



# Polio Australia Incorporated

Representing polio survivors throughout Australia



[www.polioaustralia.org.au](http://www.polioaustralia.org.au)

## Reflections of July 2012

Polio Australia has now been advised that neither of the Federal Department of Health and Ageing funding applications we put in were successful, which was an extremely disappointing result. Yet again Australia's polio survivors miss out on government support and services. Brief written feedback on the applications has been received and Polio Australia will be holding further discussions with the Department as a matter of urgency. In the meantime, Polio Australia struggles on and does what it can with only one philanthropically-funded staff member and polio-survivor volunteers. If you would like to add your support to Polio Australia's ongoing campaign to secure comprehensive, consistent, adequately funded health, disability and peer support services for all Australian polio survivors, read *"We're Still Here!"* on Page 2.

*"Happy are those who dream dreams and are ready to pay the price to make them come true."*  
~ Leon J Suenes

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### **Practical Design Fund to Help Guide the Transition to a National Disability Insurance Scheme**

**Source:** [Joint Media Release](#) - Jenny Macklin, Minister for Disability Reform and Senator Jan McLucas, Parliamentary Secretary for Disabilities and Carers - August 4 2012

Applications have opened today for the Australian Government's \$10 million Practical Design Fund. The Practical Design Fund will support practical projects to identify how best to support people with disability make the transition to a National Disability Insurance Scheme (NDIS).

The Minister for Disability Reform, Jenny Macklin, and the Parliamentary Secretary for Disabilities and Carers, Jan McLucas, said the fund would identify practical solutions and innovative approaches to assist people with disability, their families and carers and the disability sector transition to an NDIS.

*"The Australian Government is making an NDIS real so that Australians with disability get the care and support they need, no matter where they live or how they acquired their disability,"* Ms Macklin said. *"To help us reach this important goal we have committed \$1 billion to deliver the first stage of an NDIS. So far we've got agreements for launch sites in New South Wales, South Australia, Tasmania and the ACT. That means from next year an NDIS will start to be real for more than 20,000 people with significant disability across Australia."*

*"The Australian Government will continue to work with the states and territories to get ready for the first stage of an NDIS by considering critical questions like the best way to assess people's needs, how to support people with disability to exercise choice and control and how to build the disability care workforce of the future. While we work together to design an NDIS, we will look to innovative approaches taken in these practical projects."*

Practical Design Fund projects will help determine how best to deliver an NDIS. For example, projects could:

- Develop good local approaches for disability and community workers, advocates and organisations to help people with disability manage and coordinate their individual support packages;
- Suggest ways to deliver different types of services to people with disability in regional and remote areas, for example by using new technologies; and
- Develop recruitment and training strategies so that disability sector workers and organisations can provide the quantity and quality of services needed under an NDIS.

## October — Polio Awareness Month Campaign

***We're Still Here!***



Polio Australia is calling all polio survivors to join us in Canberra on Wednesday 31st October 2012 at the culmination of the National Polio Awareness Month's "We're Still Here!" campaign.

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

Group, and is intended to be the first in a series of Clinical Practice Modules for managing various aspects of the LEOP.

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

- 9.30 am Arrive at Parliament House
- 10.00 am Media and/or Photo opportunity
- 10.30 am 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
- 11.30 am Individual appointments with local MPs
- 12.30 pm Polio Survivors and Parliamentary Patrons Lunch in the Members and Guests Dining Room, Parliament House
- 2.00 pm Question Time
- 3.30 pm Depart to own activities

We ask everyone coming to Canberra to contact their local Federal Members of Parliament to make a 20 minute appointment with them in the morning to discuss the need for appropriate clinical services for polio survivors in your area and/or across Australia. This one page (double sided) [handout](#) can be copied and left with your MP on the day. Read more about how you can be involved [here](#).

## Touched By Polio Art Exhibition



Several Expressions of Interest (EOI) have now been received from accomplished artists within the polio community and/or their family members/friends who will create works of art using purpose-prepared casts (*see example left*) for a travelling exhibition to be called "Touched by Polio". However, we are still seeking more, and would also welcome EOI's from the odd 'high profile' artist, if anyone knows one!

Polio Australia is currently working with Latrobe University's Prosthetics and Orthotics department, who have offered to contribute the plaster in exchange for free talks to their students - as well as allowing us to ask if any of the students would be interested in producing the casts for charity. Fingers crossed!

Each artwork will be accompanied by the artists' bio and a short story of how they have been "Touched by Polio". Painting/crafting the casts will transform an item once related to pain into a thing of beauty and value. The artworks will be auctioned off during the "Touched by Polio" launch – anticipated to be in February/March 2013 – or sold throughout the exhibition with 50% of artist-set sale price/or total proceeds being donated to Polio Australia.

Polio Australia has also been approached by a very interested Orthotist **and** Artist in Tasmania, [John Semmens](#). So news is spreading and, therefore, so might the scope of the exhibition! We are currently tossing around the idea of a "Tassie Taster" version of the Exhibition for later this year. Watch this space . . .

We will need to apply for funding and/or would welcome any donations to pay for the cost of transporting them around the country to and from the respective artists.

Polio Australia is still keen to hear from any Rotarians (*Tasmania or mainland East Coast*) to talk about becoming an active fundraising partner in this project.

The artist who has the prototype cast (*pictured*) would like to decoupage it with 'then' (child) and 'now' (adult) photos of polio survivors, so if you would like your photos featured on this artwork, please email them as scanned, digital .jpg's to [Mary-ann](#) (high resolution).

**If you are, or have a close connection to an: Artist or Rotary Club or Donor - please contact Mary-ann on Ph: 03 9016 7678 / Email: [mary-ann@polioaustralia.org.au](mailto:mary-ann@polioaustralia.org.au) for more details**

## “The Sessions”

by Mary-ann Liethof, Polio Australia



Ben Lewin, Mary-ann Liethof, Shirley Glance, Liz Telford

On a cold, rainy Sunday winter's evening, I reluctantly left my cosy home to drive into the city to see [Ben Lewin's](#) movie, "[The Sessions](#)", which was screening as part of the Melbourne International Film Festival to a packed audience. I'm so glad I did! I had learned about this polio-related American independent film earlier in the year when news of it starting popping up in my polio 'Google Alerts'. "[The Sessions](#)" (originally titled "[The Surrogate](#)") debuted at the 2012 Sundance Film Festival, where it won the Audience Award (U.S. Dramatic) and a U.S. Dramatic Special Jury Prize for Ensemble Acting. At that

time, I included a piece about it in the January 2012 edition of "[Reflections](#)".

I was especially interested in seeing this movie as the writer/director, Ben Lewin, is not only a polio survivor but also an ex-pat Australian from Melbourne – his family having migrated from Poland in 1949 when Ben was 3 yo. Ben was actually at the screening with his wife, Judi Levine, and was scheduled to do a Q & A after the film. I also caught up with a couple of other members of the post polio community - Shirley Glance and Liz Telford - who were in the audience. I had a misguided fantasy of just being able to sidle up to Ben after the Q & A to do a mini-interview. Of course, I had an instant reality check when Ben was quickly and totally surrounded by well-wishers (justifiably). Although I managed to squeeze in a quick group photo with him, Shirley and Liz, the photo was hopelessly under exposed and Ben had moved on. (*Curse the cinema lighting and faulty flash!*)

"[The Sessions](#)" is based on the true story of [Mark O'Brien](#), an American poet paralysed from neck down due to polio who hired a [sex surrogate](#) to lose his virginity at the age of 38. [John Hawkes](#) and [Helen Hunt](#) star as O'Brien and sex surrogate Cheryl Cohen Greene respectively. [William H. Macy](#) also appeared as Father Brendan, the Catholic priest who listened to O'Brien's graphic 'confession's'. I wasn't sure what to expect but I found the treatment of the film to be tasteful, poignant and very witty. There were many 'laugh out loud' moments, as well as a few tears. Fox Searchlight Pictures acquired the film's distribution rights and will release the film for general viewing in 2012. If you get a chance to see "[The Sessions](#)", I can highly recommend it!

Below is one of Mark O'Brien's poems about his life in an iron lung from his book of poetry, "[Breathing](#)":

*Grasping for straws is easier;  
You can see the straws  
This most excellent canopy, the air, look you,  
Presses down upon me  
At fifteen pounds per square inch,  
A dense, heavy, blue glowing ocean,  
Supporting the weight of condors  
That swim its churning currents.  
All I get is a thin stream of it,  
A finger's width of the rope that ties me to life  
As I labor like a stevedore to keep the connection.*

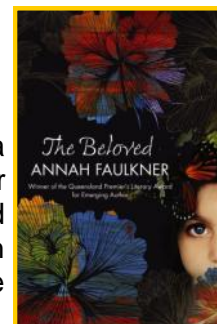
**Source:** <http://armsopenwide.wordpress.com/2007/06/25/mark-obrien/>

## “The Beloved”

by Annah Faulkner, [Pan Macmillan Australia](#), to be released Aug 7 2012

*"It came one morning with the milk, and it seemed - at first - almost as innocent..."*

When Roberta "Bertie" Lightfoot is struck down with polio, her world collapses. But Mama doesn't tolerate self-pity, and Bertie is nobody if not her mother's daughter – until she sets her heart on becoming an artist. Through drawing, the gifted and perceptive Bertie gives form and voice to the reality of the people and the world around her. While her father is happy enough to indulge Bertie's driving passion, her mother will not let art get in the way of the future she wishes for her only daughter.



But Roberta is not the only one deceiving her family. As secrets come to light, the domestic varnish starts to crack, and jealousy and passion threaten to forever mar the relationship between mother and daughter.

Tender and witty, [The Beloved](#) is a moving debut novel which paints a vivid portrait of both the beauty and the burden of unconditional love.

## WHO Anti-Polio Doctor Injured by Gunfire

Source: Herald Sun - July 18 2012



GUNMEN in the Pakistani city of Karachi opened fire on a vehicle carrying a doctor working with the World Health Organisation on an anti-polio campaign, wounding him in the stomach, the organization said.

The head of the World Health Organisation's polio eradication program in Pakistan, Dr Elias Durry, said the doctor is an international volunteer helping supervise the project. He said the man underwent surgery in Karachi.

Pakistan is in the middle of a campaign to vaccinate children under five. Taliban militants in northern Pakistan have barred the vaccination campaign from territory under their control, saying it can't go forward until the US stops drone strikes in the country.

In a statement, WHO said the attack did not appear to be specifically targeting the doctor. *"At this point, there is no evidence to suggest that this was a deliberate or targeted attack against polio eradication efforts or WHO,"* the Geneva-based organisation said. *"WHO is grateful to the Pakistan authorities for launching an investigation into this event, to determine more clearly the circumstances."*

Pakistan's largest city Karachi has struggled for years with political and criminal violence. Dr Durry said despite the shooting WHO is committed to eliminating polio in Pakistan. *"This incident will not distract from the progress Pakistan is making this year, as the country is closer than ever to eradication,"* the organisation said.

Read full article [here](#).

## Pakistani Police Called to Aid in Polio Vaccinations

by Jeffrey Bigongiari

Source: Vaccine News Daily - July 30 2012

Health workers in Pakistan have called on police to help administer the polio vaccine to children whose parents refuse the immunization on religious grounds.

*"About 20 children refused the vaccine yesterday. We called in social organizations, religious leaders and the district police officer also sent police to help as well,"* Kaleem said, the Telegraph reports. *"Today we got them all vaccinated, most by persuasion but in the case of three or four the police had to force them to take the vaccine."*

Pakistan could face harsh travel restrictions if more is not done to help eliminate the crippling childhood disease, but several militant commanders have issued bans against polio workers. Last week, eradication efforts were disrupted when a polio worker was shot dead in Karachi.

Read full article [here](#).

## World Health Organization Suspends Polio Vaccinations in Karachi

Source: New York Daily News - August 2 2012

The World Health Organization has halted Polio vaccinations in parts of Karachi due to shootings. There have been four more cases of Polio reported, bringing the total to 27 this year.

Pakistan's efforts to eradicate polio have suffered a further setback after the World Health Organization suspended vaccinations in parts of Karachi after a spate of shootings, leaving some 22,000 children at risk.

Karachi is a key battleground in efforts to rid the world of polio. The sprawling megacity is home to hundreds of thousands of refugees from Afghanistan and many more economic migrants from the north-west of Pakistan.

Pakistan, Afghanistan and Nigeria are the only three countries where the virus remains endemic. However, the number of cases in Pakistan is far lower than last year, which recorded 198 in total but health officials fear the incidence will increase if their work continues to be hampered.

Read more [here](#).



## Polio This Week

Source: [Polio Global Eradication Initiative](#) - as of Wednesday 1 August 2012

Three new wild polio virus cases were reported in the past week, all from Nigeria (two WPV1s and one WPV3). This brings the total number of cases globally for 2012 to 103 from four countries (Nigeria, Pakistan, Afghanistan and Chad). This compares to 303 cases reported from 13 countries for the same period in 2011.

### Wild Poliovirus (WPV) cases

Total cases	Year-to-date 2012	Year-to-date 2011	Total in 2011*
Globally	103	303	650
- in endemic countries	98	96	341
- in non-endemic countries	5	207	309

### Case breakdown 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		
Afghanistan	15			15	11			11	80	05-Jul-12
Nigeria	46	14		60	16	8		24	62	01-Jul-12
Pakistan	20	2	1	23	59	1		60	198	22-Jun-12
India					1			1	1	13-Jan-11
Chad	5			5	90	3		93	132	14-Jun-12
DR Congo					71			71	93	20-Dec-11
Angola					4			4	5	07-Jul-11
Niger						1		1	5	22-Dec-11
CAR									4	08-Dec-11
China									21	09-Oct-11
Guinea						1		1	3	03-Aug-11
Kenya									1	30-Jul-11
Côte d'Ivoire						11		11	36	24-Jul-11
Mali						4		4	7	23-Jun-11
Congo					1			1	1	22-Jan-11
Gabon					1			1	1	15-Jan-11
<b>Total</b>	<b>86</b>	<b>16</b>	<b>1</b>	<b>103</b>	<b>254</b>	<b>49</b>	<b>0</b>	<b>303</b>	<b>650</b>	
<b>Total in endemic countries</b>	<b>81</b>	<b>16</b>	<b>1</b>	<b>98</b>	<b>87</b>	<b>9</b>	<b>0</b>	<b>96</b>	<b>341</b>	
<b>Total outbreak</b>	<b>5</b>	<b>0</b>	<b>0</b>	<b>5</b>	<b>167</b>	<b>40</b>	<b>0</b>	<b>207</b>	<b>309</b>	

Data in WHO as of 2 Aug 2011 for 2011 data and 31 Jul 2012 for 2012 data.



## Energy Efficiency about the Essential Medical Equipment Payment

**Source:** Email Correspondence between Peter Willcocks, Post-Polio Victoria, and Martha McHugh, Assistant Section Manager, Carer Payments, Disability and Carers, Families, Housing, Community Services and Indigenous Affairs - July 30 2012

Thank you for your email to the Clean Energy Enquiries mailbox in the Department of Climate Change and Energy Efficiency about the [Essential Medical Equipment Payment](#) (EMEP). The Department of Families, Housing, Community Services and Indigenous Affairs has policy responsibility for the EMEP and your email has been forwarded to me for a response.

The Essential Medical Equipment Payment was introduced on 1 July 2012 to cover the additional costs of running essential medical equipment, or medically required heating and cooling, that arise from the introduction of a carbon price.

Since 1 July 2012 the payment has been available to people with medical needs, or their carers, who:

- are covered by a Commonwealth Government concession card or Department of Veteran's Affairs (DVA) Gold or White Card; and
- use certain essential medical equipment, or have certain medical conditions that require the use of additional heating and / or cooling in their home; and
- contribute to the payment of the energy account.

In order to qualify for the medically required heating/cooling component, a Medical Practitioner (who may be a General Practitioner or other Medical Specialist) must certify that:

- the person has a specified medical condition; and
- the person is unable to regulate his or her body temperature because of that medical condition, and requires medical heating and/or cooling in their home; and
- without medical heating and/or cooling, the person risks serious harm to his or her health.

You have sought confirmation that the Late Effects of Polio / Post-Polio Syndrome are included as one of the neurodegenerative disorders medical condition that would receive the EMEP. In developing our response we have sought professional medical advice from the Health Professional Advisory Unit of the Department of Human Services.

We are advised that Post-Polio Syndrome is generally accepted as a defined clinical entity with clinical diagnostic criteria. It is classified by the World Health Organisation International Classification of Disease 2010 as being a systemic atrophy primarily affecting the central nervous system and as such can be considered to be a neurodegenerative disorder.

However, the Late Effects of Polio refers to the myriad of symptoms that individuals with a history of polio may experience. This includes Post-Polio Syndrome, but also symptoms that result from secondary trauma, for example degenerative arthritis of joints that have been overstressed due to compensatory body mechanics. This means the symptoms experienced by people with the Late Effects of Polio do not always arise from a neurodegenerative disorder. Some patients with the Late Effects of Polio may have cold sensitivity due to damage to the intermediolateral cell column of the spinal cord from acute polio infection and could be considered to have a neurodegenerative disorder.

**The medical practitioner completing the claim form for a patient with Late Effects Of Polio has the responsibility of determining if that patient has a neurodegenerative disorder and inability to regulate body temperature, as a component of their condition.**



**POLIO AUSTRALIA INCORPORATED**

Representing polio survivors throughout Australia

**Please pass this e-Bulletin on to friends and colleagues who have an interest in the late effects of polio**

- ◆ If you are not the original recipient of this e-Bulletin and would like to receive it directly in future, please email us [here](#).
- ◆ If you do not wish to receive any further communication from Polio Australia, please email us [here](#).

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