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CONFERENCE EDITION

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The Conference articles are prepared from notes and edited transcripts of papers given at Conference. The Editor wishes to thank those members of the Editorial Board and Organising Committee who have provided them.

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EDITORIAL

Mrs. Jackie Reynolds M.C.S.P.

Jackie, seen here chatting at Conference, is a member of the Editorial Board. She is Superintendent Paediatric Physio, Anglia Harbours Trust, Great Yarmouth. She has worked in South Africa and Birmingham Childrens Hospital.
Her main interests are Neuro-developmental Physio and seating.

This edition of your Journal marks a milestone in the development of APCP. This year the Association has come of age and it was felt that the Journal was ready for a new look. The contents are always interesting and most members eager to read their newly arrived copy from cover to cover. I frequently delve into my collection looking for an article and become diverted reading all sorts of items that I had forgotten.

Over the past nine months the Editorial Board has researched presentation and format, and has taken professional advice from the publishing industry. After much consultation and deliberation it was decided to produce a larger publication with a more user friendly layout. A new distinctive cover has been designed for us by John Soper.

Our Journal is now held in a number of libraries and we are seeking registration with the British Library, for which principal articles should be referenced. We aim to create a more professional journal with referenced articles, but at the same time to retain and develop the informal news and information section. At the back of the journal you will find guidelines to assist contributors with structure and format. Hopefully this will also facilitate layout for the Editor. Short pieces about a new idea or treatment, adaptations or new equipment, letters, news and events are of equal importance and are essential to a successful publication. Do ensure that these are kept coming.

The new look journal will attract interest from new readers and encourage membership whilst continuing to provide present members with a good balance of information and news as it has done in the past.

The Journal is the professional interface of APCP and we trust that it will continue to reflect the growing standing and importance of the Association.

COPY FOR THE NOVEMBER NEWSLETTER MUST BE WITH THE EDITOR BY 1ST OCTOBER.

The Editorial Board does not necessarily agree with opinions expressed in articles and correspondence, and does not necessarily endorse courses advertised.
The Board reserves the right to edit material submitted.

LETTERS TO THE EDITOR

The following letter was sent to the Editor from the Treasurer of the Conference Committee. Mrs. E. Lewis M.C.S.P.

Jean Turner
For: Members' Benevolent Fund Committee

Dear Mrs. Lewis
I am writing on behalf of the Members' Benevolent Fund Committee to acknowledge receipt of 7 cheques totalling £320.00 which were the results of a collection at the national conference of your Group.
This is a very welcome donation - would you, at the next opportunity, please pass on the committee's most sincere thanks to your members for their generosity. Their support is much appreciated by the committee and the eventual beneficiaries.
This letter is sent in place of an official receipt.
Yours sincerely
Jean Turner

Mrs. C. Jackson (MCSP),
Research Physiotherapist,
Physiotherapy Department,
Westwood Hospital,
Beverley
HU17 8BU
Fax: 0482 866194

Dear Editor,
At present I am engaged on an Audit Project to look at Paediatric Physiotherapy advice given to parents of chronically sick or disabled children. I am hoping that one of the outcomes will be the establishment of a resource base of information leaflets and handouts that can be used to support hands-on treatment and education of carers.
This would seem to be important in view of the many research projects which highlight parents wishes to have as much information as possible, and the popularity of Parent Information Packs such as those produced by the Spastics Society.
If you or your department have produced any written information that you find helpful, and that you'd be prepared to share, I should be most grateful to hear from you.
If enough information is forthcoming, it may be possible to publicise the results in the APCP Journal as I feel sure that good written information is wanted and is of benefit to parents, children and over-stretched physiotherapy services.
I look forward to hearing from you and would like to thank you in anticipation of your help.
Yours sincerely
Carrie Jackson

Miss E. Abbott, MCSP SRP
Senior Physiotherapist
Paediatric Physiotherapy Department,
Hull Royal Infirmary,
Anlaby Road,
Hull. HU3 2JZ

Dear Editor
I am doing some research on the various treatment aspects of spastic diplegia. If members have any special experience or expertise in this condition, or know of any useful articles, books or information, please write to me at Hull Royal Infirmary.
Miss E. Abbott

Ursula Blake, M.I.S.C.P.,
Paediatric Physiotherapist,
Central Remedial Clinic,
Vernon Ave.,
Clontarf,
Dublin 3,
EIRE
Tel. No: 8332206
Fax: 8335496

Dear Editor

I am in the process of gathering material about the indications for the use of the hip block splint for children with Cerebral Palsy.

I would be interested to hear from anyone who is or has been using the splint and I would like to get some opinions on the use of the splint as a seating / night splinting device and as a therapy tool. Also I would be interested in the age group and the quality of tone of the children using the splint.

Thank you very much for your help.

Ursula Blake

Sally Jary M.C.S.P.
Sarah Dyer M.C.S.P.
Clare Alexander M.C.S.P.
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THE DAVID HART WALKER - the following article has been printed, as received on the form of a letter.

Dear Editor,

We have read with interest the items in your Newsletters concerning the David Hart Walker (1,2) But until recently have had little experience with them.

Bobath Cymru is a charity specialising in the treatment and management of children with cerebral palsy. Currently we are reviewing four children who have received the David Hart Walker. These children all have a diagnosis of cerebral palsy with a quadriplegic distribution (upper limbs more involved than lower limbs), none are able to sit on a bench independently and have limited independent mobility on the floor. They have all been assessed and prescribed with the four wheeled walker used in conjunction with calipers and brace.

Following assessment of each child using the walker, we find that we agree with many of the comments in relation to the children with cerebral palsy made by the Paediatric Staff at Airedale Hospital, Keighley (2), and would like to make the following observations:

*We agree that parents do indeed like the walker but would also like to add that everybody involved with the child seems to like the walker, including the children we have seen. It allows children to be in an upright position and so more easily participate, integrate and socialise with their peers and others. Therefore the children are the focus of much attention when they receive the walker.

*On a practical note, parents and carers feel the walker is generally easier to use than a standing frame, despite having to lie the child in supine on the floor/bed and then lift the child and calipers from supine into an upright position to suspend on a hinge on the frame. The frame is also considered easier to move in gaining access to table top activities.

*The company, now Genesis Orthotics, is very efficient in regularly reassessing the children who have been provided with the walker. However, it is worth noting that the specialised alterations necessary

with growth/progress are not without considerable cost to the parents over and above the initial expenditure. In addition, we are unaware if there is an age/weight limitation to the provision of the walker in its current design and so do not know if size/growth will prohibit its continued provision as children become larger and young adults.

*A beneficial effect of the walker was felt to be the strengthening of leg muscles (2). Due to the nature of pathology in cerebral palsy, weak muscles are not considered of primary importance in the acquisition of functional skills in this group. Therefore, we would not view the walker as having an important role in strengthening the muscles of children with cerebral palsy.

*Of particular concern is the fact that the thoracic brace and calipers can limit joint range of movement (2), in particular the hips and knees. In the four children we have seen, neither hip or knee movement reaches full extension during the full extension during the supported gait cycle. This is important in the management of the child with cerebral palsy where flexor contractures of hips and knees are very difficult to avoid.

*We also have observed the presence of associated reactions {further increase in spasticity} (2), particularly in the upper trunk, shoulders and arms with the effort of using legs to move the walker. Although associated reactions cannot be completely prevented in cerebral palsy, it is important to monitor them as they may predispose contracture and deformity. In children with cerebral palsy, particularly the quadriplegic groups where the upper body is more involved than the lower body, associated reactions as a result of using the walker may influence functional skills in other positions. For example, an increase in postural tone around upper limbs and trunk may affect the quality of head control and so the child's ability to use their eyes reliably for eye pointing or influence their oral control which may affect eating and drinking. Additionally associated reactions may affect the quality of upper limb movement and manipulation and so interfere with function such as switch use for computer accessing.

*Although the frame gives the child the experience of movement in space, we must remember that this is only dimensional movement and, as noted in the Feb. 92 Newsletter, there is no possibility for rotation of body parts. Therefore, the walker can only be considered as providing the experience of limited movement in space. It is unlikely to provide the type of movement in space prerequisited for independent ambulation.

*Despite the above comments our largest concern is that, for a variety of reasons the use of the frame may exclude the use of other postural management recommendations. There is the idea that the more the child uses the frame the more effective it will be to,

"progress the child towards independent mobility" (3).

One piece of equipment cannot meet the many needs of a child with

cerebral palsy and should be used in conjunction with other pieces of supportive equipment. Children with cerebral palsy have limited possibilities for movement and so a greater variety of movement patterns need to be facilitated at least in part by the careful co-ordination of a combination of different pieces of supportive equipment, not the unlimited use of one.

Because of our concern we are currently evaluating the use and the effect of the walker in those children known to us, initially over a six month period. We must stress that we are not in a position to comment on the use/effect of any other versions of the walker or its use in children with pathologies other than cerebral palsy.

We welcome comments from other therapists concerning their experience of the walker and by children with cerebral palsy.

Yours sincerely,

S. Jary, M.C.S.P., S. Dyer, M.C.S.P., C. Alexander, M.C.S.P., A. Gordon, S.R.O.T. and H. Holgate, S.R.O.T.

References

1. Physiotherapist's Views of the David Hart child's orthotic walker
APCP Newsletter Feb 1992
2. Hurran C.
The David Hart Walker
APCP Newsletter Feb 1994
3. Information Sheet - The Child's Orthotic Walking Trainer
Genesis Orthotics, 1 Holt Court South, Off Jennens Road, Aston Science Park, Birmingham.

Dr. Ian McKinlay

Senior Lecturer in Community Child Health,
Royal Manchester Children's Hospital.

Ian is a familiar face to those attending Conference. A loyal and supportive Honorary Member, he is known to us in various guises.

Ian McKinlay wrote this article in celebration of our Coming of Age.

Paediatric neurology has been described as the unspeakable in pursuit of the untreatable. Amongst neurologists there are some whose motivation for pulling the curtains open on a wet January morning is the thought that today might be the day to pick up a rare disorder. These are neurophilatelists, skinny people with glasses, who eat salad in moderation, sometimes risk half a glass of sherry and talk with unseemly joy and enthusiasm about a fascinating case of flatus perplexus and disastrous disability.

The function of people with rare disorders is to be investigated, photographed, presented at meetings, shown to the students, put in textbooks, sent for at exam time and to provide neurophilatelists with deep satisfaction. One case of tartan toes, revolving eyes, an engaging manner of saying words backwards and appalling halitosis is interesting. Two are a coincidence. Three makes a series, a paper in the European Journal of Paediatric Neurosciences "Decade of the Brain" supplement and a jewel in the CV. It is always suggested that there may be more of these people than used to be thought, but that more research is needed. The affected individuals can wear their badges with pride and feel pleased to have brought such happiness to their specialists.

There is no particular purpose in offering treatment in the sense that drugs and operations don't work. In any case life expectancy is limited [as opposed to neurophilatelists whose life expectancy is infinite.] However, the most fascinating case begins to pall eventually as the quest for novelty is resumed. One grand way of moving them on is to refer them to the physio for, well, anything really, but gratitude would be appreciated.

You have never seen anyone like this in your life and didn't know it was possible. Crunched up external ears like pink curly lettuce, joints seized up, spidery limbs, bizarre gait, normal intelligence and all you have to go on is the note that the child has a rare disorder called Beals Syndrome [contractural arachnodactyly] and the fascinating fact that one of Marfan's first cases probably had Beals Syndrome. After realising how lucky you are to meet the 12th person ever to have Beals Syndrome, and that he's absolutely a little sweetie, what next? How about putting him in a barrel and rolling him over to promote sensory integration at a brainstem level? Or are children with Beals Syndrome prone to motion sickness? "Luckily" it is a dominant disorder, so the mother or father may be able to demonstrate the adult features. And a sensible discussion might help to plan a realistic treatment policy.

However, it would be good to know about the condition - how do you find out? When paediatric physiotherapy was in its infancy - even working its way through turbulent puberty - the obvious answer was to ask doctor. He'd be pleased to explain the terms dolichostenomelia [long slim limbs] and arachnodactyly [spidery fingers] then to speculate about the fundamental disorder of connective tissue. As to whether Fred was going

to throw up in your barrel I'm afraid there were limits to medical science. Before you slipped, humbly, out of the conversation you would learn that you shouldn't mix up this syndrome with the other Beals Syndrome [auricula-osteodysplasia] in which a third of affected females have a dislocated hip. History does not relate their propensity to puke or the state of integration of their brain stems.

Now however, you have reached maturity and are ready to find out for yourself - how do you go about it? This will be illustrated with reference to four disorders [which turn out to be five]: Rett Syndrome, Pallister-Killian Syndrome, Angelman Syndrome and Neurofibromatosis.

The obvious place to look first is a current edition of an appropriate standard textbook. There's no point in looking for Beals Syndrome in Jean Aicardi's "Diseases of the Nervous System" [MacKeith Press/ Cambridge University Press, 1408 pages of superb reference material]. It is not a neurological condition. However, you will find nine pages of neurofibromatosis, a page and a half on Angelman Syndrome and four pages on Rett Syndrome, but Pallister-Killian is too rare to feature. For neurology Ed Brett's Churchill Livingstone book "Paediatric Neurology" and Neil Gordon's "Neurological Problems in Childhood [Butterworth Heinemann] are also excellent.

Another book to consult is the [Saunders] classic "Smith's Recognisable Patterns of Human Malformation" now in its fifth edition. It gives a brief account of disorders which cause people to look unusual, describes the body systems affected, gives relevant references and photographs. Angelman, Pallister-Killian, Neurofibromatosis [and both of Beals Syndromes] are in. However Pallister-Killian is referred to as Killian/Teschler - Nicola Syndrome [Pallister Mosaic Syndrome, Tetrasomy 12p.] Rett Syndrome is not in it - affected girls are not dysmorphic but pretty.

The bible of gene disorders is Victor McKusick's magnificent Johns Hopkins University Press book "Mendelian Inheritance in Man." Now in its tenth edition and in 2 volumes weighing several kilograms, comprising well over 2,000 pages of small print in 2 columns, it is divided into autosomal dominant, autosomal recessive, and X linked phenotypes. There are 6 pages on neurofibromatosis [autosomal dominant] with well over 100 references. Angelman Syndrome [autosomal recessive] is listed under Happy Puppet Syndrome [its old unacceptable name] and has 2 pages and about 3 dozen references. Rett Syndrome has just over half a page and just over a dozen references [Beals contractural arachnodactyly has similar treatment in the autosomal dominant section whilst his auriculosteo-dysplasia syndrome has a quarter of a page in the same section.] However, Pallister-Killian is not mentioned because it is not a gene disorder but a chromosome disorder. Two other Pallister syndromes are mentioned. [How he finds time to hold together the centre of Manchester United's defence amazes me.]

Every postgraduate medical library and children's physio department or child development centre should subscribe to the journal "Developmental Medicine and Child Neurology". In the last 3 years it has carried 4 articles on Rett Syndrome and one on Angelman Syndrome although nothing on Pallister-Killian or neurofibromatosis. However, its annual bibliography in that period lists 124 Rett references from the world literature, 14 Angelman references and 17 references on neurofibromatosis indicating current research interest. [There will have to be an annotation on Pallister-Killian soon, Dr. Bax.]

Support organisations produce good information - sometimes better than that in textbooks. Ann Worthington's In Touch [10 Norman Road Sale Cheshire M33 3DF, Tel: 061 905 2440] helps with individual links for children with a diagnosis of a specific condition. The Genetic Interest Group [c/o Institute of Molecular Medicine, John Radcliffe Hospital, Oxford OX3 9DU, Tel: 0865 744002, Fax 0865 222501] is a forum of voluntary organisations concerned with genetic disorders. Contact a Family [16 Strutton Ground, London SW1P 2HP, Tel: 071 222 2695, Fax: 071 222 3969] offers advice and support to national parents groups concerned with specific conditions and rare syndromes. Many but not all, are listed in the CaF Directory of Special Conditions and Rare Syndromes, first produced in

November 1991 and updated several times since. It gives a brief account of the conditions and full details of those organising support groups and available publications. There are British Support Groups and explanatory leaflets for families of people with Retts Syndrome, Angelmans Syndrome and Neurofibromatosis. The support group for people with Pallister-Killian syndrome is based in Naples, Florida.

If there are psychiatric problems the place to look first is Rutter Taylor and Hersov's 1122 page Blackwell book, just published in a third edition : Child and Adolescent Psychiatry : Modern Approaches. MacKeith Press/Cambridge University Press have just produced a superb book : "Rett Syndrome-Clinical and Biological Aspects" edited by Bengt Hagberg. There are several books on neurofibromatosis.

CD Rom technology has transformed information sources. Many medical libraries have Medline on silver platter disks, updated every 6 months, for use on CD Rom. This gives access to the world research literature in response to typing in key words. There is a disk for every year back to 1966. It is now possible to search for 2 or 3 hours to get information which would have taken months in the past. The system will give the total number of articles for each key word each year and will print out the details of the reference with an abstract.

The neurology database or the POSSUM database and the dysmorphology database may be available in the clinical genetics department. In the first two the diagnosis is keyed in. This prompts the generation of relevant synonyms and a brief explanation of the syndrome. Using the dysmorphology database involves keying in unusual physical features and asking whether these correspond with any known dysmorphic conditions. If two or three physical features are keyed in then the database may generate a list of several possibilities. If too many physical features are keyed in it may draw a blank. Not every unusual physical finding is part of the syndrome. While the Medline CD Rom is accessible to any medical library user the neurology and dysmorphology databases are expensive and may only be found in a few centres. Nonetheless the print out is likely to be included in the clinical notes and therapists would be interested to discuss the content with medical colleagues. Unfortunately there are no data on tolerance of rotation in barrels or needs for brainstem integration but hypotonia is recorded.

Attendance at meetings is another source of new information. The meeting on Rett Syndrome : Gene to Gesture : Recent Advances at the Royal Society of Medicine in London had 11 speakers on topics ranging from neuropathology, genetics and metabolic aspects to scoliosis, feeding disorder, breathing problems and the needs of parents and carers. Maybe you didn't go but could find someone who did.

The particular syndromes on my homework sheet are of considerable scientific interest as well as being of major importance to the people affected.

Retts Syndrome first described in 1966, is an x-linked disorder, possibly a sporadic dominant mutation, affecting only girls [1:10,000] and is therefore most unusual. For most neurodevelopmental disorders boys have a 50% excess risk at least being the frail sex. It is possible that the condition is lethal in male fetuses who are aborted. In the first months of life no abnormality of development is reported. Sometimes between 6 months and 36 months, usually by 18 months, regression in gait, [if achieved] cognitive function and hand function are observed. Two thirds to three quarters don't walk. Those who do develop an ataxia/apraxia of gait. Dementia becomes severe with autistic features, continual hand wringing, hand tapping or mouth tapping with the hands become conspicuous, there is marked deceleration of head growth and, commonly, the head circumference comes to below the third centile. It accounts for a third of girls with hitherto unexplained progressive encephalopathies.

Although some younger children with Retts Syndrome feel rigid - often through inactivity rather than spasticity - the tendency is to develop a progressive hypotonia. Neurophysiological testing shows denervation consistent with loss of arterior horn cells as in spinal muscular atrophy or motor neurone disease. Scoliosis is common. Now that the condition is recognised it has been realised that

variants occur but there is as yet no specific test.

Pallister-Killian is an odd name. Pallister reported the first two cases in 1976. Teschler-Nicola and Killian described a third case in 1981, subsequently realised to be the same disorder as Pallister's. For a time it was described as the Killian/Teschler-Nicola syndrome, the former having been on an assertiveness training course. Rivals called it the Pallister mosaic syndrome. Neurophilatelists called it 12p tetrasomy mosaic syndrome. Eventually Teschler-Nicola was dropped in favour of the more euphonious Pallister-Killian in some quarters. However arguments go on far into the night at neurosciences conferences. All of which is of little benefit to the profoundly delayed individuals affected. None has ever uttered a word of speech or walked. They have a long philtrum and a thin upper lip but look as if they are wearing a gumshield. The lower lip protrudes. Frontal hair, eyebrows and eyelashes are sparse and the skin shows streaks of hypopigmentation. Seizures and deafness are common and hypotonia is a feature with postural deformities in later years.

The scientific interest stems from 3 features. At birth the babies are long, heavy and have a large head circumference. Blood cells show **no** chromosome abnormality **but fibroblasts do** [hence the term mosaic]. The fibroblasts have 47 chromosomes of which one consists of the short arms of two extra short arms of chromosome 12 stuck together in the middle and looking like a dicky bow. The frequency of such mosaics is not yet known and probably underestimated. There have been rare cases reported of chromosome abnormalities in other tissues.

Angelman described three "puppet" children in 1965 and in the 1980's they became "happy puppets" to the annoyance of parents. The children may appear to have a cheerful mood and a tendency to unprovoked laughter and are therefore nice to know for short periods. They all have severe learning disability with autistic features. Although most can walk, with ataxia, short distances on their own or with support, this is usually without purpose. Some may gesture but none talks. 86 per cent have seizures and the EEG often shows long periods of continuous abnormality by day or night in early childhood. This reduces with age. Prognathism [prominent lower jaw] is evident increasingly after 4-6 years. In childhood stimulation is resented and often makes seizures worse. In early adult life seizures become less of a problem and stimulation is appreciated. Water play fascinates affected children.

The scientific interest lies with chromosome 15. In children with Angelman Syndrome **both** number 15 chromosomes are **inherited from the mother**. The abnormality is either a deletion or an autosomal recessive gene in the short arm. If children develop Prader-Willi Syndrome the same part of the short arm of chromosome 15 is affected, but both the child's number 15 chromosomes are inherited from the father. The usual finding is a deletion.

Neurofibromatosis is not one condition but two, deriving from dominant genes for NF1 on chromosome 17 [pericentric region of long arm] or for NF2 on chromosome 22 [central long arm]. The former is mainly peripheral NF as described by Von Recklinghausen in 1882 and accounts for 85 per cent. It affects 1:3,000, a third having developed a mutation with no family history. The latter is mainly central form.

To be considered to have NF1 an individual must have at least two of the following : at least six cafe au lait skin lesions of more than 5mm. diameter before puberty or than 15mm after puberty, 2 or more neurofibromas, axillary freckling, one or more plexiform neurofibroma [a mat of abnormal tissue as in Joseph Merrick, a third of affected people have one, one in twenty around an eye], at least 2 Lisch nodules [small hamartomas] on the iris found in a third under 6 years and virtually all after 12 years, an optic nerve glioma, an osseous lesion such as sphenoid dysplasia or tibial pseudoarthrosis or at least one first degree relative with NF 1. About a tenth of people with NF 1 show clumsiness and/or moderate learning difficulty. Other important complications include epilepsy or EEG abnormalities in 20 per cent, scoliosis and hypertension [eg from neurofibromas of the renal artery or from an adrenaline secreting tumour : phaeochromocytoma].

NF2 accounts for 15 percent. At least one of the following features is present : bilateral acoustic

neuromas [tumours of Schwann cells] an acoustic neuroma and a meningioma, juvenile sub-capsular cataracts or a history of brain or spinal tumour [not usually a glioma] in a first degree relative. The condition is not usually found in children. It should always be considered with progressive hearing loss in late adolescence and early adult life. Its inheritance is completely separate from NF1. However, it is possible to inherit each condition if each affects one parents, an unlucky experience.

There are thousands of syndromes and most are infrequent. However, now APCP has grown up you will know how to find out about them. You can educate the neurologists about the physio implications.

THE CHANGING FACE OF CEREBRAL PALSY

Professor P. Pharaoh

M.D. MSc. F.F.P.H.M.
Dept. of Public Health, University of Liverpool.

Professor Pharaoh graduated from St. Mary's Hospital in 1954. In 1963 he went into the Dept. of Public Health in Papua New Guinea and worked there for 11 years. For two of those years he was seconded as a Research Medical Officer with the Institute of Medical Research. The research concerned iodine deficiency and its effects. In 1974 he was appointed senior lecturer at the London School of Hygiene and Tropical Medicine where his interests in infant mortality, neonatal intensive care and cerebral palsy were developed.
He was appointed to the Chair of Community Medicine in Liverpool in 1979.

Professor Pharaoh first became interested in Cerebral Palsy (CP) whilst working in Papua New Guinea where there is a specific form of CP called Endemic Cretinism. The major feature is spastic quadriplegia or in milder cases diplegia. It is caused by iodine deficiency in the earlier part of pregnancy which affects the normal maturation of the brain.

When he returned to Britain in the early 1970s he decided to follow up his interest in CP and it soon became clear that there was very little data available about the numbers of cases of CP in any district or region. At the same time there were enormous changes occurring in paediatric care especially neonatal special care. Admissions to Special Care Baby Units (SCBU) had increased rapidly in the 1960s and by the late 1970s 1 in 5 infants born were being admitted to SCBU.

As neonatal intensive care improved smaller babies were surviving. The smaller the baby the greater the risk of CP and below 2 kilogram the rate rises more sharply.

With so many small babies surviving Professor Pharaoh was interested in what was happening to the incidence of CP. Although it is the commonest severe disability in children there was no data looking at trends.

In the late 1970s he began by looking at a cohort of low birth weight babies (just under 1000) born in Merseyside and at the same time he also started a register of all cases of CP, going back to 1966 in the Mersey Region (Merseyside and Cheshire).

CP is not a single entity so there were problems of definition and classification.

There are many different definitions of CP and these include:-

1. Original Little Club - A persistent, not unchanging disorder of movement and posture appearing in the early years of life.
2. Nelson and Allenburg - A chronic disability characterised by aberrant control of movement appearing in early life.
3. Martin Bax - A group of disorders of movement and posture due to a defect or lesion of the immature brain.

The terms early in life and immature brain are not easy to define so all children placed on the register have 'congenital' CP i.e. the brain damage occurred within 28 days of birth. This eliminates all acquired CPs such as head injuries, meningitis or tumours.

CP can be classified by motor symptoms - spastic, ataxic, dyskinetic or mixed; by topography - hemiplegia, quadriplegia or diplegia, or by etiology - perinatal problems, infection, genetic abnormality etc.

For the purpose of the register children were classified by topography.

Data for the register was collected from various sources including the District Handicapped registers, the Family Disability Allowance register in York, Special Schools, the Office of Population Census and Surveys, Consultant Paediatricians, hospital activity surveys and physiotherapists.

The register only included children born to mothers resident within the Mersey Region at the time of birth. Children born within the Region to mothers resident outside were excluded.

In the years 1966 - 1989 there were 1500 cases on the register. Migration of the children was monitored, 109 moved within the region and 99 moved into and 51 out of the region. There was an unexpected

discrepancy between those moving into and those moving out, but over the 23 years it was only 1 or 2 a year so was thought not to be significant.

Looking at the classifications of all the cases of CP on the register one third have hemiplegia, one third quadriplegia, one fifth diplegia and there are 9% others (this includes children classified by the paediatrician using motor symptoms with no mention of distribution).

When looking at the prevalence of CP in relation to birth weight, in the years 1966-89 for LBW infants under 1500g there was a sharp rise in numbers in the late 70s and it levelled out in the 80s. In the late 60s there were 20-40/1000 live births and by the late 70s there was a three fold increase to 100/1000. For the moderately low birth weight infants, 1500-2500g, the rate increased from 4/1000 to 10/1000 levelling out slightly sooner. For infants over 2500g there was virtually no change staying level at 1-1.5/1000 (figure 1)

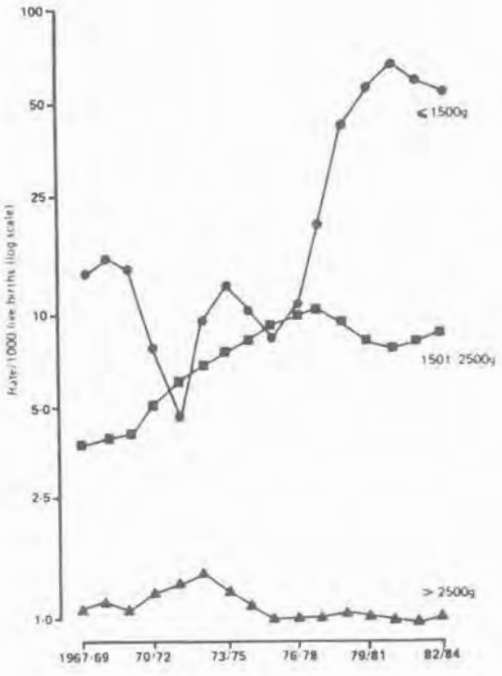

Figure 1 Birthweight specific trends in cerabral palsy.

These changes are due to the changes in neonatal care. It was thought that with the improvement in perinatal care the rates of CP would reduce. This is not so. There is a higher incidence. This is thought to be because the majority of cases of brain damage occur early in pregnancy and in the past severely brain damaged low birth weight babies died. With improved neonatal care these babies are being kept alive.

Therefore, the better the hospital, the better the neonatal care it provides the higher the rate of CP in the low birth rate infants.

Now a much higher proportion of cases of CP are children who had a low birth weight. In the late 1960s 70% CP children had a normal birth weight but it is now only 50%, and of the remaining 50%, 25-30% are under 1500g. The proportion of under 1000g infants with CP is also growing.

Within the different birth weight groups the pattern of CP is also changing. When looking at the low birth weight infants, under 1500g, in the late 1960s the majority of children had diplegia. Less children had quadriplegia and fewer still had hemiplegia. By 1987 there were equal proportions of hemiplegias, diplegias and quadriplegias. (Figure 2) In the 1500-2500g group there is a decrease in the proportion of diplegias and increase in the proportion of quadriplegias and hemiplegias. (Figure 3). The pattern has not changed in the normal birth weight group. (Figure 4)

Figure 2. Trends in cerebral palsy: birth weight <1500g (three year moving average).

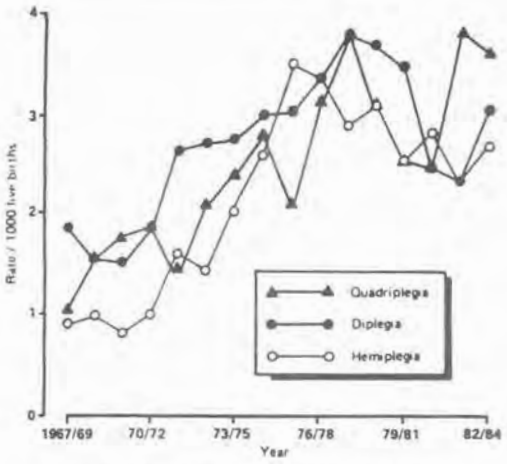

Figure 3. Trends in cerebral palsy: birth weight 1501-2500g (three year moving average).

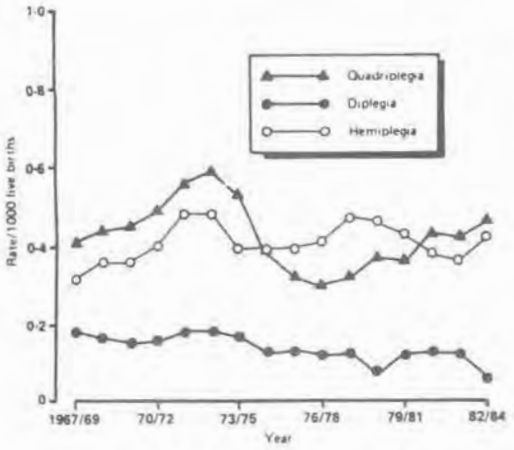

Figure 4. Trends in cerebral palsy: birth weight >2500g (three year moving average).

There has been an enormous change in the numbers of infants with a birth weight below 1000g. In the 14 year period 1966-79 there were only 6 cases of CP, 2 hemiplegias, 2 diplegias and 2 quadriplegias. More recently in a 5 year period there were 12 quadriplegias, 8 diplegias and 9 hemiplegias. This group of children are making a big difference to the numbers of CP and to the severity of cases now seen.

A comparison of the IQ of CP children in the different birth weight groups showed that over two thirds of the LBW children have an IQ in the normal range i.e. >70 and that there is a higher proportion of severely retarded children in the normal birth weight group. This is believed to be because the premature LBW infants with severe brain damage do not survive long enough to be diagnosed as having CP. They are not therefore counted on the register. However the normal weight babies do survive because they do not have to overcome the complications of a low birth weight. Over the next few years with further improvements in neonatal care, more of the severely brain damaged LBW infants will survive. There will be more children with quadriplegia and low IQ. This will not only have long term implications on the Health Service but also on Education and Social Services.

The three main points as to how CP is changing are:

1. An increasing proportion of LBW infants are surviving.
2. Amongst the LBW infants the pattern is changing. There are more children with quadriplegia in particular, and also more with hemiplegia.
3. A higher proportion are more severely affected i.e. quadriplegics with an increase in the proportion of CP children with mental retardation.

References *(figures)*

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Further reading

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BRONCHOPULMONARY DYSPLASIA

Dr. Ben (NJ) Shaw

MD MRCP

Dr. Shaw is a Consultant Neonatologist at the Liverpool and Fazakerley Maternity Hospitals. He has an interest in neonatal respiratory disease, and the follow up of neonatal problems, in particular, bronchopulmonary dysplasia.

Many children who undergo neonatal intensive care are at risk of developing a wheeze and cough in later life. The majority of these children, because they don't have severe respiratory abnormalities, are usually treated by General Practitioners and occasionally be Paediatricians. There is a group of children however, who have prolonged oxygen dependency. This group we would term as having Bronchopulmonary Dysplasia or chronic lung disease. These children we follow up much more closely because they tend to be discharged on oxygen therapy. They are at high risk of other problems because of their very low birth weight. This latter group will be the concern of this lecture.

Bronchopulmonary Dysplasia was first described in 1967 by Northway and his colleagues in the United States. He described pathological and radiological abnormalities in a group of babies. In the very early days of neonatal ventilation in 1967 most babies who required ventilation by today's standards died, and practitioners were really experimenting with neonatal ventilation. Northway looked at 32 patients who had Respiratory Distress Syndrome. Only nine of those survived longer than 28 days, despite being ventilated (five later died). Northway and his colleagues looked at X-rays and post-mortem changes and correlated these. There was a lot of post-mortem material to look at, as most of these babies died. They described four stages of disease.

Stage One was Respiratory Distress Syndrome. There were two intermediate stages and the Stage Four of the disease that they described, occurred after 28 days of the babies requiring ventilation and extra oxygen. This stage Northway and colleagues called Bronchopulmonary Dysplasia. The radiological appearance of streaky changes in the upper lobes correlated very strongly with a pathological appearance of fibrosis. These children were getting very severe pulmonary fibrosis at this stage of the disease. As more cases of Bronchopulmonary Dysplasia were recognised and as more babies were ventilated and survived, a definition evolved.

Definition

Dependency on supplementary oxygen beyond 28 days in an infant with an abnormal chest radiograph at 28 days.

Also : time of IPPV
: clinical features
: blood gases
: chest radiograph appearance
: number of days of O_2 (28 days vs 36 weeks)

It is defined as a dependency on supplemental oxygen beyond 28 days in an infant with an abnormal chest radiograph at 28 days. Other factors can be added to the definition, for example the length of time that they require intermittent positive pressure ventilation, clinical features or blood gas criteria. Chest radiograph appearances sometimes alter the definition. Some people do not like defining BPD as 28 days of oxygen dependency but rather 36 post-conceptional weeks of oxygen dependency. Therefore, if the child is born at 24 weeks it would have to have to live on oxygen for 12 weeks to fulfil the definition, whereas if the child is born at 30 weeks it would only have to live for six weeks on oxygen. This definition tends to pick out the more high risk group of babies who are at risk of problems later on.

Different chest X-ray appearances are now recognised, and have divided BPD into Type 1 and Type 2. Type 1 is associated with a better prognosis

and less severe X-ray appearance. Type 1 BPD shows diffusive pacification. This is probably more related to lung fluid and the alveoli being filled up with fluid and secretions than fibrosis. Type 2 BPD is the appearance of streaky pacification and scattered cysts with areas of hyper inflation at the lower lobes. So different X-ray appearances are now recognised.

Over the last 25 years this disease has increased in incidence dramatically. Considering the percentage of ventilated infants born with a birth weight under 2000 grams, who developed BPD at the Liverpool Maternity Hospital over the decade from 1980 to 1989, there has been an increase in incidence of chronic lung disease of BPD from around about ten per cent of this high risk group to around 40 per cent of this group. The major reason for this is the fact that many more babies within this high risk group are surviving. We are now seeing the consequences of survival and are exchanging death for disability.

CLINICAL FEATURES

The clinical features of Bronchopulmonary Dysplasia or chronic lung disease are:

Tachypnoea
Recession
Crackles in chest
Hypercapnoea
0_2 dependent
Abnormal chest radiograph

What is the cause of Bronchopulmonary Dysplasia?

Many people are now looking very seriously to find the cause of Bronchopulmonary Dysplasia and to prevent the disease occurring. The common denominator in babies that have BPD is low birth weight and low gestation. At gestation of under 27-28 weeks a very high percentage develop BPD. Many babies of 23 weeks gestation die before they get to 28 days. So a very high percentage of low gestation babies will develop this chronic lung disease. Bronchopulmonary Dysplasia is extremely rare in infants weighing over 2000 grams and is relatively common in babies under 1000 grams, reaching up to around 30-40 per cent.

Aetiology

Predisposing factors which may be associated with the development of chronic lung disease or BPD have been identified. They can be divided into damaging factors, and factors which would be protective if they were present in babies.

Factors

DAMAGING:-	PROTECTIVE (NUTRITION):-
Barotrauma	**Undernourished when acutely ill**
0_2 toxicity	**Poor response to infection**
Lung fluid	**Impaired lung growth + repair**
Infection	**Deficiency in : enzymes (SOD)**
Lipid	**: cofactors (Cu, Se)**
	: vitamins (A,E,C)
Reflux	
Genetic	

Barotrauma relates to the pressures used in the ventilator which directly damage the lung and cause scarring. Oxygen is directly toxic to lung particularly the pre-term infant's lung. Increased lung fluid may make the baby require higher ventilatory pressures, which in turn may mean that the baby gets more damage to the lung. Infection, particularly with organisms commonly found in the birth canal of most women of child bearing age, may predispose to the development of this lung disease. There has been a question as to whether giving introlipid early on in babies on neonatal units makes things worse. That is fairly debatable at the moment. Reflux is extremely common in pre-term infants, even when they are intubated. Cuffed tubes are not normally used, so gastric contents can spill over into the lungs. That is likely to add to the problems in children with chronic lung disease. It has been suggested that there may be a genetic pre-disposition in that mothers who have a family history of atrophy or asthma are more likely to produce premature babies who have Bronchopulmonary Dysplasia.

Low birth weight pre-term infants lack a number of protective factors, which we all possess, which make these damaging factors more likely to cause problems. Pre-term infants are undernourished when they are acutely ill and therefore have a very poor response to infection. So infections are more likely to cause damage to these children. Undernourished pre-term infants have impaired lung growth and repair. Specific deficiency in nutrients and enzymes may actually make things worse in terms of lung repair. Certain enzymes, anti-oxygen enzymes and a variety of other things protect against oxygen mediated lung damage, and in the pre-term infant the levels of these enzymes are very low. Oxygen toxicity, therefore, is more likely in the pre-term infant. Co-factors for these enzymes such as copper and selenium are deficient in pre-term infants.

Vitamins A, E and C, are possibly deficient in pre-term infants. Vitamin A, might be particularly important. In the Third World vitamin A has been shown to reduce mortality from respiratory infections. Vitamin A not only protects against lung damage, it also modulates lung growth and development. If children are deficient in Vitamin A they tend to grow rather dysplastic abnormal lungs in response to damage.

Thus the aetiology is multi-factorial. Anything we try to do to prevent this disease has to address all these factors. The bottom line is, if we can stop pre-term infants being born we will stop BPD occurring.

Acute Management of BPD/CLD

Oxygen/ventilation
Diuretics
Xanthines
Steroids
Bronchodilators
Nutrition

The acute management of BPD will not be described in detail but the above list provides a picture of the treatments these babies endure in the neo-natal unit, before they reach home. They require oxygen, they require ventilation, they often receive diuretic therapy, they often receive aminophylline to improve their breathing. They are often put on a course of steroids. Sometimes they will be tried on bronchodilators, although there is not a great deal of evidence that their use early on is that effective. Many different strategies are thrown at them to try and improve their nutrition, including TPN (total parenteral nutrition), tube feeding and various calorie supplements.

Outcome

In the study that we did at Liverpool Maternity Hospital over the last decade, that is up to 1990, we found 242 infants with BPD by the definition we have discussed. Of these children 18 per cent of them died in hospital of respiratory failure. Five per cent died at home, and they tended to be born earlier in the study period, between 1980-1985. Probably they were borderline hypoxic or sent home a little early when they were still hypoxic. They also died of respiratory causes. However, over 75 per cent made it home and did not die. We found that if babies were on oxygen for longer than three months their mortality was over a third.

242 Infants
43 (18 per cent) died in hospital
12 (5 per cent) died at home
If on O_2 > 3 months 34 per cent mortality

We are now sending many babies home, discharged on oxygen therapy. Potentially this could be an enormous imposition for the parents. Considerable preparation is therefore necessary before these children go home. In Merseyside we have a clinical nurse specialist who co-ordinates this preparation. She works mainly in the central Liverpool hospitals and sometimes at the more peripheral hospitals. Parents are taught how to use the oxygen equipment. We teach them resuscitation. We have a comprehensive information book on home oxygen therapy which explains all the things that might go wrong and provides contact numbers for parents. We make follow-up arrangements both in the community and at my clinic at Alder Hey, where I see many babies in the region with chronic lung disease. We inform the GP and the nurse specialist. It is essential that the GPs are well informed because they have to prescribe the oxygen concentrators. Most GPs are quite willing to do this.

These children may go home with the following equipment: oxygen cylinders, flow meters for the oxygen, nebulisers and sometimes humidifiers. Babies sometimes go home with an apnoea alarm although they are probably more trouble than they are worth. There is no evidence they make any difference in terms of outcome. If there are a lot of secretions children may have suction machines. Occasionally, more so

in the last year or so, it has been necessary to send children home with feeding tubes and feeding pumps. We try to avoid sending babies home with both oxygen equipment and feeding equipment. It is a lot for the parents to cope with. Inherent in all this is the training. Parents are trained in resuscitation, oxygen administration, use of the gastric tube, use of the suction catheter and humidifier. Occasionally we have had children with tracheotomies and occasionally we have had a child with a broviac tube.

Follow Up

The follow up of these children is very much multi-disciplinary. Many people are involved in the clinic; myself, the nurse specialists, the dietician, the social worker and often our neurological colleagues are involved and ophthalmologists, ENT surgeons and the general practitioners and community staff.

Ophthalmology	- **R.O.P.**
E.N.T.	- **tracheotomy**
Surgical	- **hernia**
	- **reflux**
G.P.	- **acute illness**
Community Child Health	- **screening**
	- **special needs**

In terms of respiratory follow up, the main aim is to prevent hypoxia. Improving oxygenation will reduce calorie consumption, which in turn will make the child grow. Improving oxygenation will also minimise the risk of pulmonary hypertension. If a baby is hypoxic the pulmonary vessels will slowly close off and will become very twitchy. They may become so twitchy that they close off completely and the baby will have a hypoxic pulmonary hypertension crisis, which can be fatal. We try to avoid pulmonary hypertension by prescribing oxygen.

For home use, in Liverpool and Merseyside we tend to use oxygen concentrate, which is a box about the size of a TV, which concentrates oxygen from the atmosphere and is given to the child through a seven foot length of tubing, via a low-flow meter. Some places provide a variety of other equipment as well as this at home, including saturation monitors, apnoea monitors and so on. I try not to provide this equipment, firstly because it makes no difference to the outcome, and secondly parents end up as nervous wrecks with a whole range of monitors by the child's bed and sitting up all night watching. It is not good for family life and normalising the child. Saturation monitors particularly, are notorious for giving false readings and not being attached correctly. Oxygen is given from 0.05 litres a minute to one litre a minute and that can provide up to 35 per cent inspired oxygen concentration. No more than that can be given to the child. If a child needs 40 per cent or 50 per cent oxygen because of an acute respiratory illness or because they are in the neonatal unit, they cannot go home with nasal oxygen. We use nasal spectacles or a single nasal canula. We keep oxygen saturation at least 93 per cent.

The children "grow out" of oxygen. We don't wean them out. It is a big mistake to start weaning babies out of oxygen - try them out for hours and "if he goes a bit blue put him back in". That is wrong, because you are predisposing the child to develop pulmonary hypertension. The baby is being allowed to develop a bit of pulmonary hypertension and is then put back in oxygen. They need to grow out of it. As their lungs grow and as they grow, their oxygen requirement will become less. Eventually the child is taken out of oxygen for a few hours a day, then all day and then eventually all night, following overnight saturation study.

As well as the oxygen concentrator a portable cylinder is provided. It is heavy, just portable, and can be put on the bottom of a pram connected with some tubing to the child. A micro controller allows the flow of oxygen to be adjusted to anything from a litre a minute to 0.01 litres per minute, depending on the child's requirement. This allows the child to be taken to the shops or for days out. It also allows them to come to clinic. If the child is in two litres a minute, the cylinder may only last a few hours, whereas if the child is in 0.01 litre a minute the oxygen will last for longer.

When these children are monitored overnight, to see whether they require oxygen, a computer programme is plugged into the back of the oximeter after the monitoring session. This indicates whether the child has been de-saturating or whether the child is well saturated, in terms of oxygen at night. A child may be hypoxic without appearing blue or distressed. On the basis of the computer data a child's oxygen can be continued if necessary. The whole process would be repeated in a month or two, when the child had grown a little more.

Infections

These children are prone to respiratory infections and have recurrent hospital admissions because of this. We have a low threshold for treating them with antibiotics, although the vast majority are probably viral infections. General practitioners are encouraged to treat them with antibiotics if they have a chest infection and are encouraged to send the children to us for review fairly readily. There is no proven place for giving prophylactic antibiotic to prevent respiratory infections in these children. In Cystic Fibrosis it is fairly well recognised that prophylactic antibiotics are useful, but there is no recognised place in these children for prophylactic antibiotics. However, I have used prophylactic antibiotics in a handful of children who have had recurrent infections on an empirical basis. In two or three cases they seem to have improved. I cannot prove whether that is a good or bad strategy.

Anti-viral therapy is important in these children. Often these children will get bronchiolitis in their first winter at home. They are a high risk group whose lung function is very much on the borderline and if they get bronchiolitis it will really tip them over the edge. Ribovirin, which is an expensive anti-viral therapy, is used for the treatment of bronchiolitis with BPD. The hospital had twenty children with RSV positive

bronchiolitis last year; we used Ribovirin on twenty occasions. It is necessary to stress to the parents that immunisations are vital. Neurological abnormalities are not an absolute contra-indication to immunisation. The respiratory consequences of getting pertussis or measles in these children can be fatal. Immunisation is very important. The 'flu epidemics also constitute a high risk for this group and we readily immunise them against 'flu.

Their major chest problems as they get older are not infections. They grow out of the propensity for chest infections in the first couple of years. They usually grow out of their oxygen requirement in the first two or three years but they are left with a predilection for developing airway obstruction, very much like asthma. If they get wheezy we treat these children as if they have asthma, even from the age of six months onwards. For a child without BPD who is wheezy at six months, it is very debatable whether bronchiodilatory steroids are particularly effective or should be used. But in these children we tend to have a much lower threshold for treating with bronchial dilators and steroids. We use the national asthma guidelines in the absence of any clinical trials which have looked specifically at these children.

Airway Obstructions

Treat as "asthma"
Ipratropium
B_2 agonists
Inhaled steroids
Short courses of oral steroids - if acutely ill

Use inhaler device appropriate for age
(e.g. spacer with mask but often nebuliser)

Often these children on inhaled steroids are under the age of two and a spacing device such as a nebuhaler with an attached mask is used. Many of my patients are on nebulisers. Although dose for dose a nebuhaler and a nebuliser should provide the same amount of drug, the actual technique of giving a nebuhaler seems to be forgotten quite quickly by parents once they get home, whereas a nebuliser is fairly easy to stick on a child's face.

Nutrition

Nutrition is important. Nutrition improves lung growth and reduces oxygen requirement. A dietician is involved in our clinic. Our dietician gives advice on general nutrition and also on weaning. Weaning advice for these children is not provided in the community, so our dietician has taken over the role of giving weaning advice. Extra calories may be added into the child's diet if they are not growing adequately or they are getting many infections. The dietician also gives advice regarding feeding problems. The feeding problems that we see in Bronchopulmonary Dysplasia may well be related to neurological disfunction, associated with Cerebral Palsy. If that is the case our neurological colleagues become involved. However, many of our children have developmental feeding

problems. They have an aversion to taking solids and seem not to like anything put near their mouth. This seems to occur particularly with the parents, and other carers can actually feed them. This is seemingly a psychosomatic illness. They have spent a long time with plastic tubes down their throats, being ventilated in an abnormal situation, lying in a neonatal intensive care unit. They have missed out their developmental window for learning to feed. They then develop developmental or aversional feeding difficulties. We have had one or two children that even at the age of four, have only just started taking solids.

Gastro oesophageal reflux and vomiting occurs quite commonly in up to twenty to thirty per cent of children. We treat those with medical means. Occasionally we have to use gastrostomy feeds, if these developmental and neurological feeding problems are severe.

Neurological Difficulties

In children with BPD there is a high incidence of co-existing Cerebral Palsy. Hearing problems may occur, because these children are very pre-term. ROP may pre-dispose to visual problems and these children might have developmental delay. Northway, who originally described this disease, found, in a medium term follow-up of these children, that 34 per cent, had some neurological deficit. Other workers have reported anything up to 90 per cent having neurological deficit.

Three studies illustrate the neurological abnormalities that can be found in children with BPD.

A study from Missouri looked at 37 children and followed them up to the age of five years. The study found that five had a progressive neurological deficit with seizures and deterioration and most of these children actually died. They suggested that there was a separate syndrome, a progressive neurological syndrome associated with BPD. No-one else has described that. I suspect that they were very poorly, asphyxiated, hypoxic babies with intractable epilepsy and bad cerebral palsy and that their neurological dysfunction was not progressive. It resulted in them getting poorlier and dying. Nine out of the 37 children had a non-progressive neurological abnormality (hemi-paresis, quadra-paresis, diplegia). The vast majority of those were associated with intraventricular haemorrhage. Intraventricular haemorrhage is a problem of pre-term infants, not a problem of BPD so the neurological deficit appears to be more coincidental than associated with chest disease.

California 1987
21/50 feeding problems (neuro 7, aversion 5, reflux 9)
17/50 neurological

14	**CP**
5	**hydrocephalus**
10	**blind**
11	**hearing**
23	**abnormal development**

Factors: **air leak**
IVH
hospital days

Another study from California looked more deeply into some of the neurological abnormalities; they found out of 50 children that 21 had feeding problems. Interestingly seven due to neurological problems, five due to aversion problems and nine of them had reflux. Thirty-four per cent, that is 17 out of 50, had neurological problems, 14 of these had CP, five had hydrocephalus, with shunt, 10 were blind, 11 had hearing problems and 23 had abnormal development. Many of these children had multiples of these conditions. The factors that they detected as being associated with these neurological or developmental problems were air leak, intraventricular haemorrhage (the strongest predictor of these problems) and the number of days spent in hospital. Having Bronchopulmonary Dysplasia itself was not related to these neurological disabilities.

In 1989 another abnormality was described from Missouri. This work described a movement disorder in children with Bronchopulmonary Dysplasia.

Missouri 1989
Movement disorders
Distal limbs, neck, trunk, mouth
Increased with respiratory failure, decreased with sleep
Extra pyramidal (?hypoxia, basal ganglia)
May improve
Clonazepam improves

They described only a handful of cases. The movements affected the distal limbs, the neck, the trunk and the mouth. These movements were increased when the baby went into respiratory failure and seemed to disappear in sleep. They described athetoid movements and postulated that this was due to hypoxia of the basal ganglia and they also felt that the condition improved as time went on. Interestingly they tried using Clonazepam, which is an anti-convulsant, in a couple of children and found dramatic improvement. This movement is only just being recognised. I do not know of any other studies which have found it elsewhere. It is something to look out for in your patients. It is something I certainly look out for. I have not seen this overtly, in any of my patients.

Socially these children may have problems. They are eligible for disability living allowance. In certain areas it may be up to the physiotherapists to tell the parents they are eligible for this support. We try and get them a telephone and pay for their transport to and from hospital. There are self-help groups, both national and local.

Outcome

What about the outcome of these children? We had a look at 42 children who had a reading age of nine, following Bronchopulmonary Dysplasia and we found that there is a very high evidence of them having phlegm with cold, wheezing and having effort intolerance, compared with a control group. Asthma had been diagnosed in half of those children that were wheezy, compared with the control group.

Incidence of Respiratory Symptoms in CLD and Control Group

	CLD	Control	pValue
n	42	24	-
Cough	16(385)	6(25%)	NS
Phlegm with cold	30(71%)	9(38%)	<0.01
Ever Wheezy	28(67%)	9(38%)	<0.05
Wheezy in last 12 months	24(57%)	6(35%)	-
Asthma diagnosed	19(45%)	4(17%)	-
Current treatment	10(25%)	2(8%)	-
Effort tolerance	15(35%)	2(8%)	<0.01

Northway has followed up these children and looked at them in their mid-teens and early twenties and looked at 26 children, together with a control group.

Northway n = 26 and controls
Age 15-21 years
↑ Wheeze + exercise intolerance
Shorter and lighter
Subtle X-ray changes
No RVH
↓ FEV, (1/4 fixed)
↑ RV
↑ Airway reactivity
TCO normal

Northway found that there is a much higher incidence of wheeze and effort intolerance, just as we found; that these children are shorter and lighter and that they still have subtle X-ray changes on the chest. There is no evidence of ventricular failure. They found the pulmonary function tests on these children showed that many of them had a low FEV 1, forced expiratory volume in one second, which is related to airways obstruction and a quarter of those that had a low FEV 1 did not reverse when they were given bronchial dilators. That is worrying and might indicate a fixed respiratory abnormality. Residual volume is a reflection of air trapping and that was increased. Airways hyper re-activity which overlaps with the propensity to develop asthma was increased, but Gas transfer (oxygenation) was normal.

Summary

The respiratory outcome of Bronchopulmonary Dysplasia is that mortality now is rare after discharge. These children can be oxygen dependent for one to two years. They often get infections, particularly bronchiolitis, under the age of one. After that they develop episodes of airway obstruction, from the age of one upwards. Obviously the long term outlook of these children is unclear, especially if they start smoking, or if they are subject to passive smoking. We don't know whether their lung infection will decline very quickly in their mid-twenties or thirties. It is necessary to do long term follow up studies to look at that.

I have discussed the respiratory abnormalities of Bronchopulmonary Dysplasia and given some insight into neurological difficulties and some of the difficulties that as physiotherapists you may come across.

RESPIRATORY PROBLEMS IN DISABLED CHILDREN

Dr. Helen Lewis

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Dr. Lewis qualified in 1971 from Oxford University. She was trained in Developmental Neurology at the Newcomen Centre, Guy's Hospital and then at the Royal Manchester Children's Hospital. Since 1983 she has been Consultant Paediatrician at Trafford General Hospital where she takes a special interest in children with disabilities.

Lower respiratory tract infections are the most common cause of death in children with severe disability whilst asthma affects 10 - 15% of normal children.

The contributory factors to respiratory problems in disabled children may result from hypotonia or hypertonia of the respiratory muscles, restriction of chest wall due to such problems as kyphosis or scoliosis, poor co-ordination of the chew, swallow and cough pattern or to gastro-oesophageal reflux.

Further difficulties may result from the inactivity of the disabled child or through inappropriate posture. Poor nutrition may lead to the risk of increased infection for a child with inadequate resistance and their inability to inhale and/or blow can result in poor breath control.

Many disabled children have feeding problems and to understand these difficulties it is first necessary to explore the physiology of normal swallowing. The purpose of swallowing is to propel food from the mouth into the stomach whilst protecting the airways against aspiration. A normal and co-ordinate nervous system is essential in order to achieve this process.

Mechanism of normal swallowing consists of various phases -

1 Oral preparatory or bolus formation
2 Oral when the bolus is propelled backwards
3 Pharyngeal
4 Oesophageal where peristalsis occurs
5 Relaxed lower oesophageal sphincter
6 Food enters the stomach

The first two, the oral phases, are of a voluntary nature but the following are reflex.

The child with cerebral palsy does not have an intact nervous system and many problems may occur with the normal swallowing process.

Problems occurring with swallowing in the Cerebral Palsied child.

* Respiration is not co-ordinate with swallowing
* Primary reflexes persist
* Swallow reflex is either delayed or absent
* Poor oesophageal peristalsis which may lead to reflux
* The diaphragm is inefficient in preventing the reflux
* Learned adverse behaviour

The retention of the primary reflexes can result in many problems. A persistence of the ATNR, extensor thrust and startle reflex can affect the posture and thus oral control and swallowing. Retention of the sucking and bite reflexes causes sever restrictions to the establishment of a normal feeding pattern, whilst a retained rooting reflex can inhibit the child's ability to get its head into the midline. Abnormal cough and gag responses can further add to the problems experienced when feeding a disabled child. Many children are hypersensitive to food in their mouth and react

adversely when touched around the mouth area and this with their inability to suck and swallow in the correct sequence can lead to possible aspiration during feeding.

Aspiration of milk can result in inflammation of the alveoli and laryngeal aspiration can cause apnoea. Children who experience recurrent aspirations may get pneumonia, interstitial fibrosis, bronchiectasis or obstructive bronchitis.

Assessment

When undertaking a neurological or speech therapy assessment there are various features to look for -

* Orofacial movements
* Hypersensitivity of the mouth and tongue
* Tongue movements and tongue thrust
* Cranial nerve function
* Dyskinesia/dystonia
* Hypotonia
* Involuntary movements
* Gag or cough reflex

It is also preferable to carry out various investigations; lung function test, chest x-rays, pulse oximetry, video fluoroscopy, oesophageal PH [for reflux], oesophagoscopy.

The latter two being particularly important when considering the possibility of a child requiring gastrostomy feeding.

Audit

An audit had been carried out on 50 patients aged between 2 - 19 years whose diagnoses were as follows;

23 spastic quadriplegia
4 spastic diplegia
9 severely mentally retarded
4 ataxic
3 paraplegia
1 hemiplegia
5 others

Of these 50 patients, 9 walked independently, 7 with assistance and of the remaining some could stand and others were completely unable to stand.

17 of the children had chest problems and on evaluation of the data related to these children, the results were as follows -

13 aspirated
3 had asthma
6 had scoliosis

27 of the 50 patients had problems with feeding and swallowing, and of those 27, 13 had feeding difficulties but no chest problems.

Symptoms of Aspiration

Symptoms of aspiration during or after feeding; coughing, choking stridor or wheezing except if the cough reflex is poorly developed.

Treatment

On looking at the treatment of children with feeding difficulties it is important to ensure that feeding is done safely and efficiently, in order to improve their nutritional intake and to protect the airways against aspiration.

It is possible through therapeutic intervention to instigate good feeding techniques and to assess the child's diet and modify as required; to investigate the possibilities of treating reflux through medication, such as gaviscon or cisapride. The physiotherapist should be involved to advise on correct posture and seating to enable a good feeding position to be established.

Specific respiratory treatment may be required when medication such as oral or nebulised salbutenol, long term antibiotics, cimetidine, gaviscon or cisapride may be used. Chest physiotherapy is also carried out on a regular basis, the frequency depending on each child's individual requirements.

PAEDIATRIC NEUROSURGERY

Dr. Paul L. May
MBBS FRCS

Dr. May is Consultant Paediatric Neurosurgeon at The Walton Centre for Neurology and Neurosurgery and the Royal Liverpool Children's Hospital. He is also Honorary Clinical Lecturer in Neurosurgery at the University of Liverpool. His research interests include Hydrocephalus, Neuroendoscopy, Paediatric tumours and Epilepsy Surgery.

The following notes were taken from Dr. May's lecture.

Conditions which may require Neurosurgery:

1. Spinal Dysraphism
2. Hydrosyringomyelia & Chiari Malformation
3. Encephalocoele (Cranium Bifidum)
4. Arachnoid Cysts
5. Hydrocephalus
6. Vascular Disorders
7. Neoplasms - paediatric brain tumours
8. Spinal Disorders
9. Epilepsy
10. Cerebral Palsy - surgery for spasticity

Congenital Disorders:

Craniostenosis

Spinal Dysraphism

Variations of Spina Bifida i) Cranio Bifida may result in extrusion of sacs containing frontal lobes. ii) Classic Myelomeningecoele (aperta). 10 years ago - 40 cases per year. At present 4 - 5 cases per year

Variations of Spina Bifida: cutaneous lesion - neurocutaneous 'signature' may have complication of cord 'tethering' in old surgical repair. As child becomes older this results in deterioration of gait, incontinence, scoliosis. Needs surgery to free cord.

Non Accidental Injury

5000 cases per year in UK, 500 of which are fatal. Many related to brain injury. 25% of survivors are abused again. 10 - 15 cases a year at Alder Hey, majority are head injuries. X ray shows egg shell appearance, multifragmented, linear fractures. Babies under 6 months may have transluminated lump on head. Penetrating injuries may be caused as child runs with pencil and falls on it. Child may appear well at first with small laceration. May develop severe epilepsy even after fragments removed.

Surgical treatment of Epilepsy

Preconditions: intractable epilepsy with unacceptable character and identifiable focus. Should be done early to avoid emotional problems especially in teenage years but most surgery done in young adults. 1 - 2 per 100,000 of population have epilepsy but only 100 resective procedures done per year in UK. Surgical approaches - excision of focus by topectomy, lobectomy or hemispherectomy or control of spread by resecting corpus callosum which improves quality but does not cure. Majority of resections are temporal for complex partial seizures - with EEG showing focus/atrophy in temporal lobe. In Toronto resection is done under GA to preserve speech areas.

Hemispherectomy - Providing thalamus is left intact child has the same level of motor function as before (only done in children with severe epilepsy, often with hemiparesis). Result of all hemispherectomies for epilepsy: 80% have complete/significant reduction of fits, 5% morbidity rate ie weakness or hemiparesis of one side, and 1% mortality.

Diastomylomyelia - boney spur - the dural sac can split when the spinal cord is pulled over spur as child grows. Traction to cord can be prevented with surgery.

Hydrocephalus:

Intraventricular haemorrhage of prematurity is now most common cause. 200 shunts fitted per year at Alder Hey. Shunt is diversionary procedure of CSF to abdomen, heart, lungs, bladder or lumbar spine. Complications include infection, obstruction, perforation, peritonitis, erosion of shunt tubing. 3000 shunts put in in UK per year - some (eg. orbis signaller) cost £1000 each.

Neuroendoscopy - enables precise surgery to rectify for example non communicating ventricles (multiloculate). Possible to use laser, biopsy forceps - using TV monitor. Improves shunting procedures and can be used to remove small tumours.

Paediatric Tumours

Under 1 year most tumours will be supratentorial. Older children usually have posterior fossa tumours. MRI scans have revolutionised treatment but early chemotherapy often needed to shrink tumour before surgery.

Stereotacty can be used to localise tumour and obtain biopsy. Megavoltage chemotherapy may be used for difficult tumours (eg. pontine glioma) to kill all dividing cells in body after taking bone marrow sample. This is then used to reactivate healthy cells after treatment.

Adults may feel risk is worth taking even if fits infrequent depending on job and lifestyle. The need to have children, drive a car etc. Counselling very important, done by some postoperative patients cured of epilepsy.

Questions:

1. Why are reservoirs sometimes put in as well as a shunt?

A. Gives easy access to take CSF or measure pressure. Not always done as may increase risk of complications.

2. Is surgery for tethered cord in older patients successful?

A. Perfect result seldom achieved and depends on neurological deficit. Could make matters worse and may have 70% retethering rate. Prevention of problem depends on good primary procedure.

3. Why is there a decrease in incidence of Spina Bifida?

A. i) Selective termination

ii) General abortion rate up.

iii) Increase in periconceptual folic acid and better nutritional standards.

4. What is the cause of spontaneous intracerebral haemorrhage?

A. Commonest cause is malformation. Accidental incidence is 1-2%

5. What are the effects of removing one cerebral hemisphere?

A. In surgery for epilepsy neuropsychology is used to check which side is defective, putting one hemisphere 'to sleep' with sodium amytal while patient conscious and testing memory and cognitive skills etc. to check adequate function remains.

Nicola Thompson

Superintendent
Physiotherapist
Marjorie Crowe
Neuromuscular Centre
Guy's Hospital
London

Guy's hospital is one of the designated muscle centres of the Muscular Dystrophy Group of the United Kingdom. There are eight across the country. Nicola Thompson's post is funded by the dystrophy group. The post is part clinical and part research.

Aetiology

Duchenne Muscular Dystrophy is a progressive form of muscular dystrophy inherited through the "x" linked recessive gene and therefore confined to males.

The gene dilution was discovered in 1987 and as a result, pre-natal testing has been made more accurate. It is now possible, where there is a history of Duchenne Muscular Dystrophy, to perform a chorion muscle biopsy at 10 weeks gestation. This is an accurate method of determining whether a male foetus is affected or not. Prior to 1987 the sex of the foetus could be established but not whether it was affected. The parents choice of whether or not to terminate the pregnancy was taken in an unknown situation. This was not very acceptable.

One third of the cases of Duchenne Muscular Dystrophy are new mutations. It is therefore impossible to eradicate the condition totally.

The average age of diagnosis is three to four years. The principal clinical sign is muscle weakness which is greater proximally. The extensor groups being more affected than the flexor groups of muscles. This latter fact is important in our management. The most affected groups at around the age of three to four are the neck flexors and hip extensors.

Functionally the most common presenting features are abnormal gait, difficulty in climbing stairs and frequent falls.

About 50% of affected boys are delayed walkers (18 mths. being considered as the upper limit of average age for walking).

The classic Gower's manoeuvre is exhibited as a result of a proximal weakness mainly affecting the extensor groups. This is not a diagnostic feature in itself as other muscle conditions demonstrate it.

As time progresses the compensatory posture as a result of the pattern of weakness is observed i.e. equina varus position of the ankles, a wide base for extra stability due to pelvic girdle weakness, which leads in turn to iliotibial band contractures. A forward tilt of the pelvis with a compensatory lumbar lordosis results from the hip flexors being stronger than the extensors. As a result, at an average age of nine to ten, the boy will no longer be able to walk unless there is therapy intervention.

The clinical definition of Duchenne Muscular Dystrophy is that the boy is unable to walk beyond the age of thirteen. This contrasts with Becker-type Muscular Dystrophy where the boys walk after the age of sixteen. Once the boys are non-ambulant, contractures and scoliosis rapidly develop.

The disease is still incurable but not untreatable.

The most prominent feature is pseudo-hypertrophy of certain muscle groups, notably the posterior tibials, but the quadriceps are also affected and American literature reports the shoulder girdle - particularly the deltoid - affected too.

This pseudo-hypertrophy is a manifestation of the disease process. In a normal muscle biopsy a cross-section would show a very delicate connective tissue around the outside of each myofibril. In a biopsy of a typical six year old with DMD there are large areas of connective tissue and fatty tissue where muscle tissue should be, and darker areas where there are lots of nuclei. These areas are actually areas of degeneration where phagocytosis is taking place.

In the early stage the degeneration is replaced by normal regeneration but gradually that becomes abnormal.

Physical Management

The four main aims of physical management are:

1. To retard contracture progression.
2. To maintain muscle strength.
3. Prolong either standing or walking.
4. Ultimately to control scoliosis.

Measurement

As Virginia Bottomley keeps telling us "You can't manage it unless you can measure it" and muscular disease on that basis is one of the easiest conditions to manage as muscle weakness is easy to measure.

The tool used to measure muscle strength is a myometer. A simple instrument easily used in a clinical situation. The myometer is placed on standardized anatomical points and produces a digital reading that measures muscle power in Kg. of force. It is therefore more accurate than the Oxford or MRC scales which are rather subjective. It is possible to measure accurately, and thereby plot, the progression of the disease.

During a research project, 60 children were measured at 6 monthly intervals over a three year period. Measurements included walking time over short and long distances, myometer readings in conjunction with the Oxford scale, percentage MRC and the Hammersmith score of motor ability. In DMD the score goes down as height and weight of the child goes up.

This information is valuable for research purposes, to measure the effectiveness of clinical intervention, to plan clinical management and to compile an average for the progression of DMD. An average DMD boy will probably stop walking at about the age of nine or ten, and his percentage MRC score will be approximately 50% of normal.

Maintenance of muscle strength

The widely held view had been that working the muscles hard causes weakness. This theory has not been substantiated by animal experimentation with a muscular dystrophy mouse and has largely been dismissed. The theory was based on one case study of a family with fascio-scapular-humeral dystrophy. There have been a limited number

of studies in Duchenne boys. One of the best was done in the 1960's by Vineos who has a forefather of managing muscle disease in the USA. He treated 20 Duchenne boys with resisted strengthening routines daily for a period of a year, and then compared them with a control group. He demonstrated significant improvement in muscle strength but not in functional activity. (This probably needs to be repeated again, in light of better and more accurate ways of measuring muscle power and more developed techniques for assessing functional ability).

Results would appear to depend on the initial muscle power. If this is less than 50% of normal then there was little, if any, improvement in muscle strength. The general results, however, were better on the less progressive forms of muscular dystrophy.

Other methods include:

1. Electrical stimulation

   Doctor Scott, a physiotherapist, has shown that muscles subjected to low frequency stimulation are more resistant to fatigue. This is still very much in the experimental phase and she is currently looking into different frequencies and refining the frequencies.

2. Drugs

   There have been many drug trials over the years. The most promising have proved to be steroids. Prednisolone and Cyclosporin have been shown to have an improvement on muscle strength. However, weight gain is an undesirable side-effect which can then minimize any benefit by reducing functional activity. There are therefore, at the moment, trials into the use of pulsed steroids to be taken, for example, for 10 days at the beginning of each month to see if this will counteract the tendency for weight gain.

3. Myoblast Transfer

   Experiment with myoblast transfers in the 1970's demonstrated the uptake of normal muscle cells when transferred to dystrophic muscle.

   There has been renewed interest in this method since the discovery and location of the Duchenne gene. This has in itself caused controversy as human studies in the USA have proved unsuccessful.

4. Gene Therapy

   This seems the most exciting prospect. The vector used is a retro-virus, rather like a "flu virus". Amazing progress has been made on experiments on the muscular dystrophy mouse and need to be upgraded to the muscular dystrophy dog. We are looking at a definite possibility of treatment in the future.

   It is therefore essential that we, as physiotherapists, keep these children in the best possible physical condition.

Prevention and delay of contractures

Basic techniques of stretching and splinting, used rigorously and regularly, have proved effective. A study of 59 boys, all ambulant, fell naturally into three groups. The first complied with neither passive movements nor splinting, the second complied with passive movements only and the third with a combination of the two.

The combination of the two, i.e. a daily programme of passive stretching, which involved holding the joints in lengthened range for a slow count of 5 and each stretch repeated 20 times, and the use of AFO's for night use, proved to be most effective. It delayed the development of contractures and did have an effect on functional activity.

This group maintained independent ambulation for a longer period.

A similar study by Harris et al in the USA, looking at over 100 children came to the same conclusion.

As the children get older, the emphasis changes. Stretching of all muscle groups and joints becomes impractical. Priorities address scoliosis and hand function, as the hands contract into ulnar deviation with shortening of the long finger flexors.

Prolonging standing and walking

The wearing of AFO's should be confined to the night. Gait analysis of the normal child walking over a force platform generating a force vector shows that the line of force should pass very close to the ankle, knee and hip joints throughout the stance phase. At heel strike and partly through stance phase, the normal child slightly flexes the knee as a cushioning effect. The quadriceps action then prevents collapse into flexion.

The Duchenne child has very weak quads and in order to effect an efficient gait and to maintain the force vector within normal limits, the child has to adopt a toe stance. This has the effect of pushing the knee back without the use of the quads. To achieve this he has to adopt a dynamic equino-varus position of the foot. The use of AFO's for walking is therefore contra-indicated.

Irwing Seagle, an American Orthopaedic Surgeon, without the benefit of gait analysis, found that TA lengthening as an isolated procedure would not succeed if the quads were weak, unless accompanied by leg bracing.

Management when the child has difficulty walking

The options are:

1. To prolong walking with ischial weight-bearing callipers.
2. To prolong standing with a standing frame or swivel walker.
3. If preferred, to reject options 1 and 2, and to opt to be a "good sitter".

Walking

In order to prolong ambulation, the timing of intervention is important. There is no point in putting a child into callipers too soon. The optimum time is when the child can just stand, can walk only a few steps with difficulty and has not developed hip flexion contractures.

Ischial weight-bearing callipers were developed in the USA about 15 years ago and recently refined by Orthotist John Florence in this country.

They are polypropylene calipers with an ischial lip so that the child's trunk is supported by the lip. They are patella-tendon bearing (to spread the load) with a fixed rigid ankle. The caliper is cut back at the metatarsals so that the child can use his toes for gripping balance.

Walking sticks should not be used because it is important to sit into the ischial lip and not bring the weight forwards.

Percutaneous tendo-achilles release is often necessary, with immediate post-operative mobilization and prompt provision of orthoses (cast pre-operatively).

It has been found that ambulation can be prolonged for 2 years using these calipers. Wearing the calipers can also delay scoliosis, particularly if a child can be ambulant beyond 13 years. Weakness as well as growth is a factor in developing a scoliosis. These orthoses can enable a child to walk and maintain some muscle power as much as possible during their growth spurt.

Realistically only about 25% of boys actually walk after 13 years of age. The average age of loss of ambulation is about 10 years.

In a wheelchair a scoliosis can progress by three to six degrees per month. Prolonging ambulation therefore has much greater benefit than just maintaining the upright position. Other benefits are psychological, both to the child and parents, and to facilitate ease of activities of daily living.

Standing frames

The use of a standing frame delays lower limb contractures; ideally it should be used for 30 minutes twice a day. It is very important that contractures are corrected wherever possible rather than accommodated.

Swivel walkers

Variable Centre of Gravity Walkers were designed specifically for the DMD boy. The base plate has a variable centre of gravity which makes its use particularly easy for children with progressive weakness to manage. They have hand grips for shoulder stability and need very little momentum to swivel. It is important to watch that they are not swivelling into scoliosis.

Upright standers and swivel walkers are better than prone standers because the muscle weakness in the neck means that there would be difficulty in holding the head up. The correction of contractures in this position is more difficult.

Sitting

Once the boys have stopped walking or standing the management of scoliosis becomes of paramount importance. Scoliosis occurs in 98% of cases.

If a spinal orthosis is fitted, an x-ray must be taken to measure Cob's angle. A jacket that is not corrective is a waste of time (other than to keep the back warm!).

The problem with bracing is that it has the effect of reducing vital capacity by 30%. Reduction of vital capacity is proportionate to the degree of curvature. However this disadvantage is preferable to no action being

taken at all.

Nowadays prophylactic surgery is often the preferred method of managing a scoliosis. Luque (a South American) developed a method of spinal instrumentation when studying paralytic scoliosis in polio. Unlike Harrington rods, the Luque procedure wires individually at every vertebral level and the child cab be mobilized immediately post-operatively. Respiratory complications are therefore reduced.

There is a "window of opportunity" for the timing of spinal surgery. As age increases the respiratory muscles are affected and the child's vital capacity is reduced by 30%.

Two studies have looked at the effect on respiratory capacity in the long term. One showed improvement and one not.

Evidence, however, points to an improvement because the diaphragm has a better fulcrum from which to work. Repeated studies need to be made.

Prognosis

In 1987 when last reviewed, the mean age of death for a boy with DMD was 16.8 years. Duchenne, in 1860, dated the mean age as 15.5 years. Despite the vast resources into research and efforts into management there has been very little change in the life expectancy for these boys. There has however been enormous benefit to the quality of life.

Lin Wakely, Chairperson of N.W. Region Organising Committee, sitting on the tablecloth donated by the region to A.P.C.P. in celebration of our 21st birthday. Made by Wirral Patchwork and Quilting Association.

National Committee Members

Our Welcoming Hosts, North West Region Organising Committee

DEEP IN CONVERSATION

Past and present Chairmen, Ann Grimley and Jill Brownson.

Pat McCoy, Chairman of council, Dr. Peggy Griffiths, Hon. Member and Liz Lewis.

Going into dinner. What a shocking story!

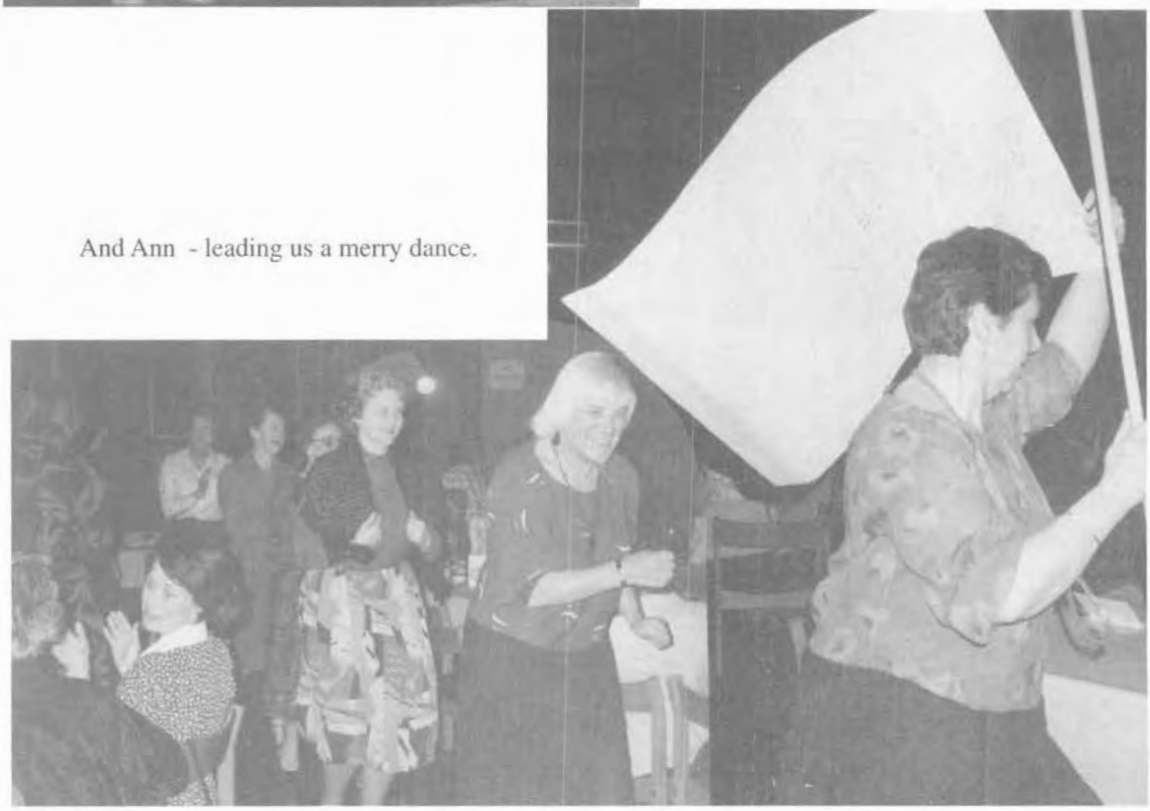
Members of National Committee, Jenny McKinlay, Rowenna Hughes, Carole Hurran.

The Top Table. Dr. Fleur Fisher, the after dinner speaker is seated on the extreme left.

A view of the conference dinner

Ian McKinlay holding the stage. As always willing to instruct a group (clutch, gaggle, stretch?) of physiotherapists.

And Ann - leading us a merry dance.



Mrs. Diane Giller
Barrier Free Co-ordinator
Wentworth High School,
Salford.

INTEGRATION A PERSONAL PERSPECTIVE

Mrs. Giller described her own journey into special education and her present post as 'Barrier Free Co-ordinator' in a Salford High School. The difficulties in the first year included the fact that the High School was still being upgraded and inaccessible. Six student for integration into year seven remained based at a Special Junior school 2 miles away. With the energetic help and support of the physiotherapist and occupational therapist many barriers were overcome and the High School now contains a physiotherapy room, disabled shower unit, 2 lifts, adapted kitchens and workbenches etc. The fourteen students (year 7 and 8) are now fully integrated with one teacher, 2 nursery nurses and a support worker.

Mr. William Wilson
BSc. Sc. (Hons) C.T.D.,
DASSpLD.
Acting Headteacher - Hearing
Impaired Services, S. Cheshire.

EDUCATING HEARING IMPAIRED/DEAF CHILDREN.

Mr. William Wilson described the difference between conductive hearing loss i.e. glue ear, and sensory neural loss as may be seen in C.P. Mr. Wilson described congenital hearing loss.

Slides of audiograms were shown;

0 - 25 Dec.	Normal
25 - 60 Dec.	Conductive
60 - 120 Dec.	Sensory
125 - 130 Dec.	Pain and Damage Zone

The deaf community have their own language and culture. Many do not want to become hearing people. They want to be accepted as a "community" in their own right, like ethnic minorities.

A video was shown of a deaf family with 4 children. Both parents were deaf as were three of the children. The adults were using British Sign Language (B.S.L.) but the children were using Sign Supported English, where mouth movements are used in conjunction with sign. The children learn to lip read and can integrate into mainstream school.

A convention was held in 1880 which insisted that signing must stop. Children were made to sit on their hands and learn to lip read. It has taken a long time to change this practice.

Deaf children are now educated in a mixture of Deaf Units, Mainstream Schools with support of the Teacher of the Deaf or in Special Schools. Manchester School for the Deaf will take children with multiple handicaps.

Aurythmics

Aurythmics is a system being developed where movement, vibration and sound are combined using large gymnastic balls and other inflatable equipment. The child "feels" the music through the equipment. This progresses to "Musical Mats" and other games where sound is used to stimulate a response of movement by the child. Aural stimulation and listening skills are very important when children are provided with hearing aids. They need to be taught to "listen" in order to obtain full

benefit from aids, especially if they have been in a silent world for some time.

Mr. Rod Thompson
M. ED. RMN, RGN, DIPAD ED
DIP. HV FP CERT.
Regional Organiser, Childrens Services
Mersey R.H.A.

IN THE BEST INTEREST OF THE CHILD

THE 1989 CHILDREN'S ACT - THREE YEARS ON.

A most interesting talk! Rod explained the background to the act, the need for child protection following some well publicised and tragic cases of abuse, ie. Jasmine Beckford, the Cleveland affair and others.

He reminded us that the Act was the most comprehensive piece of legislation that Parliament had enacted about children, replacing all previous legislation with a single coherent framework.

It applied to all children not just those "at risk" or "in need", for the first time including the right of disabled children to be treated in law as are other children in need.

Rod also explained the implications for the health service. There is now a duty on Health Authorities and Trusts to assist and co-operate more closely with social services in meeting the needs and providing the services to children.

The talk closed with questions from the audience concerning the lack of funding. This does and will adversely affect the level of provision for some necessary services both now and in the future.

Alison Skinner
BA MCSP HT Dip TP
Senior Lecturer
School of Physiotherapy,
Middlesex Hospital and U.C.L.

BAD RAGAZ TECHNIQUES

This is a method which utilises the properties of water and allows for normal anatomical and physiological functions of joints and muscles.

The techniques have some similarities and some differences to P.N.F. In fact they are often loosely termed P.N.F. in the pool.

Similarities

The techniques utilise functional patterns of movement.

Commands are short and sharp

Traction and approximation can be applied but they are more difficult than on land.

Differences

The resistance is not manual by the physiotherapist but is provided by the body moving through the water causing turbulence which results in a drag force opposing movement.

Water is an unstable medium and the patient is in free floating so stretch stimulus is not possible to facilitate a muscle contraction

Buoyancy

Buoyancy is used as a support not as a means of resistance to exercise. The patient is in side lying or lying or prone lying supported by floats round the neck and pelvis and if necessary on the limbs.

Isometric patterns

These are possible when the patient holds a position and the physiotherapist moves the patient in different directions through the water.

Isotonic patterns.

In these patterns the physiotherapist acts as a fixed point from which the patient moves towards or away. In some patterns both the physiotherapist and the patient move.

The resistance provided by the patterns is self regulating i.e. maximum resistance is regulated by the patient, the stronger the muscle work the greater the turbulence and the greater the resistance.

Resistance can be increased by:-

1. increasing the speed of the body through the water.
2. making the body less streamlined.
3. moving the manual hold distally
4. the point of fixation being moved in the direction of the movement.

Resistance can be decreased by:-

1. decreasing the speed of the body through the water.
2. making the body more streamlined.
3. moving the manual hold proximally.
4. movement of the point of fixation in the opposite direction to the movement.

Stephen Morris,

Head Coach from the Wingate Centre, Wrenbury Hall Drive, Wrenbury, Nantwich, Cheshire (Tel. 0270 780456).

GYMNASTICS FOR THE LEARNING DISABLED.

Stephen Morris' involvement started as an interested parent of a daughter with Downs Syndrome. He gained coaching qualifications for persons with special needs and is a recognised BAGA tutor.

Wingate Centre was established 10 years ago and has been housed in a new, fully equipped gym since 1992. It is the home of special needs gymnastics. Funded by charities, it is generating income by offering a wide range of services to all local users, but the main emphasis is on training the learning disabled. Gymnasts trained at Wingate have won many medals at world-wide competition, including Special Olympics.

We were shown videos of the top gymnasts in action. Both Greg and Georgina have Downs Syndrome. This has raised questions about the risks of C1/C2 vertebrae malformation and the answer is that any potential gymnasts at risk are examined by X-rays first. We were all very impressed by the level of achievement demonstrated by these gymnasts. We started to question if there are any limits at all. These seem to be:

1. strength
2. inability to come out of a movement safely
3. inability to plan a complicated manoeuvre.

The gymnasts do reach their peak after many years of training and it is important to develop their abilities sideways, into dancing, for example.

For the less able, including wheelchair users, there is a Special Needs Motor Activity Programme, where emphasis is on the following basic skills: Mobility, dexterity, striking, kicking, manual wheelchair skills,

electric wheelchair skills and floating in water. In the U.S.A. and in Ireland (Special Needs Olympics movement operates across the border over the whole of Ireland), the concept is used a lot more. In the U.K., special needs gymnastics is under B.A.G.A., which is the national governing body for gymnastics, in Newport, Shropshire. (Tel. 0952 677 137).

We came away knowing a lot more about the Special Olympics and truly impressed by the work going into the training of the special needs gymnasts as well as by their achievements.

Mrs. Philippa Hallam
MSc. MCSP
Research Assistant
Department of Child Health
Liverpool Maternity Hospital
Tel: 051 709 1000 Ext. 2362

INTERVENTION STUDIES AND PROBLEMS OF RESEARCH

Philippa worked as a clinical physiotherapist for 10 years. After completing her MSc. she took on the post of full time research assistant, which she has held for 5 years.

Two studies were briefly described.

The first study investigated the hypothesis that early intervention, in the form of advice on general positioning and care, for infants identified as having a high risk of developing CP has a positive effect in promoting motor development.

The second study - It was found that hand function was an area that shared greatest improvement in the group receiving early intervention.

It was decided to investigate the part hand function plays in overall development.

Randomised controlled trials were used.

3 tests of motor function used -

Griffiths
Movement Assessment of Infants (MAI)
Limb x Limb

Some results were significant and have been published.

Philippa provided basic advice on carrying out research.

1. Formulate hypothesis
2. Select appropriate experimental design
3. Facilitate experimentation
4. Analyse results
5. Draw conclusions
6. Discuss conclusions

Refs: 1. A comparison of 3 procedures to assess the motor ability of 12 month old infants with CP.

Hallam, Weindling, Klenka, Gregg & Rosenbloom. Dev. Med & Child Neuro 1993:35:602-607

2. Experimental Design & Statistics 2nd Ed. - Steve Miller 1984 Methuen & Co. London.

Useful Addresses.

Limb x Limb test :- O.R.C.D.P. Office, Level 3 Maternity Dept, John Radcliffe Hospital, Headington, Oxford. OX3 9DU

Movement Assessment of Infants:- L.S. Chandler, University of Washington, Rolling Bay, Washington, U.S.A.

Mr. Gordon McQuilton

SPECIAL SEATING FOR THE DISABLED.

Mr. McQuilton began by looking at the standard seating posture of 90° flexion at hips, knees and ankles. He explained the importance of obtaining a good symmetrical pelvic posture in this position by using a rampedseat cushion and sacral pad.

Mr. McQuilton talked of the difficulties involved in maintaining balanced trunk posture in upright sitting. He suggested that backward tilt-in-space of about 12° enabled trunk symmetry to be maintained more easily. However this was not best for function.

Once deformity was present in hips, pelvis and spine it should be accommodated and not ignored. Kyphosis was best accommodated for by a backward tilt of 10-15°.

He then examined the angle of hip flexion and said 135° of hip flexion was the preferred position for lumbar posture and ease of balance in sitting. This had lead him to design the saddle-type seats. Children function better in these seats because tone is reduced and the degree of disability is reduced.

He concluded by reminding us that we accentuate a child's disability when we put the child in poorly designed seating.

Mrs. Alison Harland

Teacher, St. Lukes School Humberside.

THE M.O.V.E. CURRICULUM

Mrs. Harland is an experienced teacher of children with profound multiple disabilities. She had attended one of Linda Bidabes workshops on the M.O.V.E. Curriculum and described how it had influenced her own class and school.

Mobility Opportunities Via Education or M.O.V.E., is a "top down" approach to functional movement for children with P.M.L.D. as opposed to the "bottom up" or developmental stages approach.

Children are provided with opportunities to achieve sitting, standing or walking using equipment which allows them to achieve independence or integration into the group.

The video demonstrating the development of M.O.V.E. (which is available from Rifton) was shown as well as a video demonstrating the achievement of one small child in Mrs. Harland's class.

Unfortunately there was no time for questions or discussion.

Sarah Dyer MSc. MCSP,
Therapist in charge,
Bobath Cymru, Cardiff.

CARING FOR THE CHILD WITH CEREBRAL PALSY - COMPARISONS OF PARENT'S AND THERAPIST'S PERCEPTIONS.

Introduction

Sarah is Head therapist at the Bobath Centre, Cymru. She was responsible for setting up the therapy services there.

Study and Questionnaire

- Involving the key therapist (either PT, OT or Speech and Language Therapist) and the parent/chief carer of the child.

The Study looked at three main areas:-

1. Our (the therapists') opinions and understanding of the problems of a C.P. child.
2. Our opinions and understanding of the parents' perceptions of caring for a C.P. child.
3. The parental perceptions of the problems and understanding in caring for a child with C.P.

In order to find out what the group's level of involvement with families was, Sarah asked about our commitment to home programmes.

Do parents carry them out?
Do parents direct the programmes in terms of goals etc.?
and if so, Do we carry out their wishes?
What is the level of parental compliance?

Previous studies have shown increased stress levels in parents caring for C.P. children (mothers more than fathers) but no direct increase in the more severely affected child. Also, more time is being spent in Physical care provision and less time for "self", family members and friends etc. Other studies comparing Downs Syndrome; normal children and C.P. children under five years have found C.P.s demand much more of mum's time. Therapists have made "caring" easier. Doctors often tend to overwhelm parents unintentionally with tasks, goals and info.
Sarah's research in questionnaire format was used part way through the treatment programme (2 weeks of daily treatment or 3 times a week for 3 weeks. ie. 10 or 12 days.).

Interview format - with parents or main carer.

1. What they see as child's level of functional ability.
2. Rating on scale of 1-4, their perceptions of the problems experienced in caring for the child.
3. For those problems, which 4 areas were most difficult?
   e.g. Sleep patterns, feeding, going to the toilet etc.

Also a questionnaire should be completed by the key therapist as to:

1. Their perception of the problems she thought the parents had.
2. Which specific areas of care were biggest problems
3. Which areas of care she thought would be most difficult.

Rating - 1 : No Problem
2 : Few Problems
3 : Difficult
4 : Major Problem

N.B. 89% of main carers were mothers.

Results

About 1/3 of the time, parents and therapists agreed on the difficulty. However there was a small trend for physiotherapists to underestimate the problem. (Bathing was often underestimated as being a problem) Mobility transfers were highlighted to be difficult by parents.

Conclusion

If parental participation is the aim of therapy then the therapists (at Bobath, Cymru) must change their assessment and interview procedures.

OUT OF THE MASSAGE PARLOUR

Dr. Fleur Fisher

is Head of the Medical Ethics, Science and Information Division of the B.M.A.

Dr. Fleur Fisher gave an interesting and amusing after dinner speech.

She reminded us of our early history and battle for acceptance. Letters to the Times warned of recognising a profession that could be linked with iniquitous "massage parlours". Astounding when we consider what pillars of respectability these early physiotherapists were!

Initially the techniques of holding, touch and massage were misunderstood and in more recent years they have been undervalued. Dr. Fisher stressed the value of learning from other cultures. When she worked as a Community Family Planning Officer she came to understand how Pakistani families in particular, used touch and stroking as a means of early bonding with babies and children. Dr. Fisher welcomed the fact that the wheel has turned full circle and the current swing is away from high-tech medical intervention towards a personal, "hands-on" and holistic approach. In these days of Management-Speak, it was most reassuring to hear Dr. Fisher state that the "hands-on" approach was a most valuable aspect of physiotherapy treatments, particularly with young children.

As Dr. Fisher moved into the Unit Manager role she spent time with a community physio. She travelled in an overcrowded car, happily squeezed between equipment and sweet papers. Astounded by the case load she quickly realised that the physio was trusted by the family and was the only person who offered hope and positive, practical advice about maximising potential to the family.

Physiotherapists have proven transverse networking skills that women use so successfully in their lives (compared to men who are acknowledged to network vertically.) It is this transverse networking that will be our professional strength in the future in view of current trends towards generic health professionals.

Dr. Fisher said that in these days of re-organisation and skill mix we must become political.

Fleur ended with amusing stories about her experiences of using the media. If you are informed and briefed the media can be your ally. As a professional we must not be afraid to use the media.

Editor

Anne Grimley MCSP
Miss Anne Grimley MCSP

Anne trained at Salford Royal School of Physiotherapy and qualified in 1955. In 1970 she became superintendent at The Royal Manchester Children's Hospital where she built up the Physiotherapy Department to be a local and regional centre of excellence. Anne was Chairman of APCP 1982-86 and is now an Honorary Member.

Her clinical specialities were "Clumsy Children" about which she wrote a book with Dr. I. McInlay.

I would like to thank the North West Regional organising Committee for inviting me to speak. I deem it an honour, bringing the wheel full circle, as with other colleagues in the North West, I helped organise the first ever national Conference for APCP in Salford. I would like to congratulate APCP for its growth, development, achievements and for the fulfilment of a dream.

I plan to define a Paediatric Chartered Physiotherapist by giving examples of the development of APCP, and in detailing this specialist clinical group, hope to show the relationships and interactions with other paediatric bodies, particularly the CSP - our parent body.

Being a member of the paediatric family, I also draw analogies between infant development and that of APCP.

Definition and characteristics

A paediatric physiotherapist is primarily a qualified, and in the UK, a chartered professional who, through gaining post graduate training and clinical experience, has become an acknowledged clinical specialist in the field of paediatrics.

From the beginning of our Association, it was stressed by the founder members that it was insufficient merely to work with children on a rotational basis. It was deemed essential to gain post graduate academic education along with clinical experience. We belong not only to our profession, but also are involved with the broader aspect of paediatrics. Essential requisites for any professional in paediatrics in addition to the basic qualifications, are knowledge of learning and personality disorders of children and the ensuing social and educational problems. This knowledge should be further strengthened by the development of personal interactional skills gained through membership of the varying care teams within the field of paediatrics.

History of the Association

In 1972, the NHS was reorganised which meant that Health Services took over the management of physiotherapists working in schools and community services, many of them single handed and part time. The possibility of imposition of stringent conditions of service and a consequent dilution of children's services caused considerable anxiety which drew similarly placed physiotherapists in the West Midland region together, namely Ann Marks, Denise Woods and Mary Hazlewood.

After a meeting in the West Midlands in December 1973, to which 30 people came, an open invitation was extended for other physiotherapists to attend a meeting at Great Ormond Street Hospital for Children in February 1973. 75 people attended, a steering committee was elected. A Constitution was drawn up and an Education Working Group formed.

The pace initially was terrific. We owe a tremendous debt to Moyna Gilbertson for this, through her acumen, contacts and ability to crack whips! Without her as our first Chairman we would not have shown such positive progress.

Within 12 months the Education Working Group was meeting regularly to determine a curriculum to meet post training needs. The membership of this group consisted of Professor Kenneth Holt, Dr. Lewis Rosenbloom, Dr. Gordon Malcrow, Miss Pat Waddington, Moyna Gilbertson, Mary Hazlewood and myself.

A Public Relations Officer maintained regional networking and a member's register - thanks to Felicity Birkett and Maureen Hutchinson.

A quarterly newsletter was in circulation. A questionnaire had been sent out to the membership regarding training needs. The Logo and letter headings were designed, thanks to Ann Mark and family.

A draft constitution was drawn up and presented to the membership at the first AGM in Salford in 1974.

At this AGM, no minutes were taken and the steering committee was re-elected 'en bloc'. Regional committees were formed after this meeting.

The first National Committee elections were held at the 1976 AGM and the tradition began of electing Honorary Officers from among the members of that committee.

London and Salford respectively held a series of evening schools. Paediatric colleagues in other disciplines demonstrated their support by helping with the design and delivery of these schools which the memberships assiduously attended.

We could not say we had been born until the CSP had formally accepted the constitution, but we were known to be a spirited and tenacious group of people. By 1982 we were the largest clinical Interest Group with a membership of 900. Our professional expertise, knowledge and specific skills were officially recognised. Our opinions and judgements valued. The A.P.C.P. put evidence forwards in many instances for example:

a) The International Year of Disabled Person,
b) 1979 Warnock Report,
c) 1981 Education Act,
d) 1982 CSP Congress,
e) Hydrotherapy and Paediatrics,
f) Guidelines to Good Practice,
g) 1983 Korner Reports,
and other instances.

The constitution was finally accepted by the CSP and ratified in 1984 at the Conference held at Cardiff. It was re-amended in 1991.

By 1984, the first "Introduction To Paediatrics" course was held, thanks to Pam Eckersley, Moyna Gilbertson, Marian White and Mary Clegg.

Other skills were developed as a result of the Association's activities and courses, both nationally and within the regions, - we were maturing well!

Childhood was proclaimed to be at an end with our first validated post basic training education course held at Salford. We had progressed through the adolescence phase, noisily - not being backward in stating our case.

This state was brought about by:

a) the formation of steering groups,
b) the Education Working Group,
c) Public Relations,
d) activities within the regions,
e) the Annual Conferences,
f) evidence to CSP.

It would be impossible to mention all concerned but honour must be paid to:

a) our early supporters and Education Committee workers, mentioning Ian McKinlay, Marion Whyte, Pam Eckersley and Mary Clegg in particular,
b) the Notable Chairmen,
c) the Editorial and PRO stalwarts,
d) the long suffering secretaries,
e) the clever penny calculating Treasurers.

I return to the development theme. As in an infant, organisation needs to develop in an cephalo-caudal direction. Head and central control being necessary before general distal movements and balance skills could be obtained, that is:

firm leadership and vision –> National Committee involvement –> Regional and local activities.

Growth does not cease with maturity, cells belonging to a body continue to develop and become replaced. They can also decline but if that body is able to draw on previous experience, it can still achieve its goals.

With all the current changes in the NHS and National Curriculum, we need to keep in front of us the necessity to:

a) define and redefine your role speciality,
b) responsible use of resources,
c) prove what you do is of worth to the child and family,
d) share and show others,
e) evaluate input and outcome.

Pitfalls to avoid are professional arrogance, insensitivity and narrow mindedness. Be open, thoughtful, challenging and supportive to the children and their families.

We were conceived out of good parentage. Let us mature well.

Susan Asagba
M.C.S.P. - Senior Physiotherapist, Hammersmith Hospital

Marion Main
B.A., M.C.S.P., Superintendent Paediatric Physiotherapist, Hammersmith Hospital.

MONITORING THE COMMUNICATION BETWEEN LOCAL PHYSIOTHERAPISTS AND THE PAEDIATRIC PHYSIOTHERAPY DEPARTMENT AT HAMMERSMITH HOSPITAL WHEN CHILDREN WITH MUSCLE DISORDERS ARE ASSESSED ADMITTED.

Introduction

Hammersmith hospital is a national and international centre for the management of children with muscle disorders.

In the physiotherapy department we assess up to thirty-five children every week and up to five children can be seen daily for intensive rehabilitation.

We feel that it is important to have accurate information about a child's general condition, his or her local physiotherapy management and the school and home environment to enable us to have a better understanding of the overall situation.

We have on occasion had comments from the local physiotherapist that the content of our reports sent to them after assessments do not always truly reflect the difficulties experienced at school and at home.

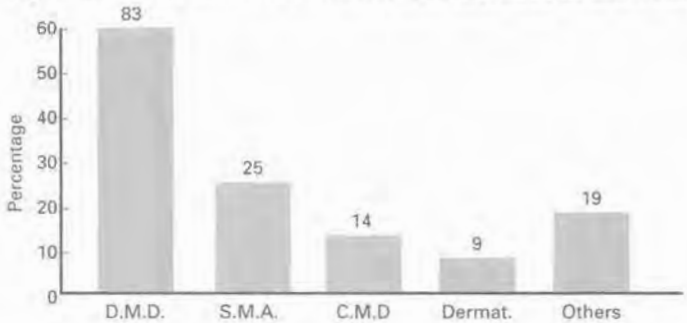
However in the absence of any communication from local physiotherapists prior to or at the time of the assessment we rely solely on the information given to us by the parents or child.

It was subsequently decided to do a small study to establish the proportion of children for whom reports/telephone calls were received prior to their assessment and to find out why local physiotherapists were unable to or felt it unnecessary to send reports prior to assessments. The study was also designed to help us to assess the usefulness of reports we sent out to local physiotherapists after assessments.

Method

Starting from 1/4/93 the first one hundred and fifty children with muscle disorders assessed/admitted in this hospital were included in this study.

Fig 1. **Children with Muscle Disorders included in this Study.**



A specially drawn up form, was used to keep a record after each assessment of whether children had physiotherapy input locally and if they did whether the local physiotherapists sent reports, telephoned or attended.

A questionnaire was drawn up, to establish whether the local physiotherapists from whom no prior communication was received were aware that the children were being assessed/admitted. It was also to establish the usefulness of our reports sent out to them from this department. These questionnaires were sent out with our physiotherapy reports following assessments to local physiotherapists from whom no communication was received.

The reports from analysis of returned questionnaires and the study forms are outlined.

Results

Of the one hundred and fifty children, fifteen children had no physiotherapy input (10%), one hundred and thirty-five children had physiotherapy input (90%).

Of the one hundred and thirty-five children with local physiotherapy input, twenty local physiotherapists sent reports, telephoned or attended the assessment (14.8%).

Of the one hundred and fifteen questionnaires sent out, ninety four were returned (81.7%)

Analysis of Questionnaires

Question 1 Table 1.1

Were you aware that .... had an appointment for assessment/ admission?

Percentage of Physiotherapists Aware of Appointments	
Aware of Appointment	76.7%
Not Aware of Appointment	21.2%
Did not Indicate	2.1%

Question 2a Table 2.1

If yes, who informed you of this appointment?

Source of Information	
Parents	76.4%
Child	6.9%
Local physiotherapist telephoned	4.2%
Others	8.3%
Did not Indicate	4.2%

Question 2 B Table 2.2

If no, have you been aware of appointments here in the past?

Percentage of physiotherapists aware of past appointments	
Aware of past appointments	50%
Aware but very short notice given	10%
Sometimes aware of past appointments	20%
Aware of past appointments but not exact date	15%
Aware after appointment	5%

Do you find the reports sent out from this Department useful?

Ninety three local physiotherapists found reports sent from this department very useful. Only one physiotherapist thought our reports were vague and not explicit enough.

Comments on Contents.

Local physiotherapists found our assessments informative and clinical with very detailed assessment of muscle power and mobility. Myometry readings were useful especially to those who had no access to the machine locally and it was felt that we assessed disabilities more accurately because of our facilities.

Our reports served as a guideline on which to base ongoing treatment plans, helpful to review the management locally and reassuringly backed up local assessments.

As we used the same format on each occasion this served as a good reference to show the possible rate of deterioration and progress against previous records thereby giving a continuity of the overall treatment programme. It also made our reports easy to read.

Some physiotherapists said our reports were useful for teamwork as it is sometimes the only contact between Hammersmith Hospital and the local physiotherapists. They also found it important to know of plans for surgical intervention written in our reports. It was thought that we gave useful advice to parents and specialist advice to them.

Our reports were found to be time saving to local physiotherapists who do not always have the time to carry out full assessments.

The suggestions below were made on ways to further improve the quality of our reports. Quite a number of local physiotherapists said that our subjective information was not always accurate and did not always address the problems experienced in the school and home environment. It was felt that we should include more long term objectives and advice for long term management.

To physiotherapists who are not familiar with our motor ability scale and myometry our findings do not have much meaning. It was suggested that

we sent a copy of our motor ability scale in our reports.

One local physiotherapist was not familiar with the abbreviations we used. eg. ITBs (ilio-tibial bands).

It was felt some more positive comments should be made for us to state specifically if our findings were an improvement or deterioration. It would also be very useful if we gave more details on the treatment techniques we recommend.

Question 3.2

Length of time between assessment and date report received.

Comments were made on the length of time between our assessments and the date local physiotherapists receive our reports.

The time varied and ranged from a few days to twelve weeks, with the majority between four to six weeks.

Fifty-seven physiotherapists commented on the time span.

Table 3.1

Comments on the Time Between Assessments and Date Received.		
Too Long	31	54.4%
Variable	7	12.3%
Prompt	7	12.3%
Improved	2	3.5%
Acceptable	9	14.3%
Impressive	1	1.7%

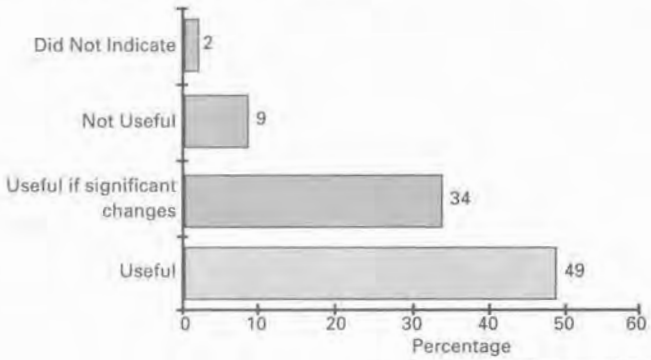
The local physiotherapists who remarked that the length of time was too long felt that they would need to receive the report quicker to implement changes sooner. They also stated that some parents tend to pass on wrong information which also caused problems.

Six physiotherapists expressed their understanding of the delay because of their appreciation of our workload and eight physiotherapists felt the delay was because our reports were sent to the wrong address.

Question 4

Do you feel it would be useful for you to send a report prior to subsequent appointments? Please comment.

Fig 2. **Percentage of Physiotherapists who felt it useful to send reports prior to subsequent Assessments.**



Comments On The Usefulness Of Local Physiotherapists Sending Reports.

Forty-nine local physiotherapists felt that it would be useful for them to send us reports prior to assessments.

Sixteen specified that they were unable to do so because they did not know the dates of the assessments whilst two said that they would try to do so in future.

Three of the forty-nine local physiotherapists would have sent reports if we had requested them and one reply stated that they would have sent a report but did not know whom the appointment was with [the doctor only or doctor and physiotherapist].

Two of the forty-nine local physiotherapists were unable to send us reports because of their heavy workload and nine stated they would have sent reports but had not received any feedback from past reports sent to our department and were therefore unsure of their usefulness. (On checking back, no reports from local physiotherapists could be found).

Eight local physiotherapists found our reports useful because of the two way communication between our department and them, and because of the fact that we see the children regularly.

Two of the forty-nine local physiotherapists preferred to communicate with us through the parents of the children via verbal messages whilst two local physiotherapists felt that parents were unreliable to pass on messages.

One local physiotherapist stated that though it was useful to send reports to us it was not necessary to send a detailed assessment.

A suggestion was made by local physiotherapists that we draw up a specially designed form with specific questions which they could fill in and return to us.

Nine local physiotherapists felt that it was not necessary to send reports. One of these nine local physiotherapists felt it would only duplicate our results whilst four local physiotherapists thought they could pass on information through the parents or children.

Two of nine local physiotherapists felt it was not useful for them to send reports because we have a different evaluation system, whilst two thought that too many assessments would demoralise the children.

Question 5

Do you know if this child has any future appointments?

Table 4.1

Number of Physiotherapists Aware of Future Appointments.		
Aware of future appointments	38	40.4%
Aware of appointments and exact date	1	1.1%
Aware of future appointments but not date	19	20.2%
Assume there will be an appointment	5	5.3%
Not aware of future appointments	28	29.8%
Did not indicate	3	3.2%

Conclusion

One hundred and fifty children with muscle disorders were included in the study (fig 1.). A specially drawn up form was used to keep a record of the local physiotherapists who sent reports, telephoned or attended assessments. It was also used to determine the number of children who had physiotherapy input locally.

A questionnaire was used to find out whether the local physiotherapists were aware that the children were being assessed in this department and to establish the usefulness of reports sent out to them from this department. These questionnaires were sent to local physiotherapists from whom no prior communication was received.

One hundred and thirty-five children had local physiotherapy input. Of these twenty local physiotherapists (14.8%) sent reports, telephoned or attended assessments. One hundred and thirty-five questionnaires were sent out and ninety-four returned. (81.7%). Of ninety-four local physiotherapists, 76.7% were aware of the appointments (table 1.1)

The main source of information for the appointments came from the parents (76.4%) see (table 2.1)

50% of the local physiotherapists had been aware of appointments in the past but 15% indicated that though they were aware of appointments they did not know the exact date (table 2.2).

Ninety three of the ninety-four local physiotherapists found reports sent out from this department very useful. Only one physiotherapist thought that our reports were vague and not explicit enough.

Local physiotherapists found our assessments informative, clinical and very detailed. Our reports served as a guideline and were helpful in reviewing local physiotherapy management.

Because we use the same format it served as a good reference point when compared with previous reports sent out from this department and made our reports easy to read.

Our reports were found beneficial for teamwork and local physiotherapists felt that we gave useful advice to them and specialist advice to the parents.

Our reports are time saving to local physiotherapists who do not always have the time to carry out full assessments.

Some local physiotherapists stated that our subjective information does not always reflect the difficulties experienced in the school and home environment.

Local physiotherapists not familiar with our motor ability scale and myometry suggested that we include a copy of our motor ability scale in our reports. It was felt that we should give more advice on long term management and more detailed treatment techniques.

The time between our assessment and the date local physiotherapists received our reports ranged from a few days to 12 weeks, the majority being between four to six weeks. Thirty-one local physiotherapists felt that the time span was too long as they needed to implement changes sooner (table 3.1). Some local physiotherapists felt that the delay was due to our heavy workload and due to the fact that our reports were sent to the wrong address.

Forty-nine local physiotherapists felt it would be useful if they sent us reports. Sixteen indicated that they would have done so if they had known the dates of the assessments. Thirty-four local physiotherapists said it was only necessary to send us reports if there were significant changes in the children's condition and nine local physiotherapists felt it was not useful to send reports. (fig 2.).

A suggestion was made that we draw up a specially designed form with specific questions which the local physiotherapists could fill in and send back to us. This suggestion was very seriously considered but was not thought to be practical. The individual needs of the children and their differing conditions (fig 1.) could not be covered on one form.

Thirty-eight local physiotherapists were aware of future appointments in our department. Nineteen local physiotherapists were aware of future appointments but not the dates, whilst twenty-eight local physiotherapists were not aware of future appointments (table 4.1).

NB: Having finished this study we have noticed an increase in the number of reports received from local physiotherapists.

Recommendations

The recommendations which arose from our study were;

1. We should inform the local physiotherapists when possible of future appointments by writing the dates of the future assessments on the reports we sent out from this department.
2. We should make it known to the local physiotherapists that we would appreciate it if they could send us reports prior to assessments.
3. We will endeavour to send reports to local physiotherapists after each assessment in the shortest possible time and in urgent cases inform them as soon as possible.
4. Local physiotherapists should give us an up-date of the name and address of the current physiotherapist so that our reports are sent to the right place.

THE "CURLY" LACE or as it is correctly called "VIZILACE".

Available from:
Able Medical Limited
Unit 82
Gravelly Hill Industrial Park
Standard Way
Tyburn Road
Erdington
Birmingham
B24 8TL
Telephone 021 327 0416
Fax 021 327 4265

Those of you who attended the National Conference of the Association of Paediatric Chartered Physiotherapists in Chester this year will remember seeing a new lace on trial. For want of a correct name they were nicknamed the "curly lace", and quickly became the hit of the show. At the time delegates were told that this product was under evaluation by physiotherapists, and their results would be reported in the next edition of the Journal, along with where and when the Vizilace would be generally available.

Originally from Australia Vizilace first came to this country in November 93 as a novelty item. Promoted through retail outlets like Hamleys and Harrods as a Christmas stocking filler, the lace had already caught the eye of some therapists as a potentially useful item, and many had bought them privately. Some of those buyers were at the Chester conference, and they reported that their laces were still going strong after four months constant use. Vizilace had also received strong coverage on both radio and television in programmes such as "Alive and Kicking", and "Tomorrows World".

Practical trials have now been completed with both special needs children, as well as a group of schoolchildren between the ages of seven and fifteen. Therapists have been delighted with their results, drawing attention not only to the convenience of Vizilace as an alternative closure to "Velcro", but also the way it encourages many cerebral palsy patients to develop their personal dexterity because they can learn to "tie" their own shoes where previously they could not manage bows. The other school children have proved that Vizilace is both durable, and desirable as a fashion item. Both groups highlighted the fact that nobody trips over a trailing lace any more as the ends curl up against the eyelet of the shoe. If you have never seen them, we should explain that the ends are simply left protruding through the eyelet, or hooked round the ski hook of the boot or shoe and that's it!

Vizilaces are made from smart materials, however you stretch and pull them, they always return to their original shape! Fitted to any shoes or trainers Vizilaces will provide a super-firm tailored grip that will allow the shoe to move and stretch freely under extreme pressure. Tough, durable, and available in a range of great colours, Vizilace means never having to tie your laces again.

Kirton Paediatric Products.
For details contact:
Gill Clifford
Kirton Healthcare
Bungay Road
Hempnall
Norwich
NR15 2NG

Kirton Healthcare have produced a new brochure - Kirton Paediatric Products (KPP). This is a new division of Kirton and a new range of Paediatric positional products.

- Available in two sizes.
- Cut be used out of the bath as a chair or wedge.
- Adjustable head support eases hair washing.
- Use as a wedge for postural drainage.
- Folds flat for ease of storage and portability.
- Single size.
- Optional grab rail and abduction block.
- Ranges from 6 months to 5 years.
- Supplied with velcro fixation straps or buckle if prefered.
- Offers support for those with moderate sitting ability.

Chairman's Report
AGM April 9th 1994

I'd like to welcome you all to the 21st Annual General Meeting of the Association.

This report will review the work of the Association and especially the National Committee over the past year - incorporating plans for the future.

As usual we have held 4 National Committee meetings; held in London at G.O.S. or the CSP headquarters, and one here on Thursday morning.

The Officers of the Association continued in office with the exception of P.R.O. Michele Lee who has previously held office as Publications Officer and Secretary took over as P.R.O. last April and combined a very busy year with producing a 2nd son, Alexander, born at the beginning of January.

This year Lyn Weekes completes her term of office as Treasurer having served 2x2 year terms. Lyn is a nationally elected member and is eligible to remain on the committee but has decided to step down. A clear thinking Treasurer is an asset on the committee, and she will be missed.

Jeanne Lacey, our Editor, is fit and well again and has resumed control of the Journal, she will want me to tell you that she is assisted by a very committed Editorial Board.

They have taken professional advice on the possible options for the design and layout of the new style journal. The aim is to provide a more exciting and visually stimulating format and a larger paged journal. They plan to maintain a high standard of referenced articles plus practical and news items. Contributions from members are needed to keep the journal lively.

It is only since I have been a member of the Core Group of the Editorial Board that I have truly begun to appreciate the amount of work that goes into producing a quarterly Journal such as ours. As ordinary members few of us realize the pressure of gathering, sifting and editing enough information to fill a substantial publication, and at the same time maintain the balance of exchange ideas and existing practice with research and scientifically based theory of practice; and yet this remains the forum for Paediatric Physiotherapy and continues to need members' contributions to fulfil its purpose.

Last year I told you that we sent a member of our Committee to the Clinical Interest Liaison Committee and from that committee representation is made onto the Professional Practice Committee of the CSP. Carol Foster, our Publications Officer and Regional Rep. to the West Midlands is, by that route, now a member of the Professional Practice Committee. The PPC are represented on Council and Carol has been proposed as a member of the CSP Journal Committee.

Through the Clinical Interest Group Liaison Committee it has been suggested that groups write Job Descriptions for Committee Officers and produce a Business Plan.

During this year members of the committee have continued to represent the membership at other meetings. The CIG conference was held at Cardiff and attended by Viv Williams and Rowenna Hughes. The topic was Skill Mix and Re-profiling, an up-date on Legal Aspects and Patient focused care.

This year the conference, to be held in May, will look at 'Protocols of Care, Outcomes and Audit. Rowenna Hughes and Carol Foster will attend.

The CSP held a post-registration education meeting looking at 'alternative methods of delivery' attended by Carole Hurran and Viv Williams.

Two representatives again attended the Annual Representatives' Conference. Terri Fearn and Elizabeth Harty went to Belfast and presented motions on behalf of the Association. This is a considerable undertaking; rewarding if the motion is well received but less so if the mood of conference swings away from you.

Last summer Fiona, the Hon. Secretary, set up meetings with the Advisory Assessment Service of the Spastics Society.

Viv Williams, Fiona and I met with the Head of Service and had a thorough and open discussion about their assessment procedure and the function and process of that assessment; this resulted in an article written by two physiotherapists who work for the Assessment Service being published in the February edition of our journal.

A further meeting in March means that we have a continuing dialogue and are developing an improved working relationship with, I think, renewed respect on both sides. It will be useful for us to be able to establish the reasons why families approach the Spastics Society for an independent physiotherapy assessment it may be appropriate for us to reconsider aspects of our practice in conjunction with standards of practice. Our plans for our next meeting in June are to look at our roles and responsibilities in relation to resources.

The Spastics Society is now quite often perceived as being 'Conductive Education' but we have been assured that the Conductive Education assessment service at Fitzroy Square is quite separate, and the Independent Advisory Assessment Service of the Spastics Society has no direct contact with it.

Two weeks ago - as the nominated CSP representative to the Spastics Society - I attended their Extraordinary General Meeting in London, where as you will have read in the press, a Motion was approved to accept the change of name to 'Scope'.

The society continues as the Spastics Society until November when it will be relaunched. The name is intended to remove any medical or diagnostic connotations and concentrate on the work done to provide: enterprise, acceptance, opportunity for action. It is intended that the name will encompass vision and give an image of confronting the caring issues for the disability of Cerebral Palsy.

The PRO and Post-Registration Education reports will inform you of other specific functions and activities of the committee.

Our current activities are looking at Outcome measures - as set up by a working party of London based Superintendent Paediatric Physiotherapists, Standardised Assessment forms, Risk assessment forms and procedures for lifting and handling, and motions for the Representatives' conference to be held in Birmingham in the autumn.

The CSP continue to ask for our comments on documents such as 'Your Job Your Safety - a Guidance on Health and Safety for Community Physiotherapists', and the 'British Paediatric Association Report on Health Services for School Age Children', or evaluate from members opinions on such topics as 'the layout of the Courses section of the Physiotherapy Journal' or the content and format of the Journal itself. We continue to receive request from the Editor of Physiotherapy for reviews for Paediatric Books.

Letters, enquiries and telephone calls from members and other agencies still occupy a section of our time. Sometimes, as a Clinical Interest Group, we can only give an opinion - not advice, the responsibility for advice may lie with the Chartered Society as our Professional body.

Our new publication - launched at this Conference - is 'Dyspraxia - a handbook for Physiotherapists' written by Michele Lee and Jenny French. It is a substantial booklet - comprehensive, very readable and well referenced, it should be a valuable adjunct to our publications.

I regret that the Paediatric standards of Practice have not yet been published; I know that the document is eagerly awaited, some of us have seen the draft document which was submitted to the Quality Assurance Working Party of the CSP in January.

The final document, in line with those of other Clinical Interest Groups has to be used in conjunction with the CSP Standards of Practice. It relates to professional practice that is specific to Paediatrics and that, by definition, is not already covered by the CSP Standards. Because of this the QAWP go through it with a fine toothcomb and have requested some alterations which need to be made, re-submitted and approved before it goes to the Professional Practice Committee for final approval. A time-consuming business - frustrating for Sandra Holt and Mary Clegg who have put so much time and expertise into producing the document and also for those of us who wait.

Those of you who anxiously await the publication in order to produce local, departmental standards should in the meantime refer to the 2nd edition CSP Standards together with the APCP Guidelines to Good Practice which are themselves well regarded by the CSP.

Finally my sincere thanks to everyone on the National Committee - we are fortunate to have had such a committee and committee meetings where, I am certain I can say, no-one goes home without having made a positive contribution either verbally or by committing themselves to doing something for the association.

My particular thanks go to the committee members whose specific roles are fundamental to the running of the association and because they are so well done make my role as Chairman so much easier; Fiona as secretary, Lyn as Treasurer, Viv as Vice-chairman and Post-reg Education Spokesman, Michele as PRO, Carol as Publications Officer, Jenny as Membership Secretary and Jeanne as Editor.

My eight years as a nationally elected Member have been stimulating and very rewarding. I recommend it to any of you.

Jill C. Brownson

April 1994.

Post-Reg Ed Report

With the N.H.S. in the process of great change we need to be looking for opportunities to develop our skills in the marketing and promotion of our services.

In the new environment of G.P. fund holding, care in the community and diminishing resources, education of the Primary Health care team is of primary importance. Participation in the training in areas such as Child Surveillance and Working in Partnership with G.P.s will give us the opportunity to help G.P.s to understand what we have to offer.

Prioritization of case loads and an increase in the importance of Research and Single Case Studies means we must develop Standards & Audit so that we can evaluate our outcomes. (In Wales we have been given a grant by the Welsh Office to carry out an Audit of Cerebral Palsy children in Wales, so funding is available).

As promised at last year's AGM, Michele Lee, Rowenna Hughes and Lyn Wakely have designed an Introductory course in Paediatrics. The format can be used and adapted to the needs of members in all the regions. The first 5 day course will be held at the C.S.P. London from October 3rd to October 7th and details will be available in the May Journal.

We have been asked to comment on the consultation report of the joint working party "Health Services for School Age Children". This is available from the B.P.A. at £6. If people wish to make comments can they let me have them by the middle of May please.

The C.S.P. wish to develop advice sheets for physios wishing to enhance or develop their specialist expertise. These would give information to assist physios in putting the case for a secondment and negotiating terms to support either formal or informal arrangements. The advice should prove especially useful to non practising physios wishing to return to a previous specialisation and requiring an opportunity to update their skills before applying for a post.

It would be extremely helpful if any members with first hand knowledge of secondments either as a recipient or educator would be prepared to let me know so that we can help the C.S.P.

Guidelines relating to Post Reg courses, development, delivery and accreditation have been produced and are available from the C.S.P.

P.A.C.E. continues to evolve to meet the changing need of the profession and the C.S.P. have created a consortium of Higher Education institutions.

The word post-Reg. Ed. is now giving way to post-Grad Education with the changeover to degree status of new members and the recognition of the diploma at degree level.

It is important that when members are pursuing post-grad education they ensure that their courses are relevant to their clinical expertise and their career development.

The Certificate in Paediatric Studies has been developed as a result of the success of the Advanced Certificate in Paediatric Physio of the University of Central England, Birmingham.

It is likely to be 3 or 4 separate weeks of study after 2 semesters with guided private study to a total of 36 credits points at M level which can be linked to a full masters degree.

Members who have already obtained their Advanced certificate will be credited with 24 points at M level. Further information can be obtained from Mary Clegg, Course Director, University of Central England, Birmingham.

As a result of the 1993 Education Act, a draft code of practice on the Identification and Assessment of Special Education Needs has been produced for consultation and will be published soon. This has implications for the delivery of our services and there are concerns about the effect on the child and his family. The stricter time schedules in the production of statements are going to cause problems.

Further information can be obtained from your local department of Education. The committee are looking at statements and we would welcome copies or examples so we can draw up guidelines.

A.P.C.P. Standards are progressing well and are with the C.S.P.

The Paediatric O/T Module at the University of East London has run for the first time this year. Sandra Holt is working with the Paediatric O/T to design a combined Physio/O.T. Modules. The rest of the modules are part of the General Physiotherapy Masters degree. Two Paediatric Physios have already completed the course. Five Paediatric Physiotherapists are in the process of taking the course.

The Modules are being restructured so that people can take modules as they choose on a full time basis over a year or part-time afternoon and evening release over two years or a maximum of four years.

Sandra Holt is also involved as a Clinical Manager organising placements and teaching paediatrics to under-graduates.

Sandra and Mary have been very active members of our post-graduate Education committee and in view of their heavy commitments have expressed a wish to change their input to the committee to that of consultants and have offered to help and advise in their special areas of expertise. This has resulted in a restructuring of the committee to meet the changing needs in Post Grad education. Carole Hurran has kindly agreed to take over as chairman, helped by Lyn Campbell and Rowenna Hughes. I have been persuaded to stay on for another year. I would like to thank the committee for their help and wish Carol and the new committee every success.

Viv Williams

Chair Post-Grad Ed. Committee.

P.R.O. Report 1994

The past year has been busy for Public Relations. In the past year I have received information about back pain week and National Continence week, a press release concerning the C.S.P.'s campaign for law change to protect the physiotherapy name so that only those suitably qualified can practice as and call themselves physiotherapists, the CSP's charter for women's health (copies can be sought from the CSP), and information about this year's centenary. Whenever newsflashes and information is sent to me I pass this on to the regional representatives and when relevant to the Editorial Committee for publication in the journal.

The Regional Representatives meet twice a year to inform each other and the nation Committee on activities in their own area and any concerns that have been raised from either their local committee or from the membership. These meetings are now minuted and a summary published in the Journal.

The CSP's centenary also marks 21 years since APCP was formed therefore making this a special year for us all. Reading the articles in the February Journal by Ann Grimley and Jean Biddle has highlighted for me howfar the Association has developed over the years. Jeanne Lacey in her editorial quoted from Jean Biddle's editorial of years past when she saw in the future that "the Paediatric Physiotherapist will become one of the most valuable and respected members of the physiotherapy profession" - a road which we continue to follow and strive for. The Association has continued to grow so that last year we had over 1000 members which makes us one of the largest clinical interest groups of the CSP. Promoting ourselves to the public, other professionals

and physiotherapists not only in what the Paediatric Physiotherapist does but also what APCP is, continues to be of paramount importance to me. The APCP stand has been updated with new photographs and information and I would be grateful to the membership if anyone has any other ideas or photographs that can be used for the stand.

APCP has now a number of booklets and information leaflets for the membership and public. The leaflets Physiotherapy in Paediatrics and What is the Association of Paediatric Chartered Physiotherapists, are frequently asked for by members for study and open days. The booklets Guidelines to Good Practice and the Children's Act - A synopsis for Paediatric Physiotherapists are also popular. The launching of the book Dyspraxia - a handbook for therapists is our first book to be published. We hope in the future for other books to be published and titles are being considered and written. Once these are complete the titles will be published in the Journal. I am also trying to organise some fact sheets and new leaflets on useful information relevant to Paediatrics as a career. I would welcome to hear from members who have any further ideas for future fact sheets, titles of books or leaflets.

The overseas membership continues to grow and we now have over 30 members. It is planned that the January 1995 Journal will have articles from these members and I look forward to reading about their work.

A group of Superintendents from London met last summer to discuss Outcome Measures. From the meeting it was decided to form a group in order to formulate these for Paediatrics and it was considered that the best way of doing this was to form subgroups according to specialities i.e. orthopaedics, neuromuscular, neurodevelopment, dyspraxia and respiratory. From these groups outcome measures were formulated. The committee has worked very hard and made good progress with most groups having finished their outcome measures and are now at the stage of trial to ensure that the measures compiled are workable. It is hoped that all measures will be completed and ready for publication in the next year and this will be in the form of an APCP booklet.

Finally my thanks go to all the Regional Representatives for their help and enthusiasm over the year and especially for assisting me during my maternity leave.

Michelle Lee.

Profile - A feature profiling the Executive Officers for the benefit of the membership

Vivienne Williams - Vice-Chairman A.P.C.P.

Viv qualified in 1959 from the Cardiff Royal Infirmary School of Physiotherapy.
She was a founder member and First Chairman of the Welsh Region APCP Committee and was on the organizing committees of the 1984 and 1991 APCP conferences. Viv was the Welsh regional rep. to the National committee and then was elected onto the committee in 1987 where she has been a member of the Post Reg. Education committee and Vice-chairman of the Association for 4 years. She was also a founder member and first chairman of the British Association for Bobath Trained Therapists. During the last 15 years Viv has been employed developing a comprehensive Paediatric Physiotherapy service in Cardiff. The photo shows Viv in Bulgaria where she has recently visited Varna at the invitation of the Bulgarian Ambassador to England to advise on the setting up of a Children's Centre.
Any spare time is spent, skiing, walking, gardening and visiting France evaluating the food and wine! Viv is married and has two grown-up children.

Association of Paediatric Chartered Physiotherapists

Application for Membership 1994

1. Ordinary Membership is open to annual subscribing members of the Chartered Society of Physiotherapy.
2. Associate Membership is open to professional people with an interest in paediatrics, subject to the approval of the National Committee.
3. **Annual Subscription for 1994 is £16.00**, and runs from 1st January to 31st Dec. All cheques should be made payable to 'A.P.C.P.'
4. Retiring members are only required to pay half the total annual subscription.
5. Subscriptions for overseas members are £2.00 less than the current full subscription.

Cheques payable to 'APCP' should be sent to:

JENNY MCKINLAY
Membership Secretary
3 Stanley Gardens
Sanderstead
S. Croydon
Surrey CR2 9AH

- I have received a P.R.O. newsletter from the C.S.P. which included the new careers poster and a publication list of leaflets available from the Public relations Dept. The newsletter also informed us that there will be another National Back Pain Week in October which will be followed by a Health and Safety at Work week. The C.S.P. are also encouraging all members to write to their M.P.'s concerning the protection of our title.

- I have also received some information about a course being held on the 17th November on Practicalities and Legalities in Cystic Fibrosis Care which will be held at Alexandra Palace in London. I have further information if anyone would like it.

- The Disabled Living Foundation have written to me asking for support for their emergency appeal. Anyone wishing to give a donation to their appeal can do so by writing to the Disabled Living Foundation, Freepost (PAM 6695), London W9 2BR.

- At the Regional Representatives meeting, it was decided to co-ordinate the courses run by regions. A yearly list/register of forthcoming study days and courses will be compiled. It is hoped this will prevent duplication of course and study day subjects in the different regions and allow for more varied topics to be discussed.

MICHELE LEE

Public Relations Officer

WOULD YOU LIKE TO GO TO CONGRESS?

The National Committee have decided to ballot a place for 1 day at this years congress Thursday September 22nd - the Paediatric session plus a ticket for the Congress dinner.

ALL CURRENT MEMBERS OF APCP ARE ELIGIBLE TO APPLY

The draw will take place on September 1st

Entries should be sent to: JILL BROWN
CHAIRMAN APCP
23 VALLANCE ROAD
HOVE
EAST SUSSEX
BN3 2DA

to arrive not later than August 31st

Entries must state clearly: Current Membership Number
Name and Address for correspondence

The winner will provide a written summary of the Paediatric session for the November issue of the APCP Journal

(travel and accommodation are not included)

REGIONAL REPORTS

SOUTH WEST
Gill Smith
23 Gunville Crescent
Castle Mead
Bournemouth
BH9 3PZ

The new committee met on April 29th. Many thanks go to both Carole Hurran, Regional Rep, and Judith Lott, Treasurer, for all their hard work over the past couple of years. Once settled in our new roles, we hope to plan and encourage other members in our area to organise some interesting events.
Dorchester are hopefully running a course in the Autumn on current research in paediatric physiotherapy - watch this space for further information!!
Congratulations to our new Treasurer Julia Leslie who got married at the end of May and who is now Mrs. Graham.

SOUTH EAST
Sheila Minet
Old Knowle
Frant
East Sussex
TN3 9EJ

Our last study day on dyspraxia was open to teachers and OT's and was fully booked, and generally successful, although the general criticism was that it was not practical enough. We therefore plan to follow it up with more of a workshop approach for February 1995.
However the next study day will be as advertised, on November 19th with Ros. Boyd as our tutor on serial plastering.

LONDON REGION
Rowena Highes
87 Norbury Hill
SW16 3RU

We had a well attended lecture on Dorsal Rhizotomy. The lecturer was Mr. Peter Bullock consultant neurosurgeon at Maudsley Hospital, London. A general discussion followed the lecture to share ideas in this new field of surgery and management.
Future courses: Saturday October 1st St. Thomas' Hospital Lecture Theatre, 9-10 Topic - 'Paediatric Update'. Kate Ferguson - Respiratory. Daniel Scrutton - Neurogenic Therapy. Nicky Thompson - Orthopaedics. For further details contact Jackie Tasker - Royal London Hospital. The Committee are still asking members for ideas on courses and venues that they would like as there has been no response from previous requests. Our membership now stands at 109 members.

EAST ANGLIA
Sue Whitby
3 Manor Way
Hail Weston
St. Neots
Huntingdon
Cambridgeshire
PE19 4LG

I have now taken over from Jackie Reynolds. On behalf of all the East Anglia members, I would like to thank Jackie and all the other retiring committee members for their endless effort and enthusiasm, which has helped to make us such a successful region.
We now have a new committee which consists of five existing members and five new members. My thanks to all those who have stayed on and welcome to all new members.
There has been a meeting of the new committee and we have great plans for the future.
We are a widely spread geographical region and, to cut down on travel, we hope to hold courses in various parts of the region; so any offers of venues (preferably free!) would be most welcome. Additionally, we would be very interested in any suggestions you may have for topics. Please contact me or any committee member.

Dates for your diaries -
1994 - Saturday October 8th C.F. Study Day - Papworth (see advert)
1995 - Wednesday January 18th Outcomes - Bury St. Edmunds
1995 - Saturday March 4th - A.G.M. + Syndromes Study Day - Cambridge C.D.C.
Committee Members -
Chairman - Linda Fisher (Thurrock)
Secretary - Marlisse Koelwijn (Thurrock)
Treasurers - Elva Mason and Jean Offord (Chelmsford)
Regional Representative - Sue Whitby (Huntingdon)
Deana Evans (Thurrock)
Trisha Brosnan (Cambridge)
Sue Keam (Great Yarmouth)
Jean Ritson (Colchester)
Pam Falla (Huntingdon)

TRENT
Margaret Cameron
Flat 6
19 Newcastle Drive
The Park
Nottingham
NG7 1AA

A successful sharing afternoon was held in Peterborough in May on foot problems. A further sharing afternoon on 'syndromes' is planned for the Autumn in Mansfield. Date to be confirmed. This is an opportunity for informal case presentations and discussion. An up-date on respiratory care will be held at the Post-Graduate Centre, Derby Royal Infirmary on November 12th. Topics to be covered include the neonate going home on oxygen, ECMO, and changes in CF management. For further details contact Margaret Cameron on (0602) 627658.

WEST MIDLANDS
Carol Foster
Physiotherapy Dept.
The Childrens Hospital
Ladywood Middleway
Birmingham
B16 8ET

The committee are busy organising a programme of evening meetings to include:
September - An evening on Strapping and Talipes and a viewing of the new Solihull Hospital by Sarah Bayin.
October - CDH and its management by Mr. O'Hara Consultant Orthopaedic Surgeon.
November - Hemiplegia in Cerebral Palsy by Colin Stevens.
Further information to be circulated in the October Journal. The A.G.M. in March 1995 will include a talk by Caroline Dunn on 'Being an Expert Witness'. The West Midlands Region will be offering several small bursaries for A.P.C.P. Members - application forms will be available via the Chairman or any Regional committee member.

WALES
Barbara Bowen
Childrens Assessment
East Glamorgan Hospital
Church Village
Nr. Pontypridd
Mid Glamorgan
CF38 1AB

Our A.G.M. in March was very well supported. Professor Silbert presented his subject 'Child Abuse' with great sensitivity and support for members who had to face such appalling issues. However, the evening ended on a much lighter note with a buffet kindly prepared by Nerys and Sian at Llandough.
The counselling course in May was excellent. We barely made the minimum number but all who attended enthused on how much they gained. The lecturer, a clinical psychologist was amazed at the amount

of 'baggage' we carry around with us without any network of debriefing. I am sure that this accounts for the high stress levels in Paediatrics and I would advise such courses for everyone in this field.
In June, Sarah Dyer of Bobath Cymru presented her research into Cerebral Palsy, a comparison of parent's and therapist's perceptions of the problems. Again an excellent day, enjoyed on a beautifully sunny Saturday at Rhymney Valley Childrens Centre with the hospitality of Sue, Shirley and Dawn.
Our next study day is on 24th September. Management of the baby with Talipes at Morriston Post Graduate Centre.
Our Christmas Social this year is a Medieval Banquet at Cardiff Castle on 18th November. Deposits of £5.00 to Penny Ayres at Maesycoed School, Barry. First come first served.
Viv Williams and a psychologist colleague have been to Bulgaria recently to advise on the setting up of a Children's Centre There. We look forward to her report.
With reference to early physiotherapy intervention with the boys identified on the early screening for muscular dystrophy, representatives of physiotherapists involved in Wales, met at Haverfordwest on 24th May. Guidelines for practice were outlined and our proposals circulated.

NORTH WEST
Alex Winney
14 Langley Road
Spital
Bebington
Wirral
Merseyside
L63 9HW

Thanks to all who supported and helped with the Conference, we enjoyed running it but thank goodness it only comes round every ten years!
We are now trying to get back into the swing of organising local study days, the first of which is to be held on Friday October 28th at Park Dene School in Oldham and is entitled 'The Older Child Into Adulthood'. Application forms will be sent out.
The AGM will be held on March 11th 1995, again hopefully in Warrington and will be linked to a study morning on 'Legal Aspects' with case studies being presented, what being an 'expert witness' involves etc; The actual content of the study morning has yet to be finalised.
Future ideas are for a joint O.T. / Physiotherapy course in June of next year on 'Dyspraxia'. Any thoughts and ideas that you have for course/ study days please forward to me.
Also another reminder that there are ten bursaries of £50 that can be applied for from Eileen Walters. I know that for a lot of courses that this is a mere drop in the ocean but every little bit counts so please do apply, sending a self-addressed envelope to:-
Mrs. Eileen Walters
Community Paediatric Physiotherapist
Community Health Clinic
Blackhall Road
Kendal
Cumbria
Hope you all have a good summer, Alex.

NORTH EAST
Liz Hardy
45 Kestrel Close
Norton
Stockton-on-Tees
Cleveland
TS20 1SF

The July Study Day was cancelled due to lack of support. Only 3 people wanted to share information on 'Syndromes' or learn more about Genetics. Your Regional Committee are meeting very soon to plan next years programme. You will find a questionnaire inserted with this journal to find out what you want. Please spend a couple of minutes filling it in and return it to me. If we don't know what you want, we can't organise it.

SCOTLAND
Lyn Campbell
19 Craidnmount Avenue North
Edinburgh
EH12 8DH
Tel. 031 530 0619

You will be interested to hear that things are at last moving for the Scottish Bobath Centre. They have got the keys for the building in Knightswood, Glasgow and a year's lease has been signed. At the present time, plans are being drawn up for refurbishment and it will hopefully be ready in April 1995. Great efforts are being made to raise money as there is no statutory funding for the Centre.

Susan Horsburgh has been appointed as superintendent physiotherapist, she is presently at the Bobath Centre in London and we are delighted that Anne Harnden, from Yorkhill in Glasgow has been appointed as her deputy.

We are continuing to be very occupied with preparations for the APCP Conference, to be held from 31 March to 2 April 1995 at Heriot Watt University in Edinburgh - make sure you put the dates in your diary! As a result of all the work involved in the Conference we shall only be running one course this year on 1st October 1994 at Yorkhill, Glasgow. It will be on Juvenile Rheumatoid Arthritis covering both medical and therapeutic aspects.

N. IRELAND
Finola Beattie
The Royal Belfast
Hospital for Sick Children
Belfast
BT12 6BF

The new committee have been working hard to organize courses that will inspire a few more members to come along.

There will be an introductory Bobath course on 4th and 5th October 1994, suitable for those new to the neuro-development area of Paediatrics. Speaker will be Colin Stevens from the Bobath Centre, London. Further details from Joy Hegarty, Musgrave Park Hospital / Fleming Fulton School. Our autumn speakers will be Professor Nevin. Geneticist, Ruth Graham. Senior Physiotherapist, speaking on 'Cystic Fibrosis' on Monday 5th September. Tish Dunn Physiotherapist, will speak on Monday 7th November on 'Physiotherapy involvement in the Muscle Clinic'. Meetings will be held as usual at Fleming Fulton School commencing at 7.45pm.

I would like to take this opportunity to thank Elizabeth Harty for all her hard work as Chairman over the past 2 years; and also to mention that she is the first N. Ireland member to be elected onto the National Committee of the APCP. Well done Liz and Good Luck.

A.P.C.P.
ANNUAL CONFERENCE
1995

HERIOT WATT UNIVERSITY
EDINBURGH
SCOTLAND

31st March - 2nd April 1995

'Practice in Progress'

INTRODUCTION
to
PAEDIATRICS

Monday 3rd October - Friday 7th October

Venue : Chartered Society of Physiotherapy
14 Bedford Row, London WC1R 4ED

Cost : £175 **Organisers: A.P.C.P.**

This course is designed to introduce junior/senior II Physiotherapists to most aspects of paediatric physiotherapy. The course is ideally suited to those who wish to enter paediatric and to physiotherapists who are beginning their first paediatric post.

It will encompass normal child development, neurodevelopmental assessment, aetiology and treatment of the more common childhood illnesses and disabilities, the use of specialised equipment and the legal aspects of paediatrics.

For further information and application form contact :
Miss L. Wakley, 2 Ash Bank, Pipers Ash, Chester CH3 7EH.

Please enclose a stamped addressed envelope.

CERTIFICATE IN PAEDIATRIC STUDIES M LEVEL POST GRADUATE STUDY

UNIVERSITY OF CENTRAL ENGLAND BIRMINGHAM

This Certificate has been developed following the successful running of the Advanced Certificate in Paediatric Physiotherapy.

The course is a complete component and offers a certificate of 36 credit points at Masters level, which can be linked into full M Sc. degrees.

Subject to validation on 21 April 1994 and due to start September 1994.

Enquiries to : Mrs Mary Clegg MSCP SRP, Course Director, University of Central England in Birmingham, Faculty of Health and Social Sciences, Perry Barr, Birmingham, B42 2SU.

MASTER OF SCIENCE IN HEALTH PRACTICE POST GRADUATE DIPLOMAS

UNIVERSITY COLLEGE SALFORD

Respiratory Care
Paediatric Neurological Care
Adult Neurological Care
Women's Health
Dysfunction of the Lower Limb
Management of the High Risk Patient

1994/95

For further details contact : Lesley Rimington, MSc Admissions Tutor, Salford School of Physiotherapy, University College, Salford, Frederick Road, Salford, M6 6PU.

PODOPAEDIATRICS

THE LANGER BIOMECHANICS GROUP (UK) LTD.

This two day course is presented for those practitioners who have a special interest in the treatment of paediatric locomotor problems.

17th, 18th September 1994

University of West London, Uxbridge.

For further details and a free seminar schedule, apply Freepost (no stamp required) to : Penny Morton, Manager of Educational Services, Langer Biomechanics Group (UK) Ltd., Brookhouse Way, The Green, Cheadle, Stoke-on-Trent, ST10 1RL. or Telephone 0538 755861. Fax 0538 755862

JUVENILE RHEUMATOID ARTHRITIS THEORY AND WORKSHOPS

YORKHILL, GLASGOW

Saturday 1st October, 1994

A study day will be held in the Physiotherapy Department, Royal Hospital for Sick Children, Yorkhill, Glasgow covering the medical aspects of intervention and with emphasis on the practical therapeutic applications.

Cost including lunch, coffee and tea, will be £15.00 for APCP members, £20.00 for non members.

Further information from : Lesley Smith, Superintendent Physiotherapist, Royal Hospital for Sick Children, Yorkhill, Glasgow G3 8SJ

"CYSTIC FIBROSIS"

Saturday, 8th October, 1994
Child - Adolescent - Adult
Venue : Papworth Hospital, Cambs. (new Cystic Fibrosis Unit).
Speakers include :

Veronica Bastow, Physiotherapist
Dr D Bilton, Chest Physician
Sister Quine - Cystic Fibrosis (adults)Team Co-ordinator
Physiotherapist from Papworth Unit (adults).

Displays and information.
The cost is £20 for APCP members, £25 others (includes lunch and drinks). No application forms needed.
For more details and to make bookings, please sent a SAE to : Deana Evans, Senior Physiotherapist, Fountain Centre, John Tulloch Centre, Thurrock Community Hospital, Long Lane, Grays, Essex Tel. 0375 364427
Closing date : 15th September 1994 - no refunds

"REHABILITATING CHILDREN FOLLOWING ACQUIRED BRAIN DAMAGE" AN INTERDISCIPLINARY APPROACH.

THE CHILDREN'S TRUST, TADWORTH
Wednesday, 12th October 1994
This Study Day will cover the philosophy, structure and process of rehabilitating children at Tadworth Court. Our approach is interdisciplinary, therefore, we welcome any individual whose clientele may sometimes include children with acquired brain damage.
The cost is £45.00
For further details please contact : Mrs Ivy Gosling, The Childrens Trust, Tadworth, Surrey KT20 5RU, telephone 0737 357171, ext. 2162.

TALIPES WORKSHOP

21st October 1994
Following the success of an initial course in November 1993, this course is now to be re-run at The Royal London Hospital, Mile End. The course will explore various modes of management and new orthotic systems with practical workshops giving participants the opportunity to practice with instruction.
Speakers: Rosalyn Boyd - M.C.S.P.,
Denise Watson - M.C.S.P.
Diane Coggins - M.C.S.P.
Consultant Orthopaedic Surgeon
Fee : £30.00 Places limited.
For application form/further details contact : Jan Josefsson, Paediatric Community Physiotherapy, Mile End Hospital, Bancroft Road, London E1 4DG. Tel. 071 377 7874.

"EUROKINE - KINEXPO 94"

NATIONAL CONGRESS OF PHYSIOTHERAPISTS
22nd October 1994
Place : Leuven, Belgium.
Organization: K. U. Leuven, branch for motoric revalidation Scientific Committee N.F.D.L.K.
The European Magazine for Physiotherapy KINE 2000
Secretariat of Congres: K.U. Leuven, Branch for Physical Education and Physiotherapy, Tervuursevest 101, 30001 Heverlee, Belgium.
Tel. ++32-(0)16/20.14.31 Fax: ++32-(0)16/20.14.60
Price : 250 BEF. (without lunch), 500 BEF. (with lunch)
Programme details to follow . . . . .

"THE OLDER CHILD INTO ADULTHOOD"

NORTH WEST REGION STUDY DAY
Venue : Park Dene School, Oldham.
Date : Friday, October 28th, 1994
The Study Day is aimed at looking at all aspects of managing the older child into adulthood (physical, family etc) There will be lectures in the morning with workshops after lunch looking at particular problems of older children in both mainstream and special schools.
Registration is at 9.00 and we hope to finish at 4.30
Cost : £20 Members - inclusive of lunch. £25 Non-members.
Everyone welcome to apply. It may be of interest to educational staff.
Application forms from : Mrs Linda Whitaker, Supt. Physiotherapist, Ann Street Health Centre, Denton, Manchester M34 2AS.

WORKSHOP ON SERIAL CASTING, THEORY AND PRACTICAL.

A.P.C.P. S. E. REGION STUDY DAY
The day will include "hands on" practical experience of casting and problems solving from videos.
Venue : Hospital for Children, Great Ormond Street, London WC1.
Saturday, 19th November,
Lecturer : Mrs Roslyn Boyd, Superintendetn Physiotherapist, Newcomen Centre, Guy's Hospital.
Apply to : Mrs Ginny Hancock, Physiotherapy Dept., Epsom General Hospital, Dorking Road, Epsom, Surrey KT18 7EG, Tel. 0372 726100, ext. 6202 or bleep 501 or answerphone 0372 740997.
Fee : £40 payable to A.P.C.P, S. E. Region.

Notes for Contributors

The Editorial Board welcomes research material; referenced articles and evaluations of physiotherapy practice; informal articles.

Manuscripts should be sent to Lin Wakely, 2 Ash Bank, Pipers Ash, Chester, Cheshire, CH4 7EH, U.K.

Copy to be submitted should be typed on one side of the paper, double spaced and with ample margins. All pages should be numbered consecutively.

Manuscripts should provide the title of the article and the author(s) name(s) and full postal address for correspondence.

References should be given in the Harvard System.

In text	Author(s) name and initials followed by the date of publication. Use a,b, to indicate more than one publication in the same year. Where there are 3 or more authors use first name followed by et al.
For books	Laszlo, J. & Bairstow, P. (1985) *Perpetual Motor Behaviour* (Rinehart and Winston)
For chapters within books	Morley, T.R. (1992) Spinal deformity in the physically handicapped child, in : G.T. McCarthy (Ed). *Physical Disability in Childhood* (Churchill Livingstone)
For articles	Scott O.M., Hyde S.A., Goddard C.M., Dubowitz V., (1981a) Prevention of deformity in Duchenne muscular dystrophy. *Physiotherapy* 67(6), 177-80.

Tables and Figures

The approximate position of the tables and figures should be indicated in the manuscript.

Keys to symbols should be included.

Tables should be numbered by Roman numerals and figures by Arabic numerals.

Figures should be supplied in a finished form, suitable for reproduction. Figures will not normally be redrawn.

Proofs will be sent to authors if major alterations have been made to the text.

The Editorial Board reserves the right to edit material submitted for publication.

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