



Volume 2, Issue 2



Polio Oz News

June 2012 – Winter Edition

Finding The Lost Tribe . . .

Bernard Peasley and Angela Gill



Personal Reflections of Polio Australia's Health and Wellness Retreat, 2012

by Bernard Peasley

Polio Australia's 2012 Health and Wellness Retreat at Marcoola Beach was the second gathering of polio survivors in the past 12 months that made me realize how far removed I have been from the world of my childhood polio. I contracted polio as an infant in 1952 and was quarantined from my family for 3 months. I was returned to them bound into a Double Thomas splint, where I remained until I was 4 years old, even though my only paralyzed muscles were the left shoulder, bicep and deltoid.

After my physiotherapy finally

ceased at 9 years of age, I did not meet another polio survivor for the next 36 years, when I attended a Polio Network Victoria (PNV) Stress Reduction Workshop in 1997. Another 14 years passed before I met more polio survivors at the Post Polio Victoria (PPV) public meeting in the Northcote Town Hall in August last year. There I found myself among 65 polio survivors who had travelled to that place across 55-65 years of life with the after-effects of their polio. Like me, they had converged to share their stories, and to find ways of dealing with emerging symptoms of Post Polio Syndrome (PPS) and the Late Effects of Polio (LEOP). I am still trying to make sense of the unexpected emotional impact of that day.

Angela and I came to Marcoola to learn more about PPS and the techniques I need in order to manage my emerging late effects of polio. But really, it was to connect with people who have this common childhood history and to learn how to better look after myself during my third age. Quite frankly, looking after myself has been on the bottom of my list of priorities for as long as I can remember. Perhaps this was an after-shock of trying to put the polio behind me and move on.

The Retreat for me was like finding myself in a jungle clearing and being joined by weary travellers, wandering in from distant places, and discovering that I was not the last of my kind, but a member of some precious, lost tribe that had been dispersed as children, but had come together to share its common history and accumulated wisdom to

continue its survival.

The strongest feeling I had during the Retreat was one of belonging and understanding. There seemed to be a common relief among the participants I spoke to that they did not need to explain themselves, nor their aids, to anyone else in the gathering. Although, in most cases I was the one who needed to explain myself. I have no obvious, outward signs of my polio – I have always been mobile and use no braces, because the effects are upper body. And so it was necessary to explain that I was not the partner of a survivor, nor a carer, but a polio survivor as well – the irony of this was not lost on me!

So into this warm, friendly atmosphere Angela and I came with fully booked programs to maximize our knowledge gathering. On Friday (the Body Day), I attended six sessions: the polio body; bracing; strength training for the polio body; guided deep relaxation; respiratory issues for polio survivors; and the highly atmospheric movie "The Epidemic". From these sessions I learned: that bracing the shoulder is tricky business; that I definitely need to investigate *sleep apnoea* as a possible cause of my fatigue, and that caring for my aging polio body would need a balance between targeted exercise and timely relaxation.

Saturday (the Mind Day) was introduced by Liz Telford from PPV, who stressed the need to unite the mind and the body to effectively care for the whole polio person. Although this might seem obvious,

Presentations and Photos

Check out the following presentations [here](#)

- Dr Peter Nolan's "The Post Polio Syndrome"
- Liz Telford's "The Healthy Mind"
- Jenny Riley's tips on "Writing Your Story"
- Kristy Rackham's "Stress Less Tool Kit"
- More about "Mindfulness"
- All about "Feldenkrais"
- View 2012 Retreat photos [here](#)

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Welcome from the President

Gillian Thomas
President

Welcome to another bumper edition of *Polio Oz News*. I continue to be heartened by the fact that, in spite of our

ongoing lack of finances or due recognition from government funding bodies, Polio Australia is still able to find innovative ways of delivering some of the programs we have identified as being so vital to the wellbeing of our post polio community. We're nothing if not resourceful! Part of the legacy of being a survivor of polio.

Not only have we completed our third and highly successful Retreat in Queensland, we are also delighted to announce that GlaxoSmithKline's Medical Team members are volunteering their skills to

work collaboratively with us on developing an important new guide for health professionals (see page 13).

The most pressing issue we face is that we are already half way through a 3 year donation which pays for our one and only paid staff member, Mary-ann. With none of the established funding bodies willing to pay for this essential 'core' expense, we continue to explore ideas of how to support our work on behalf of Australia's polio survivors. So if you have any leads, please share them with us by email: office@polioaustralia.org.au or Ph: 03 9016 7678. 🌟

From the Editor

Mary-ann Liethof
Editor

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As you can see from the happy, smiling faces of the Queensland Retreat participants (right), together with the various accounts included in this Edition of "*Polio Oz News*", it appears that a good time was had by all! We arrived on a fine, sunny day. Unfortunately for anyone hoping to get a tan, the weather deteriorated somewhat over the next couple of days. Not that that put a 'dampener' on anyone participating in all the other activities that were on offer! And I've already been advised by many participants that they are looking forward to next year's Retreat, which we intend to run in South Australia. Two 4th year Physiotherapy students from the University of South Australia, Vivienne and Alex, have been doing a wonderful job sourcing suitable venues and potential session facilitators as one of their final projects. So keep the second half of April 2013 free if you are thinking of joining in the fun in South

Australia next year! More information will be provided in the coming months. If you would like to put in an early Expression of Interest (this is not a 'booking'), please see Page 19.

Also in this Edition is an article on putting together "*A Bucket List*" (like attending the 2013 Retreat, maybe? . . .), a few interrelated articles on "*assistive technology*", and a very poignant reminder of how important it is to be informed about any medical procedures you may be considering in "*Medical Misadventure: a preventable tragedy*".

We hope you are keeping warm during these cold, rainy days, and take time to enjoy the read! 🌟

"Winter is the time for comfort, for good food and warmth, for the touch of a friendly hand and for a talk beside the fire: it is the time for home."

~ Edith Sitwell

Finding The Lost Tribe (Cont'd from P1)

I suspect that the poor care I have given my own body in the past was caused by the emotional aftermath of a polio childhood separating the mind and the body from each other, to live parallel, rather than integrated, lives. For many of us perhaps, it was sheer willpower that allowed us to recover and survive with our polio-affected bodies. I learned that I will need to ease up, be more sensitive to what my body is telling me and to work with it better if I'm to get through the next 20 years with minimum conflict. The "mindfulness" session reinforced this and provided techniques for mentally "letting go" of the daily stresses that tense my muscles into spasms and bring on

the pain. This segued nicely into a therapeutic massage in the afternoon and a drawing skills workshop – what better way to relax than to engross the mind with drawing the world we see. Saturday night saw much hilarity and mind-bending entertainment with Sir Andum Magic, who successfully baffled everyone with his illusions.

Sunday (the Spirit Day) brought reflection in the form of sessions on core values, the meaning of spirit, meditation and natural healing. I joined with the group discussing what the spirit meant to each of us, and how our different perceptions of it could guide us through difficult times. The day ended with the

closing plenary when everyone who wanted to, used the microphone to share their experience of the Retreat. It was a unifying experience and from the responses, it was obvious everyone took home renewed energy, useful knowledge and fond memories.

For me it was a very positive experience. I felt fully connected with a community of aware, sensitive, humble and caring people with wonderful senses of humour. And I was privileged to be asked to record the three days through candid [photographs](#) of presenters and participants alike. A photographer could not hope for more wonderful subjects. 🌟



2012 Polio Health and Wellness Retreat Participants

Joy and Don's Journey



Joy and Don Hay

by Joy Hay

On the 18th of April we left our home in Cairns to travel on a most fulfilling journey. Thirty four days later we returned home. On the way south by train, 17 hours later we arrived in Rockhampton and broke our journey for four days with our daughter and family. Back on the train and almost seven hours later we disembarked at Nambour where we spent a few days with Don's sister and brother in law at Sippy Downs.

They dropped us off at our hotel at Marcoola, where we started a very emotional and informative time that far exceeded our expectations. We attended the Polio Australia Health and Wellness Retreat. I will not go into all of the sessions that were so marvellously organised by Polio Australia. But I do want to say the fantastic effort and energy that went into the planning and running of this entire Retreat was really appreciated by all of us. Many new friendships were formed at the Retreat. 🌟

Oh, I Do Like To Be Beside The Seaside

Reflections on the 2012 Polio Australia Retreat

by **Angela Gill**, Partner of Bernard Peasley

When Bernard first suggested that I might like to join him at this three-day Retreat I was ambivalent, thinking that it would probably not be relevant to me. I initially thought that I would feel like an impostor and a fraud, turning up to a Retreat for people dealing with Post-Polio Syndrome (PPS) and the late effects of polio (LEOP), and that I would be perceived as an intruder. How wrong I was!

Bernard assured me that the Retreat was specifically designed for "polios" and their partners, so after a wee bit more hesitation, I decided to join him.

A short two-hour flight from Melbourne, and we touched down in sunny Maroochydore. After a five-minute cab ride, shared with Maryann Liethof (talking non-stop, of course!), we arrived at the Ramada at Marcoola Beach and settled in to our room. Wonderful balcony outlook over the pool and gardens below - and not far beyond, the Pacific Ocean, with its peaceful, rolling surf. *Why didn't I bring my bathers?* The weather was sunny, warm and still - a lovely welcome for my first visit to the Sunshine Coast.

All the keynote speakers were wonderful (one address at the start of each day): Day 1 - Dr Peter Nolan (Toowoomba Hospital) talked about the Body of the polio survivor; Day 2 - Liz Telford (Social worker and Family Therapist) delivered a presentation on The Healthy Mind; and Day 3 - Bishop Ron Williams (Anglican Diocese of Brisbane) spoke on The Healthy Spirit.

After these keynote addresses first thing in the morning, the remainder of each day's sessions was devoted to the topic of the day (Body, Mind or Spirit). There were various smaller groups to choose from, as well as a number of opportunities to indulge in massage sessions and

one-on-one medical or orthotic appointments. There was also plenty of time to get to know everyone over the leisurely lunch, dinner and coffee breaks, and to have some fun (the magician on the last night was a hoot!).



Initially, when we first looked at the Retreat's range of sessions, it was a challenge deciding what to attend - everything looked so interesting; everything looked like a must-see! In the end, we decided not to go to the same sessions - in this way, we would be able to cover most topics, and gain as much information as possible over the three days. This worked really well for us, and at the end of each day, we shared what we had learnt from the day's sessions.

What follows is a couple of the many take-aways I picked up as the partner of a polio survivor.

In the pain-management session, we learnt how to devise strategies for managing persistent pain. One suggestion really appealed to me: the presenter's own strategy (she suffered from persistent pain) was to imagine herself as a car (a "Me-car"), that always needs four pumped-up tyres in order to be able to move forward - if one tyre is flat, she can't move. For those in the session suffering from persistent pain they could decide what sort of "air" they needed in their tyres to keep them pumped up - in other words, four things they could do to minimize and manage their pain. For example, one person's pain-management "car" might have the following

"tyres": hydrotherapy, meditation, seated yoga, and singing in a choir (ie, something that you love doing).

I thought this was a great concept. However, as a non-polio person who does not suffer from persistent pain, I modified the tyres on my "Me-car" so that they contained, not *pain*-management "air" but *life*-management air: walking, meditation, yoga and music-making: four things I need in my life to keep me humming along as well as possible.

In the "Partnering Polio" session we shared experiences and thoughts with other non-polio people who are living with and supporting those with PPS and LEOP - some of them have been doing this for a very long time. For most of us, we were fully aware that our partners had experienced polio as children, however polio was not a factor in our blossoming courtships all those years ago. As we all agreed, there were plenty of other things that attracted us to our future spouses! Now, as our polio-survivor mates face the increasingly unpleasant and unexpected symptoms of PPS and LEOP, we, as their partners and supporters, are also coming to terms with the prospect of possible lifestyle changes ahead. For me, this session was very reassuring and very humbling!

The above sessions are just two examples of what I gained from the Retreat. As a partner of a polio survivor, I learned a lot, met heaps of wonderful people, shed some tears and had many hearty laughs! I look forward to doing it all again next year! 🌟



Polio Australia Congrats' on a Wonderful Retreat!



Massage Therapists (L-R) Veronica Johnston, Kristy Rackham and Ric Scott

by Veronica Johnston

Source: www.scoopsisters.com.au

It is not very often that I have the chance to deviate from my usual work routine. And don't get me wrong I love spending Mondays and Tuesdays at Coastal Physiotherapy in Maroochydore (just a little plug for the business that keeps me busy), then the rest of the week working for myself, but there is something to be said for a change of scenery. The wonderful people I met at this year's Retreat,

held by Polio Australia, really made me feel fantastic about the skills I possess as a massage therapist and gave me a sense of renewed enthusiasm for the career I have spent the last 16 years in. And here I was supposed to be making them feel great, well let's hope I had achieved this goal!

Today, Polio is not something parents have to fear thanks to a vaccination that has thankfully eradicated this disease. Unfortunately for those, who in their childhood contracted the disease the effects today has many implications. Polio Australia recently organised a three day Polio Health and Wellness Retreat on the Sunshine Coast that presented a range of talks covering self management techniques that enable sufferers to remain independent for longer and to help manage pain and fatigue.

As a massage therapist, I was delighted and honoured to be

invited to offer massage therapy treatments at this year's Retreat. Massage therapy is wonderful for relaxation and managing muscle pain and tension, perfect for those suffering the late effects of Polio.

With each person that came to see me for massage, came stories of how fantastic this Retreat was in delivering valuable information for their future health, and emotional moments of past stories shared. Overall I felt the positive energy flowing from a good time that was being had by all!

What a fantastic organisation is Polio Australia, whose site provides valuable information to polio survivors, their families, carers and the wider community.

From where I was standing, this was a highly successful and enjoyable Retreat for the 73 people in attendance. Well Done Polio Australia! 🌟

What's On Your Bucket List?

There has been a spate of articles lately talking about "Bucket Lists" providing all kinds of advice about "How To Live Without Regrets" (body+soul, Sunday Herald Sun, May 20, 2012). In this particular article, Psychologist, Cynthia Hickman, asks "When your time is up, will you be happy with the life you've lived? It's time to make those changes now."

In the article, the top regrets of the dying are:

- 1) I wish I'd had the courage to live a life true to myself, not the life others expected of me.
- 2) I wish I hadn't worked so hard.
- 3) I wish I'd had the courage to express my feelings.
- 4) I wish I'd stayed in touch with my friends.
- 5) I wish I had let myself be happier.

Now, don't get me wrong, I am not suggesting that anyone is about to drop off this mortal coil. However, sometimes it is good to remind

ourselves that we do only have a finite time in which to complete our life's objectives, and perhaps we need to be asking ourselves, "What am I waiting for?"

To this end, I asked Jenny Riley, who facilitated the "Writing Your Story" session at the Retreat, if she would like to put together an article on the subject. This is what she wrote . . .

- Ed

A Bucket List

by Jenny Riley

What's a bucket list? If you are like me you won't know what this is all about. A film called The Bucket List was released in Australia on February 21st, 2008 and starred Jack Nicholson and Morgan Freeman. The story is about two very different men (one a millionaire and the other a mechanic) who were terminally ill. They teamed up and went around the world doing things they wanted



to because they knew this was their only opportunity. From this story came the bucket list (before you kick the bucket).

So... the first question is: do you have one? No! Not a bucket... A bucket list! What?! You don't have a bucket list? Time you made one!! I decided to ask a few friends if they have one and no!... they didn't either. But I suggested they might like to jot down just one thing they would really love to do and I acquired quite a list. So, we are going to look at that list in case we can inspire you to make one up too.

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A Bucket List (Cont'd)

The suggestions seem to fall into several different categories and much will depend on your mobility (and in some cases winning lotto!). The big one seems to be travel.

Live for three months in Tuscany (Italy) Hmm... first go to a class to learn Italian.

Go to the open air opera in Verona. Do I need to know Italian for that? See above!

Visit South America... Machu Picchu especially. I have heard that the trip up to there is a bit strenuous and the oxygen is a bit sparse up there. Needs thinking about!

Ride a Harley from Vladivostok to St Petersburg. Well, my sit-upon feels sore already and have you seen the winters they have up there?

Go on a cruise or sail down the Rhine. Now the former sounds more promising but the latter could be achievable.

See the Outback or explore the Kimberleys. Yes, that does sound promising too. Have you been further west than the Great Divide or east of WA? We live in a wonderful country and the folk who live out there are great people. Put that one on your list!

Now there were a few other suggestions: dive on HMAS Brisbane (too much water), sail on a tall ship (Oops! Do you get seasick?), fly a glider (If I'm in an aircraft I want great big reliable jet engines and someone who knows exactly what to do with them), drive a semi-trailer (but my little car is fine), sky diving was suggested twice and someone said jump without a parachute!!! (What I think she meant to write was: *Jump out with a parachute* but I haven't added it to my list!)

A hot air balloon flight... Now that might work and they look so peaceful as they progress in that leisurely fashion over the heads of those below, and I'm told you get a champagne breakfast afterwards.

Just be sure you enquire first! (It seems there is a Company in Melbourne who has a basket suitable for those who have mobility problems; otherwise you need to be able to mount a ladder and stand for an hour.)

We are now back from our trip!!! What else can we put on the list? There were a few suggestions for doing things with other people. Join a choir (it helps if you can sing in tune), learn to play an instrument (one you can pick up is a good idea), learn to play cards (you might 'earn' money if you become expert), learn a language (my husband goes to Latin class and really enjoys it), go to a cooking class (how about that, fellows?) or maybe photography or computers.

We can always help others... Join a volunteer organisation for there are many jobs which need doing even if it's taking money at an Op Shop. Support a cause which you feel deserves it; they will love you for that!

How about joining a writing group or U3A (University of the Third Age) and taking some classes? If you have teaching skills or office skills use them to help. This organisation offers many classes and one thing you should investigate is writing your life story. Your family will really appreciate that, especially your love story!

If you want to research your family tree try asking if anyone at your local library does this. Many groups are based there as it is handy for reference material. While at the library why not find some books to read, jigsaw puzzles to do or DVD's to watch? How many of the classics have you read?

Now let's think about family. Can you somehow get as many of them as possible together? I know we all have blood relatives and some are classed as bloody relatives but you will have done a wonderful thing if you can heal a gap somewhere. Someone put on the list I asked people to contribute to: *Have my son and daughter reconcile*. I hope

that will happen and she can cross it off.

Now the things just concerning YOU! There were a few suggestions here too.

Organise your paperwork as you know what you want/need to happen. (Think Health Directive, Power of Attorney and Will.)

Sort out your photos and label them. (You can toss the ones you don't like and labelling them will cut out the "Now, who the heck is this one?" or "I can't believe that is really ...?")

Grow something in a pot... An orchid would be beautiful and a tomato would be tasty.

Finish at least one thing you have started (like the quilt or the bit of woodwork).

Write a poem or a song. (Thinks... find out about *self* publishing!!!)

Fellows... grow a beard or a mo or shave them off!!! Ladies... paint your nails a different colour. Have you seen the ones that have a base and then a sort of fragmented top that looks as if it's gone rusty?!!

By now I hope you will have some ideas for your own list. And what we all need to put at the top of our list is this:

Do what you can, when you can, for as long as you can and enjoy yourself while doing whatever it is!

Now, off you go and write your list! 🟡



Healthy Habits To Improve Your Bottom Line

by **Erin Murphy**

Education Manager, Continence Foundation of Australia

Incontinence affects one in four people at any stage of life, from childhood through to old age. It is linked to high-risk factors such as pregnancy, birth and menopause, and prostate disease in men. Other causes are linked to: dementia and spinal cord injury; chronic conditions such as [post polio syndrome](#), diabetes and arthritis; and neurological diseases such as stroke, Parkinson's disease and multiple sclerosis.

The Continence Foundation of Australia is the peak national organisation working to improve the quality of life of the 4.8 million Australians affected by incontinence. The Foundation is launching its Healthy Bladder and Bowel Habits campaign during World Continence Week, June 24-30, explaining how people can

prevent or better manage continence problems.

Under the slogan, "*Improve Your Bottom Line*", Australians are being asked to adopt these five healthy habits:

- **Eat Well:** consume at least 30g of fibre daily;
- **Drink Well:** limit caffeine, alcohol and fizzy drinks and consume 1.5-2 litres of water daily (unless advised otherwise by your doctor);
- **Exercise regularly:** aim to exercise for 30 minutes most days;
- **Keep your pelvic floor toned:** make sure your fitness routine includes pelvic floor safe exercises (details at www.pelvicfloorfirst.org.au); and
- **Practice good toilet habits:** go when you need to and completely empty your bladder and bowel.

Encouraging people to adopt these healthy lifestyle habits will help them to maintain or improve bladder and bowel control.

People experiencing continence problems can phone the National Continence Helpline, 1800 33 00 66, managed by the Continence Foundation on behalf of the Australian Government. This free service is staffed by continence nurse advisors who provide advice, referrals and resources to health professionals and consumers.

For more information about any of the Continence Foundation's World Continence Week activities or resources, or for a Healthy Bladder and Bowel brochure, go to www.continence.org.au or phone the National Continence Helpline (freecall™) 1800 33 00 66. 🌐



The ESSENCE of Health

by **Mary-ann Liethof**, National Program Manager, Polio Australia

I recently attended a [Chronic Illness Alliance](#) Forum where I saw [Dr Craig Hassed](#) talk about "*Mindfulness*" and "*The ESSENCE of Health*" (these subjects have also been published in books by Dr Hassed). Apart from enjoying a lively and interesting presentation, I also found it very reaffirming insofar as the theme and construct of Polio Australia's Health and Wellness Retreats are concerned.

Dr Hassed's ESSENCE of Health is an acronym which stands for:

- Education
- Stress management
- Spirituality
- Exercise
- Nutrition
- Connectedness
- Environment

Dr Hassed says, "*As community attitudes change, healthcare costs and adverse events spiral, and evidence accumulates, the*

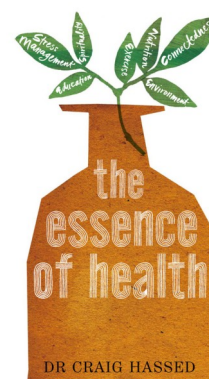
healthcare system is steadily recognizing the importance of moving towards more holistic and wellness-based models. Such models reduce costs and lead to better therapeutic outcomes." In his capacity as Senior Lecturer at Monash University's Department of General Practice, Dr Hassed has used the "ESSENCE of Health" as a basis for the Health Enhancement Program taught as core curriculum for all medical students at Monash University since 2002.

Dr Hassed goes on to report that, "*It forms a useful structure upon which educations, preventive and therapeutic approaches can be built and is readily adaptable for health professionals, individuals and public health campaigns.*"

"Another important aspect of a holistic or wellness approach is to empower the patient and their carers as much as possible. Empowerment, or become a more active participant in our own health, accords with the majority of

patient's wishes and is associated with better clinical and economic outcomes. For lifestyle interventions to be optimally effective a structured and systematic approach needs to be used. All the elements in the ESSENCE model are related to the others and they build synergistically."

To read more about this enlightened medical model, ask for the book in all good book stores: Hassed C. (2008) *The Essence of Health: the seven pillars of wellbeing*. Sydney, Random House. 🌐



Thinking Out Loud

by **Mary-ann Liethof**, National Program Manager, Polio Australia

So many mobility options, so little time! The [ATSA Daily Living Expo](#) (Assistive Technology Suppliers Australasia) is the largest display of assistive technology (AT) in Australia and this year it was held in Melbourne on the 16th and 17th of May.

This was my first foray into a display of this size and I was absolutely overwhelmed by the myriad varieties of scooters and wheelchairs (manual and electric) that could be used for sports, folded up for travel (eg. the [Luggie](#)), or equipped with 4-wheel drive for all terrain (eg. the [R44](#)); large and small; from uber-trendy to downright old-fashioned; some quite utilitarian and others with all the bells and whistles. As is said in physical disability parlance, there is no end of ways to be mobility enabled. As I am not a polio survivor myself, nor have I worked in the allied health disciplines like Physiotherapy or Occupational Therapy (OT), I sorely missed the knowledge and experience of my trusty volunteer, Jill Pickering. Jill is not only a polio survivor and a retired OT, she also LOVES her 'mobility enablers'! However, Jill was off holidaying in the UK, so I was on my own.

That got me thinking about how daunting it must be for people who are contemplating their own 'freedom on wheels'. Mind you, there's no shortage of people willing to assist. I was talking to a sales representative about the latest, you-beaut, all terrain wheelchair model, who was telling

me that the starting price was around \$8,500, then there's all the custom made add-ons like cushions, padded arm rests and so on and so on. Of course, people who use a wheelchair on a regular basis can tell you all about these additional costs. However, this plethora of options really highlights the reason why an OT is a key person to consult *before* investing in a new set of wheels. Australian states also have different government schemes which provide (partial) funding for the new equipment if prescribed by an OT. Unfortunately, this can't be done retrospectively. The other potential problem with these funding schemes can be extensive waiting times. I know of people who have been waiting for well over a year for funding for a scooter. In the meantime, the options are a compromised quality of life because it's so difficult to get out and about, or pay the full amount.

The Australian Rehabilitation & Assistive Technology Association ([ARATA](#)) is currently working on a Policy Statement and Background Paper which will be launched at the ARATA Conference in August 2012. It is hoped that the proposed Policy, which focuses on the AT system within the National Disability Insurance Scheme (NDIS), will be adopted in the formulation and implementation of the scheme. Assistive Technology such as mobility equipment is a vital and ongoing 'enabler' for many polio survivors, to ensure they have continued interaction within their communities. So a fair and just funding system across Australia can be placed directly into the human

rights category.

Now, speaking of the NDIS, did you know that in its current format, this scheme will not be available to people over 65 years of age? (Scroll down to Daniel Kyriacou's 17/10/11 comments on the [Every Australia Counts](#) feedback site.) Although, interestingly, the split off "National Injury Insurance Scheme" (NIIS) has no age restriction. I am disturbed about the age ceiling for the NDIS, especially as many of our post-polio community are approaching, or have already surpassed, this limit. It's clear that someone who is ageing with a disability is far more likely to require a greater range of Assistive Technology than their contemporaries. Maybe, whilst the NDIS is still evolving, there is still some hope that the age limit will change.

I might finish off my mental doodling where I started. That is to say that there are untold Assistive Technology options available these days, all designed to make life easier. (I haven't even mentioned the [stair lift](#) for double storey houses, or the fantastic array of [modified vehicles](#) I saw.) You can check out the range through websites like the [Independent Living Centres](#), or make an appointment with an OT* to discuss options for enhancing your lifestyle.

*ask your GP for a referral as part of the [Individual Allied Health Services scheme](#) under Medicare for patients with a chronic medical condition and complex care needs, or check at your local [Community Health Centre](#). 🌟

Polio Australia's Social Network 'Champions'



Ella Gaffney (left) from Mudgee in New South Wales, and Lyn Glover (right) from the Gold Coast in Queensland have been regular contributors to Polio Australia's [Facebook](#) and [Twitter](#) pages, so we thought we'd make it official and appoint these two social butterflies as our social network 'Champions'.



We're sure Ella and Lyn will keep Polio Australia's Twitter followers and Facebook visitors up-to-date with the latest news, as well as whatever snippets they find of interest which they'd like to share with our wider social network.

Thanks Lyn and Ella—and keep up the good work!

- Ed

Devices, Design and Identity



by **Audrey King**

Toronto, Canada

king.aj@rogers.com

Source: Post-Polio Health International
www.post-polio.org

When a caveman stuck a tree branch through the middle of two large flat stones, seated his curious body on that branch and launched himself from a hilltop, the very first wheelchair, possibly the very first Paralympian, was born.

From the 6th century, we find the earliest pictograph of a wheelchair incised in stone on a Chinese sarcophagus. In the 15th century, Leonardo da Vinci designed the earliest known prototype for a self-propelled vehicle. One hundred years later, King Philip II of Spain is reported to have used an elaborate rolling chair to get around, which King Louis XIV of France later re-created and dubbed his very own "roulette."

The devices we, as polio survivors, use and the environments in which we use them define us. Centuries old stigmatized notions of people "confined to" a wheelchair explain why it is often so difficult for people to accept the freedom that comes with using one, especially a model with power.

It can be said "we have come a

long way." In today's world we have wheelchairs that tilt, recline, stand up, climb stairs and go at incredible speeds. But, I have found that a state-of-the-art Olympic driven wheelchair – swifter, higher, stronger – can force me into identities I don't want.

While leaning forward to check out a "universally accessible" bathroom sink design at a Toronto design exhibition, my wheelchair tilt control got stuck under the sink and could not be reached. All of a sudden I found myself tilting relentlessly upwards – swifter, higher, stronger – prying the sink off the wall with my knees. To escape, I quickly reversed my chair, at which point the sink came off of the wall, shattering into a vast sea of millions of ceramic shards. My preferred identity is not that of a demolition expert; my mobility device seemed to prove otherwise.

More often than not, good design encompasses simplicity, ease-of-use and uncluttered-ness. It also involves consideration of the environment in which such devices are used.

A merchandise display rack packed tightly together in high-end clothing stores did not interface happily with my power wheelchair. The result was a totally "seized-up" chair, stalled between the racks. The only clue to the problem was a \$500 price tag dangling from the spokes,

still attached to the cuff of a silk Giorgio Armani blouse. Poor design can result in embarrassment all the way up the chain of command from an innocent shopper to a chief manager humiliated and on his knees trying to release both parties snippet by snippet.

In today's world, it is gratifying to see more and more people out and about in our communities using all kinds of mobility devices. I meet elderly people proudly driving shiny red scooters like the latest fashion in golf carts, telling me how far they have gone, or about a particular park with awesome accessible paving and water fountains.

People with walkers stop and ask, "Should I get a scooter or power wheelchair? What are the pros and cons of each?" Not so very long ago such strangers would have deliberately been walking on the other side of the street.

Yes, perceptions about people once "confined" to wheelchairs are changing, thanks to our increasing visibility and involvement in the not-always-designed-for-us world. Let's just keep on rolling.

Audrey King, MA (Psychology) is a Toronto artist, author and advocate who worked with children and youth with disabilities for 30 years. She is currently involved in teaching, research and consultation. 🌈

AT and Prediction of Happiness in People With PPS

by **Spiliotopoulou G, Fowkes C, Atwal A**

Source: [Brunel University, School of Health Sciences and Social Care, Uxbridge, UB8 3PH, UK](#)

PURPOSE: To explore the relationship between level of happiness in people with post-polio syndrome (PPS) and assistive technology (AT) by taking into account confounding factors such as age, gender and house composition.

Results: Ownership of AT did not predict happiness, whereas the perceived need for AT was a significant predictor of feeling less happy. Among the different types of AT needed, only need of home adaptations combined with major equipment was close to being significantly associated with less happiness. Being older and living with a partner significantly increased the likelihood of feeling happier.

CONCLUSION: The findings indicate the importance of the contribution of need for AT in explaining happiness in people with PPS. The fact that users reported unmet equipment needs urge for increased user decision making and better understanding of why perceived needs are not resolved. 🌈

Why Hasn't This Equipment Worked?

by **Mary-ann Liethof**, National Program Manager, Polio Australia

Sourced and adapted with permission from a presentation by Andrea Salmon and Neti Caird, MS Australia, at the Assistive Technology Suppliers Australasia Daily Living Expo, 17 May 2012

The following paragraph is a summary of what this presentation covered:

"In Multiple Sclerosis (MS) the missable symptom of fatigue is among the top 3 disabling symptoms for up to 80% of clients. Have you prescribed a piece of equipment to assist in managing fatigue and yet found that the client's level of fatigue hasn't improved? The strategies to assist clients in managing fatigue are as much about helping them to change their attitudes, priorities and beliefs as it's about prescribing the correct piece of assistive equipment. How do you determine the impact fatigue is having and how do you develop a therapeutic relationship that can challenge and facilitate change in attitude that brings about a positive impact on their fatigue. What equipment is generally assistive and how do you combine the two approaches?"

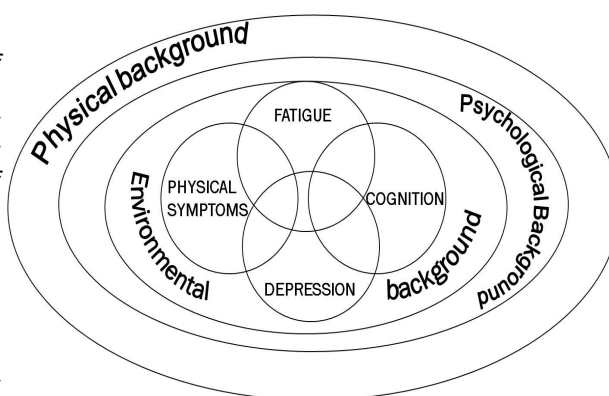
Sound familiar? Well, how about these symptoms:

- Fatigue
- Weakness in the arms or legs
- Heat intolerance
- Pain
- Problems with speech and/or swallowing
- Continence problems
- Cognitive change

Although MS is an auto immune disease and the late effects of polio (LEOP) are the result of an earlier viral infection, there are a number of similarities in the neurological symptoms. Of course, people living with the LEOP also have biomechanical symptoms resulting from living a lifetime with a

residual physical disability, such as abnormal curvature of the spine (scoliosis/kyphosis), arthritis, chronic tendonitis/bursitis and nerve compression. And let's not forget the respiratory problems - oh, and the osteoporosis . . . Umm, where was I? That's right, **FATIGUE!**

An interesting graph based on [Philip Kinkel's](#) work was used to explain Fatigue in MS, which I thought might also be useful to illustrate just how complex 'fatigue' can be.



The presentation went on to describe the Types of Fatigue as follows:

MS Fatigue

- Llassitude: Specific to MS. Described as "hitting the wall". Can occur at any time of day for no reason. Usually worse in the afternoon.
- Nerve Fibre Fatigue: Activity related failure of demyelinated nerve fibres to conduct messages. May find ability to continue an activity suddenly diminishes or stops after repetition. Usually resolves with short rest.

Secondary Fatigue

- Sleep disturbance, infection, exertion/deconditioning, medication, depression/stress, environment.

Fatigue Management Strategies included:

- Rest breaks
- Exercise
- Diet
- Sleep
- Energy conservation and work

simplification (including equipment)

- Planning and prioritisation

Many problems as to "why the equipment hasn't worked" and people's continued fatigue levels boiled down to a reluctance for people to prioritise daily activities (hmm, where have I heard that before?). A quick prioritisation tool is set out below:

A – Critical / must be done today
(Or what? Does ironing, housework, and/or gardening fit here?)

B – Important / should be done today (ditto above)

C – Trivial / if I get time today (ditto above)

D – Discard / no need to do it at all (ditto above)

The general presentation and following Take Home Messages were aimed at Occupational Therapists but should be considered by anyone wanting to both reduce fatigue levels and make the most of any new 'assistive technology' or mobility equipment:

- Is the piece of equipment sufficient to meet their needs?
- Does the client need other fatigue or symptom strategies in combination with the equipment?
- Does the client need to review their values and standards to make full use of the piece of equipment and the other strategies suggested?
- Is the client motivated to take action to change?
- Does the intervention need to be paced to make achieving the goals possible?

Clearly, post polio is not the same condition as MS, and there are a number of variations in symptoms with quite specific management strategies for each. But our post polio community sure understands the "hitting the wall" type of fatigue people with MS experience. So maybe it's a timely reminder to review the A, B, C, D's in our life. 🌈

Medical 'Misadventure': a preventable tragedy

by Fleur Rubens



Vivian was infected by polio in the last Irish epidemic in 1956. He was in an iron lung for a short period of time, and then in a rehabilitation hospital in Dublin.

In 1960 the family moved to Australia. At 14 years of age Vivian went to the Yooralla school in Carlton. He received some basic education and occupational therapy like basket weaving. He was determined to complete a secondary education so he left Yooralla to go to Moreland High School. He matriculated in 2 years, gaining entry to Monash University. Every day he travelled from Fawkner to Clayton, walking a good kilometre to the station, and then by train and bus. This he did wearing iron callipers, a body brace and crutches. Within a couple of years he had discarded these and was aided only by a walking stick. He never saw himself as having a disability.

During his time at Monash he also supported himself teaching part time at Williamstown Tech - another long journey showing his fierce determination. Ironically, on graduation the Education Department would employ him but without the benefit of superannuation available to 'able-bodied' teachers. In any event his service to the Department was short because of our desire to travel. We backpacked through Europe and Asia. On return to Australia, Vivian set up his own business which also required extensive travel.

In his early 40's Vivian noticed the first signs of physical deterioration, or what is now known as Post Polio Syndrome. Eventually he had to start using crutches again, but he swam and had massages to keep healthy and mobile. His mobility declined slowly. By the age of 60 he was using a scooter for longer distances. Due to scoliosis, and the weight bearing on the shoulders he experienced severe pain that was managed by increasing doses of opioids. Vivian was not happy to rely on medication. He consulted a neurosurgeon who was not in favour of an operation at that time. Fortunately his GP suggested a spinal clinic where the pain causing nerves could be cauterised by laser. This was a very expensive but successful and non-invasive treatment, but only lasted 2 years until the nerves re-grew and the pain returned. However the procedure can be repeated. It was definitely preferable to taking opioid pain medication. (I have since read that opioids are not a good medication for polio survivors to be taking).

At the next consultation 2 years later, the surgeon again took extensive x-rays, and this time recommended surgery. Without surgery there was a possibility of paraplegia due to further compression of the nerves and narrowing of the spinal cord.

We were informed of the possible risks of surgery: infection, blood clots, heart attack etc - the usual risks of surgery.

Vivian's Occupational Therapist at the Polio Clinic advised him to get a second opinion. We went to the GP to get a referral but were told that his particular surgeon does not operate lightly and that if he decides to operate it is really necessary. We didn't go ahead with a second opinion, but felt as if we were informed, and happy to go ahead.

Unfortunately I don't think that we, the surgeon or the anaesthetist were sufficiently informed about the residual effects that polio was to

have on the operation.

Vivian had a respiratory test the day before the operation that the doctors were happy with.

The anaesthetist contacted him on the day before his hospital admission, and we informed him that some polio survivors have complications with anaesthetics. He said he would research this before the operation.

The operation took about 6 hours (instead of the predicted 2 hours), and Vivian spent a bit longer in the recovery room than normal. After the operation he appeared alert and looked well however he complained about difficulty in breathing. The medical staff thought this was due to his anxiety. The operation had caused the main muscle in his good arm, the one he relied on for walking, to become paralysed. The neurosurgeon was hopeful that movement would come back.

A few days later Vivian got a touch of pneumonia and was put in intensive care. With antibiotics and oxygen supplements he recovered quickly and went back to the general ward where they thought he improved. He had difficulty sleeping, but we thought this was due to the noisy ward. Despite having a contingent of respiratory specialists in attendance no one ever acknowledged the critical nature of his breathing difficulties. From my perspective they didn't look for an explanation.

Just before he left hospital for rehabilitation, he was given a sleep test. This resulted in a recommendation that when he got back home it could be beneficial for him to have oxygen supplements while sleeping. Nothing pressing.

At the rehab hospital he seemed drowsy, and I didn't feel he was doing very well. I regularly asked about his oxygen levels but they were OK. The physio was pleased with his progress. The movement in his arm was not coming back but he was slowly learning to improve

Medical 'Misadventure': a preventable tragedy (Cont'd)

his mobility with the current deficits.

I was never too happy with his progress, but when friends came to visit they found him better than I had described. His complexion was rosy. I felt that maybe I was exaggerating his condition, being unduly negative, expecting too much etc. After Vivian's death I learnt that what look like a healthy ruddiness is in fact a sign of excessive carbon dioxide in the blood.

Eventually in rehab, they decided he was lacking in iron, and were planning to do an iron infusion. I was pleased, as this could be an explanation for his drowsiness. The infusion never took place because he was rushed to emergency resuscitation where they very crudely asked if we wanted any extra-ordinary measures taken! I knew that he didn't want life-prolonging intervention for the sake of it. But the whole thing came as a big shock, as we had been told that he was doing OK.

He had a touch of pneumonia again, but the biggest shock was that I found out at this late stage that the nerve to his diaphragm (the phrenic nerve) was also damaged in the operation. No-one had mentioned this earlier, so I am still doubtful if this was previously diagnosed. The effect of phrenic nerve damage is that other muscles in the diaphragm have to work harder in order to breathe. Because of the extra stress, these muscles, also somewhat affected by polio, quickly wore out. Vivian died one month after surgery.

I don't know why there was no action taken if they knew there was a problem with the phrenic nerve. He could have been given intermittent supplementary oxygen and this could have prevented the stress on the breathing.

I myself don't think they were aware of the phrenic nerve damage and/or of its consequences.

The drowsiness was caused by a

build-up of carbon dioxide as the lungs were not expelling sufficient air. So while the oxygen levels were ok, the CO2 levels were excessive. This was never tested until he got to the resuscitation room. When I asked why not, the hospital said that to take blood gases is an invasive procedure. To me this is not sufficient explanation. At the time I wasn't aware of CO2 levels as a measure of respiratory health. I was only aware of oxygen saturation levels.

Apparently the hospital is going to introduce CO2 measuring into the oximeters in the near future.

With the benefit of hindsight . .

If you are undertaking an operation consider these points:

- Get as much information as possible about the operation, the anaesthetic, the rehab etc.
- Ensure that all the medicos are informed of extra problems for polio survivors. (Suggest professional sources of information.)
- Regarding anaesthetics – polio survivors should have local anaesthetics or spinal blocks in preference to general anaesthetics. During the recent [Parliamentary enquiry](#) into the Late Effects of Polio, I was shocked to hear 3 accounts of anaesthetists ignoring their patient's warnings regarding their special needs!
- Have a respiratory test to see if you could benefit from oxygen therapy, especially if you have difficulty sleeping. Always have a respiratory test prior to surgery. The critical factors for polio survivors is not only oxygen levels, but levels of endurance.
- Listen to your own instincts. Keep asking questions until you are properly listened to.
- Always have an advocate when you go to hospital. You need an advocate to ask questions and solve problems. Someone who knows you is the best person to judge your condition and know when things are not right for you.
- Inform the nursing staff about your mobility problems and how that may affect your nursing requirements. Extra equipment may be required and difficult to procure (it always seems to be in short supply). Extra nursing staff may be needed. Hospitals are busy places and they have fixed expectations of the nursing care that patients need for each type of procedure. Hospitals have a no-lift policy. Sometimes 2 staff are needed to use a lifting machine, and it is difficult to get 2 staff available at the same time. The extra care that patients need is not always obvious until explained. eg If you can't move yourself in the bed, you may need 2 staff to turn you, or lift you when you slip.
- Beware of opioid medications, sleeping pills and benzodiazepine (Valium), muscle relaxants. They put extra stress on the respiratory system and muscle function.
- Be aware of the 2 measures of respiratory health – oxygen and carbon dioxide levels. Insist that they are both measured.
- Advocate for a polio clinic with specialist doctors who can liaise with medicos.
- Push for a comprehensive booklet and on-line source of information for polio survivors and their doctors. (Again at the Parliamentary enquiry people reported that some doctors 'don't believe in post-polio syndrome'.) Many also reported that it took approx 6 years to get a diagnosis! ●

Memories of Vivian Endean

1945 - 2011

We're Still Here!



Polio Australia is calling all polio survivors to join us in Canberra on Wednesday 31st October at the culmination of the National Polio Awareness Month's "We're Still Here" campaign.

To mark the occasion, Polio Australia aims to launch a new learning resource for healthcare professionals, which is being developed in collaboration with volunteers from GlaxoSmithKline's Medical team through their corporate volunteering program. This overview of the Late Effects of Polio (LEOP) is also being reviewed by Polio Australia's multidisciplinary Clinical Advisory Group, and is intended to be the first in a series of Clinical Practice Modules for managing various aspects of the LEOP.

We ask everyone coming to Canberra to contact your local [Federal Members of Parliament](#) to make a 20 minute appointment with them in the morning to discuss the need for appropriate clinical services for polio survivors in your area and/or across Australia. Everyone has a personal experience to relate (see "Medical Misadventure" on the previous page). However, a specific one page handout will be provided to people highlighting the overall issues for Australia's post polio community, and can be left with your MP. We are currently awaiting the Report from the [Roundtable](#)

[Forum](#) on the Late Effects of Polio held in March, which will inform this handout.

Still to be confirmed, the proposed order of the day will be:

9.30am
Arrive at Parliament House
10.00am
Media and/or Photo* opportunity
10.30am
Launch of the "Overview of the Late Effects of Polio Clinical Practice Module" with post polio community, Parliamentary Patrons and Parliamentary Friends of Polio Survivors
11.30am
Individual appointments with local MPs
12.30pm
Group lunch at Parliament House
2.00pm
Question Time
3.00pm
Depart to own activities

*A suggestion for a group photo is to bring along one of your first braces (if you still have it) to indicate that the post polio community still require adequate services "because children grow up".

What to do if you want to join us:

- If you are a member of one of the state-based [Polio Networks](#), please contact their office to advise your intention and have it

recorded. They will keep you advised about the day's program and any state-based group arrangements.

- If you are not a member of a Network, please email [Mary-ann Liethof](#) or Ph: 03 9016 7678.

Note: As Polio Australia only receives irregular philanthropic 'project' funding, we are unable to assist with travel or accommodation. However, we do know that Rotary and Lions Clubs can be quite generous to members in their local communities when approached directly.

Unless your state's Polio Network makes specific arrangements for its members, accommodation and transport will need to be organised by you. Check [here](#) for options.

We all know that there is strength in numbers, and this day will be an opportunity to stand/sit up and be counted. If Polio Australia is to achieve its Mission to "standardise quality polio information and service provision across Australia for polio survivors", we depend on **your** support. 🌟

Polio Australia Thanks . . .

Polio Australia is immensely grateful for any donations, as we receive no funding through membership or from government sources. Apart from a generous 3 year donation from the [Balnaves Foundation](#) which pays for our National Program Manager, we only receive irregular philanthropic funding for specific 'projects' such as the Health and Wellness Retreats.

Therefore, we would like to thank the following individuals for their generous donations so far this year:

- Barbara Burnett (Qld)
- Ruth Harrower (NSW)
- Jill Pickering (Vic)
- Veronica Schmidt (Qld)
- Heather & David Shirley (Qld)
- Joy Shore (Qld)
- Gwen Skinner (Qld)
- Fay Wheeler (Qld)

If you would like to join this list, you can donate online [here](#), or email [Mary-ann Liethof](#) for other options.

This (enlightening) Life

by Roger Wooller

Source: [The Australian](#), 19 May 2012

I became a volunteer for the wrong reasons. Money. Polio had given me a life on sticks.

This entitled me to a fuel allowance for the car while working as a teacher. When I retired, it stopped. "Unless you become a volunteer," Centrelink said. "Volunteer retirees get the mobility allowance." Joining [Sailability](#) was easy. I wandered past the "volunteers wanted" sign. Kev the president said, "We certainly do need you, can you sail?" I hesitated. It seemed like overkill but what the hell. "Um, in 1991 I took my wife and two sons sailing round the world in our 40-foot yacht, Hagar the Horrible. Does that count?" A 20-minute test out on the water reassured him. "You're on. Can you start now?"

This was unexpected. I needed time to think. I looked around at the wheelchairs and my teenage demons came to visit. At 17 I had been sent from Kenya to England. I was living in digs, studying for my A levels, and fiercely resented being regarded as disabled. For the most part I forgot that I walked on sticks and expected others to as well. I didn't get out much so my

landlady thoughtfully arranged for me to go to a concert. She hadn't told me it was organised for all the disabled people in the district.

I had been the only disabled person I knew until then and the number and variety was a shock. Being identified with them was the antithesis of my self-image. (Like my father protesting, "I can't go into that nursing home it's full of old people.") I suddenly hated my elbow crutches. I was embarrassed, and furious with my landlady for putting me in this situation. It was the start of a long denial.

For most of my life I had little to do with other disabled people. Until now.

My first passenger looked a little frightened as he was winched from his wheelchair into the 3.3m dinghy. I explained how safe it was with its 40kg centreboard and its roller furling jib and mainsail. I have no idea whether he understood me, but by the time we had tacked our way back into harbour he had nuzzled confidently up to me, my shirt was soaked in his saliva and his gentle crooning told me he had enjoyed it beyond imagining.

I envisaged the four walls he was going back to and thought how lucky I had been.

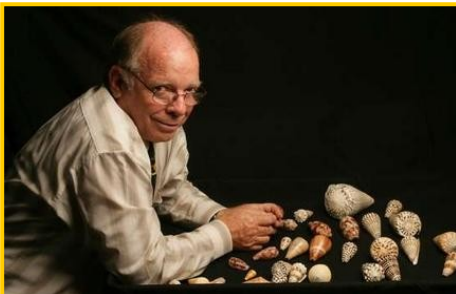
My next passenger fell asleep early, lulled by the rocking. I like to think she got something out of it. The third one, his carer said, could understand everything, though he couldn't speak and moved with difficulty. So while sailing I chatted about our circumnavigation and was rewarded by his hand squeezing my arm, tentatively at first, then firmly. The eloquence of that gesture moved me. I think I have grown up. I am not embarrassed. I am happy to be with this crowd. They make me feel good.

I would volunteer to take them sailing even if there were no fuel allowance. 🌊



A Fortunate Life: Walking in the Footsteps of Giants

by Bruce Livett



I contracted polio at age 5 (the epidemic of 1948) after attending a playmate's birthday party in Ashburton, a suburb of Melbourne. The virus was quick to act. I remember visiting my mate two days later to help him play with his birthday presents and having to

excuse myself as I felt the 'flu' coming on. I struggled to walk home although it was only two houses away. My limbs ached and I ran a temperature. I experienced painful contractions of my lower limbs and found it difficult to sleep. It was a very painful and exhausting experience. After some days the local doctor was called in but misdiagnosed it as rheumatic fever and so I was pumped full of penicillin twice a day for 6 weeks.

How I hated the injections and dreaded the front door bell announcing the arrival of the district nurse for the next jab. Of course, the penicillin was ineffective - polio being a viral disease not bacterial. All it achieved was

making me allergic to penicillin for the rest of my life. Eventually, I was visited at home by the legendary (Dame) Kate Campbell who diagnosed polio and gave my parents the option of sending me to one of the treatment centres where other polio victims were confined. My mum declined the offer and managed me at home. I am eternally thankful to my parents for taking on that responsibility. It was not easy for them and the family was ostracised by many of the neighbours out of fear that contact would place them at risk of contracting polio. My playmates stayed away too, but with time they came to visit, although keeping their distance. It was great when,

A Fortunate Life (Cont'd)

later, they came after school to play in our backyard and I could watch them from my pram on the back veranda and share the fun.

I later learned that one of the young boys at the party was a polio carrier and although he did not succumb to the virus himself, by the time they tracked him down, he had passed on polio to another 20 in the City of Camberwell (now Boroondarra). But I was one of the more fortunate, I was not confined to an iron lung.

For 18 months, I was strapped to a splint and kept horizontal. The polio principally affected my left leg and left arm and to a lesser degree my right leg. I did not attend school for 2 years, however, I continued my studies at home through 'School of the Air' and managed to jump a grade! During this time I received regular visits from the physiotherapist and my mobility slowly improved. My pet cat and dog were my constant companions. What a difference they made. My morale was boosted too by visits from my favourite grandfather who journeyed out each Sunday from Sunshine to visit and often brought me a wooden toy he had made during the week. Listening to the radio (no TV back then) I developed a real interest in music of all kinds, an interest that has sustained me throughout life. How fortunate is that? As soon as I was able, I took lessons on the family piano, and in later life joined an amateur choir and played bassoon professionally in several Melbourne orchestras. One thing the physiotherapy did for me was develop my upper muscle strength and a good set of lungs!

The 'School of the Air' experience taught me to be self-reliant and I developed good study habits that I believe determined my career path into academia. At school, I participated in sports to the best of my ability, later playing field hockey at Carey, and rowing, but was never going to run the 100 yards in record time.

As I progressed through school, I read all the books I could lay my hands on dealing with the brain and nerve regeneration. I well remember borrowing a book from the Camberwell Library 'Bookmobile', the local community mobile library (remember those), that recounted the true story of Phineas Gage, the foreman of a railway construction gang in Cavendish, Vermont, USA, who on 13th September 1848, accidentally blew a metal bar through his head. Most of the front part of the left side of his brain was destroyed. Not only did he live to tell the tale but continued to work. I was intrigued by the redundancy of the central nervous system and its apparent plasticity. On another occasion my parents despaired of me one Easter holidays at Broadford where instead of going out in the sunshine with my cousin to collect wild mushrooms I spent the time engrossed in a book about frontal lobotomy. The die was cast, I could not wait to get to University.

I loved Science and entered the Science Talent Search obtaining a bursary two years in a row. I graduated with a BSc (Hons) and PhD at Monash and then proceeded to postdoctoral studies in Pharmacology in Oxford. Returning to Australia as a Queen Elizabeth II Fellow, I was on staff at Monash for 5 years before heading to Canada with my wife Dianne, a triple certificated nurse and midwife. There I took a sabbatical in Neurosciences at McMaster University in Hamilton, Ontario before moving to join the staff at McGill University, Montreal becoming Professor in the Departments of Neurology and Neurosurgery and Biochemistry. Montreal was a great centre for study of neurosciences and neuromuscular disorders and, no doubt influenced by my past history of polio, I embarked on research into muscular dystrophy and the study of pain mechanisms.

After 6 years we returned to Melbourne. I joined the staff at Melbourne University and became

Reader and Assoc. Prof. of Biochemistry and moved to the new Bio21 Research Institute in Parkville. At Melbourne, I taught medical and science students and headed a research group on pain mechanisms. Our two children, Andrew and Erica, both born in Montreal, followed their parents in pursuing interests in biomedical subjects, Andrew graduating in Pharmacology and Erica in Anatomy from Melbourne University.

During the last decade of my academic life, I became aware of the increasing and unmet need for better pain relief. Morphine is great for short-term treatment but, being an opiate, is addictive and is not well tolerated for long-term conditions such as neuropathic pain. I embarked on a project to explore the potential of Australia's marine environment as a source for a better analgesic. Our research led to the discovery of a novel peptide analgesic, termed ACV1, which entered clinical trials reaching Phase II before being abandoned. ACV1 was isolated from the venom of *Conus victoriae*, a small and pretty cone shell found along the NW Kimberley coast, a remote but magnificent region of Australia that few get to visit. ACV1 has recently been modified by Dr David Craik at the Institute of Molecular Biology in Queensland and his cyclic orally active form is currently undergoing clinical trials. Here's hoping.

There is a historic building at the triangle formed by Exhibition Street, Latrobe Street and Victoria Street, Melbourne. Most pass by it without a second thought. I know - I did for 40 years as I travelled to work. Founded in 1859, the Royal Society of Victoria has been the home of Science and its members have provided valued advice to successive governments on matters of scientific and technological importance. I was fortunate to be elected President of the Society from 2004-2006 and during that time was invited to be guest speaker to the Rotary Club of

A Fortunate Life (Cont'd)

Carlton - about how we went about recruiting new members. That in turn lead to me becoming a member of Rotary and I soon became aware of Rotary International's innovative End Polio Now campaign. New members of Rotary are invited to introduce themselves "The Person Behind the Badge" and, as part of my talk, I told them of my personal experience with polio. I can attest to how my personal story heightened interest in polio among the members.

Soon polio will be conquered. But we need to continue awareness and keep vigilant to prevent other outbreaks. I encourage you to speak about your personal experience with polio at Rotary and other groups as it is the best way I know to raise awareness and motivate others to the cause. The Post-Polio networks require funding too!

At age 65, I took my leave and headed to the Kimberley to 'do' the Gibb River Road, a 4 wheel drive odyssey, an item on my bucket list. That is when I truly fell in love with the Kimberley and decided to 'retire' to Kununurra, half way between Darwin and Broome on the mighty Ord River. Our property, "Zebra Rock Gallery and Tearooms" (www.zebrarock.biz), has 400 mango trees that we harvest at the end of October each year. We are noted for our delicious mango smoothies, mango fruit cake and mango cheesecake. Our main activity is crafting items for sale from 600 million year old zebra rock and related siltstones unique to this area of the East Kimberley. We have a mining lease on Lake Argyle and a workshop that employs three people during the tourist season. I maintain my interest in music, and still play piano and bassoon. We hold regular recitals where visiting musicians provide the entertainment in the Gallery and outside on the lawns facing the river. All in all it keeps me busy.

Now 'retired', I continue to take an

active interest in polio through Rotary's End Polio Now campaign. In March this year, I organized for Kununurra Rotary our second annual fundraiser for the END Polio Now campaign. We held a "Wine & Cheese Night" at Gulliver's Tavern, Kununurra (see photo). Brad Rayner, one of the local teachers at Kununurra High School, has a passion for cheese and presented each new cheese providing much interesting information. The wines to match were selected by Colin Kuiper, a fellow Rotarian, who manages Gulliver's Tavern and prepared the tasting notes on each wine. We also ran a Quiz with questions on Rotary, Polio, Wine and Cheese. Various businesses around town donated prizes which were raffled and used to raise further funds.

Over 70 residents (many of them non-Rotarians) attended the function and had a fun night where four courses of exquisite French cheeses (obtained from Blue Cow, Perth) were matched with 4 excellent Aussie wines. Our three recently arrived Rotary Exchange students, Billy, Tim and Gabriel, were kept busy replacing the cheeses and home baked bread on the tables between courses. The event raised over \$2,000 towards the "End Polio Now" campaign.

We were asked when the next event would be held, so I guess I will be organising another later in

the year (and definitely next year). My wife, Dianne, also a Rotarian, arrived back in Kununurra the night after the event, so she too is keen to see it run again.

As time progresses I manage the consequences of my polio, the weak ankles, stiff joints, the lack of proprioception, poor circulation in lower limbs resulting in venous leg ulcers (not helped by living in the tropics), and sleep apnoea. Knowing that the Post Polio networks are active and receptive to our special needs is a great comfort.

When I view the videos from Rotary International about the management of polio in the Indian sub-continent, there is no doubt that we, in Australia, are the fortunate ones. To all my fellow polio survivors, I wish us the best of health and continued success with our efforts to raise awareness of polio and of its long term consequences. 🌐

Further reading:

- Dame Kate Isabel Campbell (1899 - 1986) - in [Australian Dictionary of Biography](#)
- Pain Killer Comes Out of its Shell: by Graeme O'Neil - [The Age](#), July 25, 2005
- [Phineas Gage's Story](#) - Deakin University
- Rotary Australia - [End Polio Now](#)
- [Zebra Rock Gallery](#), Kununurra, WA



Photo (left)

Bruce and Dianne Livett (owners) and brother Scott Whelan (manager) of Zebra Rock Gallery, Kununurra, displaying items (water bird and bowl) crafted from 1200 million year old siltstone unique to the East Kimberley

Clayton's Story

by Pam Harrison

I have returned from my 5th trip to Zimbabwe where my organisation, AFADU, (Aid For Africa Down Under www.afadu.com) supports a purpose built orphanage called the Lirhanzo Children's Village (LCV). Lirhanzo means love in the local Shangaan dialect so the orphanage is known as "The Village of Love".

Through sponsorship programs we supply funding for the wages of guardian mothers and staff who look after the kids at LCV and also for their food, education, and clothing. We also fund a variety of self sustainable projects which support them and their surrounding community. These include a water irrigation project which ensures that crops do not fail and vegetables are plentiful all year round, a sewing factory and a grinding mill. As a registered nurse I have been most keen to support and fund raise for the Chikombedzi Hospital School of Nursing and AFADU has raised much of the money required for the infrastructure. Once completed this school will ensure that school leavers, including our own orphans, will have another career option in this poor, rural community and that the standard of care at the 160 bed hospital which has one doctor and supports a population of 100,000 will rise as more nurses graduate.

In 2010 I took over a Kiwi lass called Alison Lewin who was so taken by the community and the children that she decided to stay. She was the one who found Clayton. Alison had heard he was really doing it tough and was crawling to get around so when a few wheelchairs were sent in our Container program (we have successfully sent 14 Containers since 2004) she earmarked one for him. When she delivered it she asked him what could be done to further improve his lot in life and that's when he told her that people brought all their broken electronic phones/radios/cassette players etc

and he was clever enough to figure out how to repair them but had no equipment to actually fix them. On this trip I took over some money from private individuals for a few small projects so it didn't take much deliberation to decide to support Clayton and we spent \$200 on buying him a solar panel, battery and inverter, along with a soldering iron and multimeter for testing. We also procured him some tools. As he told Alison he can now fix radios and cassette players himself and get a little bit of money to buy food.

Alison always suspected he had polio as he had all the classic symptoms and the fact that he was well until 14 and then lost his two brothers with the same illness has confirmed it for her.



This is Clayton James and he is 27 years old. He lives by himself and has resided in the same house for most of his life. His home area is the Muhlungulani within Chiredzi District, about 35km from Chikombedzi.

As a small child he was well, but around 14 years of age he became

sick and started to have physical problems which gradually became worse. By the time he was 25 he could barely walk and is now permanently using a wheelchair. He had 2 brothers with the same problem – both have since died.

He could not say what his illness was but I suspect he has post-polio syndrome as he exhibits all the classic symptoms. Polio is relatively common around the Chikombedzi area seen mainly in people from late teens and up.

He has not received much in the way of treatment for his symptoms but I am organizing a regular supply of pain killers to help him through more difficult periods.

Clayton has always had an interest in radios, cassette players and other small appliances. Over the years he has taught himself how to find faults and fix these things. However, he didn't have the right equipment to make the repairs himself and much of the time could only tell people what needed to be done and they had to get someone else to make the repair.

We purchased for him a solar panel, battery and inverter, along with a soldering iron and multimeter for testing. He says that this equipment is very helpful for him as he can now fix radios and cassette players himself and get a little bit of money.

He will use what money he earns to buy food. In the future, if he can increase his income, he would like to build a more spacious house as well as a proper Blair toilet that can accommodate his physical needs. (at the moment he tends to use the bush, as it is easier in the wheelchair). He would also like to buy himself some goats and cattle so he can have a regular supply of meat. 🍖

**Read more
about Pam
[here.](#)**



Now or Never: On The Edge of Polio Eradication

by **Alexandra Phelan**

Source: [ABC The Drum Opinion](#), 30 May 2012

At some point in recent history, Australians forgot about the iron lung; the full-body metal chamber, changing air pressure so that polio sufferers could simply breathe in, and out.

We forgot about the Australian children who were left paralysed or whose legs were permanently deformed.

At some point, we lost our deep, dark fear of polio. Forgetting, thankfully, was perhaps as a result of an incredible medical advancement; when Australian Dr Percival Bazeley CBE, working with Dr Jonas Salk, developed, and then pioneered the Australian delivery of the Salk polio vaccine.

This remarkable moment in medical science is at the centre of events this week at the 65th World Health Assembly of the United Nations World Health Organization; the world's highest-level health policy forum. Ministers of Health, national delegations, and leading international health experts and advocates converge on Geneva, Switzerland to meet and discuss the world's most pressing health issues, such as pandemic influenza.

On Friday, Geneva time, I watched the World Health Assembly, composed of 194 countries, declare polio a global health emergency and that vaccinating children across the world is an immediate international health priority.

Although we have come incredibly close to the complete global eradication of polio, a sudden escalation of cases has demonstrated the vital importance of consistent, community-wide vaccination. According to the World Health Organization, we are facing a "now or never" moment to permanently eradicate polio globally.

Vaccination is the solution. Since the introduction of a coordinated global vaccination effort 20 years ago, led by the World Health Organization and Rotary International, the number of polio cases worldwide has dropped 99 per cent. No longer are millions of lives around the world lost to polio, and no longer are nearly 1,000 children permanently paralysed every day.

For doctors, scientists and health human rights experts the possibility of global polio eradication is both exciting and inspiring. For those living in endemic polio areas, and for the 200,000 children who are predicted to otherwise be crippled by polio, this is simply life.

The dangers of failure to vaccinate are too great; not only for individuals, but for communities, and as has been seen in this case, the entire globe. Consistent vaccination is absolutely essential. Contrary to the cries of anti-vaccination lobby groups, failure to vaccinate is not only scientifically and medically unfounded selfishness, but dangerous. Laurie Garrett, Senior Fellow for Global Health at the Council of Foreign

Relations, has not only expressed that "[w]e're so close on polio eradication that it hurts", but that the rise of anti-vaccination movements are causing the "export" of vaccine-preventable diseases, including polio, to developing countries where ready access to vaccinations is sparse.

As a result, in addressing its international legal and moral responsibilities in this global health emergency, it is essential that Australia takes steps to continue to ensure that parents are provided with education on the medical and scientific facts of vaccination. Maintaining and ensuring consistent, community-wide vaccination, even here in Australia, is the only way global eradication of polio will become a reality; ensuring the health and human rights of millions around the world.

Ban Ki-moon, Secretary General of the United Nations, last week warned that:

"Wild viruses and wildfires have two things in common. If neglected, they can spread out of control. If handled properly, they can be stamped out for good. Today, the flame of polio is near extinction - but sparks in three countries threaten to ignite a global blaze. Now is the moment to act."

Now is the world's moment to act. Now is every Australian parent's moment to ensure that their child is vaccinated against polio, and that the iron lung is relegated back to its rightful place in museum exhibits of the remarkable achievements of medical science. ●



Alexandra Phelan is an Australian international health and human rights lawyer, presently based in Geneva, Switzerland. She holds a Bachelor of Biomedical Science/Bachelor of Laws (Honours) from Monash University, and is completing her Master of Laws (International Law) at the Australian National University. Ms Phelan has worked as a corporate and human rights lawyer in Melbourne, Australia before undertaking a sabbatical in 2012 in the Gender, Equity and Human Rights unit at the United Nations World Health Organisation and at the GAVI Alliance.

The Emergency Explained

by [The End of Polio](#)

Friday, May 25, 2012

So polio has been declared an "emergency for global public health" by the World Health Assembly – but what does that mean exactly? Here's a quick summary of the implications of the World Health Assembly's Resolution:

1. Polio eradication has reached a tipping point. While the world is more than 99% of the way towards eradicating the disease, a funding shortfall has already caused vaccination activities to have been cut back – putting vulnerable communities at risk from the disease.
2. If we fail to eradicate polio, the consequences will be disastrous. Research has shown that the world would soon see more than

200,000 cases a year. This is why the continued transmission of polio is now an emergency.

3. This resolution gives countries greater powers to combat polio. For instance, they can choose to require travellers to and from polio-infected countries to be vaccinated against polio. Polio-infected countries have been urged to draw up emergency action plans for combating the virus.
4. The resolution also calls for the World Health Organization's 194 Member States to fully fund the Global Polio Eradication Initiative.



Declaring polio an emergency for global public health is an important step forward, yet we will only see the end of polio if the funding gap is filled. This is why we are asking world leaders to go beyond words and ensure that the Global Polio Eradication Initiative is fully funded. You can sign the petition at www.theendofpolio.com

2013 Polio Health and Wellness Retreat

**Body / Mind / Spirit
South Australia in April 2013**

Expression of Interest

Polio Australia will once again be facilitating its 4 day/3 night day Polio Health and Wellness Retreat for polio survivors and their partners from Thursday 18 to Sunday 21 April, 2013 (TBC), this time in the culture-rich state of South Australia. The holistic 'Body / Mind / Spirit' theme will continue and include:

- Interactive group sessions and one-to-one consultation opportunities with a variety of allied health professionals
- Hydrotherapy and exercise options
- Latest orthotics, aids and equipment displays
- Seated Yoga and Meditation Sessions
- Activities To Keep The Mind Active
- Creative Workshops and Singing for Health
- Massage therapy

See details of previous Retreats at www.polioaustralia.org.au / **What we do / Self Management**

Polio Australia's Health and Wellness Retreat—South Australia

Expression of Interest only

(Estimated registration fees for 3 nights accomm, all meals and most activities = \$350 pp double / \$400 single)

Please provide me with more information on the 2013 Polio Health & Wellness Retreat when available.

Name: _____

Address: _____

Phone/s: _____ Email: _____

Return to: Polio Health & Wellness Retreat, Polio Australia, PO Box 500, Kew East, VIC, 3102 or Email: office@polioaustralia.org.au