

# Polio Australia Incorporated

Representing polio survivors throughout Australia



www.polioaustralia.org.au

# Reflections

of June 2012

There is always a sense of anticipation at end of the financial year to see what initiatives, benefits, changes will commence with the new Federal budget. In this edition, you can read about Essential Medical Equipment Payments, Home Care Reforms, and changes in the cost of certain medicines - all of which impact on a number of people in our post polio community. Polio Australia is also delighted to announce the release of the "Discussion paper on the late effects of polio/post-polio syndrome" which is the result of the Roundtable Forum held in March. This discussion paper can now be used as a catalyst for further discussion and we are inviting all willing and able polio survivors to join us in Canberra in October for the Polio Awareness Month campaign, at which time we can demonstrate that "We're Still Here!" and worthy of recognition. In the meantime, we would like to hear from any Artists and/or Rotarians for an exciting new fundraising project we are planning to launch in February/March 2013 - see page 5 for more . . .

"The economy depends about as much on economists as the weather does on weather forecasters." ~Jean-Paul Kauffmann

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### **Essential Medical Equipment Payment**

Source: Department of Human Services Website

The Essential Medical Equipment Payment is an annual \$140 payment to people who experience additional increases in home energy costs from the use of essential medical equipment to manage their disability or medical condition (including ventilators). This payment must be claimed, and payments will be available from 1 July 2012.

You may be eligible for this payment if you or the person in your regular care at home:

- are covered by a Commonwealth concession card issued by the Department of Human Services or the Department of Veterans' Affairs
- provide proof that the specified equipment or heating/cooling is medically required. This proof can be provided as:
  - ⇒ certification from a Medical Practitioner, or
  - ⇒ evidence that the essential medical equipment currently qualifies for assistance under one of the state or territory government schemes, or the Department of Veterans' Affairs Rehabilitation Appliances Program.

Note: this evidence option does not apply to medically required heating/cooling.

Check here for the list of qualifying medical equipment, including alternative names for equipment.

Millions of Australians are also eligible to receive other financial assistance through the Australian Government's Household Assistance Package. Check here for details.



## **Late Effects of Polio Discussion Paper Released**

Source: House of Representatives Committees Website - 4 July 2012

The House of Representatives Health and Ageing Committee today released its discussion paper, Late Effects of Polio/Post Polio Syndrome which highlights the need for greater awareness to improve diagnosis and management of the condition.

Key recommendations of the report include establishing measures to help estimate the number of people living with the late effects of polio/post polio syndrome (LEOP/PPS) and increasing awareness of LEOP/PPS amongst medical students and experienced medical practitioners.

Although polio was eradicated in Australia in the year 2000, it is believed that between 20,000 and 40,000 Australians were infected by the virus between the 1930s and 1960s. Many years after contracting the initial infection, some polio survivors have developed a range of biomechanical and neurological symptoms known as LEOP/PPS.

Committee Chair, Mr Steve Georganas, said that with LEOP/PPS symptoms being largely unrecognised to date, there is a clear need for improved diagnosis. "It is imperative that awareness of LEOP/PPS is raised within the medical community, including during undergraduate medical training and also within the community at large. These initiatives would be aimed at ensuring that clinical history of polio is considered when assessing symptoms," Mr Georganas said.

The committee's report, which focussed on a number of key areas including the prevalence, diagnosis, management, treatment and support of LEOP/PPS was based on a roundtable that brought together a range of participants with interests in the advocacy, support, treatment or management of LEOP/PPS. It highlighted the substantial physical, social, emotional and financial effects that LEOP/PPS has on its sufferers.

"Improved diagnosis will lead to better estimates of the prevalence of the condition and in turn better management and treatment outcomes for LEOP/PPS sufferers," he said.

Copies of the committee's discussion paper are available from the committee's website <u>here</u>, and a summary can be viewed on Polio Australia's website <u>here</u>.

Polio survivors can be assured that Polio Australia and its member State Networks will be vigorously following up these recommendations over the coming months including a concerted effort during Polio Awareness Month in October. If you are able, please join us in Canberra on 31 October 2012 and let your Federal Parliamentary representative know that you want to see not only the above recommendations turned into action, but also the work being done on your behalf by your state and national polio support networks receive funding. We are still here - and we still have a lot of fight in us yet!

# Adult Immunisation: the weak link

Source: Chain of Protection website



A new video has just been added to the "Chain of Protection" website highlighting the late effects of polio (amongst other diseases) under the title: "Adult immunisation: the weak link". It stars Polio Australia's President, Gillian Thomas.

The "Chain of Protection" website and associated videos was produced by Professor Robert Booy from the National Centre for Immunisation Research & Surveillance (NCIRS) at The Children's Hospital at Westmead and The University of Sydney in conjunction with Blirt Marketing and Jenny Granger (marketing consultant). The Chain of Protection series of videos and the website have been made possible by an educational grant from Medicines Australia.

Professor Robert Booy is Head of Clinical Research at NCIRS. He is an Infectious Diseases Specialist and Paediatrician. Professor Booy trained in paediatrics during the 1980s at the Royal Children's Hospital, Brisbane, and spent much of the 1990s doing epidemiological research on life threatening infectious diseases in the United Kingdom. This included 4 years in Oxford where he completed a doctorate on the epidemiology and prevention of Haemophilus influenzae type b disease.

In 1999 Professor Booy appointed Professor of Child Health, Head of Department, Royal London Hospital, Queen Mary and Westfield College, University of London. He returned to Australia in early 2005. Professor Booy has conducted extensive research into serious infections and their prevention with over 150 scientific publications to his credit. Professor Booy is also a member of Polio Australia's <u>Clinical Advisory Group</u>.

#### **2012 Queensland Retreat Photos**

All photos of the Queensland Polio Health and Wellness Retreat are now available for viewing online here.

# 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.

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. Read about how you can be involved here.

#### **Cost of Medicines to Fall for Thousands of Australians**

Source: Media Release - 24 June 2012 The Hon Tanya Plibersek, Minister for Health

Around 45,000 people will benefit from new, cheaper medicines following the Government's approval of eleven new medicines on the Pharmaceutical Benefits Scheme (PBS).

"The listing of these medicines on the PBS will offer patients access to new, affordable treatments which will directly benefit their health," said Minister for Health, Tanya Plibersek. "Australians will also benefit in the coming months from the Australian Government's decision to provide subsidised access to a further 10 medicines through the PBS. This will ensure more patients have greater access to the medicines and treatment they need at subsidised prices," she said.

#### The new medicines are:

- aflibercept (Eylea<sup>®</sup>) for the treatment of age-related macular degeneration in patients new to drug treatment
- auranofin (Ridaura®) for the treatment of rheumatoid arthritis
- bortezomib (Velcade<sup>®</sup>) for the treatment of newly diagnosed bone marrow cancer for patients who are eligible for high dose chemotherapy, as part of combination therapy
- cabazitaxel (Jevtana<sup>®</sup>) for the treatment of a certain type of metastatic prostate cancer
- denosumab (Prolia<sup>®</sup>) for the treatment of osteoporosis in women aged at least 70 years with a bone mineral density measured as a T-score of -2.5 or greater
- etanercept (Enbrel®) for the treatment of children with severe chronic psoriasis
- human menopausal gonadotrophin (Menopur<sup>®</sup>) for the treatment of infertility as part of the IVF (in vitro fertilisation)/GIFT (Gamete Intra-Fallopian Transfer) program
- icatibant (Firazyr®) for the treatment of attacks of hereditary angioedema (unpredictable episodes of swelling in people that can impede breathing if affecting the throat)
- pazopanib (Votrient<sup>®</sup>) for the treatment of a certain type of kidney cancer
- rasagiline (Azilect®) for the treatment of Parkinson disease in certain patients.

Listings are subject to final arrangements being met by the suppliers of the medicines.

The Government has also agreed to increase the price of six medicines currently listed on the PBS. This will ensure a number of essential medicines continue to be available. They include: heparin injection (preservative-free) for the prevention and treatment of blood clots, idarubicin capsules (Zavedos®) for the treatment of leukaemia, levonorgestrel intrauterine (Mirena®) for use as a contraception and treatment of abnormally heavy and pronged menstrual bleeding, metformin with glibenclamide (Glucovance®) for the treatment of diabetes, methyldopa (Hydopa®) for the treatment of high blood pressure and oestradiol vaginal tablets (Vagifem®) for use as hormone replacement therapy for postmenopausal women.

The price increases for these medicines will have no impact on concessional patients which constitute around 80 per cent of PBS prescriptions. The maximum amount they will pay for their prescriptions is \$5.80. General patients will continue to have access to subsidised medicines and will pay between \$0.57 - \$3.54 more for these medicines. A full list of the price increases is available on the PBS website at: <a href="http://www.pbs.gov.au">http://www.pbs.gov.au</a>

#### Home Care Reforms to Benefit More Than 500,000 Seniors

Source: Media Release - 30 June 2012

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



This Sunday will mark the delivery of a major part of the National Health Reform Agenda. From 1 July 2012 the Australian Government has full responsibility for Home and Community Care (HACC) services that support more than 500,000 older Australians to live independently in their own homes and communities.

Minister for Ageing, Mark Butler said the transfer of responsibility for HACC services for older people to the Australian Government rationalises the system and paves the way for the reforms outlined in Living Longer Living Better.

"Supporting older Australians to remain living in their own home is a key focus of our recently unveiled Living Longer Living Better aged care reform package." "We're investing an extra \$880 million over the next 5 years for 40,000 new home care packages to help older people stay living at home," Mr Butler said. "The HACC Program provides a foundation for future aged care reforms and is one of the first steps in the development of a consistent aged care system covering basic care at home through to high-level care in aged care facilities."

The Commonwealth HACC program replaces the former joint Australian Government and state government-funded HACC program in all states and territories except Victoria and Western Australia, where basic community care services will continue to be delivered under the old arrangements.

State and territory governments will continue to fund HACC services for people under 65 (or under 50 for Aboriginal and Torres Strait Islander people). HACC consumers will continue to receive services from their current provider and remain in the most appropriate care setting regardless of their age.

The Australian Government has allocated more than \$1 billion for the Commonwealth HACC program and will continue to support the joint HACC program in Victoria and Western Australia.

More information on the Commonwealth HACC program is available at: www.health.gov.au/hacc

#### **TGA Applied Stricter Regulation to Joint Implants**

Source: Media Release - 29 June 2012

The Hon Catherine King MP, Parliamentary Secretary for Health and Ageing

Hip, knee and shoulder joint implants will be reclassified as high risk, Class III medical devices from 1 July 2012, the Parliamentary Secretary for Health and Ageing, Catherine King, announced today.

"This new classification will bring greater rigour to the way the Therapeutic Goods Administration (TGA) assesses these devices before they can be used in Australia," Ms King said. "It will also ensure an improved level of monitoring is undertaken once the product is on the market, and will allow easier product recall. This change will also allow better identification of these products on the Australian Register of Therapeutic Goods (ARTG) as they will now be included as individual products rather than allowing a number of products to be included on the ARTG under a single entry. Overall it will better assure the safety, quality and performance of joint replacement devices."

Ms King said the reclassification is in response to recommendations of the Health Technology in Australia review and following concerns over the quality of some hip replacement implants that have needed to be recalled in recent years.

"There has been widespread stakeholder consultation and I believe all parties see the need for closer scrutiny of joint replacement devices," Ms King said.

Further general information on the reclassification of hip, knee and shoulder implants, is available in the medical device section of the TGA website.

#### For more information:

Implementation commences 1 July 2012 to reclassify hip, knee and shoulder joint implants Increasing scrutiny of hip, knee and shoulder joint implants

Regulation impact statement for reclassification of hip, knee and shoulder joint implants

#### **Polio This Week**

Source: Polio Global Eradication Initiative - as of Wednesday 27 June 2012

In Nigeria, a significant surge in field staff continues to be deployed to the worst-performing Local Government Areas in the highest-priority states in the north of the country. At the World Health Organization alone, staff is being increased from 744 professionals to 2,951, an increase of nearly 300%. The bulk of these new staff is already in place, and the full recruitment of the surge is anticipated to be completed over the coming weeks. The Government of Nigeria and UNICEF are undertaking similar staff surges, with UNICEF scaling up its Community Volunteer Network to a planned 2,150 staff. The overriding priority is now on rapidly integrating the new surged workforce into a well-functioning and operational outfit.

### Wild Poliovirus (WPV) cases

Total cases	Year-to-date 2012	Year-to-date 2011	<b>Total in 2011*</b>		
Globally	84	241	650		
- in endemic countries	80	79	341		
- in non-endemic countries	4	162	309		

### Case breakdown by country

Countries		Year-to-date 2012			Year-to-date 2011			Total in	Date of most	
	WPV1	WPV3	W1W3	Total	WPV1	WPV3	W1W3	Total	2011*	recent case
Nigeria	36	12		48	11	5		16	62	05-Jun-12
Afghanistan	10			10	8			8	80	29-May-12
Pakistan	19	2	1	22	54			54	198	22-May-12
India					1			1	1	13-Jan-11
Chad	4			4	77	3		80	132	21-Feb-12
DR Congo					59			59	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
Total	69	14	1	84	216	25	0	241	650	
Total in endemic countries	65	14	1	80	74	5	0	79	341	
Total outbreak	4	0	0	4	142	20	0	161	309	

Data in WHO as of 28 Jun 2011 for 2011 data and 26 Jun 2012 for 2012 data.







## **Touched By Polio**

#### Wanted! Artists and Rotary Club Partners

In order to raise awareness, and desperately needed funding to work with Australia's post polio community, Polio Australia is proposing a travelling exhibition of approx. 50 artist-painted/crafted plaster cast torsos and legs (purpose made).

Expressions of interest are now being sought from people within the polio community and/or their family members/friends who are artists/crafty to paint/craft (e.g. decoupage) the casts for the exhibition which is to be called "Touched by Polio".



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 will need to apply for funding and/or would welcome any donations to pay for the production of these casts, art-related materials, and the cost of transporting them around the country to and from the respective artists.

Polio Australia is seeking to 'partner' with a number of Rotary Clubs to move the "Touched by Polio" exhibition from town to town. In 2004/05, Rotary organised "A world without Polio: Truly Remarkable" travelling exhibition, which worked really well. This project would be a wonderful opportunity for Polio Australia to partner with a number of Rotary Clubs which could be 'chain-linked' to move this exhibition along week by week along the East Coast of Australia, as per the 2004/05 exhibition.

How Polio Australia sees Rotary Clubs being involved is through the contribution of their member's collective skills to:

- identify/book a suitable and wheelchair accessible exhibition venue in their respective area;
- promote the exhibition within their local area (local newspapers, schools, etc);
- set up and man the "Touched by Polio" exhibition;
- record any sales and bank donations;
- arrange for transportation on to the next Rotary Club.

Polio Australia expects that the participating Rotary Clubs would also use the "Touched by Polio" exhibition as an opportunity to promote the "End Polio Now" campaign. In terms of joint fundraising, those attending the "Touched by Polio" exhibition would be charged an arbitrary gold coin entry fee to go to Polio Australia – plus \$2.00 to go to the "End Polio Now" campaign as a separate donation. Rotarians are also encouraged to fundraise for their own Clubs around this exhibition, e.g. sausage sizzles, product sales, dinners, etc.

So, if you are, or have a close connection to, an - Artist, Rotarian (East Coast), Donor - please contact Mary-ann on Ph: 03 9016 7678 / Email: mary-ann@polioaustralia.org.au for more details

# 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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Support Polio Australia's work by <u>donating online</u> today! Join us on <u>Facebook</u> and <u>Twitter</u> too!