# The IOPTP Newsletter

The International Organisation of Physical Therapists in Paediatrics

Edition 17, November 2016

## *President's Message*

Greetings all,

I hope you have all had a wonderful summer with some time for vacation with family and friends. It's been a very special time for my family as our first grandson arrived June 10. The IOPTP board is preparing for the upcoming conference next summer. Our committees continue to work diligently to meet strategic plan goals in the areas of education, practice, research, communication, and programs. We welcome additional volunteers to serve on these committees as well are resources and ideas you have to promote the work of the IOPTP.

**WCPT in 2017**

We hope you will join us at the WCPT conference in Capetown, South Africa, July 2-4, 2017. From the WCPT:

WCPT is pleased to announce the opinion leaders and innovators in physical therapy who will present the key sessions at the WCPT Congress 2017.

Seventeen focused symposia will be presented featuring over 75 prominent international speakers from across WCPT's five regions. High quality speakers have been selected, covering cutting edge topics of vital importance for the profession across a wide variety of practice and research areas and policy perspectives. Focused symposia are always a popular feature of WCPT congresses, drawing large audiences, and providing the opportunity not just to hear from world authorities, but to engage with them in discussion.

View details of the focused symposia at:
www.wcpt.org/wcpt2017/fs/sessions

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For submissions or questions regarding the newsletter please contact the newsletter editor Erin Wentzell PT, DPT, PCS at

**ewentzell@gmail.com**

Access the full list of speakers at: www.wcpt.org/wcpt2017/speakers.

The focused symposia include Paediatrics: pelvic health and Paediatrics: physical activity. There are symposia on a wide variety of topics including intensive care, pain, HIV, PT in disasters, global health, fragility fracture, critical PT, clinical practice guidelines, men's health, and stroke.

Networking sessions and an afternoon meeting and tea will be hosted by the IOPTP. We hope to see you in Capetown in 2017.

In the US, we are preparing to visit Keystone, Colorado for our 8th Section on Pediatrics Annual Conference (SoPAC). We welcome your participation in this conference. There will be pre-conferences on aquatics, cortical visual impairment, hip health, Pediatric Neuromuscular Recovery Scale, and Spasticity Management in Children with Spastic Diplegia. Each of the special interest groups have programmed multiple sessions on their specialty area along with networking sessions, practice fairs, and posters. Fitness events and fun are embedded throughout the conference.

Other news in the US: The APTA's Section on Pediatrics has a new name: Academy of Pediatric Physical Therapy. You will see a new logo and look to the website and published materials as well as a new name for SoPAC: APPTAC coming in 2017.

We hope to hear from you all about the accomplishments in your organization. We also welcome any ideas and questions you have.

Kind regards,

Sheree York

Sheree York PT,DPT,PCS,cNDT

President, IOPTP

The IOPTP FACEBOOK page is a great resource for upcoming events and information on the IOPTP and the WCPT. It is also a great resource for information on pediatric physical therapy with an international prospective on research, practice and advocacy.

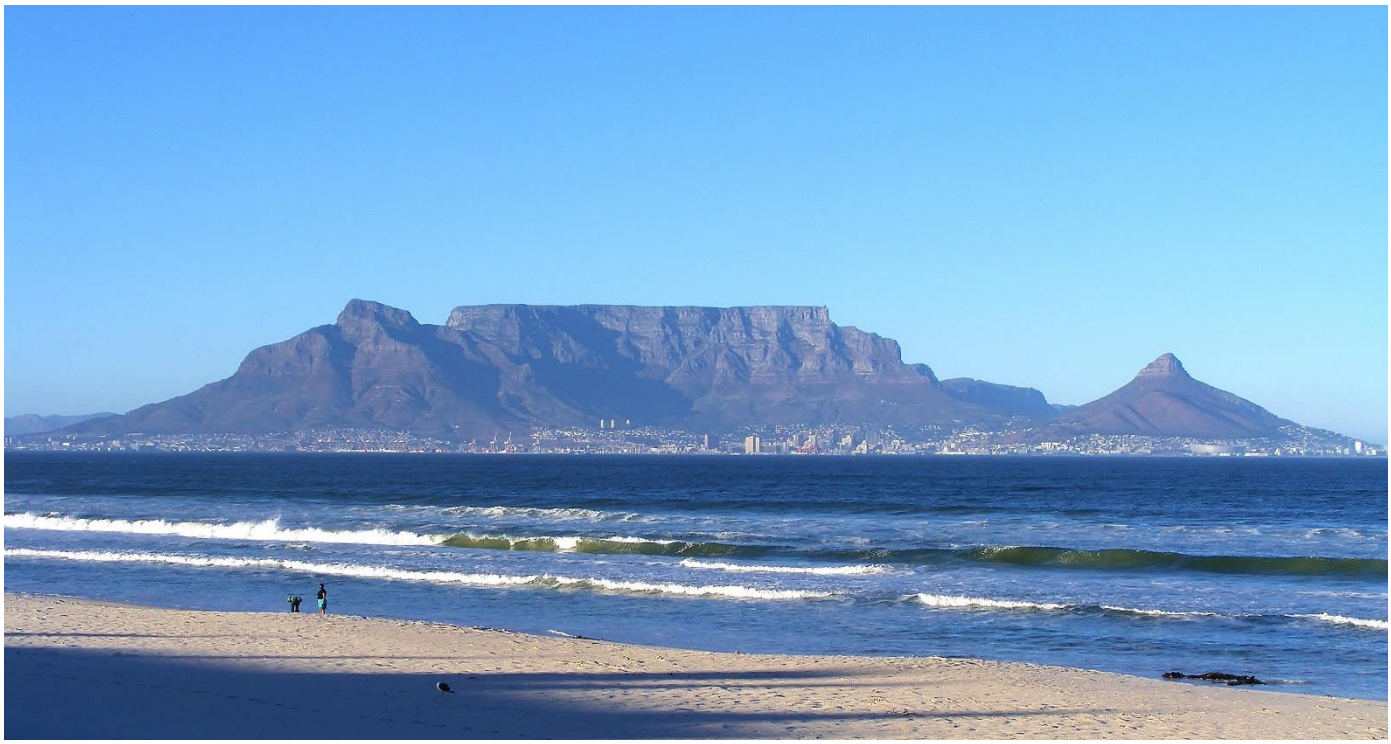

photo credit: Mandi Smallhorne

## *Spotlight on WCPT 2017*

### *Diana Coetzer,* Communications Committee of IOPTP

WCPT2017 is hitting Cape Town South Africa in July 2017 and the country is buzzing with excitement! With this being the first time there is a WCPT Congress in an African region this congress is promising to be something special.

Cape Town is synonymous with Table Mountain and that is the background setting for this congress. With the vast number of tourist attractions that Cape Town as well as South Africa holds delegates attending the congress are in for an exciting time.

South African physiotherapists are among the most passionate in the world. We are proud of our profession and can not wait to host the world to see what we offer.

The clinical visits that are on offer for the paediatric physiotherapy community are going to be memorable. The Red Cross Children's Hospital manages around 260 000 patient visits each year, the majority of which are from exceptionally poor and marginalized communities. One third of the little patients are younger than a year. This extraordinary place of healing advocates that no child will be turned away. St

Joseph's Home (SJH) for Chronically Ill Children is a registered non-profit organization. It is one of the only institutions in South Africa who supports children, families and communities from poorly resourced areas in free paediatric intermediate health care (a step down facility between acute hospital and home). This multi-disciplinary and holistic model includes:

- 24 hour specialised and general nursing care,
- rehabilitation: physio-, occupational- and speech therapy, social work support and psychological counselling.
- on site school education, parental empowerment, specialized nutrition, logistical support, a nursing school, pastoral care, outreach and follow-up visits and volunteer placement programmes enhance the holistic approach.

Each year at St Joseph's more than 300 vulnerable children from impoverished families, receive a second chance at childhood. Lastly, Western Cape Rehabilitation Centre , for Persons with Physical Disabilities, is a specialized rehabilitation centre, which accepts appropriate referrals from all levels of health services (i.e. tertiary, secondary, district and primary level health services). Clients can also refer themselves to the WCRC Out-patient clinic for one-stop assessment and management purposes.

Paediatric physiotherapy in South Africa ranges for a variety of conditions as it is across the world. At the clinical visit sites physiotherapists are sure to see a variety of interesting conditions which will get your brain flooding with new and exciting information and ideas!

On behalf of the South African Society of Physiotherapy we welcome all paediatric physiotherapists to register to attend WCPT 2017 in Cape Town, South Africa.

# *Committee Spotlight: Research Committee*

**Ethics in research and practice**

In 2015, the IOPTP Research Committee asked the questions:

a) Could the IOPTP Research Committee develop a document or article/guidelines on the Ethics of Research and Clinical Practice for physical therapists who work with children or whose focus is on children's health and well-being to ensure protection of children and their health records?
b) Could such a document discuss the ethics around clinical research (and practice) to ensure the protection of children and their health records, while also promoting research for children's issues?
c) Could such a document be made available on the IOPTP website and be included in an IOPTP newsletter?

**International Organization of Physical Therapists in Pediatrics (IOPTP) (Research Committee): Principles for Ethical Pediatric Physical Therapy Research**

*Compiled by Brenda Morrow (PhD; PG Dip (Health Res Ethics); BSc (Physiotherapy)) Department of Paediatrics and Child Health, University of Cape Town, IOPTP Research Committee*

*Background*

There are numerous historical examples of unethical pediatric human research studies, including but not limited to the experiments on child concentration camp prisoners in Nazi Germany during World War II and the Willowbrook State School study (United States in the 1950's), in which children with intellectual disabilities were purposely infected with hepatitis. Although flagrant human misuse and abuse during research is thankfully now uncommon; all human research, including physical therapy research, potentially places participants at risk of harm, discomfort, or inconvenience in the hope of benefitting others [1-3].

In a review of physical therapy-related research (including pediatric research) published between 1996 and 2001, only 48% of articles included information on both research ethics committee (REC)/ Institutional Review Board (IRB) approval and informed consent, often considered the "twin pillars" of human research protection; whilst 29% provided no information on either of these protections [1,3]. Clearly, increased attention to ethical compliance is needed in physical therapy research and publication.

The Research Committee of the International Organization of Physical Therapists in Pediatrics (IOPTP) strongly feels that pediatric physical therapy research is essential to inform practice and optimize the safety and efficacy of therapeutic interventions (i.e. evidence- based practice/EBP) [4]. Such research includes, but is not limited to: meta-analyses, systematic reviews, randomized controlled trials, cohort studies, non-randomized prospective clinical outcomes studies, case-control studies, case series, and case

reports. Ethical vigilance is required to ensure that pediatric physical therapy research is conducted in a respectful manner, and one which is concerned with protecting the rights, safety and well-being of the child participants and their families [1,5,6].

*Ethical principles*

The Belmont report (1979) presents three fundamental concepts for research ethics [7]:

1) Respect for persons: this principle requires that each participant is treated as an autonomous agent, for example by obtaining informed consent for research participation. People must also be treated with due regard for their personal dignity and intrinsic worth as individuals, and should not be seen merely as a means to an end [3]. Those with diminished autonomy, including children, require special protection, which is explored more below.
2) Justice: this principle requires the fair distribution of both the potential risks and benefits of research. Vulnerable populations such as children should only be included in research when absolutely necessary, but it is also important not to exclude children from research if this population might benefit from the research findings [3].
3) Beneficence and non- maleficence: researchers must act to maximize potential benefits to their participants, and minimize associated research risks.

Ezekiel Emanuel (2000) expanded the above principles to the following requirements for ethical research:

1) Societal and scientific value - research should be responsive to local disease prevalence and need.
2) Scientific validity - if research is not scientifically sound it is also not ethical because the results cannot be generalized and will therefore not appropriately inform practice. Participants would be placed at risk of harm without the potential for personal or societal benefit, thus making the research unacceptable in terms of the risk: benefit balance [3].
3) Acceptable risk: benefit ratio - research-related risks should be minimized, and there should be at least some foreseeable benefit to the research participant and/or the population being studied (even if that benefit is improved knowledge about a condition).
4) Informed consent - in order to ensure that autonomy is respected, potential research participants should freely consent to their participation, after being fully informed of the reasons for the study, research procedures and interventions, as well as all potential risks and benefits.
5) Fair selection of participants - supporting the principle of justice, vulnerable groups should neither be specifically targeted for, nor excluded from participation in clinical research.
6) Independent review by an institutional review board (IRB) or research ethics committee (REC).
7) Respect for potential and enrolled subjects [8].

*Children as a vulnerable research group*

Most young children lack decision-making capacity, and are generally considered a relatively vulnerable population, owing to their developmental and cognitive levels and dependence on adults for care and protection [9-11]. Ethical research can be conducted with vulnerable populations, including children, provided additional safeguards are in place to protect them from potential exploitation and harm [7,12-14]. These safeguards include the “necessity” and “participant-condition” requirements, whereby the research cannot

reasonably be performed in a non-vulnerable surrogate population; and the participant must have the specific condition being investigated [11].

*Risk of harm*

Risk of harm encompasses physical (e.g. worsening of symptoms and adverse events); social (eg. breaches of confidentiality and privacy); and psychological/emotional (e.g. introducing a sensitive topic that might traumatize the participant) harm [2]. Even using questionnaires or conducting interviews can involve collecting sensitive information that could be damaging if discussed outside the research environment [1,3]. In order for research involving children to be approved by an REC/IRB, the risks of research must be acceptably low [11]. In the United States the level of risk threshold for pediatric research is "minor increase over minimal risk" [15].

Research risks can also be minimized by careful inclusion/ exclusion criteria; appropriate participant screening; and suitable training in clinical research and good clinical practice [3].

*Therapeutic misconception*

Whilst clinical care is focused on providing benefit to individual patients, research primarily aims to generate generalizable knowledge to benefit future patients [3]. Failure to understand the distinction between research and clinical care is termed "therapeutic misconception", and may lead to questionable or invalid consent. There are a number of misconceptions around clinical research, including the belief that randomization is a way of rationing access to scarce or expensive medical care; and that the participant would directly benefit from study interventions [3]. The potential for therapeutic misconception is particularly high in patients with incurable conditions [16].

*Independent review*

All protocols for research involving humans must be subject to independent review to determine potential risks and benefits; and to ensure other ethical requirements are upheld, before the research can be conducted. The requirement for IRB/REC review includes research involving retrospective collection of data from medical records, prospective observational studies and interventional studies [3]. Case reports and small case series (usually describing fewer than five patients) may be exempt from ethical review, but consent should be obtained from the included patients for the use of their data, and this should be stated in the research paper [1]. Systematic reviews and meta-analyses of published studies do not require REC/IRB review, but if articles included in such reviews do not mention ethical oversight, this should be stated in the review article.

*Informed consent and assent*

The informed consent process provides a mechanism for participants to protect themselves. For informed consent to be valid, the participant or surrogate must have intact decision-making capacity and be legally competent; full and understandable information must be provided and understood; the participant or surrogate must be given the opportunity to ask questions; and the consent given must be truly voluntary, with no coercion or undue influence [17,18]. Where the participant is unable to provide informed consent, as is the case with children, proxy consent for child enrollment, from an appropriate surrogate (usually the parent/ legal guardian), is required [11,16].

Some categories of research may be awarded a waiver of the need for informed consent following REC/IRB review, for example where the research holds only minimally increased risks above standard care; where important research would not feasibly be possible without the waiver; and in emergency research situations[14].

Importantly, parental choice does not necessarily reflect the views of their child [19]. Therefore, assent should be sought wherever possible in awake, aware children of sufficient age and developmental level to understand basic research concepts and implications [7,10,20,21]. The assent process engages with the child about his/her participation in research, thereby respecting the child's developing autonomy [11]. Assent should be obtained in a developmentally appropriate manner [22], and dissent should always be respected, regardless of parental consent [11,12,15,22].

*Conclusion*

The IOPTP Research Committee supports ethically conducted, responsive pediatric physical therapy research, in order to improve the scientific evidence base for this important area of physical therapy practice.

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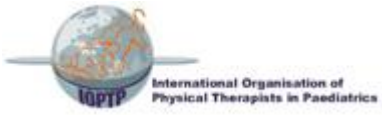
## *The Research Committee Introduces: Brenda Morrow*

Brenda Morrow is an Associate Professor in the Department of Paediatrics, University of Cape Town (UCT), South Africa. A physiotherapist by training, Brenda worked clinically from 1995 to 2006 at Red Cross War Memorial Children's Hospital in Cape Town. She developed a special interest in paediatric respiratory diseases, particularly in the context of critical care and the management of children with Cystic Fibrosis, and embarked on a Master's Degree in 2001, which was upgraded to PhD in 2003. In 2005 Brenda was awarded a PhD for her dissertation, "*An investigation into nonbronchoscopic bronchoalveolar lavage and endotracheal suctioning in critically ill infants and children*". In 2008 she completed a two-year postdoctoral fellowship funded by the Medical Research Council of Southern Africa (MRC). In 2009 she was awarded an MRC Career Development Award to develop clinical research using electrical impedance tomography – an emerging, noninvasive imaging tool which allows real-time quantitative analysis of ventilation distribution. In 2012 she was promoted *Ad Hominem* to Associate Professor. Since 1998, Brenda has been engaged in teaching and supervision of undergraduate and postgraduate students. Her current job description includes expanding the African Paediatric Fellowship Program to train paediatric allied health and rehabilitation therapists throughout Africa and to facilitate the concept of a

multidisciplinary, holistic approach to child health practice and research. In 2014, she completed a Postgraduate Diploma in Health Research Ethics (with Distinction) through the University of Stellenbosch. Brenda is Chair of the Department of Paediatrics' Research Committee; a member of the Faculty of Health Sciences Research and Human Research Ethics Committees; and a member of many special interest, editorial and advisory boards. She has published and presented her research findings widely, and won several awards. She is deputy editor of the *Southern African Journal of Critical Care* and a regular reviewer for many international journals.




## *Clinical Spotlight: Fitness Evaluation for Physical Therapists: What you need to know.*

*Connie C. Johnson, PT, DScPT, PCS*
Academy of Pediatric Physical Therapy Regional Director, Region V

Assessing physical fitness is very important when working with people who have disabilities. By every government and published statistic, people are not adequately fit, and fitness is worse for those with disabilities. We know that globally, 81% of adolescents age 11 to 17 were insufficiently physically active and the girls are less active than boys and less than 30% of high school students get at least 60 minutes of physical activity per day (WHO). Our youth are overweight and have poor activity levels which puts them at risk for heart disease, stroke, diabetes, and some cancers (CDC, 2015) The US government recognizes this and has health initiatives supporting good nutrition, and increased activity levels (Subcommittee, 2008). The APTA has initiatives regarding obesity and a guide for physical therapists (APTA 2014). Obesity causes a multitude of musculoskeletal problems: alignment (genu valgus, pronated feet, ligamentous laxity), poor posture (lumbar lordosis, weak abdominal muscles, compensatory kyphosis), and decreased activity level because the energy expenditure required for functional tasks is just too great.

The components of physical fitness are: body composition, cardiorespiratory endurance, musculoskeletal endurance and flexibility. Body composition is easy to obtain using parent report of height and weight with an online BMI calculators (NIH, 2013). If a child is in the overweight or obese range, referrals should be made to appropriate providers such as physicians, nutritionists or weight management clinics. Anthropometric information is also useful to understand biomechanical reasons why a person can't do something: if you are overweight it might be difficult to reach to the floor, if you are underweight you might lack the energy to complete tasks.

As physical therapists, we are well trained to assess flexibility and musculoskeletal endurance. Manual muscle testing is inappropriate for most young children, but we can use functional measures that test musculoskeletal endurance including Timed Floor to Stand (Weingarten, 2006), 5 times sit to stand test (Wang, 2011), Floor to Stand Test (Weigarten, 2016). Teens may benefit from Functional Movement Screen (Cook, et al 2006) or the HiMAT. Cardiovascular measures include 2-minute walk test, 6-minute

walk test, Timed Up and Down Stairs Test (Zaino, 2006), Standardized Walking Obstacle Couse (Held, 2006), and Timed Up and Go (TUG). Cardiovascular Endurance can be measured via any of the timed walking measures or the Energy Expenditure Index. Many of these measures have published norms for youth with and without disabilities.

Body composition is inherently body/structure function measures per ICF Model. Most of the measures discussed (with the exception of BMI) are activity measures, but the results will correlate with body/structure function impairments. For example, if you have a deficit in the 5 times sit to stand test, it may correlate with muscle weakness (hip extensors? Trunk?), cardiovascular (can't complete 5 repetitions), or range of motion (can't extend hips to stand up straight). Assessing fitness and analyzing the results within the functional movement limitations that are present will lead to better outcomes. You will be able to fine tune our interventions to identify deficits.

IOPTP International Organisation of Physical Therapists in Paediatrics

## *Clinical Spotlight: Physiotherapy in the school setting. Then and now – a change in approach to achieve physical activity as a lifestyle norm for adolescents with severe disability*

### *Submitted by Kathleen Jakowetz and Hilda Mulligan (New Zealand)*

As all physiotherapists know, physical activity is important for children & adolescents because it is crucial to their physical, social, emotional and educational development. It is also important for community adjustment and transition into adulthood, creates meaningful life experiences through inclusion and participation, and is a basic human need and a basic human right.

Our Unit for adolescents with severe physical and/or cognitive disabilities is part of a state high school. Students are enrolled in the high school and depending on their individual needs, spend most of their time each day in the Unit and as much time in mainstream classes as they can manage. The individual student, his/her family, and school staff (including a physiotherapist) together work on a goals focused, individualized education plan to meet the communication, physical, and life skills the student needs to succeed as a functioning member of society. Acquisition of skills needed for participation in

leisure activities therefore forms an integral part of the Unit's programme. This is where the physiotherapist's skills and expertise come to the fore.

In contrast, physiotherapy at school for students with disabilities 20 years ago was quite different. Physiotherapy then consisted of 'whipping' them out of their chairs for passive movement, stretches and position changes. For the more physically able, active movements were encouraged. Students may have also attended swimming, horse riding or sport lessons but did so outside of physiotherapist's working hours and input. As the years passed, the number of children with disability attending mainstream schooling grew and so too did the types of disability they presented with. When the first student with autism arrived at our Unit, we didn't know what to do with him. He could move faster than we could, so did not require stretches! We soon learnt that our way of providing physiotherapy for these students needed to be adjusted. We found we needed to provide physical activities, as physical activity calmed him and led to a better frame of mind for learning. We also learnt that we could facilitate fun, inclusive, physical and group learning, and introduce new movement experiences for such students.

We then branched out and began taking children to a local school gymnasium and playground for half a day once a week. This new environment facilitated lots of different experiences that increased group interactions, and provided fun, while working with classroom teachers also enabled us to incorporate learning from other subject areas like math or English. For example, we used words to experience each session – under the rails, around the post, through the gap. We learnt to break down skills into smaller parts to facilitate student learning. When that opportunity closed, we continued but used local parks, playgrounds and other community facilities instead.

It was around this time that we realized that physical activity needed to happen regularly, be incorporated into the day and that the physical activity needed to be tailored to the individual needs of each student. To this end, we worked as a team with the classroom teachers to incorporate physical activity into the student's programmes. We've made sure the students' physical activity programmes met the New Zealand curriculum for health and physical activity and included at least 30 minutes of exercise daily. We got mainstream students involved with our students and their physical activity programmes. We also started taking our students to the local council-owned community gym and pool.

This was new for staff at the gym, as at that stage the gym wasn't seen as an inclusive facility for people with disabilities. We worked hard developing a relationship with the trainers at the gym, firstly by providing information about disability and its impact on people's lives. We also taught them how to adjust the gym exercises to the ability of the student. Over time we have built up good relationships with the gym and pool staff. To facilitate interaction between the staff and students, we use written, pictorial or electronic devices depending on each student's needs and abilities. Our aim is to set up our students to be able to independently access the local gym and pool after school hours and when they have graduated from school. We have also campaigned for more suitable equipment. The gym and pool now have an overhead hoist, up/down change table, rails in the changing rooms, parking for people with disabilities close to the building and equipment suitable for use by people in wheelchairs.

Physical activity improves general health and fitness. We have found physical activity and exercise does improve our students' overall health, for example, being less prone to respiratory infections and improved balance and walking ability. We also use physical activity to break up the school day, to de-escalate behavior and calm the students so they can concentrate on school work. We have also heard from parents that their children sleep at night instead of keeping their families awake with disruptive behavior.

There are of course barriers to achieving the goal of physical activity every day for every child. Examples are cost of access to facilities, the weather, and people not seeing the point and having low expectations of children with disabilities. Generally though, we find that as one door closes, another opportunity presents itself.

Physical activity doesn't only have to be based around exercise or sport. Many of our students are involved in drama, dance and practical classes such as metalwork, woodwork or gardening. Others obtain physical activity via work placements. In fact, we do WHATEVER WE CAN THINK OF to increase physical activity. Laughing is also good exercise. So is singing. We are opportunists with a "can do" attitude. We add new physical activity experiences as the opportunities arise.

In summary, fitness / exercise programmes and other ways of being physically active are embedded into the school day, and are tailored to individual needs and requirements. We use all opportunities we can find for activity, all school staff are an integral part of these activities, families are involved to continue activities out of school hours, and programmes are set up for students when they leave school. Yes, definitely different to 20 years ago!

**Acknowledgements**

We wish to acknowledge school students and staff at Hillmorton High School, Christchurch, New Zealand.








# Get Involved in the IOPTP! Join a Committee Today and become a part of this dynamic organization

http://www.wcpt.org/ioptp/committees

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*We are seeking submissions for the next newsletter.*

*Submissions are due by February 2017.*

*Please send submissions to Erin Wentzell at ewentzell@gmail.com*