



Volume 2, Issue 3

Polio Oz News

September 2012—Spring Edition

Sleep At Last

by Peter Willcocks (Victoria)
August 2012

"I can't breathe! I have only been in bed for an hour or so. I roll over. I listen to the continuous pressure of air swirling around my mask, my mouth, and somewhere down my throat. I gasp for air, I swallow, my mask leaks. I am so tired, I am so sore. My arms ache, my chest is heavy, my legs twitch and cramp. I am exhausted. I choke, I splutter, I can't breathe. All I can hear is the continuous pressure of air forcing its way from my mask. I feel a flat pain across my chest.

I sit up, remove my mask and take a deep breath in and out, in and out. I am groggy with sleep – but too tired to lie down again and face that machine. I sit up for an hour or so, try to read, have a cup of tea, and watch another 3am repeat of the Leyland Brothers outback adventures. By 4.30am I am strong enough to lie down and listen to the pump press air into me." Well that was the way it was until a couple of months ago.

In 2005 I first started using a CPAP (Continuous Positive Airway Pressure) machine for sleep apnoea. The first few months were great and I got about six hours of good sleep every night. No longer was I awoken by a jolt of adrenalin kick starting my breathing. This jolt of the body being kick started is not only painful and exhausting but it is also very frightening. I often dozed while watching TV only to be sparked awake with pain, to sit up to take a deep breath and then I would desperately try not to fall back to sleep.

Life before CPAP was an exhausting time and at first I did not realise that my poor health was due to the later effects of polio. Fortunately I discovered Dr Stephen de Graaff and his wonderful team of physios, speech therapists, OT's and a psychologist who struggled to get me to slow down. The hospital where Steve was at the time did not have an in-house sleep clinic so the sleep stuff was contracted out.



The hospital that I chose from Steve's list had a clinic run by ResMed technicians. All good, but to get a referral to a respiratory doctor you had to do it via them. The technicians at that hospital knew little of the later effects of polio and the respiratory doctor that I saw seemed more fascinated with polio than informed. They relied heavily upon readings from

my CPAP and from overnight sleep studies.

By 2009 I was struggling again with energy, being tired for much of the time. A very good friend ours, Jill Pickering, referred me to an article in a polio newsletter on the use of Bi-PAP (Bi-Level Positive Air Pressure) machines for polio folk. Bi-PAP machines utilise two levels of positive air pressure; the first to provide a larger breath than the weakened muscles can take in, and the second, a much lower air pressure to allow the person to breathe out normally. It seemed like I should be using a Bi-PAP. OK, new respiratory doctor, new hospital. Everything will be sorted – ha!

During my first appointment I suggested that perhaps my CPAP was not doing what it could for me. Let's run some tests. Over the next three years I had five overnight sleep studies, six or seven hour long exhausting breath strength tests, regular blood tests to check for CO₂, changed to four different types of masks, and privately trialled two slightly more flexible CPAP machines that had some variable pressure. In 2011, in a desperate effort to help, a friend gave me their older style ResPironics M series CPAP that had C-Flex which follows breathing patterns and provided some relief from the continuous air pressure.

The respiratory specialist at hospital didn't think the benefits from the ResPironics M series machine would be that different from my existing ResMed CPAP but felt C-Flex was worth trying. It was better than my old CPAP but as the

Cont'd P 3

Polio Australia Inc

Representing polio survivors
throughout Australia

Suite 119C, 89 High Street
Kew Victoria 3101
PO Box 500
Kew East Victoria 3102
Phone: +61 3 9016 7678
E-mail: office@polioaustralia.org.au
Website: www.polioaustralia.org.au

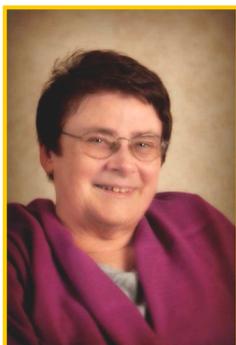
Contacts

- President - Gillian Thomas
gillian@polioaustralia.org.au
- Vice President - Arthur Dobson
arthur_dobson@bigpond.com
- Secretary - Tessa Jupp
poliowa@upnaway.com.au
- Treasurer - Neil von Schill
neil@polioaustralia.org.au
- National Program Manager
Mary-ann Liethof
mary-ann@polioaustralia.org.au

Inside this issue:

- [Sleep At Last](#) 1
- [Jetstar Appeal](#) 3
- [Walk With Me](#) 4
- [NDIS Forum Your Say](#) 4
- [The Dragonfly](#) 5
- [Dream and Do!](#) 5
- [The Indomitable Mrs P](#) 6
- ["We're Still Here" Campaign](#) 8
- [Polio Legacy Still With Aust](#) 9
- [Medicare Local Alliance](#) 9
- [Personally Controlled Electronic Health Records](#) 10
- [Triclosan Warning](#) 10
- [A Journey With Polio](#) 11
- ["Touched By Polio" Exhibit](#) 12
- [2013 Retreat—SA](#) 13
- [Polio This Week](#) 14
- [Paralympics News](#) 15

Welcome from the President



Gillian Thomas
President

Since the last issue of Polio Oz News we have been busy in Canberra again, with two days lobbying on 20 and

21 August, led as usual by our hard-working Patron, John Tierney.

We met with the Managers of the two Flexible Funds that we had unsuccessfully applied to for funding (the outcome being that while our applications were sound there is never enough money). We also met with a number of key parliamentarians, and were privileged to be given time once again to address the House Standing Committee on Health and Ageing. While we were in Canberra the Committee's Discussion Paper was debated in the House of Representatives. To our delight this exposure

generated a flurry of [media reports](#).

We are now looking forward to the next Canberra foray on 31 October for our "We're Still Here!" campaign, accompanied by many of you – you can make a difference so we hope you will join us (see page 8). Mary-ann is off to Italy for a well-deserved break but will be back at work at the beginning of October to keep this campaign rolling along.

In the meantime, please sponsor a walker in Polio Australia's first Walk With Me fundraiser in Melbourne on Sunday, 9 September (see page 4) - we have set an [ambitious target](#) and need your help to achieve it. 🌟

From the Editor



Mary-ann Liethof
Editor

Unless otherwise stated, the articles in Polio Oz News may be reprinted provided that they are reproduced in full (including any references) and the author, the source and Polio Australia Inc are acknowledged in full. Articles may not be edited or summarised without the prior written approval of Polio Australia. The views expressed in this publication are not necessarily those of Polio Australia, and any products, services or treatments described are not necessarily endorsed or recommended by Polio Australia.

Firstly, please accept my apologies if this Spring Edition of "Polio Oz News" is a little less packed than usual. My excuse is that I am just about to head off to Italy for the month of September and, as always, there are so many things to do before I go! Although the weather is slightly less frigid than it has been in Melbourne of late, it's still cold—so the warmth of northern climes is calling me loud and clear.

However, I know you will find the stories included in this edition to be an interesting read. People are so interesting, aren't they? Every day I feel privileged to hear about what people have and are still achieving in their lives—often whilst enduring considerable physical duress.

You will read about Peter's search to find a respirator that actually works for him; Roger and the fun he's having with his Dragonfly handcycle; how "Mrs P's" rehabilitation

from childhood polio led to a lifelong passion for music and dance; John retiring from the world of finance to take up art; and how Pakistani polio survivor Mudassar Baig dreams of winning a medal at the London Paralympics.

So this Spring edition is really a celebration of the fulfilling and often amazing lives of Australia's (and the world's) polio survivors. It is all of you who provide the ongoing inspiration to those of us at Polio Australia to keep fighting the good fight to ensure that there are proper services made available so that people living with the Late Effects of Polio can continue living their lives to the full!

Now, I'm off to catch a plane! 🌟

Spring is God's way of saying, "One more time!"

~ Robert Orben

Sleep At Last (Cont'd from P1)

months passed my breathing softened to the extent that the air just swirled around the top of my lungs leaving all the bad air (CO₂) to mix with my blood. Again I awoke feeling like someone had poured poison into my veins. I needed to get up, move around, take deep breaths, only then would the pain and the toxic taste decrease.

About 12 months ago I received advice from a senior clinician from the Victorian Respiratory Support Service to talk to my sleep specialist about Hypoventilation. Yeah, right, like I am a doctor and I can talk their language. I gave it my best and received an answer something along the line of "Yes you do indeed have a reduced ability to breath out but there is very little evidence of hypoventilation from your current tests, we will run some more and see what the results suggest."

More tests and more lying awake at night as I listened to the air swirl around my mask, my mouth, and somewhere down my throat and then about 2 months ago... "Perhaps we need to try something different. It is very difficult to monitor CO₂ levels in your blood during normal home sleep patterns. You say you wake up at night and the only way you can breathe is to

sit up and take deep breaths...". Two days later I began a trialling a ResMed VPAP III with full Bi-level Positive Air Pressure.

I am now into my second month of sleep filled nights. Occasionally I tease my Bi-PAP and stop breathing but I am quickly kick started with a puff of air with the pressure quickly decreased to allow me to breath out before the next puff starts. The Bi-PAP that I have is armed with a siren that wakes the dead if there is an air leak or if the cat inadvertently decides my time is up and wacks the power plug from the wall.

My brain is alive again and I can and want to do more stuff. But even better I no longer begrudgingly take strong pain relief from Tramadol supported by Endone two or three times a week just to get by. I now get sleep and my muscles get the rest that they have for so long sought and I no longer feel like my veins have been topped up with their nightly dose of poison (CO₂)

Solving sleep problems is not always straight forward and I have been fortunate to have had great support from my respiratory specialists. I suggest if you are struggling don't give up, have another chat to your specialists and work together to find a solution. ●

Notes

Hypoventilation: Generally, in people with neuromuscular disorders who are having breathing problems, the main problem is hypoventilation (underventilation) - not breathing deeply and/or often enough. Muscle weakness, scoliosis and/or chest wall stiffness make it difficult or impossible to fully inflate the lungs. Hypoventilation results in an imbalance in the carbon dioxide (CO₂) and oxygen CO₂ exchange in the blood; too much CO₂ is retained, too little O₂ is taken in. Because hypoventilation usually first occurs during sleep and because several of the signs and symptoms overlap, it can be misdiagnosed as obstructive sleep apnoea (OSA).

Source: Rancho Los Amigos Post-Polio Support Group article by Judith R. Fischer, MSLS, Editor, Ventilator-Assisted Living *with thanks to Josh Benditt, MD, University of Washington, Seattle; Peter Gay, MD, Mayo Clinic; Diana Guth, RRT, Home Respiratory Care, Los Angeles; E.A. Oppenheimer, MD, (retired) Los Angeles; and Jesper Qvist, MD, Respiratory Centre East, Copenhagen, Denmark* ●

Woman in Wheelchair Loses Jetstar Appeal

by **Jamelle Wells**, Court Reporter

Source: [ABC News](#), August 23, 2012

A 78-year-old woman has lost her appeal against a ruling that Jetstar did not have to let her on a flight because she was in a wheelchair.

Sheila King, who had polio as a child and was also injured in a car crash, booked her Jetstar flight between Adelaide and Brisbane online in August 2008.

The airline contacted her and said she would not be able to fly that day because there were already two passengers on her flight who needed wheelchair assistance.

Ms King tried to sue the airline claiming she was discriminated against. But in January this year a court ruled against her, noting that she failed to select wheelchairs on a special section of the website and that Jetstar offered her another flight that she refused to take.

The Federal Court in Sydney today dismissed Ms King's appeal against the January judgment. ●



Walk With Me



Polio Australia is delighted to be joining in with Scope's Walk With Me event in marvellous Melbourne on Sunday, 9th September 2012 - bringing together people of all abilities to 'walk' along the scenic Yarra River.

Registration is from 9:00am with the 'walk' set to start at 11:00am. Length of the 'walk' is 2km or 4km.

About Walk With Me

"Walk With Me" is an event conducted nationally through Ability First Australia's eight member organisations, of which Polio Australia is one. The focus of the walk is to raise awareness and celebrate inclusion of people living with disability, as well as raising much needed funds.

It is not a fun run, nor a competitive fitness event but a recreational walk, providing family, friends, colleagues and members of

the general public with the opportunity to 'walk' side by side in a non competitive, lively, fun and very public environment.

The difference we can make together

Funds raised for Walk With Me will be used by Polio Australia to pay for much needed program development including annual Polio Health and Wellness Retreats, Regular Polio-Related Publications, Clinical Practice Modules, Community Education, and Systemic Advocacy.

Ways people can help

- **Join our walk** – register to get involved with this inclusive community activity
- **Create your own fundraising team** – when you register, there is an option to be a team captain so that others can join your fundraising team
- **Sponsor a walker!** - choose who you would like to support – donations are tax deductible and can be made online.

Simply go to [Polio Australia's Walk With Me web page](#) and follow the prompts!

About Polio Australia

Polio Australia is a national not-for-profit community based organisation that represents tens of thousands of Polio Survivors living in Australia today. We strive to ensure all polio survivors in

Australia have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices.

About Ability First

Ability First Australia is a national body of leading disability organisations working to achieve a fair go for Australians living with a disability. Seven members of AFA were established from the 1920's onwards to support children living with physical disabilities. The "polio kids", now grown up, are represented through Polio Australia.

About Walk With Me

Walk With Me is a national event organised in conjunction with Ability First Australia, a registered charity and national body representing eight leading Australian disability organisations working to achieve a fair go for Australians living with a disability. 🌟



NDIS Forum – Your Say

Source: [NDIS Website](#)

A National Disability Insurance Scheme will transform the way disability services are delivered in Australia, it will take a lifelong approach to providing care and support.

The Australian Government has established the NDIS Advisory Group to help steer the development of the scheme and ensure people with disability are involved in the design. Over the next few months, the NDIS Advisory Group will be asking design questions about the scheme and seeking your feedback.

You have a [forum](#) to present your views on design elements of the scheme and there's also space for you to share your [stories and experiences](#). Your views and opinions will be critical in helping to deliver the first stage of an NDIS.

Get involved and help us transform the way disability care and support is provided in Australia. This is your NDIS – your say. 🌟

The Dragonfly

by Roger Beale (ACT)

For the last few months I have been enjoying using a Dragonfly Handcycle attachment for one of my wheelchairs. It is an 8 speed handcycle which clips onto the wheelchair to turn it into a hand powered trike.

On flat terrain it will get up to about 12-15kmh and it is excellent aerobic exercise without the impact on rotator cuffs and carpal tunnel that using the wheelchair has. I find I can comfortably ride for an hour without too much difficulty.

On the flat you go faster than most middle aged or less fit joggers - I really only get passed by the 'professional' men and women runners (the lycra-wearers with clear ability and fitness).

It is not much good on hills as there is not a lot of mechanical advantage, unlike a racing hand cycle where you use most of your upper body as well as your arms, and because of the short wheel base the front wheel tends to spin (i.e. loose traction).

The great advantage is that unlike a competition cycle it is easily transported in a medium size car (I have a Subaru Liberty wagon) at the same time as your wheel chair. I find that I can attach it in about 5



minutes and reverse the process in about double that time.

It weighs about 13 kilos so it is about as heavy as an average wheelchair. I prop myself against the boot and lift the wheelchair out with one hand and then slide the Dragonfly out. While neither of my legs has much strength, I do have still very considerable upper body strength and I am fairly fit.

[However, the Dragonfly is] not

cheap - about 2-3 times the price here as in the US. It is made by RioMobility and members will find [YouTube](#) clips if they Google as well as the [US web site](#).

I recognise that I am in the privileged position of being able to afford high quality equipment - both wheel chairs and orthoses - and of having stayed pretty fit and active - but it could be relevant to others. 🌟

Dream and Do!

Source: Email from [Doug J. Cornfield Sr.](#)
Dave Clark Foundation, Ltd.

I wanted to connect with your organization regarding Dave Clark who is a polio survivor and now suffers with Post Polio.

Dave's story is extraordinary in that he is the only professional baseball player to ever pitch from crutches. His story can be found on two websites:

www.daveclarkfoundation.org
and
www.daveclarkbaseball.com

On YouTube there is a channel of his videos which can be found by searching Dave Clark Baseball.

Let me draw your attention to a new video called "Crutches 2 Champions" that can be found on the Foundation home page or on YouTube.

Please feel free to contact me for more information. Dave is now a keynote speaker sharing his remarkable story and Post Polio gets explained and mentioned at his talks. 🌟



Dream & Do!

The Indomitable Mrs P

The story of Mrs Tanya Pearson OAM was recently aired on ABC TV's "Australian Story", revealing that "Mrs P" is actually a polio survivor. Having immediately written to her Classical Coaching Academy, Polio Australia was kindly granted permission to include Mrs Pearson's fascinating story in "Polio Oz News". The following account appeared in the Programme for an August 2012 performance entitled: "**Mrs P - 50 Years - A Celebration**".



Born in 1937 in Russia, not far from Moscow, Tatiana Jacubenko's early years were anything but easy. She never knew her father as he abandoned the family not long after Tatiana's younger sister, Nellie, was born. From that day, Tatiana's mother, Anna, never talked about her husband. All that is known is that he was an actor and musician, and ... he had a sister who was a ballet dancer.

Anna's health suffered greatly and she became seriously ill with diphtheria and was sent to recover in a sanatorium in Crimea, while both Tatiana and her sister Nellie were placed in an orphanage in Russia. Conditions in the orphanage were dire and, tragically, baby Nellie died of malnutrition within her first year. Tatiana's grandparents were

unaware of the plight of their daughter and granddaughters until they were informed of Nellie's death. They collected Anna and Tatiana and brought them to live with them in Nikolayev, a town near Odessa on the Black Sea.

In Nikolayev, Anna regained her health, and mother and daughter became inseparable. These happy times in The Ukraine were short lived however, due to the outbreak of World War II. Under German occupation, they were ordered to leave their homes with only the possessions they could carry. Separated from the men - Tatiana, her mother and grandmother were put on to a train - never to see or hear of her grandfather again. Transported like cattle, they were packed into the carriages - with no food or water - and escorted into Germany not knowing their fate. They were displaced, without home, identity or country.

Arriving in Germany, most of the people on the train were taken to concentration camps - however, for a reason lost in history, a kind Catholic Priest took Tatiana and her family to live in his home in a village in the Black Forest. There, they found shelter. Anna worked as a housekeeper and the family adopted a German identity, changing their surname to Schaefer. Tatiana became Erna Schaefer during her years in Germany.

At the end of the war, the family moved to Heidelberg, where Anna obtained a job translating at the University. Although the family was still very poor, life slowly began to look up. Anna's irrepressible optimism and her love of music and singing had a profound influence on young Tatiana's life. These were happy years full of imagination, fairy tales, music and hope.

And it was here in Heidelberg that Tatiana accidentally discovered the magic of ballet

Suffering from a weakness in her right leg (much later to be diagnosed as Polio) she was sent to

regular physiotherapy sessions - which happened to be held in rooms in the local Heidelberg theatre. On one particular day, Tatiana went through the wrong door and discovered a whole other world ... ballet. There on stage was a ballet company rehearsing and young Tatiana was mesmerised.

From that day onward, she avoided her physio sessions, opting to hide at the top of the theatre watching the performers rehearse.

When Tatiana was 11 years old, her grandmother and aunt decided the family should immigrate to Australia. Devastated to be leaving Europe, but knowing the remaining family must stay together, they uprooted once again to begin a new life in a new country on the other side of the world.

This new life began in a migrant camp in the New South Wales countryside, with Anna finding work as a housekeeper - and eventually a new husband. And in keeping with their new life, Tatiana became Tanya.

In Australia, Tanya was now free to pursue her love of ballet. She began her ballet studies with Raisa Kouznetzova - an original Ballet Russes member with a thriving ballet school in Bridge St, Sydney.

As an ambitious late starter, Tanya progressed very quickly and at 17 she was offered a scholarship to train with the Borovansky Ballet Academy in Melbourne. As a scholarship student, Tanya had to teach younger students every Saturday morning. This was her first introduction to teaching and Madame Boro complemented Tanya on her 'good eye' and natural teaching style.

A few years later, Tanya joined The Borovansky Company working alongside such great dancers as Katherine Gorham, Peggy Sager and Leon Kelloway. Sadly, Edouard Borovansky died towards the end of Tanya's first year and the Company known as The

The Indomitable Mrs P (Cont'd)

Borovansky Ballet soon disbanded. Many of the dancers were out of work and devastated... but not Tanya! She quickly found employment as a resident dancer with HSV Channel 7 performing in variety shows such as *Sunnyside Up* and at a time when Newton and Kennedy were emerging as big stars! It was the heyday of the television era and the start of the swinging 60s! ...

Some 18 months later, on the recommendation of guest choreographer George Carden, Tanya boarded a ship for England with only £10 in her pocket and no return fare.

With fellow Australians Barbara Chambers and Heather McRae, Tanya performed throughout London before all three were cast in the film - *The Life Of Fanny Elssler* starring Olga Ferri.

It was here that Tanya met her Prince - Keith Pearson. The two fell passionately in love, married in London and had two sons. In 1964, Keith and Tanya returned to Sydney with two young boys in tow and went on to quickly have two more girls Gabrielle and Nicole.

Tanya was offered a position with the newly-formed Australian Ballet, but she turned down the opportunity, deciding to hang up her pointe shoes and begin the next chapter of her life - as a wife, mother and teacher.

She started teaching local students in the ground floor of her Forestville home, but her reputation soon spread and young women and men flocked to the studio.

In 1971, Mrs P rented larger studios at Belrose and set up the Northside Ballet Academy expanding her training into RAD and other syllabi.

That same year she established the Northside Ballet Company to provide talented young dancers the opportunity to perform in full-length ballets alongside renowned guest artists from professional

companies such as Barbara Chambers, Kate Geldard, Karl Welander, Glenys Bush, to name just a few, and the Company's first production of *Nutcracker* featured an 11 year old boy by the name of Danilo Radojevic!

A former Artistic Director of the Australian Ballet, Anne Woollams, was so impressed by the company that she urged the Governor of NSW and the Sydney City Council to support it by providing funding and premises. Relunched as the Sydney City Ballet Company, the company employed over 20 dancers and performed at the Regent and Capitol Theatres, as well as touring throughout NSW.

With Marilyn Jones as Artistic Director, Hassan Sheta as Ballet Master, and Sir Robert Helpmann as Patron, the company featured many International Guest Artists including Wayne Eagling who performed with the Company in 1982.

Several years later, the Government subsidy was unfortunately withdrawn. There were insufficient funds to survive as a professional ballet company, but Mrs P was determined for it not to disappear altogether. Subsidising it herself, she re-formed it as the Sydney City Youth Ballet - with the continued aim to provide emerging dancers the opportunity to perform full length ballets and put into practice what they learn in the studio on stage.

Featuring numerous guest artists from The Australian Ballet, as well as International companies, each year the Sydney City Youth Ballet has continued to perform full-length ballets to the general public including the perennial favourite *Nutcracker*, as well as *A Christmas Carol*, *Cinderella* and the world premiere of *Polar Express* choreographed by Paul Boyd.

In 1987, Mrs P established the Glen St Academy with Janece Graham, and then went on to run the ballet department of the Dynamite Dance Studios with David Atkins in 1989.

Mrs P eventually established her selective coaching academy at Crows Nest - turning her main focus to assisting talented students to achieve their dreams of a career in Classical Ballet.

Over the years, many of her students have taken top medals and scholarships at local and international ballet competitions including the Sydney Eisteddfod, Prix de Lausanne, the Genee, and the Youth America Grand Prix.

As early as 1983, Mrs P began taking students on international tours to Russia, Europe, England and the United States, so that they could experience the broader ballet world and take classes with some of the world's greatest International Schools. In January of this year she completed her 23rd annual overseas study and audition tour.

Awarded the Outstanding Teacher Award by her international peers at the 2009 Youth America Grand Prix, Mrs P this year received The Medal of the Order of Australia for service to the performing arts, particularly ballet, as a teacher and mentor to young dancers.

Today there are companies all over the world with dancers who have trained with Mrs P - from the Australian Ballet to the National Ballet of Canada, the Royal Ballet, the Hamburg Ballet, the HET Nationale Ballet, Bayerisches Staatsballett, the Croatian National Theatre, Zurich Opera Ballet, Birmingham Royal, Magdeburg Theatre and the Slovak National Ballet to name just a few.

This performance is in tribute to the indomitable Mrs P.

"We're Still Here!" Campaign



Polio Australia is delighted to announce that we now have approximately 30 polio survivors and their family members joining us in Canberra on Wednesday 31st October at the culmination of the National Polio Awareness Month's **"We're Still Here"** campaign.

Those coming are making 20 minute appointments to see their local [Federal Members of Parliament](#) in the morning to discuss the issues identified at the [Roundtable Forum](#) on the Late Effects of Polio held in March, and detailed in the resulting [Health and Ageing Committee Discussion Paper](#). We recommend copies of this one page (double sided) [Handout](#) be left with the MPs, which highlights the three recommendations made by the Committee and a call to action, namely:

"I am one of Australia's hundreds of thousands of polio survivors who needs access to polio-specific services. I want to see not only the above recommendations turned into action, but also the work being done on my behalf by my state and national polio support networks receive long-overdue funding. Show your support for the post polio community by

taking this to your Party Room or Caucus for discussion.

We are still here - and we still have a lot of fight in us yet!"

The proposed order of the day is:

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

Lunch at Parliament House

2.00pm

Question Time

3.30pm

Depart to own activities

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.

We have also been advised that MPs are often able to provide a modest contribution to members of their electorate for the purpose of travelling to Canberra to meet with them.

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 it's Mission to "standardise quality polio information and service provision across Australia for polio survivors", we depend on **your** support.

Denton Trieu



Denton has recently joined the hard-working team at Polio Australia. He is currently in his final year of study at Monash University, completing a Bachelor of Business (Marketing).

Denton is volunteering at Polio Australia, taking care of the "We're Still Here!" campaign. With the help of the Polio Australia team, Denton is working on this project to bring greater awareness of the late effects of polio to a cross section of the Australian community. Denton also will be looking to appeal to a younger audience using social media. 🌐

Polio Legacy Still With Australia

Source: skynews.com.au - Monday August 20, 2012

Thousands of Australians may be suffering from the delayed effects of having polio without knowing it, a federal parliamentary committee has found.

It's a legacy from the days when Australia suffered epidemics of poliomyelitis, a potentially crippling and sometimes fatal viral infection.

It was wiped out in Australia by comprehensive vaccination programs starting in the late 1950s.

However, the House standing committee on health and ageing has found, following a roundtable with health officials and polio groups, that many years after the initial infection, an increasing

number of survivors have developed a range of symptoms.

These include fatigue, muscle weakness and pain, respiratory and sleep problems, speaking and swallowing difficulties and intolerance to cold.

However, doctors have been slow to recognise it.

Liberal MP Steve Irons, the committee deputy chair, said on Monday there were no particular tests for the condition which could take up to six years to diagnose correctly.

The committee chair, Labor's Steve



Georganas, said it was unclear how many were affected, but it was likely to be in the thousands, with many sufferers still unrecognised.

The committee has called for better estimates of the number of Australia's polio survivors and the proportion suffering late effects, and greater awareness of the condition among medical groups. ●

Australian Medicare Local Alliance Launched

Source: [Joint Release](#)

The Hon Tanya Plibersek MP, Minister for Health

The Hon Mark Butler MP, Minister for Mental Health and Ageing, Minister for Social Inclusion, and Minister Assisting the Prime Minister on Mental Health Reform
16 August 2012

Australians can look forward to more effective and cohesive primary health care with the launch of a new national body to lead the network of Medicare Locals.

Minister for Health Tanya Plibersek and Minister for Mental Health and Ageing Mark Butler today attended the launch of the Australian Medicare Local Alliance in Parliament House, Canberra.

Ms Plibersek said the Australian Medicare Local Alliance will play a key role in ensuring Medicare Locals function effectively and efficiently and work as a cohesive group, responsive to changing Government priorities.

"Medicare Locals will improve the coordination and integration of primary health care in local communities, addressing service gaps and making it easier for patients to navigate their local healthcare system," she said.

"As the body responsible for supporting Medicare Locals at the national level, the new Australian Medicare Local Alliance will assume a key leadership role in primary health care."

Mr Butler said the Alliance will support Medicare Locals to become high performing organisations and, from 1 January next year, coordinate the provision of state-based functions on behalf of the Medicare Local network.

"The Alliance will play an important role in preventive health and health promotion, and will work with a wide set of stakeholders, including those in general practice, allied health, and the aged and social care sectors," he said.

"The Australian Medical Local Alliance will play a vital role in

ensuring the 'big picture' in primary health care across the country comes into focus and I look forward to working with the Alliance in building a better health system."

Nationally, 61 Medicare Locals have been established to identify gaps in primary health care services at the local level, especially for high need and underserved groups, and to better target services to respond to those gaps.

The Australian Government has committed a total of \$493 million from 2010-11 to 2012-14 for the establishment and operation of Medicare Locals. It will also be the primary funder of the Australian Medicare Local Alliance. ●



PCEHR System Now Live

Source: [Consumer Health Forum](#)



CHF Chair, Stephen Murby, discusses the PCEHR with other consumer representatives at a CHF workshop

The Personally Controlled Electronic Health Record (PCEHR) system went 'live' on 1 July 2012.

Consumers can now register for their own record (online, by telephone or in person at a Medicare office) and access a consumer portal. Health professionals will be able to access the PCEHR system and upload information to it in the coming months.

CHF has maintained a strong interest and involvement in the development of the PCEHR system, and will continue to do so as the system evolves. With some health professional groups raising concerns about how patient control will impact on the completeness of the record, CHF has strongly maintained that personal control is a fundamental element of the system, and that the record should only be a starting point for discussions between consumers and health professionals.

"Patients typically do not give full and complete information about their health to their doctor, and there are often legitimate reasons why they don't," said Ms Bennett.

"There will only be a very small minority of cases in which people will choose to restrict access to key information in their PCEHR that could affect the quality of care they receive."

"The idea it is going to be a widespread problem is spurious at best." 🟡

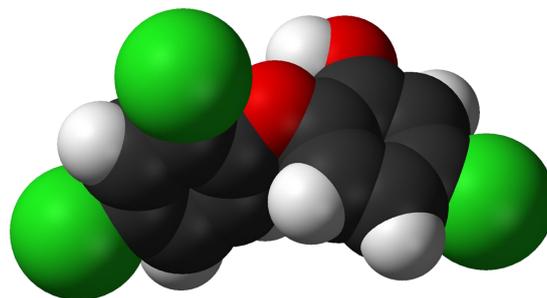
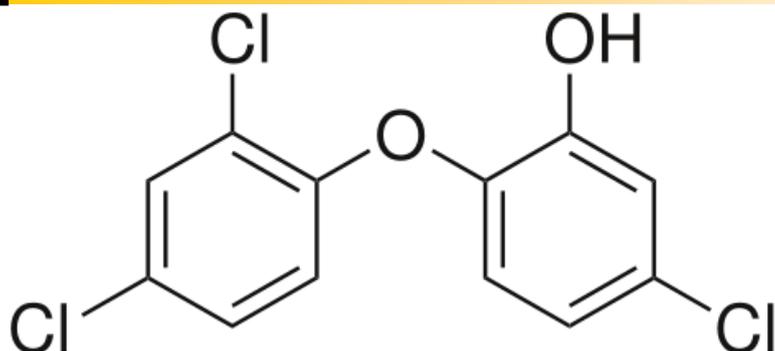
Triclosan Warning

by Dr Margaret Peel (Queensland)

A 2012 publication in an early edition of the American PNAS (Proceedings of the National Academy of Sciences) reports that the antibacterial agent triclosan potently impairs the contractility of skeletal (and cardiac) muscle. Triclosan is widely used in personal care products, such as mouth washes, toothpastes, deodorants and antibacterial soaps, as well as cleaning agents and it has even been incorporated into fabrics and plastics. The reference is: Cherednichenko G, Zhang R, Bannister RA. Triclosan impairs excitation-contraction coupling and Ca²⁺ dynamics in striated muscle, 2012. Read the abstract [here](#).

In view of these findings, it seems to me that it would be prudent for those of us with Late Effects of Polio/ Post Polio Syndrome to avoid personal products and cleaning agents that contain triclosan.

Read more about triclosan here: <http://en.wikipedia.org/wiki/Triclosan>



A Journey With Polio

by **John Marsh** (NSW)



One morning in April 1951 I got out of bed – or tried to – and fell, and found that I was unable to walk. Polio was quickly diagnosed; Sydney had an epidemic at the time.

My family lived at Parramatta, and at 10½ years of age I was sent to the isolation ward at Prince Henry Hospital, Little Bay. Both my legs were affected; the right with total loss of foot, ankle, knee and hip function, the left leg and my back only slightly impaired. Both left leg and back did recover really well, but the right leg remained with little function.

November 1951 saw me moved to Parramatta Hospital for rehabilitation and the fitting of a full leg calliper. Learning to walk again was not easy after 6 months in bed, especially on a frame and with little physiotherapy!

Fortunately, schooling continued while I was at Prince Henry, perhaps inadequately, but it got me by. In addition, to the amazement of staff and visitors, my parents arranged for the Sydney Morning Herald to be delivered each day, an initiative that helped my reading skills to develop.

Swimming was recommended for exercise, so in 1952 my parents bought a weekend place at DeeWhy where I learned to swim in the local rock pool. (We moved to DeeWhy in 1953.) In late teens I had my right ankle stabilised and learned to walk by locking my right knee back. The caliper was thrown away! Walking wasn't fast, but I could get to the beach and could swim more easily, which led to many hours of body surfing, much sunburn and a good social time with the local peer group as well as a lifetime physical skill.

Leaving school in 1957, I went to Sydney University to gain an Economics degree. Most of the degree was done part-time while working on a cadetship in the general insurance industry; accessing the university buildings with their multitude of steps and lack of railings was almost as hard as the exams! However, the insurance office was on the direct tram/bus route to University and therefore much easier. At the time I was very fit from swimming and could walk a long way, albeit rather slowly!

With a degree, and accounting and secretarial qualifications plus an Insurance Diploma behind me, I accepted a transfer to the Auckland Head Office of my employer, South British Insurance. There in Auckland I met my wife, Margaret, and we married in 1966. My mobility and exercise pattern remained pretty static, apart from a few falls (one of them on our honeymoon!).

Margaret received a postgraduate scholarship in 1967 and it was off to London, she to London University, myself to work in the London branch of South British. London's snow and ice did defeat me when they happened, but in our time there we were privileged to go regularly to the opera and ballet at Covent Garden (sitting in 'the gods') and to Royal Festival Hall, as well as travelling on the continent in holiday times. We lived in central London, 550 metres from Regent

Street – closer to the city office for me than for any other staff member!

On our return to Auckland in 1970 I took up a position as an investment officer in South British Insurance Head Office, always making the time to fit swimming into the schedule. We bought a house, and had two children, a daughter in 1973 and a son in 1976. I could still walk unaided but the right knee was becoming more unstable; carrying a child was definitely not on the agenda!

Various promotions with my employer saw a year's temporary secondment to Australia Head Office (Sydney) to assist in a corporate restructure, after which I became General Manager for NZ of NZI Insurance in Auckland. The trip back to NZ was made rather complex when I fell and broke my right knee cap, and this led to the decision to undergo an operation to permanently stiffen the right leg in a straight position. I started my new job on crutches, with my secretary driving me to and from work each day!

The straight leg worked well and gave much greater stability on the whole, but its disadvantages included difficulties in the regular air travel that was part of my work (my seat needed to have some extra room in front of it), and in driving (the car bulkhead needed to have extra height to position the leg). I drove using my left foot only (as I still do) and kept up the swimming regime.

In 1987 the family moved permanently to Sydney where I took on a position as General Manager Finance for the worldwide operations of NZI Insurance. After yet another merger took place I left my long-time employer and worked briefly as CEO of The Spastic Centre of NSW, then for 5 years as Insurance Division Manager of The Work Cover Authority of NSW. I enjoyed my time in government, especially the policy-related work dealing with

A Journey With Polio (Cont'd)

the Scheme, and meetings with all the lobbyists seeking Scheme changes!

Another few falls shortened my final business role at MMI (now Allianz). My left leg was now weakening, no doubt after having worked so hard for so many years. (Only later did I learn that this was actually due to the late effects of polio.)

I retired early and we moved to Blackheath in the Blue Mountains where, through our own efforts, we established an attractive cold climate garden and I took some art lessons – something I had always wanted to do. Community involvement encompassed various roles in Blackheath Rotary, on the Board and as President in 2002. I became very involved in The Blackheath Art Society, where I was President for 5 years, and with The Blue Mountains Rhododendron Garden as Treasurer. Towards the end of our mountains sojourn I was appointed Treasurer of Great Community Transport, the operator for Penrith and the Blue Mountains Local Government Areas (a role I continue at the time of writing).

Amidst all this a triple bypass heart operation slowed me for a while; interestingly, the heart specialist was clear that heart problems are

very common, almost normal, in post-polios.

Gradually declining mobility and another broken knee cap (on the 'good' leg this time) persuaded us that it was time to leave the mountains, and even to give up the garden we had so much enjoyed - the joy of it being particularly in doing it ourselves. But where to go? We took the plunge and returned to Sydney into a self-care retirement complex in Mosman, a move that has proven to be timely (and has led to much pleasure) since I have encountered further gradual weakening in my mobility.

Attending the first Post-Polio Retreat in Sydney I learned of the late effects of polio, and much else, as well as for the first time meeting a range of people similarly affected to myself – it's amazing but in all my life's journey I had ever only met one or two such souls!

By this time I was using a walking stick for security outside the house, and the Retreat advice led me to get a full physical assessment and request a full suite of exercises geared to mobility/stability maintenance. How much I owe to that Retreat! A physio then warned me that I should consider using a walker outside since I was 'at clear

risk', and I have now acted on that advice and need to use a walker both in- and out-side home. Falling is so easy – it's just not worth the risk. I exercise daily and attend a gym several times a week.

Painting is a favourite pursuit still, and I have had a number of exhibitions in rural NSW, and won a number of awards at art society and municipal shows in Sydney and the Blue Mountains. (*see below*) Margaret and I both enjoy travelling to rural areas very much, and regularly go for short or longer breaks. Closing the door to the unit is easy! I can't walk the country high streets as I used to but can still manage most galleries and sites (and motels) with good access, few or no steps, and small distances to walk.

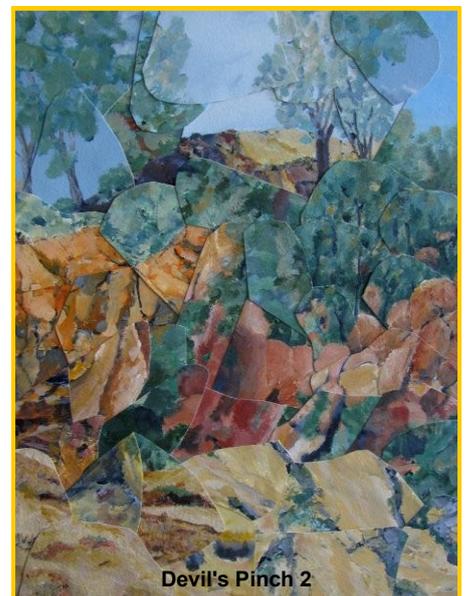
So, the journey continues – adapting as necessary, and blessed by marriage, family (our daughter is now a university liaison librarian, and our son a research scientist), friends, a very comfortable and friendly community in our retirement complex . . . plus good books, the web, art, music, daily exercise . . . and last, but certainly not least, the assistance and wisdom offered by the range of medical and physiotherapy services, and organisations like Polio NSW and Polio Australia. ●

"Touched By Polio" Art Exhibition

As mentioned in previous publications, Polio Australia is planning an Art Exhibition titled "*Touched By Polio*". This Exhibition is based on plaster cast torsos and half legs being painted or crafted by people who have been "*Touched By Polio*" - John Marsh is one of 20 artists who have agreed to contribute so far. The idea is that the completed artworks travel between Melbourne and Sydney, and are on show for one week in each location. We hope to launch the Exhibition in February/March 2013. The works will be auctioned during the launch or sold throughout the Exhibition in order to raise much needed funds to support Polio Australia's work for our post-polio community. A second "*Touched By Polio*" Exhibition is in the planning for Tasmania, which is being driven by Launceston-based artist and Orthotist, [John Semmens](#).

We are very thankful to La Trobe University, whose Orthotics students are volunteering to make the casts, and Bunnings Hawthorn for materials support. We are still very keen to find Rotary partners to work with us.

For information/enquiries about how to contribute, email [Mary-ann Liethof](#).



Devil's Pinch 2

Express Yourself!**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. This time we will be enjoying the hospitality of the Stamford Grand in the delightful seaside suburb of Glenelg, 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

Polio This Week

Source: [Polio Global Eradication Initiative](#) - as of Wednesday 29 August 2012

Remembering our colleagues in Nigeria: 26 August marked one year since a devastating explosion hit UN House in Abuja, Nigeria, where WHO, UNICEF and other UN organizations were based. This week, we remember our polio colleagues who gave their lives during this attack: Mr Johnson Awotunde, Monitoring and Evaluation Specialist UNICEF; Mr Ahmed Abiodun Adewale-Kareem, Logistician UNICEF; Mr Fred Willis, Logistician UNICEF; Dr Edward Dede, National Professional Officer for Routine Immunization WHO; Musa Ali, Engineer and Zonal Logistics Assistant for the North West Zone WHO; and, Prince Abraham A Osunsanya, Administration of Immunization Programmes WHO. In total, the explosion claimed the lives of 23 people and injured many more. This event was a tragic example of the dangerous conditions in which our colleagues are frequently working under, in their efforts to protect children everywhere from polio.

Wild Poliovirus (WPV) cases

Total cases	Year-to-date2012	Year-to-date2011	Totalin2011*
Globally	128	356	650
-in endemic countries	123	122	341
-in non-endemic countries	5	234	309

Case break down by country

Countries	Year-to-date 2012				Year-to-date 2011				Total in 2011*	Date of most recent case
	WPV1	WPV3	W1W3	Total	WPV1	WPV3	W1W3	Total		
Nigeria	61	16		77	19	7		26	62	28-Jul-12
Pakistan	26	2	1	29	76	1		77	198	21-Jul-12
Afghanistan	17			17	18			18	80	21-Jul-12
India					1			1	1	13-Jan-11
Chad	5			5	106	3		109	132	14-Jun-12
DR Congo					75			75	93	20-Dec-11
Angola					4			4	5	07-Jul-11
Niger					1	1		2	5	22-Dec-11
CAR									4	08-Dec-11
China									21	09-Oct-11
Guinea						2		2	3	03-Aug-11
Kenya									1	30-Jul-11
Côte d'Ivoire						35		35	36	24-Jul-11
Mali						7		7	7	23-Jun-11
Congo					1			1	1	22-Jan-11
Gabon					1			1	1	15-Jan-11
Total	109	18	1	128	302	56	0	358	650	
Total in endemic countries	104	18	1	123	114	8	0	122	341	
Total out-break	5	0	0	5	188	48	0	236	309	

Data in WHO as of 30 Aug 2011 for 2011 data and 28Aug 2012 for 2012 data

Paralympic Spotlight on Polio Eradication



Paralympic athletes at the garden party sponsored by Rotary in Great Britain and Ireland (RIBI), in association with UNICEF, the Bill & Melinda Gates Foundation, the British Pakistan Foundation, and the Global Poverty Project.

Photo by Jordi Matas

by Ryan Hyland

Source: [Rotary News](#) - 31 August 2012

Perseverance and dedication are qualities that both Paralympic athletes and Rotarians use to reach their goals.

To highlight this common bond, British Rotarians used the excitement surrounding the opening day of the 2012 Paralympic Games on 30 August to rally government dignitaries from the United Kingdom and Pakistan to raise funds for Paralympic athletes and Rotary's PolioPlus program.

"We wanted to celebrate the achievements of these amazing athletes and Rotary's hard work towards polio eradication," says Judith A. Diment, PolioPlus national advocacy adviser for the UK and a member of the Rotary Club of Windsor St. George, England. "Both groups have persevered through great odds to be where we're at today."

Rotary in Great Britain and Ireland (RIBI), in association with UNICEF, the Bill & Melinda Gates Foundation, the British Pakistan Foundation, and the Global Poverty Project, sponsored the garden party in London attended by more than 100 people, including five Paralympic athletes, three of whom are polio survivors.

The event raised thousands of dollars for PolioPlus and the Pakistani Paralympic Committee and advocated for a polio-free

world. Wajid Shamsul Hasan, the High Commissioner of Pakistan to the United Kingdom, praised Rotary's efforts to eradicate polio in Pakistan and spoke about his government's commitment to step up resources to rid his country of the disease.

Diment said advocacy efforts have become more important than ever, as funding shortages have forced the [Global Polio Eradication Initiative](#) (GPEI) to cancel or scale back immunization activities in high-risk countries, leaving more children vulnerable to the disease.

The GPEI launched an [emergency action plan](#) earlier this year but is US\$1 billion short of what it needs in order to implement the plan through 2013. Rotarians can help, Diment says, by lobbying their governments to commit funding for polio eradication and by spreading the word about the immense benefits of finally eliminating this crippling disease.

"We must continue to reach out and put Rotary's effort in front of the opinion makers and governments so they act in helping us achieve our goal of polio eradication worldwide," says Diment.

[Visit the new End Polio Now website](#) to help Rotary advocate for a polio-free world.

[Read](#) other ways Rotarians in the United Kingdom are supporting Paralympic athletes.

Polio Athlete Hopes To Inspire Pakistan

by Shahid Hashmi

Source: [AFP](#)

KARACHI — Pakistani polio survivor Mudassar Baig dreams of winning a medal at the London Paralympics, hoping to inspire a nation troubled by corruption, Taliban violence and lost sporting glory.

"It's a dream come true for me and I want to be a role model - not only for disabled people in my country but also for the able-bodied who lose courage," said Baig, whose right leg was left shorter than his left by polio in childhood.

The 33-year-old post office clerk who thought life was over when he couldn't run as fast as the other boys growing up, is one of four athletes representing Pakistan at the London Paralympics from Aug 29 to Sep 9. ♦



Photo: Mudassar Baig, whose right leg was left shorter than his left by polio in childhood, will compete in the 200 and 400m (AFP/ File, Str)