Injuries Unit at Tadworth Court will be present on the day. Please advertise

this locally, it should be a good day. There will be a day on Management of Scoliosis in October and also one on Clinical Audit in January. Congratulations to Jo Douglas (Hunnions), a Conference Committee member, who had a son, Joshua, in February.

Trent: **Jenny Gill, 42 Brittania Avenue, Arnold Road, Nottingham, NG6 0EB.**

West Midlands: **Carol Foster, Physiotherapy Dept., The Children's Hospital, Ladywood Middleway, Ladywood, Birmingham B16 8ET.**
The West Midlands Branch of APCP have had a successful year with a variety of well attended lectures - this has been due to a hard working committee under the chairmanship of Maggie Moore. - Supt. Physio Children's Division South Birmingham Health Authority. The AGM was held on 31st March 1993 at the Post Graduate Centre BCH - Dr. John Cash gave a lecture entitled "Parents Views of the Professionals" - an amusing but thought provoking subject. The evening was supported by sponsorship from a variety of equipment firms who donated the supper. Sincere thanks to all committee members for their hard work and support over the past year. Work has started on next years programme which begins with a lecture on MRI Scans given by Dr. Shavda - Consultant Neuro Radiologist Midland Centre for Neuro Surgery, Holly Lane, Smethwick - on Wednesday 26th May 1993 at 6.30 p.m. A series of three evening lectures on splinting, bracing and orthoses is planned for the Autumn.

Wales: **Barbara Bowen, Children's Assessment Centre, East Glamorgan Hospital, Church Village, Nr. Pontypridd, Mid Glamorgan.**
On March 6th we held a Study Day on hemiplegia. The day was very well attended by Physios and O.T.'s and proved a great success.
We held our A.G.M. during the lunch break. The new additional Committee Members are Julie Harvey and Christine Wetterwald, both Senior Community Paediatric Physios in Swansea, Donna McDonald, Senior Physio based at Prince Charles Hospital, Merthyr and Penny Ayres Superintendent Physio at Maes y Coed School Barry. We will be meeting soon to discuss the programme for the year. Please contact me with any ideas for study days, courses and possible venues.

North West: **Alex Winney, 14 Langley Road, Spital Bebington, Wirral, Merseyside, L63 9HW.**

North East: **Carrie Jackson, 4, Abbotsway, York. YO3 9LB.**
Thirty-two applicants attended a very successful study day on "visual problems in the Multiply Handicapped Child" on March 6th in York. Wendy Harrison, Senior Orthoptist from York C.D.C. gave us an extremely interesting morning of talks, workshops and discussion, followed in the afternoon by the presentation of a paper on "Body Image and a Sense of Self" by Sylvia Downing, specialist teacher for the visually impaired from Gateshead. The branch AGM was held at lunchtime and attended by the

APCP members present. The next study day planned for mid June will be on "Hands-Anatomy", functional development and splintage". Later in the year we hope to run some study days aimed at Physiotherapists who are new to, or considering, Paediatrics and these will include: Neuroanatomy and Physiology in Paediatrics and Head Injury Management. More details later but please make every effort to attend and support your regions activities.

Scotland: **Lyn Cambell, 19 Craigmount Avenue North, Edinburgh, EH12 8DH.**

N. Ireland: **Elizabeth Harty, MCSP, 43 Ardress West Road, Tullyroan, Dungannon, BT71.**

The first aim of this year's committee was to compile a Register of the Paediatric Physiotherapists in the province. It was felt some were working in isolation and unaware of the support given by the APCP. As a result of our questionaire a comprehensive list of names and work places was compiled and distributed to all APCP members. Our membership has risen from 37 to 41 and still rising! Other questions revealed that Belfast was the preferred venue for meetings, a week day in preference to a Saturday for study days and 27 subject topics were suggested. Our thanks to all who took the trouble to reply. Events have been well attended especially evening meetings and we have been pleased to include students to all of these. Evening topics have included, Autism, Respiratory Care and Suctioning Techniques, the Ilizarov Fixator and leg lengthening discrepancies, and rheumatology. A Study day was held on Alternative Therapies and an informative 2-day workshop on statementing and auditing by Mrs. Mary Clegg. We are looking forward to having Colin Stevens again with us for 2 days in May in the University of Ulster, Jordanstown, to demonstrate problem solving with a wide variety of children using Bobath Techniques.

My thanks again to Ann Shanks and Maria Ash and the staff at Brookfield House School for sharing their time and knowledge on a visit I made while in London for the January APCP meeting.

PHYSIOTHERAPY SWEATSHIRTS

ACPC Members who attended the Conference in Bath will have seen the

'CHILDRENS PHYSIO' SWEATSHIRTS

designed by one of the Physios at the West Dorset Children's Centre at Dorchester.

These are now available nationwide. Details and order forms are here so you can order **"NOW".** A reliable Company has been found to embroider the shirts and we are sure you will receive a good service.

A colour photograph (returnable with your order) is available on request.

We look forward to your order forms and cheques arriving.

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