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Polio Oz News

June 2011—Winter Edition

Body, Mind and Spirit!

In April 2010 Polio Australia, with input from the Post-Polio Network (NSW), conducted Australia's first three day "Polio Health and Wellness Retreat" in New South Wales. The purpose of the Health and Wellness Retreat was to provide a holistic approach to managing the Late Effects of Polio (LEOP) and finding life balance.

This chronic condition self-management program was based on a [2009 Polio Retreat](#) facilitated by [Post-Polio Health International](#) and held in Warm Springs, Georgia, USA. Each day focussed on a different aspect of health and wellness: Body, Mind and Spirit.

Four Australian polio survivors and Polio Australia's National Program Manager, Maryann Liethof, attended and brought the concept back to Australia. In April 2011, Polio Australia facilitated its second Polio Health and Wellness Retreat in Mt Eliza, Victoria, for 64 polio survivors and their respective spouses/carers/family.

There were 43 polio survivors and 21 spouses/carers/family members. People came from all over Australia (except the Northern Territory), with 27 'return' participants from last year.

Key note speakers were Dr Stephen de Graaff (Body), Dr Andrew Sinclair (Mind) and Maureen Anderson (Spirit). A list of all presenters can be found [here](#). A visit was also arranged to the Mt Eliza



2011 Retreat Group, Mt Eliza (above) / Keeping the Mind Active (below)



Rehab Centre where many polio survivors spent a good part of their childhood.

Throughout this edition of *Polio Oz News* you can read articles which have emerged from this Retreat including Pain

Management, Bracing, the Alexander Technique, Occupational Therapy, Dysphagia, Aids and Equipment, and Story Writing, to name a few.

Keep visiting Polio Australia's website for details of the 2012 Retreat in Queensland. 🌟

Presentations and Photos

- Read Dr Stephen de Graaff's "The Polio Body" [here](#).
- Read Dr Andrew Sinclair's "The Healthy Mind" [here](#).
- Read Abby Foster's "Hard to Swallow?" [here](#).
- Check out more 2011 Retreat photos [here](#).

2011 Retreat Participant Feedback

"We enjoyed the retreat so much. Apart from the excellent presenters, the other 50% of enjoyment came from the friendships and conversations with the other participants — something you can only get from a residential event, being with people who have shared experiences and understand the challenges and triumphs."

"I would like you to know just how much I enjoyed the weekend at Mt Eliza. For most of my life I just got on with it. Now I am finding the information about polio and the way it has affected me in later years very useful for helping me maintain my independence."

"I just wanted to thank you for the wonderful experience this weekend. I have come

away a different person. I met so many amazing people and was privileged to hear parts of their stories. These touched my heart and I came away humbled by the courage, fortitude and positive attitudes that they all had. There was much shared laughter and gratitude for families and supports such as yours." (volunteer massage therapist)

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Welcome from the President



Gillian Thomas
President

We are very excited to bring you Australia's first national newsletter for polio survivors, families, friends, carers and health professionals — *Polio Oz News*.

In this first edition our National Program Manager and Editor, Mary-ann Liethof, has put together a wealth of information which will start the collection of a great ongoing resource for polio communities.

As well as distributing

Polio Oz News to individual subscribers in Australia and overseas, every State Network will also receive it for onward distribution to their members in the form that best suits their State and their existing publications. The national articles and news items in each quarterly *Polio Oz News* will complement existing State Network newsletters.

We welcome feedback from readers on any aspect of *Polio Oz News*.

From the Editor



Mary-ann Liethof
Editor

In this, our very first edition of "*Polio Oz News*", we bring you a variety of articles and items which will be of interest to our polio community.

Many readers will know that we launched Polio Australia's e-Bulletin, "*Reflections*", last October to coincide with Australia's National and Post-Polio Health International's annual Polio Awareness Campaign: "We're Still Here!"

Polio Oz News will be produced on a quarterly basis for electronic distribution in June, September, December and March and will replace the *Reflections* of the previous month. Although there's usually no shortage of news, there are only so many hours in the day!

We would like to bring you a spread of information in this quarterly newsletter and welcome any

submissions, ideas for articles, or general feedback [here](#).

Of course, *Polio Oz News* will also be uploaded to [Polio Australia's website](#) and we encourage readers to either forward this newsletter on to others who you think might be interested, or suggest they subscribe on-line.

Polio Oz News is not available in hard copy, although Polio Australia is happy for this newsletter to be copied and sent to those who do not have internet access.

We hope you enjoy the read!

Mary-ann Liethof

The first step towards getting somewhere is to decide that you are not going to stay where you are.

John Pierpont Morgan

Mum Doesn't Like to Wear Shorts

My name is Michelle and I am a daughter of a polio survivor. My mother was five months old in the 1960's when she contracted polio in Germany. Her parents were very upset and were advised to move to a warmer climate to help my mother with her condition. At the time, her polio infection was a bit of a mystery as the epidemics had already ceased. As I was growing up I remember wondering why my mum limped and when I was old enough to understand she explained it to me. I recall being very upset for her and that she would just laugh it off saying, "I might limp but I can still catch you!"

The years spent at primary school were full of incidents where other children would ask me why my mother limped, "has she broken her leg?" they would ask. Also questions as to why, in summer, my mother would always be in jeans? "Mum doesn't like to wear shorts" was always my response. Then there were the students who would tease me about my mother and her "condition", as they termed it. Their attitudes towards my mother and others within the community who had disabilities used to really upset me and cause a lot of conflicts between myself and the popular kids at school. Children can be so cruel and hard on one another. I remember bringing this up with my mum and having a cry on her shoulder. What gave other kids the right to judge someone just because they have a limp or one arm shorter than the other? "Shell," she said, "what I don't hear and don't see can't hurt me."

At high school the other students understood more about the fact that polio was something my mother could not have stopped happening to her. It was not because she did drugs, drank heaps or was a rebel and defied her parents; it was just a neurological virus she caught as a young infant, which unfortunately she had no defence against.

I am now in my second year of Occupational Therapy at Deakin University in Geelong (Victoria). As an Occupational Therapist we look at a person's individual functional capabilities and assess means of aiding them to improve their overall participation in any activity in daily living they wish to be a part of that they may feel limited or restrained with due to their conditions and diagnosis. In other words we can help a large variety of people with a large variety of conditions to participate in an almost unlimited number of activities within their daily lives.

Initially, when asked by family members and friends why I wanted to become an Occupational Therapist, I couldn't find an answer to the question. Having now had the chance to think about it, and experience the past 18 months in the course, I do believe my interest in Occupational Therapy stems from growing up with mum having had polio. Growing up with her "not going to keep me down" attitude and her determination to succeed in whatever it was she put her mind to (including coming home from work at 6.00pm and having a gourmet meal on the table by 6.45pm), showed me that any physical limitation can be brought down to mind over matter if the individual has the will power and desire to achieve their goals.

So basically, as an Occupational Therapist, I can give individuals a little push and the support needed to get them motivated and on their way to success. 🌟

We were delighted to welcome Michelle, together with her mother, Therese, at the 2011 Retreat. Michelle was able to incorporate the Retreat Program into her course work and wrote the following "Personal Reflection" in her Report:

"This weekend away with my mother extended my knowledge of the polio virus and what it does to the neural pathways and muscles in the human body—the wasting effect. It also gave me an insight into other people's conditions and their struggles and past experiences—a world I never knew had existed—with being taken away from their families and having painful corrective surgery and long rehabilitation and other medical complications. My mother was definitely one of the luckier ones.

This weekend also gave me an introduction in what a person with post polio requires in their daily lives and where health professions such as occupational therapists, physios, doctors and so forth can assist. I really enjoyed the weekend away and am grateful for the opportunity to meet people with post polio and share in their experiences."

Our post polio bodies are in good hands with people like Michelle leading the way for our future health professionals. 🌟

—Ed



Michelle (front right) with mother Therese (front left) at the 2011

The Evolution of Pain and the Polio Survivor

by Dr Stephen de Graaff

June, 2011



Dr de Graaff Speaking at 2011 Retreat

Synopsis

It is important, where possible, to define the cause of one's pain. This allows for the appropriately targeted treatment. In the polio survivor situation a clear understanding of the sequelae of polio is necessary to ensure all preventative and interventional treatments are appropriate.

The perception of pain

Pain is what the patient says hurts. There are multiple factors that influence the perception of pain. These can include unique patient aspects, beliefs and concerns, psychological symptoms, cultural issues, physical symptoms, coping strategies and the social context in which the pain was felt. Pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Persistent pain is pain that continues beyond the usual time of healing or expected time of recovery, i.e. greater than three months.

The conundrum for the polio survivor is that the pain may be due to multiple factors, including post polio syndrome (muscular and/or neurogenic pain), overuse and delayed effects of polio (biomechanical pain).

Types of pain

Pain can be classified as:

- *Acute pain* – This is usually due

to definable acute injury or illness and has a definite onset and its duration is limited. It is often accompanied by anxiety and features such as fast heart rate, fast breathing, high blood pressure and sweating. Treatment is usually directed at the illness or injury causing the pain.

- *Persistent or chronic pain* – This results from a chronic pathological process and can have a gradual or ill-defined onset and continues unabated and may become progressively more severe. The patient will present as distressed and withdrawn and may have features associated with depressive symptoms, including lethargy, apathy, anorexia and insomnia. There may well be personality changes occurring due to the pain, with alterations in lifestyle and functional ability. Treatment in the persistent chronic pain picture is directed at an underlying disease where possible, as well as targeting psychological features and social supportive care.

At times patients may have certain activities that cause pain and this situation would be known as incident pain.

Acute pain can also occur in the persistent pain profile – an example of this would be longstanding headaches where they can have features of persistent pain, i.e. chronic headache, with exacerbations of severe headache pain (acute pain).

Common sites of pain in polio survivors

Osteoarthritis and associated pain can be noted in the back, neck, shoulders, hips, knees, hands and feet. There may be muscle pain associated with post polio syndrome. Strains in muscles and tendons are common and may involve the arm tendons, bursae over the hip and ligaments in the feet and hands. Problems with tendons and muscles around the

shoulders, elbows, hips and knees may also be noted.

Occasionally patients will complain of nerve type pain in the arm (arising from the neck) and in the leg (arising from the back). These are known as radiculopathies. Nerve compressions, such as carpal tunnel syndrome or ulnar nerve compression are also common.

It is important to understand that persistent pain is common, reaching maximum prevalence from the age of the late 40's and moving into the early 70's.

Quality of life and pain

Pain impacts upon one's quality of life. Physical wellbeing, social wellbeing, psychological wellbeing and spiritual wellbeing can all be affected. It is important to attempt to treat acute pain early to break the cycle of chronic pain. Where chronic pain occurs the patient can feel quite helpless and depressed, angry and out of control. This can be compounded by social stresses, financial challenges and reliance on treatments and medications.

The management of pain

It is important that a multidimensional pain assessment is undertaken in the polio survivor. The polio survivor may present with persistent pain and it is important to understand the biological, psychological, behavioural and social impacts of that pain.

The principles of disability prevention and management include:

- *prevention*
- *early detection and intervention*
- *partnership*

and subsequent to this a goal orientated rehabilitation plan. It is important that the polio survivor is treated with respect and dignity.

The use of cognitive behavioural therapy is important in the management of persistent pain. Initially one should address fears and encourage resumption of normal activities, with structured intervention such as physical

The Evolution of Pain and the Polio Survivor (cont'd)

exercise and applying the appropriate psychological support and management with encouragement to be active and take control again.

Education of the polio survivor with respect to pain involves the understanding of the causes of pain, methods of pain assessment, management and evaluation and setting out appropriate goals for treatment. Expectations of the treatment should be clear and not overly optimistic and options of treatment should be outlined. Medications have a role, but should be seen as augmenting the improvement of the quality of life of the polio survivor. It is important that the management of the pain is driven by the polio survivor and to outline the type of activities the polio survivor can do themselves.

Therapy Roles

Pain can be reduced by altering biomechanics, changing lifestyle and reducing the activity or developing discretionary strategies.

Pain management includes physical, cognitive and psychological strategies. Local measures such as hot and cold, ultrasound, TENS machines, massage and differentials can be of use. Exercises targeting joint protection and stabilization, as well as stretching, range of motion, and mobilisation can also assist. The use of orthotics and aids to minimise stressors and improve energy efficiency is justified.

The use of a pain diary to assess the severity of the pain, the behavior of the pain over the day, exacerbating or relieving factors, sleeping patterns, use of medication and functional behavior can also assist in the management of pain.

Psychological therapies are an excellent adjuvant in pain management. The use of psychological strategies does not mean that the pain is not real and does not mean that the treating practitioner is not taking the pain seriously.

Medication Role

The management of pain is not by medication alone. It is a combination of factors including the aforementioned physical therapy, cognitive and psychological therapy, self management and medication to augment these.

Medications in pain management can include simple analgesics such as Paracetamol, non-steroidal anti-inflammatory drugs, anti-depressants and anti-seizure medications to modify the neurological component of the pain, pulses of oral steroids and local and systemic injections where appropriate. Muscle relaxants and anti-spasticity medications may well be of value.

The use of opioid medications is considered where the non narcotic analgesics are not having an effect on the pain.

The principles of using analgesics include selecting the drug appropriate for the type and severity of the pain, following an analgesic ladder starting at simple analgesics to ultimately strong opioids, using adjuvant analgesics such as neuromodulators e.g. anti-depressants and anti-seizure medications, but one should never use a placebo.

Ongoing Management

Regular assessment of the situation for the polio survivor with pain is essential. This is undertaken to maximise functional wellbeing, optimise pain relief, minimise side effects and engender the best quality of life for the polio survivor.

Final Comments

As previously mentioned, in the polio survivor situation a clear understanding of the sequelae of polio is necessary to ensure all preventative and interventional treatments are appropriate. Optimal management of the patient with reduction in pain and return to the previous role is a primary goal associated with improved function or maximal functional improvement whilst using limited resources most efficiently. In essence, we are managing the pain and improving quality of life. 🌟

[Dr Stephen De Graaff MBBS, FAFRM is the Medical Director of Pain Services at EPWORTH REHABILITATION – RICHMOND](#)

Visit [Chronic Pain Australia](#)

Pain and Suffering

The following is an extract from a book by polio survivor and Professor of Clinical Psychology, [Rhoda Olkin](#), entitled: [What Psychotherapists Should Know About Disability](#) (reprinted with knowledge of the author)

"Pain" is not the same as "suffering". This is an important distinction, because persons with chronic pain often do suffer, and in a sense the treatment mostly is to reduce the suffering and less so the pain. When thinking about living with chronic pain over the long term, a client needs to understand that it is not synonymous with long-term suffering. A second important distinction is between cognitions that tend to exacerbate the experience of pain and causing or being responsible for one's own pain. When clients are taught ways to ameliorate pain by changing beliefs and behaviours, it is easy for them to hear this as blame for causing or exacerbating their pain. After many doctor visits in which they are told their pain is psychogenic or disproportionate to an injury, such persons become sensitized to intimations of blame. Treatment can inadvertently tap into such feelings by suggesting responsibility for lessening pain. The best way to handle such feelings is directly and openly, with a discussion of the meaning of getting better, and if the client doesn't raise these issues the therapist should. 🌟

Embracing the Brace

by Peter Willcocks

May 2011

- 1998 Golly gosh – I got sick – try lots of exercise.
- 2000 Golly gosh – I got worse – need lots more exercise.
- 2004 Prostate Operation – Golly that hurt!
- 2004 Dropping my bundle – Maybe Polio Stuff? "Nah", GP said, "if it is, nothing can be done about it anyway".
- 2005 May: Neurosurgeon confirms nothing that bad about my spine but some muscle wastage, "Hmm . . . interesting . . . probably best that I retire." I didn't.
- 2005 July: Dr Stephen de Graaff diagnosed Late Effects of Polio and most likely Post Polio Syndrome. Prognosis – learn to manage well and work until 65 at least.
- 2005 Rehab – outpatient lots of good stuff, good recovery.
- 2005 Began using ventilator CPAP (Continuous positive airway pressure)
- 2005 Physiotherapist suggests bracing – NOT GOING THERE – I am not going to wear callipers again – learned to walk slower.
- 2007 Work place injury – damaged nerves in left shoulder.
- 2008 Start to use walking stick more often than not.
- 2009 Mobility Scooter.
- 2009 Start to use crutches.
- 2010 Discussions about Back Surgery to relieve pain.
- 2010 Bought wheelchair.
- 2010 Changed ventilator from CPAP to CFlex (CPAP with a variable positive airway pressure).
- 2011 Fitted with GRAFO (Ground Reaction Ankle Foot Orthosis).

Now we have some history let's move back to 2005, I missed out on an opportunity. I let vanity get in the way of my good health. The physiotherapist that was helping me suggested bracing – well it was

like telling my granny that she was old. There was no way that I was going to go back into callipers. Those bits of iron that were 'one size fits all' strapped into place with leather straps that plain just hurt when you moved. Of all the bits of help that I was offered, bracing was perhaps the most important. Simon, my wonderful physiotherapist, someone for whom I have the greatest respect, backed off for a year or two but kept in regular contact.

It took a while but in 2010 Simon caught me with the light turned on. I was using a scooter, a wheel chair and, more often than not, crutches. I was looking enviously at special vehicle conversions for loading wheelchairs. I was frustrated by curbing, access ramps into building, lack of handles in toilets to hang onto, and embarrassed that every time I went somewhere concessions had to be made for me.

I had also been fortunate that I had bumped into [Ron Bell](#) (pictured below) in 2008 at Polio Day in Frankston (Victoria). Ron was standing next to a couple of doctors and 'non polio's'. Ron stood tall, he didn't flinch or wobble, they did. They were not supported by Horton Stance Control. I was fascinated. I



crept around Ron like a mongrel dog inspecting its prey, looking for any sign of weakness. Ron just stood there solid as a rock. How can this be? How can he walk with such ease? I just wondered "of course Ron's polio leg was far worse than mine!"

People talk about life's journeys –

I'm more into *excursions* or *trips*. Sorry, I should have been more honest – *excuses* and *falls*. Either way, I fell at the right time and had Simon to pick me up. He tried all the stretching and exercise stuff that he is known for but quad muscles just got weaker and the pain became more and more unbearable.

OK . . . I WILL WEAR CALLIPERS – anything to stop the pain!

What a process getting braced is. Before things started to happen in any physical sort of way it took a couple of months of assessments. You know the type. Will he or won't he? Will he be able to put up with the process, the pain, and the wait? Let's just watch him until we are sure. All this, of course, happened in the background. I sort of gathered what was going on and had been prompted by such supporting language as "Bracing is not for everybody, you know.", and "Sometimes we find that bracing just doesn't work."

I started to ask around and, to my surprise, I discovered many who had tried bracing on their legs but found it more comfortable when the braces were in the wardrobe. Knowing the folks pretty well, I was surprised as I knew them to be tough, no knocks polio sorts. They were all people that I respected. So when I was next told, "Sometimes we find that bracing just doesn't work", I was ready. And although the "will he or won't he?" hadn't been answered, it was pretty obvious to all that I was ready to "take on a new challenge", as they say.

[Polio Services Victoria](#) had a 12 month waiting list. Stephen (Orthotist) and Simon recognised that the sooner I got braced the sooner the falls would be under better control. Simon & Stephen consulted with Darren Pereira at [Neuromuscular Orthotics](#) and an appointment was made for two months hence. Darren proposed a [Horton Stance Control](#). I was quite excited about get fitted with the "real thing".

Embracing the Brace (cont'd)

After Darren's assessment I was given a Victorian [Aids & Equipment](#) application for funding form to complete with my GP and return for Darren to complete. The current maximum subsidy for a leg orthosis is \$2,200. Darren gave me rough indication of cost somewhere between \$6,000 and \$7,000, for some people the cost could be over \$10,000 depending up the type of bracing. Bracing is such a fine art of minimalism to create a light weight brace and from what I now know – a lot of trial and adjustment. It was hoped that my brace would weigh in under 2kg. I have heard of modern bracing weighing as much as 5kg and more. Like many polio survivors my hip is a bit dodgy after years of throwing my polio leg in front and swinging the body after it. Clumsy way of walking but it works.

Four months later the Aids and Equipment funding was approved so time for another appointment with Darren. It took time to get an appointment. He was so busy BUT I now know that there was a very good reason for this, more about that later. When I arrived for my appointment a below knee plaster cast was made, that brought back memories but thankfully the plaster was not hot and did not stay on for weeks. Darren consulted with physiotherapist, Louise, and together they discussed my leg and best options. Any questions? "Will I be able to take my dog for a walk and will I be able to bend down and pick up his doggy-doo?"

I was aghast when they both suggested holding off on Stance Control because they were worried about my hip. It was proposed that I have a GRAFO (Ground Reaction Ankle Foot Orthosis) made. I was disappointed – I wanted the sports model. The advantage of a GRAFO is twofold: it weighs less, gave me time to work with bracing and, when ready, Stance Control could be fitted to my GRAFO. The GRAFO that Darren made was basically the bottom half used with Stance Control.

When the day came for fitting my new brace, I was anxious to say the least. Would it work? And, if so, how well? Darren slid my foot into the brace. It slid on comfortably. Immediate relief. It belonged. Darren removed the brace, gave me something to read, disappeared into his work shop and banged out a couple of adjustments. Once back, on the GRAFO went, on with the shoe. But I couldn't get it on myself. In the end Darren had to do it. It would get easy with practice he assured.

I drove home with GRAFO and discovered another advantage of the brace without any weight on it – the toe of the foot lifts up. It's hard to keep your foot on the gas! Got home, showed it off and spent the rest of the day as proud as punch.

First Day: on my own. I struggled and struggled but I just could not get it on my shoe. Exhausted, I eventually asked my partner to help.

Day Two: I struggled again and just got my shoe over the brace before I collapsed. I stood up and my foot really hurt. Don't give up. Give Darren a call. "Come in tomorrow." More adjustments were made.

During the first week I had to ask my 16 year old son and 11 year old daughter to 'shoe' me. They did, as if it was just a matter of fact. It wasn't for me – where was my independence if I couldn't even put the brace on? I wore it all day, afraid to take it off. The pain from my quadriceps and spine had almost disappeared.

Six Months later: I soon learnt how to put my shoe on over the brace. I must admit this improved as the inflammation in my polio leg decreased. For the start weekly visits became the norm. Each time, more adjustments. I now realised why it took so long to get an appointment with Darren. Once a brace is fitted, adjustments and support are an

essential part of the process. Each time I ring to let Darren know of a problem, I always get an appointment within days. It might take a long time to get an initial assessment with an orthotist as they provide ongoing support.

I have now been wearing the brace for over six months. It still hurts sort of, my foot keeps rolling in the brace. Each time it is supported - great for a couple of weeks, then it rolls a bit more and, unfortunately, quadriceps and back pain has returned. I am becoming unsteady on my feet. My next appointment with Darren is two weeks away. Perhaps I am now ready for stage two; Stance Control. And I am comforted that my wheelchair still sits idle in a garage of dust. I am not frustrated by curbing, access ramps into buildings, lack of handles in toilets to hang onto, and I am lucky that I can go anywhere when I choose. I can walk my dog and pick up doggy-doo without joining it.

I last saw Darren three weeks ago. I was tired and unsteady on my feet. He suggested I rest and recover which, we both knew, would take a polio survivor time. It was quietly understood that I had been doing too much; embracing the brace. 🌟



Peter Willcocks is a Co-convenor of Bayside Polio Support Group in Victoria

Stance Control for Lower Limb Mobility

by Darren Pereira



Knee Ankle Foot Orthoses (KAFOs) are prescribed for patients who have hip and knee weakness, with or without foot pathology, who cannot be adequately managed in a below knee device. Conditions in which this may be common include Polio, Spinal Cord Injury and Stroke. Patients with severe lower limb instability may require their knee to be locked in extension during stance to create a stable limb and enable safe ambulation. Traditional KAFOs keep the knee extended throughout the gait cycle requiring one or more compensatory movements such as hip hiking, circumduction and vaulting to clear the limb during the swing phase. These gait deviations substantially increase the mechanical work of walking, particularly at hip level. In clinical

practice, many patients often reject the use of a KAFO after a short period of time. The literature reports this rejection rate to be as high as 58–78%. Studies have demonstrated that the high rejection rate of KAFOs are primarily due to the increased energy demands of walking with a locked knee.

Darren Pereira and colleagues recently published a paper on the benefits of stance control in this population. The full article can be made available on request or can be found at: *Davis, Bach, & Pereira, 2010, The effect of stance control orthoses on gait characteristics and energy expenditure in knee-ankle-foot orthosis users. Prosthetics and Orthotics International: 34(2): 206–215* and the abstract is as follows:

Knee-ankle foot orthoses (SCO) differ from their traditional locked knee counterparts by allowing free knee flexion during swing while providing stability during stance. It is widely accepted that free knee flexion during swing normalizes gait and therefore improves walking speed and reduces the energy requirements of walking. Limited research has been carried out to evaluate the benefits of SCOs when compared to locked knee-ankle foot orthoses (KAFOs). The purpose of this study was to evaluate the

effectiveness of SCOs used for patients with lower limb pathology. Energy expenditure and walking velocity were measured in 10 subjects using an orthosis incorporating a Horton Stance Control knee joint. A GAITrite walkway was used to measure temporospatial gait characteristics. A Cosmed K4b2 portable metabolic system was used to measure energy expenditure and heart rate during walking. Two conditions were tested: Walking with stance control active (stance control) and walking with the knee joint locked. Ten subjects completed the GAITrite testing; nine subjects completed the Cosmed testing. Walking velocity was significantly increased in the stance control condition ($p=0.001$). There was no difference in the energy cost of walking ($p=0.515$) or physiological cost index (PCI) ($p=0.093$) between conditions. This study supports previous evidence that stance control knee-ankle foot orthoses increase walking velocity compared to locked knee devices. Contrary to expectation, the stance control condition did not decrease energy expenditure during walking.

[Darren Pereira](#) is the Director of [NeuroMuscular Orthotics](#) and the Principal Orthotist

The Young Ones

Darren also currently sees approximately 150 young polio adults (under 30 years old) who predominantly contracted their polio on the sub-continent, southeast Asia and Africa.

"Their orthotic issues are a little different to our older polio community as many have either not had orthotic management or been poorly managed with orthoses during their childhood/teen years," reports Darren. *"Many present with far more severe deformity and require a combination of orthopedic opinion/management, rehabilitation and orthotic management to enhance ambulation and function."* Darren goes on to say, *"With such tremendous advances in technology available to the young adult, the client is also seeking orthoses that provide recreational opportunities as well as optimal orthoses for walking."*

The question is, if just one clinic is seeing 150 young polio survivors, how many are there throughout Australia? This number goes to prove that we will still be requiring services for polio survivors well into the future. This is also reflected in ["Experience with Younger Patients in a Post-Polio Clinic: A case series"](#) by Judith Glaser, DO and Lauro Halstead, MD in the USA. ●

—Ed



[Ramesh Ferris](#) is one of the "young ones" who was born in India and raised in Canada. Ramesh is an inspirational speaker on polio eradication and an accomplished sportsman.

From Aids & Equipment to Assistive Technology Solutions

An Update on Policy and Funding in Australia

by Natasha Layton

Who uses assistive technology?

Each one of us is likely to use some form of assistive technology (AT) or environmental adaptation today - this might be a pair of reading glasses, a handrail along a staircase, or a kerb cut between pavement and roadway to enable easy manoeuvring of a shopping trolley or wheelchair.

Many of us, particularly if we are living with the effects of impairment, are also likely to have discovered the close relationship between human capabilities, our environment, and assistive devices. For example, a bathroom with a large stepless shower, a rimless shower screen, and a built in ledge, may remove the need for assistive technology devices such as a shower stool or grab rail, or indeed for some human assistance. Alternately, a roller bench device may eliminate the need for costly bathroom renovations, and can enable use of a shower-over-bath without fear of falling.

Person, environment, and activity: a myriad of human variation

As humans, we all have a wide variety of capabilities and characteristics which are dynamic over time as we develop, age, and move through life tasks and roles.

We are also unique in terms of our social and physical environments - a single urban dweller has many different resources and challenges when compared with a rural caregiver or an outer suburban breadwinner. And finally the activities or tasks which we wish to accomplish in the course of our day or our lives are unique to us, as well as the meanings we attach to them. For example, getting showered and dressed may not hold the same importance to everyone: an individual living with low energy and endurance may elect to use personal support, and

to bathe every second day, and instead expend their energy on more valued participations such as parenting, or some hours of work.

A myriad of solutions

Add to this human in their unique context, the huge range of enabling technologies on the market today. Nearly 20,000 assistive devices are listed on the international assistive technology website [ABLEDATA](#) and the International Standards Organisation (ISO 9999) lists nearly 850 separate categories of assistive device for persons with disabilities (2007)¹. Combining innovative devices with suitably modified homes and communities, and elements of personal care or support, is extremely effective in minimising the impact of impairment on life outcomes (ref: The Equipping Inclusion Studies, 2010)² Given the reality that all three elements are ingredients to an effective solution to daily living despite impairment, a broader definition has evolved:

Assistive technology solution:
... an individually tailored combination of hard (actual devices) and soft (assessment, trial and other human factors) assistive technologies, environmental interventions and paid and/or unpaid care.

(AT Collaboration n.d)

Choosing the most effective solution - the role of Soft Technologies

With so many options in the market, establishing the best solution to enable you to do the things you wish to given your own particular needs and situation, can be complex. Unlike buying a car or a fridge, assistive technology devices can have impacts upon a person's functional capacity and ongoing health, for example an ill-fitting mobility device can lead to postural and pressure care issues, or purchasing a scooter without a trial of its turning circle in the home environment might limit its usefulness. While some equipment

suppliers are knowledgeable about their products, setting up the product for your particular need and with regard to your specific environment is not always within a supplier's expertise or capability.

Soft Technologies is the term used to describe the human or non-tangible elements which support decision making for assistive technology devices. Research shows much better outcomes when a device (hard technology) is coupled with appropriate soft technology support to assess, prescribe, trial and adapt as required.

There are a number of ways to source soft technology support, for example:

- research available equipment through [Independent Living Centre](#) databases
- find out about available funding and ways to access allied health professionals through local community health centres or aged care assessment services
- collaborate with allied health professionals such as occupational therapists, speech pathologists and orthotists to plan and implement the best AT solution for you



Swan Bath Seat

(Cont'd Page 10)

From Aids & Equipment to Assistive Technology Solutions

(Cont'd from Page 9)

How well is society providing needed equipment and adaptations?

Despite a patchwork of over 100 aids and equipment programs across Australia, there is evidence of substantial problems from a consumer perspective. In Victoria for example, less than 13% of the device categories on the market are actually on the list of allowable equipment of the State funding body, and evidence of major funding shortfalls is related to extensive waiting lists^{3,4}. Other issues include:

- High levels of unmet, partially met or inappropriately met need
- Lost productivity and reduced participation in all aspects of life including: personal aspirations, employment, education, family and community life
- Cost shifting to individuals and families who can least afford it through high co-payments for some equipment, limited lists of available equipment in public schemes (often including no or very limited funding for home and vehicle modifications); and a patchwork of eligibility requirements
- An ad hoc and uncoordinated patchwork of aids and equipment programs, with dysfunctional consequences such as equipment provided to assist at work not being able to be used in the community or at home
- Cost shifting to more expensive down-stream services
- High levels of administrative and structural inefficiencies
- Inability to deliver on a range of commitments and obligations such as the UN Convention on the Rights of People with Disabilities, and the intended outcomes of the National Disability Agreement and the National Disability Strategy.

Taking action to improve aids and equipment provision to Australians

At an individual level:

Ricky Buchanan (a blogger and equipment user) has set up the Obstructed Technology website to capture stories of people's issues with the aids and equipment system. Experiences of under-funding, over-complication and slowness in Australian Assistive Technology Schemes are invited, and used to argue for better systems and outcomes for all technology users. See the full story [here](#).


At a State level:

A number of State-based organizations are involved in lobbying for better aids and equipment funding and services. Victoria is the only state which has formalized this into the Aids and Equipment Action Alliance, which is a non-profit, multi-member group consisting of people with disabilities, advocates, health professionals and service providers working to improve the availability of aids and equipment to aged and disabled Victorians. In its fifth year of operation, the AEAA have conducted research into the unmet need for AT in Victoria, and been involved in the current government review of aids and equipment funding to the State. The AEAA are in regular contact with a variety of organizations from other States and Territories, sharing ideas and encouraging the formation of more State-based lobby groups. Further information is available at [AEAA](#).

Another initiative is Victoria's [Universal Housing Alliance](#), which is working to improve the accessible features of new buildings and therefore future-proof housing stock.

At a National level:

The National Aids and Equipment Reform Alliance (NAERA) has been formed to lobby for a national aids and equipment policy framework and strategy. NAERA believe that

aids and equipment is an essential prerequisite to achieving the intended outcomes of many government programs and policies, and a more inclusive society. Therefore, the timely and effective provision of aids and equipment must move from the fringes of public policy, and be more clearly recognised and delivered as an essential service. NAREA consists of peak bodies from across the health, aged and disability sectors, and is co-ordinated by Dr Michael Summers of MS Australia. 

¹ ISO9999. (2007). *Assistive products for persons with disability — Classification and terminology*: ISO.

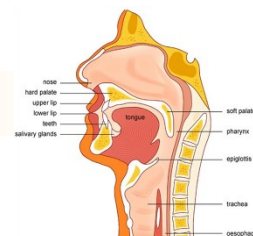
² Layton, N., Wilson, E., Colgan, S., Moodie, M., & Carter, R. (2010). *The Equipping Inclusion Studies: Assistive Technology Use and Outcomes in Victoria*. Melbourne: Deakin University.

³ Wilson, E., Wong, J., & Goodridge, J. (2006). *Too little too late: Wait times and cost burden for people with a disability in seeking equipment funding in Victoria*. Melbourne: Scope (Vic).

⁴ Coalition for Disability Rights. (2006). *Call to political parties - 2006 Victorian State Election*. Melbourne Coalition for Disability Rights.



[Natasha Layton](#) is an Occupational Therapist—she is currently studying for her PhD



Hard to Swallow?

by Abby Foster,
Speech Pathologist

Abby Foster was one of the presenters at the 2011 Health and Wellness Retreat. At the time, Abby was working at St Vincent's Hospital but has since left to pursue further studies. Below is a composite of her presentation notes and the full version can be found [here](#).

Swallowing can be divided into three phases and swallowing difficulties can occur in any one of them:

1. What happens in the mouth (Oral Phase)

- Sealing your lips
- Chewing
- Mixing food with saliva
- Forming a "ball" with the food
- Moving the food into the throat

2. What happens in the throat (Pharyngeal Phase)

- Start the swallowing reflex
- Airway is sealed to stop things going down the wrong way or choking
- Squeezing food down the throat

3. Problems that can happen in the food pipe (Oesophageal Phase)

- Dysphagia
- Impaired swallowing function
- Difficulty moving food from the mouth to the stomach

Bulbar Signs

Bulbar 'signs' are difficulty breathing, clearing throat, speaking, singing or swallowing.

Post Polio Syndrome

- New signs of muscle weakness
- Difficulty walking, breathing or swallowing

Many people are only mildly aware of any changes, and others who don't think they have swallowing difficulties actually do.

*Source: Sonsie, B. C. (2010). [Swallowing Difficulty and the Late Effects of Polio](#). Post-Polio Health, 26 (3), p. 7

Is it muscle over use?

Over use may be responsible for swallowing problems that are emerging as new symptoms or reappearing in people who previously recovered from their earlier swallowing difficulties:

- 'Over use' of remaining 'nerve fibres' and muscles can result in slow deterioration
- Weakening of the muscles of the face, palate, tongue, throat and lips
- Changes in the muscles of swallowing may also result in changes to speech as many of the muscles are the same

What are some of the signs of swallowing difficulty?

A wide but consistent range of complaints noted including food sticking in the throat, trouble swallowing pills, coughing during eating, food backing up from the throat, eating a meal takes longer, and unintentional weight loss. A self-assessment questionnaire for dysphagia (swallowing disorders) listed below can help determine if you need further attention.*

If you answer YES to more than three of the following questions, seek consultation from a Speech Pathologist.

If you have many of these symptoms, contact a Speech Pathologist who specialises in dysphagia. They may be located in a hospital, community health centre, or private clinic. Visit [Speech Pathology Australia](#) to help you find a Speech Pathologist in your area.

Key Messages

- Swallowing difficulties are not uncommon in people who have or have had polio
- Take time to know your own swallowing, and know the signs of when to seek help
- Managing swallowing difficulties is a team approach
- You are the key member in the team
- Your Speech Pathologist is important too!
- Problems with swallowing can happen in your mouth or your throat
- Thorough assessment can help your Speech Pathologist to tailor a management plan for you
- Ask questions if you're concerned – and even if you just want to know more
- Seek help if you need it 🌈

Do you have difficulty swallowing?	YES	NO
Do you have difficulty chewing hard foods?	YES	NO
Do you have an overly dry mouth?	YES	NO
Do you have excessive saliva or drooling?	YES	NO
Do you cough or choke during or after swallowing?	YES	NO
Do you have a feeling that food catches or remains in your throat?	YES	NO
Do you have continual mucous dripping into the throat?	YES	NO
Does your voice become hoarse or gurgly after you swallow?	YES	NO
Do you have food particles backing up into your throat or mouth?	YES	NO
Do you have heartburn or indigestion?	YES	NO
Do you have difficulty swallowing liquids?	YES	NO
Do you have difficulty swallowing solids?	YES	NO
Do you have difficulty swallowing pills?	YES	NO
Do liquids sometimes come out of your nose?	YES	NO
Does it take longer than everyone else to eat your meal?	YES	NO
Have you had episodes of airway obstruction/choking during eating?	YES	NO
Have you had frequent pneumonia or aspiration pneumonia?	YES	NO
TOTAL:		

Alexander Technique—Making Effort Easier

**By Jane Coker
(Dip AT, Mem AUSTAT)**



I recently led an Alexander Technique (AT) workshop at Polio Australia's 2011 Polio Retreat. It was part of the "Mind" themed day, which is appropriate because AT is all about consciously choosing how you "use" yourself (and hopefully making choices that help rather than hinder you in your daily life).

Together the workshop participants explored sitting in their chairs in ways that used the minimum of effort and tension. They explored how they had come to their habitual ways of moving and sitting. Some obvious influences through their lives had been difficulties they experienced due to polio – compensating for immobility, stiffness, pain etc. – but some people also identified other possible reasons for their postural habits such as fear, shyness or embarrassment causing them to withhold themselves and habitually contract. Finally all but one of the participants gamely agreed to lie on their backs on the floor for 20 minutes in the AT "Semi-supine" position known also as "Constructive rest". With feet flat on the floor, knees pointing to the ceiling and heads on a few paperbacks, the spine is elongated and therefore compression between the discs is eased. The discs themselves re-fill with the fluid that keeps them plump and able to absorb impact, while all the big muscles of the back as well as the neck, shoulders, hips, arms and legs get a chance to return to a less contracted state.

I helped those whose stiffness or immobility prevented them from taking this posture to find practical ways to lie which kept their spines

long and their limbs comfy. And I made it clear that anyone who wanted to get up before time was up was up was more than welcome to do so, so that no-one would feel "stuck" if it was not comfortable for them. Everyone stayed on the floor!

Daily practice of this lie-down conditions the musculo-skeletal system as well as the nervous system and is one of the key ways in which people who learn AT start to re-train their minds and bodies to stop, think, rest and be more easeful in their daily lives. After 20 minutes on the floor, and with some mutual assistance in getting up without undoing all the good work, people said they felt "refreshed", "taller", "more relaxed", and that included the participant who had chosen to take part in the exercise in a seated position.

One of the earliest Alexander Technique teachers was Judy Liebowitz – an American who came to the Technique in the 1940's because she had had polio as a child. With the muscle strength in her feet at level 1 (as it was then measured), "muscles like iron", a severe limp and her body becoming increasingly distorted she says "I was hiding behind my disability – I didn't want to meet people, go out and talk and do things" (from her Book *Dare to be Wrong* Pub: Mornum Time Press).

The Alexander Technique is about our thinking and how that affects what is going on in our bodies. Judy says "The Technique helped me feel better about myself. There are many things I can't do but now I was able to centre myself and move more easily and freely. I was able to do things I couldn't do before. For instance, if I was walking down the street and happened to drop my glove, in the past I couldn't bend down to pick it up because I didn't have anything to lean on, but with the Alexander Technique I was able to bend without needing any extra support" She also says "The major

part of my limp disappeared."

Judy then trained as an Alexander Technique Teacher. She says she found it fascinating "because dealing with the way a person moves is dealing with the way a person thinks".

The way we think can imprison us or it can free us. A participant in a recent workshop I led with Polio people said something like "Polio people are good at being adaptable. We have to be – we have to deal with change all the time." This is true of many people living with disabilities and other disadvantages in this society and responding to change with a flexible attitude is certainly a key to survival, but we can all go further: We can invite change in ourselves. We can think outside the square and change how we move for the better. Alexander Technique gives us the tools with which to do this, including

- Body mapping – increased understanding of how our bodies are designed to work and how we as individuals may be unconsciously preventing them from working as best they can.
- Slowing Down – "Don't just do something – Sit there!" Practical approaches to prevent us from habitually rushing into action. We learn to pause and choose ways of moving that do not cause long-term damage and are more efficient.
- Conscious control – we learn to think so that we can free our necks in order to allow our heads to move, our bodies to lengthen and widen and our spine and limbs to be springy and strong.
- Co-ordination – we learn how each part of our body is connected to every other part and how to think clearly in order to use our whole body for each action, not just bits of ourselves.
- Patience and self love – we learn to accept that we are who we are and our bodies and minds have limitations. We start

Alexander Technique—Making Effort Easier (Cont'd)

from this point and move forward at our own pace, forgiving ourselves for our mistakes and inadequacies and honouring our personal stories.

Alexander Technique requires patience. It's not like going to the chiro for a quick fix. Once on the journey people continue throughout their lives to learn and discover new things about themselves and their habits of thinking and movement. But it gives us autonomy, control, optimism, a positive sense of what our bodies and minds can achieve. It puts us in the driving seat so that we can understand our pain and physical limitations, make conscious choices that are in our

own best interests and use our bodies to their best advantage.

To return to the words of Judy Liebowitz: "We don't know where we're going; we only know where we have been. And while much is learned or experienced on an unconscious and subliminal level, true control comes from conscious choice. Practicing what FM Alexander called "constructive conscious control" brings into sharper focus all sorts of awareness – kinaesthetic, visual, intellectual, conceptual, sensory, tactile, and philosophical, etc. One is dealing with the whole psychophysical entity, and let us not forget the soul!"

If you want to know more about

Alexander Technique contact the Australian Society of Teachers of Alexander Technique (AUSTAT)

Jane Coker is available for private lessons in Brunswick. She can be contacted on 0400 053266 or email jane.coker@optusnet.com.au

The following comment is feedback from one of the participants who attended Jane's session:

"Reminded me (yet again!) that I am in charge of my posture and to be aware of this and how it affects other aspects of my body."

- Ed

Chinese Medicine in Support of Polio Survivors

by Dr Andrea Galgoczi-Kratochvil

The prime symptoms polio survivors often present with are FATIGUE, MUSCLE WEAKNESS and PAIN. Managing these symptoms is a vital factor in maintaining and potentially improving their quality of life.

The recent Polio Health and Wellness Retreat held in Mt Eliza, Victoria, provided an in-depth overview of various treatment options available to patients including 30-minute try-out sessions of the benefits of Acupuncture, a modality of Chinese Medicine.

The purpose of this article is to give a brief introduction to Chinese Medicine and how it can contribute to the management of polio related patient complaints.

CHINESE MEDICINE IN A NUTSHELL

Chinese Medicine is an ancient healing system of primary health care, the history and use of which in China and East Asia dates back several thousands of years. Chinese medicine embraces the logic that balance is reflected in good health, whereas illness manifests as a result of imbalance. Chinese medicine

treatments aim to restore balance in the human body.

Chinese medicine offers a variety of techniques used as stand-alone treatment options. In order to increase treatment efficacy two or more techniques are usually used in conjunction. The most frequently used therapeutic modalities are the following:

• Acupuncture



Acupuncture is a safe and effective treatment modality to stimulate body energy and blood circulation in order to restore balance in physiological functions. The technique involves shallow insertion of fine sterile needles into specific points of the soft

tissue of the body. Acupuncture treatments are generally painless. The sensation associated with needle insertion is a brief, dull ache. Needles are retained for about 20 to 30 minutes, during which time the patient is encouraged to relax. Electro-stimulation may also be used to enhance the efficacy of treatment.

• Cupping

Cupping is another therapeutic technique, which uses small jars to create a vacuum in order to promote blood circulation, alleviate pain and release toxins and tension from the musculoskeletal surface of the body.

• Moxibustion

Moxibustion is a therapeutic method that involves applying heat to certain locations of the body. Mild heat is generated in the form of burning moxa sticks prepared from the leaves of *Artemisia Vulgaris*, a species of chrysanthemum. Heat penetrates into the muscles and regulates the energy and blood circulation in order to improve certain conditions.

(Cont'd Page 14)

Chinese Medicine in Support of Polio Survivors (Cont'd)

(Cont'd from Page 13)

• Auricular Therapy

Traditional Chinese medicine has been supplemented over the past 60 years by a new form of acupuncture called auricular acupuncture. Dr Nogier, a French doctor, mapped and decoded the functional correspondence between certain points of the ear and various organs of the body. Applying tiny needles to auricular (ear) points results in a prolonged stimulation of the affected body parts.



• Chinese Herbs

Chinese herbal medicine is based on thousands of years of clinical practice combined with modern laboratory research. According to legend, it dates back to the times of the Yellow Emperor (third millennium BC) when the first herbalist in China gathered and documented the curative effects of herbs.

Today there are more than 400 substances commonly used in Chinese medicine governed by strict distribution rules in Australia. Raw herbs are taken as teas, but Chinese herbs are also available in manufactured form as pills, tinctures or external ointments and plasters.

MUSCLE WEAKNESS AND ATROPHY - THE CHINESE MEDICINE VIEWPOINT

Chinese medicine has been known for centuries to address muscle weakness and atrophy. Whether characterized by muscular weakness, loss of motor control, wasting or paralysis, sudden or gradual onset muscle weakness and atrophy is caused by the pathology of the muscle tissue or of the motor nerves that supply the muscles.

According to Chinese medicine an external pathogenic invasion is the cause of paralysis and muscle wasting we now associate with poliomyelitis. Initially a febrile disease with its usual signs and symptoms proceed to the depletion of body fluids and energy, which in turn are not able to nourish and maintain the muscles and sinews. Constitutional weakness may predispose a patient to more easily develop muscle weakness, while other factors such as inappropriate diet and lifestyle or humid climate may also accelerate the deterioration process.

Muscular weakness and wasting patterns are difficult to treat;

since cure is unlikely where nerves and muscles are seriously damaged. Acupuncture and herbal treatment, however, can be effective treatment tools by invigorating blood supply to the affected organs and body parts, as well as strengthening the patients' immune system and overall constitutional strength.

Chinese medicine - while rarely curative - can often assist physical functioning of patients affected by polio and potentially arrest further deterioration. When devising management plans, polio survivors may want to explore these options if not yet tried before. ●



ANDREA GALGOCZI-KRATOCHVIL can be contacted at reception@accentonwellbeing.com.au for any further enquiries.

Andrea is a registered Chinese Medicine practitioner (CMBR) and a member of the Australian Acupuncture and Chinese Medicine Association (AACMA). Andrea has a PhD in Economics, a Bachelor of Health Science in Chinese Medicine (Acupuncture & Herbal Medicine) and a Diploma in TCM Remedial massage.



Follow the Trend and Write Your Story!

by Joan Smith

Advice promoting our wellbeing tells us to live for today, put the past behind us and not to worry about tomorrow. However, I observe that my baby-boomer friends share my joy in reminiscing as they fantasize about recording their life and family stories when they experience the ever increasing pace of change.

As a polio survivor, I felt it was particularly important to tell my story and encourage others to do the same. We don't wish to boast or to complain, but simply to understand what has shaped our lives. I also decided that the more people who know about polio past and present, the better will be my future.

Telling my story, initially for family and friends helped put the past into perspective and enabled me to appreciate and celebrate my lifetime of achievements. There was so much more to life than just polio. I now feel better equipped to live for today and to know I will manage whatever the future brings.

There are lots of reasons why polio survivors choose to tell their story. It is important to share the past,

often hidden or dismissed, with family and friends, or to contribute to historical records. We need to educate our health and age-care providers, and our local communities must understand our current needs. Politicians at all levels need to acknowledge we are still here in large numbers, requiring resources, and the younger generation needs to know the value of vaccination. However, I do believe the most important reason is to do it for ourselves.

Telling stories for different reasons requires different techniques. There are occasions, such as speaking to friends or groups, which are verbal; or pictorial means such as scrap-booking photos with short texts. Interviews and brief articles to the press are the way to go for some, while others embark on poetry, artwork, personal diaries or longer written stories. All are valid and have a place.

The target audience and reason for telling your story both have implications. They define the length of your story, the type of language used, the story emphasis, depth of detail, identifying people and places and revealing your personal details,

feelings and value systems. For example, you can avoid offending others and creating potential conflicts for yourself by recording any negatives without attaching names. It is valuable to use a critical friend to review your work if it is to be made public. They can provide feedback on interest level, sequence, making connections, filling the gaps, repeating words and phrases, and using political correctness where appropriate, to name a few.

To start your project, break the task down to manageable steps. Jot down major headings of what you want to cover, then fill in some sub-headings. These can be added to as you progress. You can start to add in the details as you feel ready. It doesn't have to be done in sequence and there may be parts you can't share or re-visit at all. It must be in your own comfort zone.

Your story as a whole doesn't have to begin in sequence. It may start with a current event which then takes you back in time, such as a family death or new health issue. Changes in time can add more interest and relevance to the story. Photos or recollections by others can help provide your detail. Reading others' stories will often prompt memories that may have faded with time.

Technology allows us to stop, start, add or delete whenever we choose. It doesn't all have to be achieved in the first attempt. It also allows you to use selected parts for specific purposes or readers.

Whatever way you choose to tell your story, enjoy the journey, tears, celebrations and sharing with the important people in your life. Most importantly of all, do it for yourself.

Joan was the Project Manager, Editor and Co-writer of *"The Calliper Kids"* published in 2009. Enquiries: joansgra@bigpond.com



Joan Smith (centre, standing) with her fellow "Calliper Kids"

What are the Numbers?

by Gillian Thomas (President)
and Mary-ann Liethof (National
Program Manager)
Polio Australia

In June this year, a delegation from Polio Australia will be making its [sixth lobbying visit](#) to a number of our country's leaders – including our four [Parliamentary Patrons](#) – at Parliament House in Canberra. Once again, this visit will be led by our [National Patron, Dr. John Tierney](#), PhD, and Former Federal Senator for NSW. There is no doubt that John knows his way around those long, long corridors as we are not the only organisation he has assisted in negotiating the maze that is our Federal Government. However, there is one big difference; although John was acting in his capacity as Director of a lobbying group called "[Government Relations Australia](#)", he provided his services to Polio Australia pro-bono. Why? Well, one reason is because John has also had polio; just one more Australian who survived polio and went on to become a major contributor to society. As John is starting to 'listen' more to his body and understand more about the impact of the late effects of polio (LEOP), he has wisely decided to retire from paid work. But that won't stop him from coordinating Polio Australia's ongoing quest for some, in fact, **any** government funding to support its work.

Understandably, one of the first questions any funding body will ask is "What are the numbers?". Therein lays the problem because Australia, like most other western countries, has a paucity of accurate records from the epidemic period of the early 1900's to the 1960's, by which time most children were being vaccinated.

To add to the confusion, there are conflicting numbers identified in the Department of Health notifications, the Australian Bureau of Statistics Year Books, Hansard records, and newspaper reports. To date, there have been no studies to rationalise these figures. Of course,

then it's a matter of extrapolating the data to take into account the numbers of polio survivors who might still be alive today, and those who may have migrated to the country since, to find out the potential numbers of people who might now be living with the LEOP in Australia.

Although polio became a notifiable disease in 1922, contemporaneous evidence during the epidemics last century and more recent State Network records reveal that many cases of polio were not reported. Reasons include people being cared for at home, living in isolated areas, or the stigma attached to having contracted polio, for example. In addition, many hospital records have since been destroyed due to practices at the time or as the result of hospital fires, moves, or closures.

We also know there were a large number of 'sub-clinical' cases – including siblings of polio survivors who had polio – who only experienced 'flu-like symptoms' and were never actually diagnosed with polio. Added to that are the number of people who were misdiagnosed with, for example, encephalitis or influenza.

In addition, evidence exists that there may have been unreported cases of vaccine-associated paralytic poliomyelitis (VAPP) as indicated in the discrepancy between a 1994 Clinical Record cited in Sullivan A, Boyle RS, Whitby RM. Vaccine-associated paralytic poliomyelitis, *Med J Aust* 1995; 163 : 423-424 which was not reflected in the National Notifiable Diseases Surveillance System: Number of notifications of Poliomyelitis, Australia, in the period of 1991 to 2009 and year-to-date notifications for 2010. It appears that the doctors were certain this was a case of VAPP but could not unequivocally prove it. This leads us to believe that if an apparent case didn't make it into the official records in the mid 1990s it is not surprising that

cases went unreported (or undetected) earlier in the century.

It is evident that recorded numbers are just the tip of the iceberg.

The 'invisible' polio survivors

Arguably, polio survivors form the largest single group of people with physical disabilities in Australia, yet this is unrecognised by policy makers, the community at large, and indeed the polio survivors themselves. Polio survivors are to a large extent 'invisible' in the community. Knowledge about the LEOP, and their impact upon the lives of polio survivors and their families, is almost non-existent amongst the medical profession and organisations such as Centrelink, for example.

The LEOP have a dramatic impact on the ability of those polio survivors affected to maintain their mobility and independence and successfully undertake the activities of daily living. The only organisations which specifically cater for the unique information and support needs of polio survivors, while working in partnership with care givers, are largely volunteer organisations established and managed by fellow polio survivors.

Complications for people experiencing the Late Effects Of Polio

There is a high cost to both polio survivors and the health system in trying to get a diagnosis. Some people are simply diagnosed with individual symptoms which make up the LEOP, for example: arthritis, osteoporosis, sleep apnea or chronic fatigue. The possible consequences of the condition not being treated holistically and knowledgeably can not only be expensive, but can also have a significant and negative impact on that person's lifestyle. For example, some traditional treatments for loss of muscle strength can actually exacerbate the damage to motor neurons, leading to an even more rapid decline in physical capacity and mobility. The extension of this is

What are the Numbers? (Cont'd)

the need for expensive aids and equipment and home modification, an increased dependence on partners/spouses/carers, the implications for those partners and their relationships, the need to engage support workers, admittance to hospital for falls, and the possible need to move to a nursing home.

Polio: The Second Wave Study

[The Balnaves Foundation](#) has acknowledged the dilemma faced by Polio Australia and our polio community in not having "the numbers" to produce for Australia's funders and policy makers. As

such, they have granted funding to commission an analysis of the prevalence and incidence of polio in Australia. Following this, a second phase of the study aims to quantify the economic, social and public health burden of the LEOP in this country.

The current situation where governments at all levels do little to directly assist people with the LEOP is leading to escalating costs both to the governments and to the community at large.

Once the complete study has been published we believe it will substantially enhance Polio

Australia's arguments for increased service provision for polio survivors throughout Australia, and improve our success in securing much needed funding to fulfil [our charter](#).

Our prime objective of not only increasing but improving the effectiveness of service delivery to people with the LEOP will thereby be achieved.

However, this complex and comprehensive study will not come cheaply so Polio Australia continues to seek additional funding to complete the work. 🌐

Polio Australia's Accomplishments to Date

January 2010	Established office in Kew , Victoria
March 2010	Launched " Parliamentary Friends of Polio Survivors " at Parliament House
April 2010	Organised Australia's first Polio Health & Wellness Retreat (NSW)
September 2010	Developed and launched website
September 2010	Launched " Australian Polio Register "
October 2010	Wear Orange for Polio Day Awareness Campaign
October 2010	Launched Polio Australia's monthly e-Bulletin
February 2011	Held first Clinical Advisory Group (CAG) teleconference
April 2011	Organised second Retreat (VIC)
Current	Organising 2012 Retreat in QLD * Polio: The Second Wave Study * (<i>check website for new Australian Polio History page</i>)
June 2011	Launching Polio Australia's quarterly Newsletter, Polio Oz News
August 2011	Attending European Post Polio Conference to deliver oral presentation on Australia's Retreats
October 2011	Polio Awareness Campaign (Wear Orange!) *
Ongoing	Working with CAG to develop Best Practice Recommendations for Health Professionals *

* **Funding Required**



Australian Polio Register

Polio Australia encourages every polio survivor living in Australia (whether you contracted polio in Australia or overseas) to join the Australian Polio Register. Our strength lies in our numbers — please help us to get you the services you need by filling out the form on line [here](#).

The [Registration Form](#) can also be downloaded, completed and forwarded to: Polio Australia, PO Box 500, Kew East, Vic, 3102 or scanned and emailed to: register@polioaustralia.org.au

All for a Good Cause

by Audrey Clarke



Audrey (left) with her mum, Olive Haslam

The [City2Surf](#) run in Sydney is a perfect opportunity for me to involve myself with a charity close to my heart and I am delighted to be able to raise funds for a much needed charity such as Polio Australia. I will certainly be wearing my Polio Australia charity t-shirt with pride on Sunday August 14th in Sydney for both my wonderful mum who is an inspiration to me and for a wonderful charity who I know makes a huge difference to those who have been affected by polio.

As my mum is a survivor of polio I have seen the effects of what this disease can do and whilst my mum has never let polio stop her from achieving anything in her life I know how important the post-polio charity at home in Ireland is to her in helping her through the effects of it. It is amazing to see how enthusiastic Polio Australia

has been in supporting me to raise these much needed funds as it is a not a government funded charity and I know that my efforts will make a difference to those dealing with post polio.

Please help me to help others affected by polio by sponsoring me for the 14km City to Surf run in Sydney this August 14th. All donations will go directly to the charity. Details on how to sponsor me to raise funds for this great charity are listed below.

Direct Debit donations can be made out to Polio Australia Incorporated / Westpac / BSB 032078 / Account 000555766 - please make reference to: **'Audrey Clarke City2Surf run'**

Fun Run and general donations can also be made to Polio Australia via PayPal [here](#).

Out and About

May was a busy month for Polio Australia's National Program Manager, Mary-ann Liethof. She was invited to speak at the Toowoomba (Queensland) Post Polio Support Group's 60 Year Anniversary Lunch, as well as addressing PolioSA's members in Adelaide.

The Toowoomba Post Polio Support Group's Coordinator, Father Brian Sparksman, contracted polio during the polio epidemic which swept through Australia in 1951 and left more than 180 people in Toowoomba hospitals with the most severe form of the disease – hence the 60 Year Anniversary.

From those 180 people hospitalised, Father Brian has a list of 82 survivors who he knows are still alive today; 47 have died; and there are about 51 others with whom there has been no contact. The Group would very much like to hear from any of Toowoomba's 'unknown' polio survivors. Father Brian can be contacted on: 07 4632 8835. Read more about the [60 Year Anniversary](#).



PolioSA also hosted a gathering for approximately 70 polio survivors in Adelaide at the Hillcrest Community Centre. Two physiotherapy students who have been updating PolioSA's handout information gave a presentation on where they are up to with the project.

The Notes from Mary-ann's presentation are now available from PolioSA's President, Brett Howard - 08 8265 3241.

Check Polio Australia's website regularly to keep up to date with [What's on in Your State](#).

Making the News



Bruce Aylward: How We'll Stop Polio

[Bruce Aylward](#) is a Canadian physician and epidemiologist who heads the polio eradication programme at WHO, the Global Polio Eradication Initiative (GPEI).

Polio is almost completely eradicated. But as Bruce Aylward says: "Almost isn't good enough with a disease this terrifying. Aylward lays out the plan to continue the scientific miracle that ended polio in most of the world - and to snuff it out everywhere, forever".

See Bruce Aylward speak [here](#).

Heads of G8 Countries Reaffirm Commitment to Polio-Free World

28 May 2011

G8 leaders unanimously re-affirmed their commitment to polio eradication at this year's G8 Summit in Deauville, France, on 26 -27 May. In its declaration, the G8 reaffirmed their intention to complete the job of polio eradication: "We stress our continuing commitment to the eradication of polio," the statement read. "Our past support has contributed to the 99% decrease of polio cases in the developing countries. We flag the need for a special focus on this issue and renewed momentum. To this end, we will continue to support the Global Polio Eradication Initiative."

See details [here](#).

National Health Reform Full Steam Ahead

Department of Health and Ageing
Media Release: 3 June 2011

It's full steam ahead for national

health reform in the lead-up to the Council of Australian Governments' (COAG) finalisation of the national health reform agreement next month.

Releasing the Government's report card on national health reform implementation today, Minister for Health and Ageing Nicola Roxon said the vast majority of the Government's health reform initiatives are well and truly on track.

"As today's implementation update demonstrates, our road map to achieving a fundamental shift in our health system—to get the basics right for the long term sustainability of Australia's health system—is delivering results," Ms Roxon said.

Read the full Media Release [here](#).

After Hours GP Helpline

Department of Health and Ageing
Media Release: 2 June 2011



After-hours contact with a GP will be just a phone-call away from July 1. Minister for Health and Ageing Nicola Roxon today announced that Medibank has been appointed

to be the operator for the after hours GP helpline and has already recruited over 100 doctors.

Minister for Health and Ageing Nicola Roxon explained the *after hours GP helpline* is an important part of national health reform as the Gillard Government makes it easier for families to contact a doctor when they need to.

The *after hours GP helpline* will be added to existing telephone-based nurse triage, information and advice services currently available across the country.

The service will be available in most states and territories from 1 July 2011, with Queensland from

early 2012, building on Queensland's existing nurse advice line. The Gillard Government has offered to connect the *after hours GP helpline* to Victoria's nurse advice line, and is awaiting Victoria's response.

The service will be free to callers from landlines within Australia and will operate between 6pm and 8am Monday to Friday, 6pm Friday to 8am Saturday, 12pm Saturday to 8am Monday, and on all national and state/territory public holidays.

Read the full Media Release [here](#).

Extra Support for Older Australians After Hospital Stays

Department of Health and Ageing
Media Release: 2 June 2011

More than 30,000 older Australians each year will receive customised care and support to return to everyday life after a spell in hospital, Minister for Mental Health and Ageing Mark Butler said today, announcing expansion of the Transition Care Program by 651 places - bringing the total number of transition care places to 4,000.

"We recognise Australia is an ageing society and we are putting plans in place now rather than waiting for the problem to overwhelm us," Mr Butler said. "No government in Australian history has spent more on aged care and community care."

Read the full Media Release [here](#).



Eradicate Polio with the Yellow Boat Road

By **Carol Raabus**

Source: www.abc.net.au

It's a disease that paralyses and kills children across the world and you have the power to wipe it from the planet for just \$10. Polio is a rare disease in most westernised countries these days, but in places such as Afghanistan, Nigeria, Pakistan and India, Polio is still paralysing and killing thousands of children. And with increased travel, it is possible for polio to strike anywhere in the world if people aren't vaccinated against it.

In Australia, children are vaccinated against Polio before school age and this has seen the disease nearly completely disappear, but the affects of Polio are still felt in our society.

In 1937 Tasmania was hit hard by an epidemic of Polio with 1,006 cases of the disease across the state, which per capita was the world's second worst epidemic of the disease ever. Rebecca Round was just seven years old when

she and her 12 year old sister contracted the disease. They were first taken to the Devon Hospital in Latrobe before being moved to the Launceston Hospital where the girls lived for three years.

"You eventually got used to it," says Mrs Round. Mrs Round spent her time in a Thomas Splint, the common treatment for the disease at the time. "[Y]our feet were about six inches apart and you had a metal plate at the bottom and a flange around your feet to stop them from going from side to side, you were strapped at the ankles and knees and at the hips.

"Your arms were out at right angles from your shoulders, mine were only strapped to the elbow, my arms were not actually paralysed, and then you had a round canvas pad under your head with pegs, I guess they would have been a couple of inches high to stop your head from wobbling from side to side. "A lot of us were like that. "There were so many children affected by Polio in the summer of 1937-38 that the Launceston Hospital ran out of

room for them in the wards, so children were put in beds out on a balcony.

"I was included in that," says Mrs Round. "We were put out on a balcony and they dropped the awnings down at night and so there was this long long row of children in beds on a balcony."

After three years of living in hospital, with her mother making the journey from their family home in Railton to Launceston on bicycle every Sunday, the girls were taken home where her mother continued to massage the girls and help them walk again.

Rebecca Round was left with a weak left leg, which has now developed into a clubbed foot, but she was one of the lucky ones as many others were left with severe impairment and some children were killed by the disease.

"Some people cope very well with the after affects of polio, some people didn't cope well at all," says Mrs Round.

Read full article [here](#). 🌐



Robert Pennicott and Rebecca Round

On Thursday 2 June 2011, Tasmanian entrepreneur Robert Pennicott departed for an epic journey entitled "Follow the Yellow Boat Road", as he circumnavigates Australia in a 5.4m inflatable yellow dinghy to raise funds for Polio eradication. His aim

Follow the Yellow Boat Road

is to raise the additional \$39 million needed by Rotary International to hit the \$200 million benchmark, to which Bill Gates has pledged to contribute \$355 million more. The grand total of \$555 million is anticipated to lead to the total worldwide eradication of polio, with a donation of just \$10 vaccinating 17 children.

Find out more about Robert Pennicott's journey [here](#).

"Follow the Yellow Boat Road" was also featured

on the [7:30 Report on ABC TV](#)



"I deeply believe that when I die I want to have made a substantial difference to the world. I have dreams to give away a lot more money than what I do now, so I have come up with an idea that will make me the catalyst to hopefully raising many millions of dollars."

Robert Pennicott

On The Eradication Trail

Queensland's Jenny Horton has made an outstanding contribution to the eradication of polio worldwide. She has served as one of more than 1,000 volunteer team members who have travelled to 60 countries to provide technical support for polio eradication since 1999.

The following is an excerpt from Jenny's May edition of her newsletter "Manna from India".

"Namaskar,

Today I was wondering when one starts to get excited about the status of polio in India. This year there has been just one wild polio

(WPV) case reported in the country, but in our team there is no feeling that we can relax. Certainly each week that passes without a case is positive and exciting for all, but also there is the knowledge of gaps in the program that present an open door to the virus. We know we are dealing with an opportunistic virus that can find the cracks and take advantage. The last WPV in India was on Jan 13 2011 and now Uttar Pradesh has passed a year without a case, both these incredible milestones never reached before."

Read more from Jenny's May 2011 "Manna from India" [here](#). 🌍



Jenny Horton (centre) is a member of the Rotary Club of Kenmore (Queensland)

The Global Poverty Project Polio Eradication Campaign

THE GLOBAL POVERTY PROJECT

A major public advocacy and awareness campaign Global Poverty Project is running on polio eradication in the lead up to Australia's hosting of the Commonwealth Heads of Government Meeting (CHOGM) to be held in Perth later this year.

Polio and the Commonwealth

We have an unprecedented opportunity to protect future generations from the crippling disease of Polio. Thanks to global efforts led by Australian Rotarians in 1979, incidences of this disease have been reduced by 99% worldwide. With only \$665 million of extra funding, the Global Polio Eradication Initiative could eliminate Polio from our world forever.

Australia is in a unique position to ensure we see an end to this debilitating disease. In October, leaders of all the Commonwealth nations will travel to Perth for a Heads of Government summit. With 3 of the 4 countries in which Polio is still endemic being members of the Commonwealth, this event provides a perfect opportunity to get an international commitment to end this disease.

Our campaign

The Global Poverty Project will embark on a national education and advocacy campaign in the lead up to CHOGM to raise public awareness about the unprecedented opportunity we have to see an end to polio. Starting from the 23rd of July, we will campaign for a hundred days in the lead up to CHOGM. The campaign will reach an international climax on Friday 28 October, the opening day of CHOGM, with *The End Concert* being held in Fremantle.

How you can help

Personal stories are far more effective and compelling in

engaging members of the community than mere statistics. As part of our campaign, we are looking to share and tell the stories and personal journeys of polio survivors in order to build momentum around the need to End Polio once and for all. We are also seeking stories of ordinary Australians taking incredible actions in the fight to eradicate polio. These personal stories will be shared in a number of different ways via publications, media outlets and online video messages.

If either you, or someone you know, has a story about polio that you are willing to share, we would love to hear from you! You can do so by emailing Renee Carr at renee.carr@globalpovertyproject.com.

Please include your full name, contact phone number and a brief description of the story you're willing to share with us. We will then contact you for further details if required.

Michael Sheldrick
Campaign Manager 🌍