



Polio Oz News

March 2013-Autumn Edition

Thinking Ahead with Housing

by George XinosPrincipal Consultant
Functional Access Solutions

For most people, the purchase or renovation of a home can be the single biggest investment they make in their lives and one

which has an enduring influence on the way they live. All of us need to think and plan ahead when approaching such significant undertaking, be it whether we have a young family which will and eventually leave the family home, or an older person who understands that their physical needs will change and so too will the type of home they need to live within.

Having current difficulties with mobility, movement and strength further highlights the need to plan ahead for any changes which may

occur or can be anticipated. Planning to accommodate for a wheeled walking aid now might not accommodate using a wheelchair later.

There are a number of resources out there to help, with many of the ideas and suggestions in them appearing

in different forms across these. Some of these have been provided below.

An enduring Australian Standard which seems to be the source of many of these ideas is AS 4299 (1995) Adaptable Housing. 'Adaptable Housing' as



defined by the standard, intends to provide a means for housing to be easily and cost-effectively adapted to the needs of any user. The premise is that by i m p l e m e n t i n g t h e recommendations set out in this standard, relatively little additional initial cost should allow minimum inconvenience

and cost in later modifications.

The circulation and areas set out in the standard are largely informed by AS 1428 Design for Access and Mobility parts 1 and 2. It should be noted that the research that these standards are based on are aging

themselves and there have also been some questions raised with regard to how valid the research was to begin with. The importance of including suitable professionals in the process, both therapists and designers, who understand your specific needs cannot therefore b e understated.

The costly most changes in any remodelling of building are generally structural changes, and these standards provide guidance some planning around this issue. For example a 1.2m clear width is

generally required on a path for a person using a wheelchair to be able to independently travel along. Doors require additional circulation depending on the direction of swing and the direction from which a wheelchair user approaches the door from.

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From the President



Dr John Tierney President

Although I have been involved with Polio Australia since its inception, and served as its Patron and probono government lobbyist, this is my first time in the role of President. Of course, Gillian Thomas is still doing as much as ever in her new capacity as Vice President, so not a lot has changed as we all continue to do our best for Australia's polio survivors. This includes giving evidence at the NDIS Senate Inquiry in Canberra earlier this month. The NDIS is a pivotal opportunity for us and we have certainly been working hard to make sure our voices are heard. And with this being an election year, now is definitely a good time to lobby government, so I encourage everyone to speak

with their local Members and Senators to drive home the point that polio survivors receive little or no support, and that we need special programs to manage the Late Effects of Polio. With only 9 months left until the 3 year donation which pays for staff salary runs out, Polio Australia faces the additional challenge of securing funding to ensure we can continue to provide the services and programs you have come to expect. After all, who else it going to do it? A financial commitment by the government would certainly show their true support!

From the Editor



Mary-ann Liethof Editor

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March already, and although it's now technically Autumn in the Southern hemisphere, in Melbourne Victoria we've been sweltering through more than 9 consecutive 30°C plus days - which is record breaking - and not a drop of rain. If only we could drain some of Queensland's flood waters away for them!

The next couple of months are set to be quite exciting for Polio Australia, with the fabulously creative "Touched by Polio" art exhibition and fundraising auction being launched on 27th March (see p 6) and the 4th Polio Health Wellness Retreat taking place in mid-April (contact me to check if any places left - p 18).

As Australia is one of the many Western countries experiencing an increasingly ageing population, the two very different articles discussing putting some thought into accessible

housing (cover story), and Canadian Audrey King's touching tribute to her late mother (p 8), will both strike a chord with many readers, I'm sure.

Speaking of ageing, the keenly anticipated National Disability Insurance Scheme (NDIS) comes under critical review by the post-polio community as we struggle with the inequity of an age 65 cut off on the premise that the aged care system will cater for everyone's needs . . . Polio Australia has been strongly advocating for this criterion to he abolished, as very few polio survivors would have access to the NDIS otherwise.

We hope you enjoy the read. •

Change is a measure
of time and, in the
autumn, time seems
speeded up; what was is
not and never again will
be; what is, is change.

~ Edwin Way Teale ~

Thinking Ahead with Housing (Cont'd)



Addressing these considerations now will have a dramatic effect on the bottom line for any refurbishments later.

Larger builds of course also make for more expensive builds. Circulation spaces can be shared to minimise the amount of space required. This can be achieved by designing 'open plan living, dining, kitchen or even study spaces which can lend circulation to each other in general use.

Another strategy could be to plan for the removal of internal walls to achieve a similar

outcome later. Laundries and bathrooms are often placed together to reduce the cost of running plumbing service to multiple areas within a home. Planning the removal of a wall between the two can increase the circulation available to the shower, basin and toilet, washing machine at a later time. To make this as efficient and cost effective as possible any wall to be however, removed should be constructed without any plumbing electrical services and should not be load bearing. Having your designer or architect produce pre and post adaption layouts for these spaces can assist with getting it right.

Other ideas used in the past have been extending floor finishes under joinery and providing flexible plumbing to enable cheap and easy relocation. Installing additional framing in existing walls to allow the future fitting of grab rails, or a lintel allowing the part removal of a wall to create a 'European style' laundry or study are other examples.

A recent publication which has been gaining additional exposure of late and which provides a lot of useful guidance is the 'Liveable Housing Design Guidelines' which is freely a v a i l a b l e a t www.livablehousingaustralia.or g.au. Many of the dimensions included in this guideline are derived from the aforementioned standards.

Also worthwhile is the "Welcome - Design Ideas for Accessible Homes" publication produced and available from the Building Commission in Victoria. It provides simplified diagrams and explanatory information for all areas of a home

An invaluable resource are the Independent Living Centres (ILCs) present in most states and territories across Australia. which provide useful on-line information and freely available advice from Occupational Therapists and other professionals on staff. Find your local ILC or browse for equipment and advice on their database at ilcaustralia.org.au.

A number of private providers also specialise in housing for people with disabilities and offer a range of services including preliminary planning, design reviews, design and documentation as well as project management.

iDoctor-The Future of Medicine?

Reporter: Dr Nancy Snyderman

Source: <u>rockcenter.nbcnews.com</u> — 24 January, 2013

One of the world's top physicians, Dr Eric Topol has a prescription that could improve your family's health and make medical care cheaper. The cardiologist claims that the key is the smartphone. Topol has become the foremost expert in the exploding field of wireless medicine.

Watch the video interview here.



National Disability Insurance Scheme (NDIS)

The NDIS is a hot topic for everyone in the disability sector, with potentially great benefits for people who have, or may acquire a disability in the future - as long as they are less than 65 years of age and already accessing disability services when the scheme is rolled out across the country in 2018. The theory being that anyone over the age of 65 will come under the aged care system.

Clearly, this criterion is a major sticking point for Australia's polio survivors, who are an ageing, albeit finite, population thanks to the introduction of the Salk and Sabin vaccines in the late 1950's/early 1960's respectively.

Earlier this year, Polio Australia was one of the 1,597 individuals and organisations to put in a <u>submission</u> into the Inquiry into the National Disability Insurance Scheme Bill 2012, arguing against the aged 65 cut off and highlighting the inability of the aged care system to adequately meet the needs of people ageing with the late effects of polio.

From this submission, Polio Australia was invited to participate in an "NDIS and Aged Care" Roundtable Forum hosted by the Department of Families, Housing, Community Services and Indigenous Affairs in Adelaide, and attended by Minister Jenny Macklin MP and Minister Mark Butler MP (photo right). In addition, Post Polio Victoria gave evidence on behalf of polio survivors at an NDIS public hearing held in Melbourne, and Polio Australia's President, Dr John Tierney, and Vice President, Gillian Thomas, gave evidence at another public hearing in Canberra.

Significantly, Polio Australia's evidence on 4 March was widely broadcast in the media, including this article in The Australian.

On Thursday 14th March 2013, the House o f Representatives legislation passed set up Government's NDIS. The NDIS Bill passed with the support of all MPs. Minister Jenny Macklin also moved amendments to the

first reading version of the Bill; some of these amendments were made in response to matters raised in submissions to the Senate Community Affairs Committee Inquiry into the legislation.

The <u>Committee's Inquiry Report</u> was released on March 13. The sections of the report that refer to Polio Australia's submission/ evidence and to the Late Effects of Polio and can be found on PDF pages 69, 70 and 72.

At the end of the majority report there is also interesting section entitled "NDIS Additional Comments -Australian Greens" (starts PDF page 165). Greens Senator Rachel Siewert (Deputy Chair of the Committee) comments about the age 65 cut off, with specific reference to polio, on PDF page 169.

According to the peak disability organisation National Disability Services, the amendments to the Bill (as incorporated in the third reading version) will ensure that all people who are NDIS participants will be able to



choose to remain in the Scheme after they turn 65; early intervention can apply to people diagnosed with a degenerative condition; and the definition of early intervention will include 'improving functional capacity'.

It is hoped that these a mendments prove beneficial to our cause insofar as polio survivors not being excluded from the NDIS on the basis of age.

But that, of course, remains to be seen as work proceeds by those responsible for implementing the NDIS.

Appendix 1 to the Senate Committee Report (PDF pages 181-250) details (where not confidential) the authors of the 1,597 submissions received by the Committee. Post Polio Victoria's submission is #511 and Polio Australia's submission is #637. All non-confidential submissions can be downloaded from the Committee's website - click here.

Appendix 2 (PDF pages 255-268) details the organisations

NDIS (Cont'd)

(and the few individuals) who gave verbal evidence to the Committee. All this evidence is recorded in Hansard for posterity - click here for transcripts.

The third reading version of the Bill, which was passed by the House of Representatives, incorporates 77 amendments to the first reading version originally introduced into Parliament on 29 November 2012.

The sections of the Bill which are most relevant to the post polio community at this stage can be found on PDF pages 36-

37, 39-40, and 42-43.

The NDIS legislation will now go before the Senate, anticipated to occur later this month, where the Bill is expected to pass with support from Labor, the Greens and the Opposition.

There were 105 speeches in Parliament between 6 and 14 February and again this week, all supporting the NDIS in one way or another. A number of the speeches mentioned polio and the inequity of the age 65 cut-off. Polio Australia's Vice President, Gillian Thomas, personally wrote to each of the Parliamentarians and thanked

them for bringing our issues to the foreground - this level of awareness shows that our Canberra lobbying efforts over the last several years are now bearing fruit.

So, where to from here for Australia's polio survivors, with particular reference to the age 65 cut-off? As usual, the devil is in the detail. For example, how will the NDIS Rules, which interpret and elaborate on the Bill's Objects and Principles (see PDF pages 16-19 of the Bill), deal with this issue, noting that the Rules are still being developed? Only time will tell.

House of Reps Passes NDIS Bill

Source: ABC News – 14 March, 2013

The House of Representatives has passed legislation to set up the Government's National Disability Insurance Scheme (NDIS).

The bill, which will allow the scheme to be launched from July, passed with the support of all MPs. Disability Reform Minister Jenny Macklin broke down as she wound up her speech on the bill.

Commonwealth funding includes:

- \$342m over three years for individually funded packages for people with significant and permanent disability;
- \$154m over three years to employ local area coordinators;
- \$58m over three years to assess the needs of people with a disability in launch locations; and
- \$240m over four years to build and operate an NDIS IT system

"This bill is an enormous step in ensuring people with disability, their families and carers, receive peace of mind," she said. "It will bring an end to the tragedy of services denied or delayed and instead offer people with disability the care and support they need over their lifetimes. It will end the cruel lottery that besets people today, where the care and support they receive depends on where they live or how they acquired their disability."

Ms Macklin says the scheme will initially benefit about 26,000 people in launch sites in five states and territories.

The legislation will now go before the Senate, where it is expected to pass with support from Labor, the Greens and the Opposition.

Proposed by the Productivity Commission, the NDIS aims to shift funding for disability away from welfare to a system based on social insurance, with all taxpayers contributing.

Instead of funding of being allocated to service providers, individuals will instead be given direct access to funding, which they can then administer either directly or through brokers.

The focus of the scheme will be on early intervention, building on the concept that significant initial financial outlay can offset greater costs incurred if problems are left untreated.

The scheme aims to cover 360,000 people with a profound or severe disability, with a separate national injury insurance scheme to cover people who suffer a catastrophic injury.



Polio Australia

presents

Touched by Polio

~ from casts to catharsis

"You could say that Polio is an equal opportunity virus.

It doesn't discriminate between
Property of the polio is an equal opportunity virus.

Seneration or gender..."

art exhibition and fundraising auction

Launched by Senator Mitch Fifield
Shadow Minister for Disabilities, Carers and the Voluntary Sector

Auctioneer - Ross Hedditch

Wednesday 27 March / 6:00 pm to 08:00 pm Kew Court House 188 High Street Kew Victoria

RSVP for catering by COB Monday 25 March office@polioaustralia.org.au / 03 9016 7678

"Once-upon-a-time tens of thousands of Australian children contracted polio, recovered, got on with their lives (some even became artists!), and they all lived happily ever after."

~ The Fnd ~

Or not . . . This exhibition tells a myriad stories through thirty-five 'artified' leg and torso plaster casts.

Many polio survivors have vivid memories of wearing plaster casts to keep their limbs from becoming deformed during recovery and rehabilitation.

Twenty-four artists who have been 'touched by polio' in some way - survivors, family, friends - have contributed thirty-five art works to the "Touched by Polio" exhibition.

All art works can be found on the "Touched by Polio" Exhibition website www.polio.org.au



Bound by Ekaterina Panorgious

Enduring by Glenys Donnelly





Equal Opportunityby Roslyn Dux

The Long Climbby Pauline
Derrick



Vale Dr Jacquelin Perry

Born: May 31, 1918 Died: March 11, 2013

Email from <u>Richard Daggett</u>, President, Polio Survivors Association (Los Angeles, USA):

"I just received word that Dr. Perry died this morning. She was at home, and evidently died in her sleep. She was 94 years old. I saw her recently and she was in good health (for 94 years of age) and full of life."

Note from the Editor

In 2008, Jill Pickering (polio survivor, donor and volunteer) and I were fortunate enough to meet with Dr Jacquelin Perry in the context of my Churchill Fellowship Study Tour around post-polio institutes in the USA and Canada. Richard Daggett, who had been treated by Dr Perry from childhood through to adulthood, helped to arrange this visit. Dr Perry was definitely an extraordinary woman who has left a huge legacy for polio survivors across the generations.

The following is an extract from Dr Perry's biography sourced from <u>Polio Place</u> – a service of Post-Polio Health International.

Known among her peers as the Grande Dame of Orthopaedics, Dr. Jacquelin Perry was one of the first ten women to be certified by the American Board of Orthopedic Surgery. She broke new ground in laboratory research by becoming the country's foremost expert on gait analysis. She is co-author, with Judith Burnfield, of Gait Analysis: Normal and Pathological Function, the classic text on gait analysis.

In the early 1950s, she jump-started the surgical program for post-poliomyelitis patients at Los Angeles' Rancho Los Amigos Medical Center. The medical staff was looking for ways to provide stability for the more significantly disabled polio patients who had paralysis of the neck and trunk. Recognizing that bracing was not adequate, she, along with Dr. Vernon Nickel, pioneered the use of halos for spinal surgery and rehabilitation.

Perry's contributions to the body of knowledge of understanding human movement included studying all forms of functional assists from canes, to crutches, braces and wheelchairs. She compared the effectiveness of various forms of bracing and prostheses, total joint replacements, resection arthroplasty and other surgical



L-R: Dr Jacquelin Perry, Mary-ann Liethof and Jill Pickering

interventions.

In 1955, she joined the medical staff at Rancho Los Amigos and was Chief of the Pathokinesiology Service for 30 years. She once stated that her polio experience at Rancho broadened her medical experience (and that of others) because they developed a team concept of patient care; nurses and therapists were encouraged by the physician to take responsibility for evaluation and treatment planning.

She was honored with "Woman of the Year for Medicine" in Southern California by the Los Angeles Times in 1959.

When polio patients started coming back to her with post-polio symptoms in the late '70s, she counseled them not to push themselves but to modify their lifestyles and implement energy conservation techniques in order to accommodate their new reality. In an article called <u>General Information Letter for Polio Survivors:</u> Why are "old polios" who were stable for years now losing function? What should they do about it? Perry advises, "Be an "Intelligent Hypochondriac" – Listen to your body and adopt a program that avoids the strain."

In 2000, PHI honored Dr. Perry at its 8th International Post-Polio and Independent Living Conference held in St. Louis, Missouri. She, along with Dr. Augusta Alba, was recognized for her dedicated years of supporting polio survivors by combining her medical expertise with practical advice.

Click <u>here</u> to read the full biography.

Click <u>here</u> to read *Los Angeles Times*Obituary.

On Losing a Polio Mom

by Audrey King

January 2013

When you are a child you think like a child, like the 9-year-old I was.

Being in a box – an iron lung – trapped in a bed, the horror of food at mealtimes, resolving not to cry during today's therapy, saying goodbye yet again to those who mattered most. Those were the day-to-day

dramas that filled my head. There were also some joys: getting up first time in a wheelchair, going on a picnic with parents, floating to a place in the therapy pool where staff could not reach me that brought а powerful surge of pleasure, a momentary autonomy.

I didn't think about survival, about walking again, the weight of lost dreams, life-long responsibility and

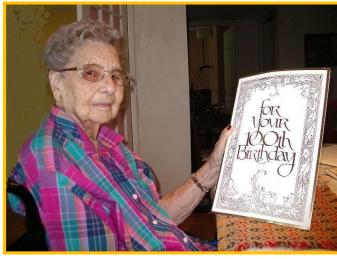
dependence. I was but a child.

I had no idea of such things until I grew older, eventually discovering my mother's diary my early polio years (frequent illnesses, the fight to get me in school, battling authorities, acceptance) and, many, many decades later, finding my own self in a similar place. It wasn't easy for her, a mother of four with an often absent father and no community supports at the time.

The role reversal was gradual. My mother lost her energy and abilities slowly. The changes were so subtle others could not see them, and I began to wonder if the problems were in my head. At first I was puzzled, frustrated, even angry at her illogical, independent episodes. I had no knowledge of aging or

early dementia. But, once I began to understand and to recognize some of my own tenacious traits in her character, to see myself in her, situations often became humorous rather than helpless and much more manageable.

As adults, our mother-daughter relationship had always been one of autonomy and respect for each other. We lived together but had separate



interests. We had no difficulty encouraging and supporting each other's interest to travel and explore new ventures. I was the wage-earner who went out to work each day. She was the homemaker. In many ways, we were good friends.

We discussed major decisions, including what she wanted to do as she got older. I needed to know her choices so that I could honor them, but she could not, would not, broach the subject. I did not want to take over or make decisions for her. Lurking in my past was the knowledge of what it felt like to lose autonomy and control over your own life, to have others assume they know what is best.

If my mother wanted to move to a retirement residence or ultimately a nursing home, we could begin the process together, but she could not, would not, decide and the months and years ticked by. We applied to a number of nursing homes, but my mother rejected all of them one by one. The time never seemed right.

I increasingly took on the homemaking role through hired help and assumed responsibility for her medical needs and appointments. A major merger

was making work life difficult, and I was experiencing post-polio challenges. I had always been able to use my head to overrule my paralyzed body, but exhaustion and overwork led to episodes of serious illness. I had no choice but to give up work.

While I was hospitalized yet again with serious pneumonia and on life support, family members placed my mother temporarily in a nearby

nursing home. I visited her on the way home from hospital discharge. She was miserable and desperate to come home. I could not leave her there.

I knew all too well the fear, the feeling of abandonment, the helplessness of nobody listening understanding. memories were too powerful, too imprinted on my brain to resist. After all, during those early years many people, including healthcare practitioners, had encouraged my mother to place me in lovely homes that existed for people like me. She had refused and, in doing so, had provided me with family life and opportunities to achieve in both education and career.

As the months went by and my mother's dementia and physical

On Losing a Polio Mom (Cont'd)

needs increased, I brought in more and more daily help. Often her brilliant wit and reasoning shone through. She didn't want a bath today, NO – she didn't want to eat – why should she? Why were we pushing her around like a child? At times she was quite competent, and it was a challenge to balance competency versus choice.

Giving a person choice, enabling them to be who they want to be and assisting them in doing what they are driven to do that's what it's all about when it comes to persons with physical disability. How and why is it different for someone whose thinking and reality is altered? Many times she wanted to go to the basement to see if her car was okay, to drive home to Saskatchewan, to start cooking for the family coming back for Christmas. We tried to humor this but inevitably frustrated all of us even more and sometimes made things worse.

I realized it was not my mother who was the burden. She just happened to have physical and cognitive deficiencies that come with advanced age. It was the system that I had to battle constantly to get more caregiver hours, to discontinue healthcare specialists that contributed nothing but greater challenge in coordinating appointments and making useless suggestions, not to mention the wasted expense of our health care. It was the multitude of caregivers who left my mother in a mess for the next person to clean up.

I was constantly in the middle. It was like running an office with employees who expected you to solve problems but would not take direction because they were not accountable to you. (The exceptions were the ones I hired who also bore the brunt

and burden of incompetent government-funded caregivers.)

I learned many lessons. I learned how to fight, to charm, to write letters, to be an effective advocate. I discovered the shock value and unimagined power of being a quadriplegic caregiver in a wheelchair.

I periodically wavered in my decision to keep my mother at home with me, especially at the worst of times. Each time I inevitably decided, although it was tough, it was easier for me to keep an eye on her care, intervening and advocating as needed.

Aside from the transportation difficulty of visiting a nursing home on a regular basis, I would have no influence and little awareness of what was happening to her when I was not there. And I already had equipment at home that she could use – a Hoyer lift, an extra wheelchair, a commode, a ceiling track lift over the bathtub. I could teach others in their proper use and supervise.

My long career experience as a psychologist in a rehabilitation setting gave me knowledge of systems, budgets, negotiating skills and human resource techniques that I could use in assisting my mother. How could I not put these skills to use for someone who had invested so much of herself in enabling me to grow and develop and become the person I was?

I learned much from my once proud, independent mother through her inevitable decline. I saw grace and humor in the face of the humiliation and embarrassment her failing body caused her. I marveled at her wit and charm and ability to appreciate what caregivers did for her, even in the face of pain and suffering. Her tenacity and

determination carried her to the end.

She wanted to leave this world. She felt her job was done and she didn't want to be a burden. She said it so many times and in so many ways. But we, and myself in particular, would not listen. We mounted continuous concerted effort to get her to eat, to get her dressed and out of bed each day when all she wanted to do was sleep and sleep. It was clearly painful and exhausting.

When she finally left us, I felt relief - for her and for myself. I felt incredible lightness and freedom. The burden was gone for both of us. I felt guilt for not being devastated, distraught, grief stricken. But I realized that I had lost who she was many months before, and my grief and sorrow had been stretched over many years through the heart-wrenching ups and downs of each day. I had already the loss grieved of the marvelous mother she had been.

Guilt about keeping her alive, in spite of her wishes, followed. Was I selfish in not wanting to lose her? Whose life was it anyway? I still ask myself.

When I get old and decrepit enough to consider life not worth living, will those more able than I, who are responsible for my care, listen? Will they hear what I am really asking through my confusion? It isn't quite as simple as having a living will. When you realize someone who loved you so immensely and completely removed the massive boulders blocking your way, forged the path that enabled you to "walk" in her footsteps, it's not easy to let go. 🔸

Home Medicines Review

Source: NPS <u>MedicineWise</u> website

Home Medicines Review

Do you know your medicines? If medicines aren't used properly, or if the wrong ones are used together, the results can be serious. Read how a Home Medicines Review can help.

Each year more than 140,000 Australians have to go to hospital with problems caused by their medicine. It has been shown that in up to 69% of these cases the problem can be avoided. Older people are particularly at risk. As a response to this problem, The Pharmacy Guild of Australia has developed the Home Medicines Review (HMR) Program.

What's involved in a Home Medicines Review (HMR)?

An HMR involves your GP and a community pharmacist of your choice. Your GP sets up the review by writing a referral to the pharmacist. A pharmacist conducts an interview, preferably in the comfort of your own home, and then writes a report back to the GP. The GP will discuss any

recommendations with you and may make appropriate changes to your medication regimen. The solutions may involve:

- showing you how to take your medicines correctly
- explaining why and when to take them
- explaining where they should be stored
- what to expect when taking them
- what problems you should report to the GP
- checking that prescription medicines, over-the-counter medicines and vitamins are appropriate to take together
- clarifying any confusion with generic medicines
- giving you some help so you can remember to take your medicines
- changing your medicines.

Who should have an HMR?

HMRs are particularly useful for people who:

- take more than five medicines a day
- have recently spent time in hospital
- are concerned about their medicines
- are confused about their

medicines

 do not always remember to take their medicines.

How much does it cost?

The pharmacist's review and report is paid for by the Australian government, so it will not cost you anything. Your GP may bulk-bill or charge you for the GP consultations.

If you (or someone you care for) might benefit from having an HMR, talk to your GP or pharmacist about organising one. HMRs are available in all states and territories.



LinC

Unemployment, redundancies, forced early retirements, a greater demand on state and federal funding in the human services areas underline the urgent need for increased involvement of churches in their local communities. LinC believes the church has all the resources and gifts needed to make a difference in local communities.

LinC mobilises the untapped potential of church people to serve with a view to empowering people to develop personal skills of self-reliance. LinC works in conjunction with human services agencies and offers assistance to all people regardless of belief, gender, race or ethnic background.

Each <u>LinC affiliate</u> provides services appropriate to the needs of their community and the skills of their volunteers. Some of these are:

- Driving clients to medical appointments; to exercise classes; other activities.
- Providing short term assistance in the home, maybe following an accident or injury.
- Assistance with home repairs; gardening; mowing.
- Providing food parcels
- Assistance with budgeting.
- Family support following a multiple birth; severe illness of a parent.

Feature: Polio Network Members of Polio Australia

Polio Australia is the peak, national body representing polio survivors in Australia. The Committee of Management is made up of two representatives from each of the original six state polio networks.

Starting with this edition, *Polio Oz News* will feature one of those networks in each edition, the first being the Post Polio Network - Tasmania Inc., now sadly disbanded. The following article was written by past-Secretary Arthur Dobson.

This organisation was formed in May 1998 by polio survivors for polio survivors and was modeled on the Post - Polio Network (NSW) Inc. which had been formed nine years earlier.

There had previously been an organisation known as TAS POLIO SUPPORT operating in Tasmania which unfortunately was wound up when its founder, the late Bill Sullivan, could not continue for health reasons and no one else was prepared to shoulder the responsibility and workload of running it.

Our membership quickly grew to around the 110 to 120 mark with inquiries bringing just enough new members to replace those who pass away or leave for other reasons. Three Support Groups meet regularly on an informal basis. The main method of communication is however by our 40 page newsletter, TAS POLIO NEWS, which incorporates the National Polio Oz News.

Having no designated specialist services for polio survivors in Tasmania, we have been encouraging our members to take advantage of Dr Stephen de Graaff's generous offer to see Tasmanians at his Melbourne clinic. A number of our members have made the trip to see Stephen and all have come back in a much more positive frame of mind as a result of being able to talk one on one with a doctor who does understand the problems they are experiencing.

We had a very successful meeting in 2003 with the State Chief Health Officer who was principal adviser to the Minister. He was very sympathetic to our situation and knows the problems of dealing with the old school medical professionals. He told us that we have every right to refuse any treatment or medication that we believe may cause us problems and that we must encourage our members to be more assertive and demand that they be listened to and that we should wherever possible provide written information to back up our claims. We therefore promoted the Queensland Health website and the paper "The <u>Late Effects of Polio - Information for General</u> Practitioners" as the best source of information to start from.

It is becoming increasingly obvious that the pharmaceutical industry has a lot to answer for in releasing drugs on to the market before proper testing has taken place and we know that no testing is ever carried out on people with disabilities or who are suffering from various chronic conditions. If we can prevent polio survivors from taking inappropriate medication many of our problems would be overcome.

Polio Network Victoria has produced an outstanding video "Post Polio Syndrome – The Australian Experience" and has made it available to us. Every member of our network was contacted and everyone who could viewed the DVD or VHS tape with many also purchasing a copy. A copy of this DVD has been purchased by the University of Tasmania, School of Medicine, Clinical School which operates from the Launceston General Hospital. A number of General Practitioners have also purchased or borrowed the DVD.

The 25th June 2007 will be a date for us all to remember, for this was the day the Tasmanian Department of Health and Human Services acknowledged our existence by holding a Public Forum on the Late Effects of Polio/Post Polio Syndrome with Dr Stephen de Graaff at the Rehabilitation Centre in Hobart. In the morning Stephen addressed approximately 45 health professionals where he spoke in a language relevant to them. The afternoon Public Forum was presented in a language more related to us polio survivors. Approximately 55 people from as far away as Wynyard, Strahan and Legerwood made the journey to hear this inspiring speaker whose knowledge of the problems we experience is unsurpassed.

It was a real eye-opener for Kathy O'Dea, the State Manager, Community Assessment & Care Management, with the DHHS who was very impressed with knowledge we already had about our condition and the help we need to live with it.

Polio Network Members of Polio Australia (Cont'd)

Chairperson Billie Thow and Secretary were actively involved in the formation of the national body Polio Australia and are on its Committee of Management. This body is now the principal reference point for Tasmania's Polio Survivors as the Post Polio Network - Tasmania was wound up in December, 2012 because of the lack of personnel to administer it after the secretary, Arthur Dobson, had to resign for health reasons.







Billie Thow

Scientists Create New Strain of Polio Virus

Scientists create new strain of polio to protect vaccine factory workers

Original Source: kaiserhealthnews.org and reprinted in News-Medical.Net - 20 February, 2013

"Scientists have created new strains of <u>polio</u> intended to protect workers in factories that make polio <u>vaccine</u>," the <u>New York Times</u> reports. "The new strains have the same ability to invoke an immune reaction as the live <u>viruses</u> now used to make vaccine do, but there is virtually no risk anyone will get polio if one of the new strains somehow escapes," the newspaper notes, adding, "The research team, at the State University of New York at Stonybrook, is led by Eckard A. F. Wimmer, a molecular geneticist who made headlines in 1991 when he synthesized polio <u>virus</u> in the lab from its chemical components, the first time a virus had been made outside of living cells."

"Currently, factories making the injectable Salk vaccine used in the United States and Europe start with the dangerous wild-type viruses known as Types 1, 2 and 3," the New York Times notes. "After growing a large batch, vaccine makers 'kill' the virus with formaldehyde and prepare it for syringes," the newspaper writes, adding, "The finished product is safe, but if the growing live viruses ever escaped 'because of a leak, an explosion, an earthquake, a tsunami, a flood,' Dr. Wimmer said, 'the spill could spread like wildfire.'" (McNeil, 2/18).

Read article from News-Medical.Net here.

Daily Living Expo

In 2013, ATSA (Assistive Technology Suppliers Australasia) will hold a Daily Expo in Sydney Living (Rosehill Gardens Racecourse, Rosehill, Sydney on 15-16 May 2013) and for the first time in (Sheldon Brisbane Conference & Entertainment Centre, Redlands, Brisbane on 23 May 2013).

In Sydney, the exhibition will have over 100 exhibitors displaying a wide range of products and services for

people with disabilities and the elderly. On display will be the latest in assistive technology, mobility solutions, pressure care, employment support, accessible recreation/ holiday ideas, modified motor vehicles and a lot more.

A key feature of the Expo is the FREE Clinical Education Program - run over 2 days in rooms conveniently located above the exhibition floor. The three track seminar program has over 20 speakers. In Brisbane, the one day event will have over 50 exhibitors, as well as an extensive one day seminar program.

Admission is free to therapists, the general public, end users & ATSA members for both events.

For all Expo information, visit ATSA's website here.

Public Transport Discrimination

Court finds direct discrimination by Murrays Australia

Source: <u>Public Interest</u> <u>Advocacy Centre</u> Website – 14 March 2013

The Federal Court today ruled on wheelchair user Julia Haraksin's three-year battle to have bus company Murrays Australia comply with national Disability Standards.

Justice Nicholas found Murrays Australia had directly discriminated against Ms Haraksin when the bus company refused to accept a booking from her because none of its buses were wheelchair accessible.

Justice Nicholas also said Murrays Australia had breached the Disability Standards.

The Public Interest Advocacy Centre (PIAC) represented Ms Haraksin in her action against Murrays Australia.

"Today's decision puts all public transport operators in Australia on notice," said PIAC Principal Solicitor, Alexis Goodstone.

"Public transport operators



cannot afford to ignore the Disability Standards. They have a legal obligation to comply, and people with disability who are sick of being treated like second class citizens will hold them to account," Ms Goodstone said.

PIAC has been advocating for accessible public transport for people with disability for several years, acting in cases against Virgin Airlines, the NSW Department of Transport and two large taxi companies, and most recently, RailCorp.

In Haraksin v Murrays Australia, PIAC claimed Murrays breached national Disability Standards for Accessible Public Transport when it refused Ms Haraksin's booking in 2009.

The Disability Standards came into effect in 2002. They require all new public transport vehicles to be wheelchair accessible and required 25% of transport operator's existing fleet to be accessible by 2007.

"This decision reinforces a very basic principle: everyone has a right to equal access to public transport," Ms Goodstone said. "People with disability should not have to go to court in order to catch a bus."



SNAP!

This photo (*left*) was taken in Cairns in February 2013 by polio survivor, Joy Hay.

Thank you Rotary!

All about Polio Eradication

For anyone who didn't see Ewan McGregor's "Cold Chain Mission" on SBS One recently, you have until 20 March 2013 to watch it online here.



Summary:

The Congo - Ewan McGregor is on a mission to immunise some of the hardest-to-reach children in the world. However, the fragile nature of the vaccines means they must be kept constantly cold as they are passed along the supply chain. In the final episode, Ewan journeys up the mighty Congo River, where he passes through frontier towns in the wilds of Central Africa, encounters a unique subculture for whom style is a religion, and ventures deep into the jungle in search of Pygmy tribes. (From the UK) (Documentary Series) (Part 2 of 2) PG CC

Dream of a Better Future for all Children

by Akram Azimi

Source: The Sydney Morning Herald - March 12, 2013

We are closer than ever to wiping out Polio - largely because of international aid, writes the Young Australian of the Year.

Imagine a world where the arbitrary location of your birth does not determine your health and educational opportunities. I dream of this world for a generation not yet born because I do not want them to grow up as I did, in the bleak reality of Kabul and Peshawar, far removed from the comparative serenity of Australia.

I can still recollect walking down the dusty cobbled streets in Peshawar, seeing children my age with wasted limbs, crawling along the ground using cut-up pieces of tires and sandals to pad their knees and hands. Curious, I asked my mother, what

happened to these children? She responded with one quietly spoken word: Polio.

"Could I catch this disease? Would I end up begging on the streets alongside these other children?" I asked. In her warm embrace she told me: no, you are protected. Luckily for me, I had received the polio vaccine – a vaccine partly procured with Australian aid dollars.

But those images have stuck with me, serving as a stark reminder of what my life could have been like, but for international aid. So I ask you dear reader: Is there anything more than the blind chance of birth that separates me, and indeed you, from those children left without hope on the streets of Peshawar? I think not, because no one has ever chosen the circumstances of their birth.

It is this inequity that our international aid addresses – it provides health and educational opportunities for

those who may otherwise not receive such chances.

The Australian government currently gives 35 cents out of every \$100 of national income to overseas aid. That's not much, and although many may question the effectiveness of aid, when strategically directed it achieves results. I am living proof of this.

In gratitude for all that Australia has given me, I want to give back by nurturing my fellow young Australians to dream of a different future for ourselves and our children – a future where all children have access to healthcare and education irrespective of where they are born.

That's why this week I will join 1000 young Australian leaders in our nation's capital to highlight the life-saving impact of international aid. As part of the Road trip to End Poverty, these young leaders will speak to communities in metropolitan and regional

Dream of a Better Future for all Children (Cont'd)

Australia about how together we can help end extreme poverty, ahead of meetings with our national leaders.

The message is simple. Good aid works. Last year alone Australian aid saved at least 200,000 lives and put more than half a million children in school around the world.

We've been no less generous when it comes to ending polio. At CHOGM 2011, the Australian government announced a fouryear, \$50 million commitment to the global polio eradication effort. This milestone achievement was a result of the cumulative efforts of thousands Rotarians and ordinary Australians who believe a life free from the threat of polio is a right not a privilege.

And it has paid off. Australian support has proved to be a real game-changer in global polio eradication efforts. Our contribution has ensured that millions of children receive the

protection of the polio vaccine, and our leadership has helped convince other nations that polio eradication is worthy of action at the highest levels of government.

As a result, we are now seeing the fewest polio cases in the fewest countries in history. We're getting so close, reducing polio by more than 99 per cent and halving the number of people living on less than \$2 a day. Our aid dollars are having a real impact, and that's something worth celebrating.

This coming federal election is the last before the deadline for the Millennium Development Goals is reached in 2015. Therefore, I want to use my time as Young Australian of the Year to draw attention to the incredible progress we've made so far and how together we can end extreme poverty within our lifetime.

contribution has ensured that I look forward to the day that I millions of children receive the can stand side-by-side with

other young leaders in front of the world stage and say: We did it, together we eradicated extreme poverty and put an end to debilitating diseases like polio.

Akram Azimi (pictured below) is the Young Australian of the Year 2013.

Read full article <u>here</u>.



WHO, Islamic Leaders Summit to Stop Polio Attacks

by James Grubel

Source: Reuters / Chicago Tribune

28 February, 2013

CANBERRA (Reuters) - Top World Health Organisation officials and Islamic leaders will meet in Egypt next week in an effort to stop attacks on polio workers which are hampering the eradication of the virus in some countries with large Muslim populations.

"Shooting health workers who are protecting kids from this crippling disease is against the Koran and everything Islam stands for," WHO's Assistant Director-General Bruce Aylward told Reuters in Canberra on Friday.

Gunmen in Pakistan and Nigeria have killed more than 20 health workers in the past three months in a series of attacks linked to a backlash against the immunization program against the crippling virus.

"Muslim leaders have been great advocates of immunization and generally the support has always been there. In Cairo, we are meeting senior Islamic leaders to get a sense of what we can do, and ask them how can you help us," said Aylward.

The WHO has successfully eliminated polio from most nations after a 25-year campaign, but the crippling condition remains endemic in three nations, Afghanistan, Pakistan and Nigeria, where some influential Muslim leaders have opposed the program as a conspiracy of western medicine.

WHO remains on target to eradicate polio globally by 2018, Aylward said, despite a violent backlash from militant groups in Pakistan and Nigeria.

WHO, Islamic Leaders Summit (Cont'd)

But there are also worrying signs of persistence, with the polio virus found in sewers in Cairo in January, with the type linked to the indigenous strain in Pakistan. Egypt has not had a case of polio since 2004.

Aylward said the violence has forced the WHO to revise its approach to immunizations in both Pakistan and Nigeria.

"The goal is to put tools in the hands of the communities to immunize their own kids," Aylward said.

"The overall risks (of contracting polio) are getting smaller, because we are finally getting into some of these difficult places," he said.

Since 1988, the WHO has cut the number of global polio cases from 350,000 to just 225 in 2012, with India declared polio free in January 2012.



Islamic Scholars Call for Urgent Action on Eradication

Source: <u>Polio Eradication</u> Website

Cairo, 7 March 2013 - The Grand Imam of Al-Azhar, Doctor Ahmad Al Tayyeb, today called for the protection of Muslim children against poliovirus transmission ensuring they receive the required polio vaccine. He stressed the importance of increasing the awareness of the correct Islamic teachings on the subject to combat all deformed and false beliefs. and confirmed that Al-Azhar is ready to continue to exert all efforts to enlighten Muslim individuals and communities about the rights of children to be protected against polio and all other diseases and the obligation of all Muslims to ensure that their children are protected. "Crippled children lead to a crippled Muslim Ummah" Dr Al-Tayyeb warned.

This was announced today at

a meeting held at Al-Azhar during which the Grand Imam met with Muslim scholars from several countries. The scholars expressed their solidarity with the children of Islamic world reaffirmed their resolve to support the people, health workers and governments of the three countries where polio is not yet eradicated, namely Afghanistan, Nigeria and Pakistan.

The Global Polio Eradication Initiative, launched in 1988 by the health ministers of the Member States of the World Organization, Health been successful in stopping transmission of crippling disease in all but these three countries of the world. for Except in Afghanistan, Nigeria Pakistan, Muslim communities and countries everywhere have eradicated polio, 54 57 out of including member states of the Organization of Islamic Cooperation (OIC) that have successfully interrupted transmission o f wild poliovirus. This has been through achieved the application of proven eradication strategies, the administration of the safe oral polio vaccine and with financial and political support from the Islamic world.

Recognizing with grave concern the ongoing transmission of wild poliovirus parts of Afghanistan, Nigeria and Pakistan, and the remaining political, cultural, societal security and challenges preventing children in these areas from being vaccinated against polio, and in particular the tragic and deadly attacks against frontline health workers in parts of Pakistan and Nigeria in the past three months, Islamic scholars from several countries are meeting for two days in Cairo from 6-7

Call for Urgent Action on Eradication (Cont'd)

March to discuss the major obstacles preventing these countries from stopping polio transmission and trying to reach a consensus on how the Islamic leadership can help Muslim communities to overcome these barriers and ensure protection for all Muslim children.

Photo: Grand Imam of Al-Azhar receiving Muslim Scholars to discuss children rights to be protected by vaccination by WHO/EMRO



Polio This Week

Source: Polio Global Eradication Initiative - as of Wednesday 12 March 2013

Wild Poliovirus (WPV) Cases

Total cases	Year-to-date 2013	Year-to-date 2012	Total in 2012		
Globally	10	25	223		
- in endemic countries	10	24	217		
- in non-endemic countries	0	1	6		

Case Breakdown by Country

Countries	Year-to-date 2013				Year-to-date 2012				Total in	Date of most
	WPV	WPV3	W1W3	Total	WPV1	WPV3	W1W3	Total	2012	recent case
Pakistan	5			5	12		1	13	58	12-Feb-13
Afghanistan	1			1	5			5	37	31-Jan-13
Nigeria	4			4	5	1		6	122	31-Jan-13
Chad					1			1	5	14-Jun-12
Niger									1	15-Nov-12
Total	10	0	0	10	23	1	1	25	223	
Total in endemic countries	10	0	0	10	22	1	1	24	217	
Total out- break	0	0	0	0	1	0	0	1	6	

Data in WHO as of 14 March 2012 for 2012 data and 12 March 2013 for 2013 data.

2013 Polio Health and Wellness Retreat







2013 Polio Health and Wellness Retreat Body / Mind / Spirit South Australia in April 2013

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 hospitability of the Stamford Grand in the delightful seaside suburb of Glenelg, South Australia.

Contact Mary-ann to check if places still available

This is a fantastic opportunity to learn techniques to better manage symptoms of the Late Effects of Polio from a range of health professionals and other "Body, Mind, and Spirit" practitioners.

Participants will also enjoy the chance to share strategies with other polio survivors, explore ideas and activities they haven't tried before, be entertained, and enjoy gourmet food, all in 5 star accommodation with wonderful views of the ocean!

Take a look at the Program and Presenters List below:

2013 South Australia Polio Health and Wellness Retreat - Program (PDF) 2013 South Australian Health and Wellness Retreat - Presenters List (PDF)

