International Organisation of Physical Therapists in Paediatrics

Newsletter January 2008

In this issue

President's Message

Welcome to the second newsletter for the International Organisation of Physical Therapists in Paediatrics!

Since the last newsletter, the IOPTP has been active in identifying the full members and the associate members of our organisation. We are pleased to announce the following member organisations as FOUNDING members of the IOPTP representing over 10,000 paediatric physical therapists around the world.

Australia	(421)	Norway	(600)
Canada	(410)	South Africa	(97)
Denmark	(391)	Sweden	(690)
Hong Kong	(96)	Switzerland	(450)
Ireland	(188)	Taiwan	(100)
Netherlands	(986)	UK	(1207)
New Zealand	(126)	USA	(4952)

Our paediatric forum (a part of the WCPT forums) has become more active during the past six months with members from around the world participating. Please look at the forum for discussions and requests for information on topics such as adolescent idiopathic scoliosis; PNF; the MFM scale; cystic fibrosis; cognitrain for paediatrics; clubfoot; myofascial release; and spider-suit therapy. You can access the forums at http://www.wcpt.org/smfforum/index.php

We are working on a joint conference with the Section on Pediatrics of the American Physical Therapy Association to be held in Orlando, Florida on January 10-12, 2010. We will be soliciting an international speaker for one of the General Sessions. The topic is International Health Issues. If you are interested in speaking or would like to suggest a speaker, please contact one of the members of the IOPTP executive committee. Please see other details later in this newsletter in the Secretary's report. We are excited that we may be able to have an international meeting between the June 2007 WCPT and the June 2011 WCPT meetings.

You will note that our newsletters are focused on an area of interest/practice for our members. In the first newsletter, we focused on obesity and the role of paediatric physical therapists in the management of children who are obese. In this issue, we are focusing on children with HIV/AIDS. We hope that you find the information presented on these topics informative and helpful to you in your practice. We welcome your suggestions for future issues of the newsletter.

During the past six months, the IOPTP has had the opportunity to contribute to the WCPT through participation in the establishment of GUIDELINES FOR PHYSICAL THERAPY RECORD

KEEPING AND THE STORAGE AND RETRIEVAL OF RECORDS FOR PATIENT/CLIENT MANAGEMENT. Comments were solicited from our members by the Practice Committee and then our suggestions were submitted to the WCPT Executive Committee.

We have also been informed by the WCPT of a new publication by the World Health Organization focused on prevention of child injury. This publication can be accessed at: http://www.who.int/violence_injury_prevention/child/injury/world_report/en/.

I hope that each of you will be willing to participate in activities of the IOPTP when possible and support the IOPTP as we attempt to network physical therapists in paediatrics around the world.

With kind regards

Barbara H. Connolly DPT, EdD, FAPTA

Secretary's Message

How exciting it has been to watch our membership grow to 10,000 paediatric therapists from 14 countries around the world! Please share the news with colleagues from other countries.

The Section on Pediatrics of the American Physical Therapy Association is planning its first annual section conference in Orlando, Florida, in January 2010. The IOPTP Executive Committee has agreed to collaborate and hold IOPTP meetings in conjunction with this conference. What an excellent opportunity to learn and network with colleagues from around the world while enjoying Disney World!

For those who participate in marathons: Paediatric Physical Therapists and their families are invited to join a team to participate in the Walt Disney World Marathon Jan 9-10, 2010. A full marathon will be held on Jan 9 and a half marathon on Jan 10. Participants can run in either or both races. Those who complete both will receive a specially designed Goofy medal. This will be an opportunity for Physical Therapists to spread the word that we are "Goofy for exercise". For registration and information go to: www.disneyworldsports.com. Plan to register early: registration for both races is likely to close by March 2009.

The Pediatric Physical Therapy conference will begin at 1:00 Jan 10 and end at 3:00 Jan 12. Programming will include general sessions with keynote speakers, breakfast networking sessions, lunch forums, concurrent session, and social activities. The topics for general sessions include international health issues, cultural competence, lifespan issues, and the future of pediatric physical therapy education around the world. Networking sessions and forums will focus on specialty areas and common challenges such as funding for research, risk management, evidence based practice, and niche practice. Vendors and posters will exhibit throughout the conference. Begin making plans to head to Disney World in Jan 2010. Watch for registration information on our website. If you have ideas or want to volunteer, please contact Cindy Miles at bike4ever@verizon.net.

I look forward to hearing more from you through our forums or meeting you in 2010.

Respectfully

Sheree York Secretary, IOPTP

Treasurer's report

Activities of the IOPTP are funded through an annual membership subscription. The membership subscription rate was set at the General Meeting in Vancouver in 2007. The rate for 2008 was US$ 1.0 per member of each member organisation (US$ 0.5 per member in countries where the GNI per capita is less than US$ 3000 per year).

The Statement of Financial Activities for 2008 shows net incoming resources of £ 9507.00 and payments of £693.00 for the Web page and newsletters.

Ria Nijhuis Treasurer, IOPTP

SPECIAL FOCUS: CHILDREN LIVING WITH HIV/AIDS

In this the second newsletter of the IOPTP we highlight the impact of the HIV/AIDS pandemic on children's lives. This pandemic affects the child at many levels because of its effects on families and communities – hence the concept of children living with HIV/AIDS, which is defined by UNICEF and UNAIDS as **"**those under 18 years of age who are living with HIV or have lost one or both parents due to AIDS or whose survival, well-being or development is threatened or altered by HIV".

The availability of antiretroviral drugs for young children means that more children are surviving beyond the age of 2-3 years of age. Although children are living fairly healthy lives, early infection with HIV impacts on the child's cognitive, language and motor development which has implications for the provision of intervention programmes to promote optimal development.

However the majority of children living with HIV/AIDS live in the poorest communities where families have been decimated by the AIDS pandemic, often in countries with very limited resources for health care and early education. These children will be growing up with no access to intervention programmes that can help them overcome the impact of the disease and their environments on their development.

Pam Versfeld Chair, Communications Sub-committee

Fact sheet

Compiled by Anna Versfeld

Basic HIV/AIDS statistics

- Worldwide 2.1 million children under the age of 15 are living with HIV/AIDS
- 15 million children under the age of 18 have lost one or both parents due to HIV/AIDS – of these 12.1 million live in sub-saharan Africa
- Five million new cases of HIV infection occur worldwide each year.
- Internationally, young people aged 15 to 24 years now account for half of the new infections

Infection and early years

- The majority of children are infected before and during the birth process and some later on through breastfeeding.
- In the absence of any intervention, the risk of HIV transmission from an HIV positive mother is 15–30% if the mother does not breastfeed. When an infected mother breastfeeds, the risk is between 20 and 45%.
- Without treatment, approximately half of children with perinatal HIV infection will die by age 2 years.
- HIV/AIDS remains the leading cause of deaths amongst children under five years of age in South Africa.

- HIV is more difficult to diagnose in children than in adults. Often the first signs of infection are opportunistic infections or neurological complications
- HIV-positive infants show developmental delays, and their ability to reach developmental milestones continues to decline with age.

Treatment

- Internationally only 10% of children living with HIV receive antiretroviral therapy.
- Treatment is often inhibited because it means that mothers have to reveal their status
- Children are less likely to adhere to treatment programmes than adults as this requires informing all caregivers and persuading the child to ingest the medication.
- In most provinces, less than half the children who require ARV treatment are receiving treatment.

Broad effects

- In countries where HIV prevalence exceeds 15%, such as South Africa, most children are directly or indirectly affected by AIDS.
- Many children become responsible for care of sick relatives and for the care of younger siblings when parents become incapacitated due to the effects of HIV/AIDS
- Many children, especially girls, are taken out of school due to family responsibilities. Lack of access to education in turn increases children's chances of becoming infected by HIV.
- Many HIV/AIDS affected households cannot afford to pay for education.
- Orphans living with extended families or in foster care are frequently subject to discrimination and are less likely to receive health, education and other needed services. This is largely due to stigma.
- Studies have found that some 37% of mothers with HIV-positive children are depressed.

Sources and resources

- 4th Global Partners Forum on Children Affected by HIV and AIDS (http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2008/20081008_GPF.asp)
- Coalition on Children Affected By Aids (http://www.ccaba.org/resources.html#A)
- Children count (http://www.childrencount.ci.org.za/content.asp?TopLinkID=12&PageID=49)
- UNICEF – Children and AIDS (http://www.unicef.org/aids/index_introduction.php)

The impact of HIV / AIDS infection on a child's development

Pam Versfeld

According to studies about 30% - 40% of children infected with the HIV virus will present with developmental delay (Bellman et al 1996, Potterton and Eales 2001). This may be the first sign of an HIV infection and can occur in the absence of any other clinical signs or symptoms. What starts as a mild delay in the development of motor milestones progresses to signs of definite neurological involvement, including pyramidal tract signs, ataxia, abnormal muscle tone, pseudobulbar palsy, acquired microcephaly and encephalopathy (Tardieu 1998).

The neurological complications that accompany HIV infection are a direct effect of the virus as well as co-factors such as metabolic and endocrine disturbances, maternal illness, stress and substance abuse, prematurity, the side effects of treatment, and opportunistic infections such as meningitis (Tardieu 1998 Belman 1992).

Most of the research on the development of children living with HIV/AIDS infection comes from sub-Saharan Africa. In this region, the child's development is also adversely affected by poverty

and the impact of living in home environments that have been adversely affected by AIDS infections or death of parents.

Baillieu and Potterton (2008) assessed a group of 40 children between the ages of 18 and 30 months with vertically transmitted HIV who attended the Hariet Sezi Paediatric HIV Clinic at the Chris Hani Baragwanath Hospital, Gauteng, South Africa using the Bayley Scale of Infant Development II. These children showed significant delays in cognitive, motor and language development. Gross motor development was particularly affected. The researchers surmised that part of this delay could be attributed to overall loss of muscle strength as well as CNS involvement. The findings of this study support the results of previous research on the development of children infected with HIV (Abubakar 2008). Children with HIV who are on retroviral treatment also show language, motor and cognitive developmental delays (Davids 2008).

There is very limited research into the value of physiotherapy on the quality of life of children infected by HIV. However the small scale studies that have been conducted show promising results. A longitudinal study over 6 months showed that children living in an institutional environment where they received optimal medical care, good nutrition and regular stimulation showed greater developmental progress than children living at home with families with very limited resources and where caregiver stress is very high (Davids 2008). Another longitudinal study (Potterton 2006) investigated the effects of a home stimulation programme under the guidance of a physiotherapist on development. The children in the experimental group showed a significantly greater improvement in cognitive and motor development when compared to children in the control group.

As children and adolescents infected with HIV continue to live longer, and paediatric HIV becomes a chronic rather than an acute disease, the developmental and educational needs of these children will take on a greater significance. More research is needed to establish the effectiveness of providing family centered physiotherapy support to promote optimal development of children living with HIV/AIDS, particularly in developing countries where resources are limited at the family, community and national level.

References

Abubakar A, Van Baar A, Van de Vijver FJ, Holding P, Newton CR.(2008)
Paediatric HIV and neurodevelopment in sub-Saharan Africa: a systematic review.
Trop Med Int Health. 13(7):880-7.

Belman A, Muenz L, Marcus J, Goedert J, Landesman S, Rubenstein A, Goodwin S, Darako S, Willoughby A 1996 Neurologic status of human immuno deficiency virus –1 infected infants and their controls: A prospective study from birth to two years. Pediatrics 98(6): 1109-1118

Burns S, Hernandez-Reif M, Jessee P. A review of pediatric HIV effects on neurocognitive development. Issues Compr Pediatr Nurs. 2008 31(3):107-21.

Baillieu N, Potterton J. (2008) The extent of delay of language, motor, and cognitive development in HIV-positive infants. J Neurol Phys Ther. 32(3):118-21.

Davids N. (2008) The motor development of HIV negative and HIV positive children aged three to six years residing in institutions and in foster care. Unpublished MSc Thesis, University of Cape Town.

Jelsma J, Ferguson G (2007) Motor Development in Children Living within Resource Poor Areas of the Western Cape South African Journal of Physiotherapy 63 (7): 35-40.

Potterton J, Van Aswegen H 2006 Paediatric HIV in South Africa: An Overview for Physiotherapists. South African Journal of Physiotherapy 62 (1):19-22

Potterton, JL. (2005) A Longitudinal Study of Neurodevelopmental Delay in HIV Infected Children. Doctoral Thesis, University of Witwatersrand.

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Van Rie A, Mupuala A, Dow A. (2008) Impact of the HIV/AIDS epidemic on the neurodevelopment of preschool-aged children in Kinshasa, Democratic Republic of the Congo. Pediatrics. 22(1):e123-8.

Looking past the disease and seeing the child – the impact of HIV/AIDS on physical therapy services

Pam Versfeld

This week I took a walk across the Rondebosch common from the leafy suburb where I live and work to the Red Cross War Memorial Children's Hospital, a large state tertiary care hospital which provides specialist in-patient and out-patient care for the children living in Cape Town. I was on my way to chat to the physical therapists that work at this hospital – I wanted to know how the AIDS pandemic was affecting their work as physical therapists, and how they coped with the emotional stresses that I felt must be created by the high rates of infection among children in their care.

Red Cross War memorial Children's Hospital, Cape Town

South Africa, home to some 44 million people, is a country of many contrasts, the largest being the huge discrepancy between the richest and the poorest. For the middle classes who have medical insurance the medical care is sophisticated and very good. For the poor the quality of health care varies and is not always accessible. However those attending the Red Cross Children's Hospital will receive care that is of the highest standard, for this is a world-renowned children's hospital, with highly specialised and dedicated staff. That dedication is well stretched by the HIV/AIDS pandemic that is part of the lives of most of the children who attend this hospital. It is estimated that up to 70% of children in the medical ward are infected by HIV/AIDS, and much of the medical care is geared towards treating the failure to thrive, neurological disorders and opportunistic infections associated with HIV/AIDS.

Question – what is the impact of HIV/AIDS on your work as physical therapists

- In the medical wards the physical therapists see children with neurological complications of HIV/AIDS infection, sometimes with the added burden of TB infections, who had been started on antiretroviral medication. This can be very satisfying because these children's medical status slowly improves and bit by bit they regain their abilities, although there is usually some residual neurological fallout. Even in children presenting as end stage IV AIDS the clinical picture may be turned around and this is very rewarding.

- Following the introduction of antiretroviral medication children with neurological disorders attend the outpatient clinic for follow up intervention. Most of the children present as diplegic

CP – the reason for this presentation is not known. These children progress well if the carers are able to follow a home programme and provide the child with the extra stimulation needed.

- Sometimes there is a request to provide palliative care for a child very sick with AIDS – but this is not a large part of the workload as children who are very ill with AIDS are cared for in other centers.

Question – How do you cope emotionally dealing with so many children who are infected by HIV/AIDS

- We look beyond the infection and only see a child like any other child who needs our care and attention.

- The best way to cope with the high rates of infection is to simply assume that all children are HIV positive – this is a safety precaution on the one hand, but more importantly it means that all children are treated equally. Emotionally this is very important as you are not put in a position of labeling a child as this or that – each child you encounter is a child in need of care and you provide that care without prejudice.

What are the challenges working with in the out-patient clinics?

- The biggest challenge for physical therapists working in the outpatient clinic is the wider impact of illness and death associated with AIDS on families and the poverty that grips the home environments of most of the children. Many are orphans who are being cared for by a grandmother who may have other children in her care and also has very limited financial resources.

- Education of parents and carers is key to the work with these children who are ill, on medication and not developing in the usual way – it is easy to forget that there is a little child there who also needs to play and have fun learning and exploring the surrounding world.

- It is also very important to keep parents motivated for the long haul – and to give hope.

- Sometimes it is hard, knowing that the long-term outcomes remain uncertain for these children and the families you get to know well over the years.

Thank you to the physiotherapy team at the Red Cross Hospital for taking the time to me to talk to me and being willing to share their thoughts and feelings about working in this difficult environment.

Links

Red Cross Children's Hospital Trust
(http://www.childrenshospitaltrust.org.za/home;jsessionid=EBCD1B53D1F5EFC2989E454A932ACC42)
Red Cross War Memorial Children's Hospital
(http://www.capegateway.gov.za/eng/pubs/public_info/R/103416/1)

A visit to two facilities in Honduras

Dale Deubler

Perhaps this brief information about a visit to two children's facilities in Honduras will open the door for conversation from other members about their work with children who are living with AIDS/HIV or who have had experiences with PT in Honduras.

The incidence of AIDS/HIV in Honduras in among the highest in the western hemisphere. Recent government sponsored programs to deliver anti-retroviral medication is helping to decrease the mortality.

> UNICEF 2008 statistics indicate there are 2,400 children under the age of 15 in Honduras who have HIV. [1] I had the opportunity to get to know 33 of these amazing children who are thriving because of the care they receive at Montana de Luz.

Montana de Luz (MdL) is a residential non-profit organization for children with HIV/AIDS located near the small village of Nueva Esperanza about an hour from the capital city of Tegucigalpa in rural south-central Honduras. The children are orphans or from families who are unable to provide adequate care. Many of the children arrive in weakened, malnourished condition and are very ill. The priority of MdL is to help them heal, thrive and grow in a small family-like environment. With individual care, proper nutrition and medical care, most of them look forward to independent living as productive Hondurans. The staff functions as a caring family for the children who receive specialised medical care, an abundance of nutritious food, plentiful clean water and education. The children develop skills needed for successful family life and for integration into Honduran society, learn to manage their illness and are educated about HIV/AIDS related issues. On-site preschool classes are held daily while school aged children attend school in the community. The children participate in after school tutoring, computer classes and a daily recreation program. (For more information about Montana de Luz: www.montanadeluz.org **)**

I visited MdL in September 2008 with an Ohio State University service learning course. My goals were to promote the independence for a child living at MdL who has cerebral palsy and to determine the potential for establishing relations with health care providers in the region. child at MdL who has limited participation in physical activities. Working with the only child at MdL who is limited in participation in physical activities was a highlight of the trip; the staff and I discussed and shared goals as would happen in PT encounters with families. We worked to identify kindergarten readiness skills and developed a plan for additions to her exercise plan to ensure she will be ready to participate when the new school year begins. Much to her delight, she was able to participate in a wider range of recreation activities than she has previously experienced, with the addition of some modifications. As part of an ongoing need for education about cerebral palsy and treatment, I plan to provide the staff with a variety of materials and ideas to foster increased participation and independence.

I also visited SOS Village Valle de Ángeles, a facility for children and adults with a wide range of disabilities. This large beautiful facility is part of SOS-Kinderdorf International, an organization that has "special consultative status" with the Economic & Social Council of the United Nations (UN) because it shares UN objectives. I believe this is the only SOS facility that provides services exclusively for people with disabilities. SOS Village Valle de Ángeles consists of 9 family houses, a school for those who cannot attend the local school, a workshop, and a soccer field, as well as administration and service areas. As home to about 200 individuals, each house is home to 11 people, 3 of whom are the women who manage all aspects of family life. While other SOS villages throughout the world are orphanages for children and work toward community integration, Valle de Ángeles provides homes for adults with disabilities and has no upper age restriction. Because SOS funds can only be used for homes for children, this Village is facing a significant financial challenge. The Village employs 2 PTs, who like many PTs, have caseloads that exceed their capabilities. They were very interested in the idea of having assistance from PT volunteers and students. For more information about SOS: http://www.soschildrensvillages.org.uk/children-charity.htm

References

1 UNICEF Honduras statistics http://www.unicef.org/infobycountry/honduras_statistics.html

Recommended resource for additional information on pediatric AIDS/HIV

Children on the Brink. UNICEF July 2004

http://data.unaids.org/Publications/External-Documents-Restored/unicef_childrenonthebrink2004_en.pdf
This publication includes a list of paediatric age group related developmental risks and opportunities pertaining to AIDS/HIV awareness and education.