At the end of 2010, we were delighted to welcome Dr John Tierney as the National Patron of Polio Australia. John retired in May 2011 after six years as a Partner at Government Relations Australia Advisory, and 14 years of distinguished service in the Australian Parliament where he served as Senator for NSW. In his former role, John provided strategic advice on government matters to corporate clients across a wide range of industries at both a Federal and State level in NSW. Additionally John undertook pro bono advisory work for Lifeline Australia, Polio Australia and the Australian Association for the Education of the Gifted and Talented.
Mission Statement

Polio Australia provides quality information and facilitates service provision across Australia ensuring that polio survivors have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices.

Background

In order to help themselves, polio survivors in each state have formed ‘Post-Polio Networks’ over the last 20 years. These Networks have been proactive in a number of areas including developing support networks, disseminating information, and arranging seminars and conferences. Unfortunately, in the majority of states, the Networks are operating without any funding and this is not a sustainable or adequate model of support.

In May 2007 at their national self-funded ‘Designing a Future’ conference, the Networks resolved to establish a national organisation Polio Australia to articulate the needs of polio survivors in Australia through centralised information provision and in the development and delivery of comprehensive education and training programs to the polio community and their health professionals. Polio Australia’s information and education programs will lead to prompt diagnosis and effective professional and self-management of the late effects of polio, achieving a comprehensive set of outcomes for polio survivors, their families and carers, health professionals and the community.

Polio Australia was incorporated in 2008 and is governed by a Committee of Management made up of two representatives from each state Polio Network:

- **New South Wales**: Post-Polio Network (NSW) Inc
- **Queensland**: Spinal Injuries Association Inc
- **South Australia**: Post Polio Support Group of SA Inc
- **Tasmania**: Post Polio Network - Tasmania Inc
- **Victoria**: Polio Network Victoria (a service of Independence Australia)
- **Western Australia**: Post Polio Network of WA Inc

Polio Australia’s programs will ensure that all polio survivors have access to adequate support and information together with comprehensive and consistent health, disability and aged care services from a range of well-informed and appropriately educated professionals.
The purpose of Polio Australia is to:

- Educate and inform polio survivors, their families and carers, and the community at large about the late effects of polio.

- Provide information, education and training to General Practitioners and a range of medical specialists and other health professionals to improve the diagnosis and management of the late effects of polio.

- Facilitate the provision of appropriate and consistent health, disability and aged care support services across all states and territories to improve the treatment and management of the late effects of polio.

- Provide outreach to culturally and linguistically diverse and Aboriginal and Torres Strait Islander polio survivors to ensure their diverse needs are being met in a culturally appropriate way.

- Advise governments on policy development and programs in relation to the late effects of polio.

- Stimulate research into the late effects of polio.

- Assist the state Networks to support polio survivors and their families, friends and carers at the local level.

- Facilitate and encourage the co-ordination and further development of activities within and between the state Networks.

- Support and promote polio immunisation at a national level, and provide assistance to the state Networks to do so at the local level.
Mary-ann Liethof, National Program Manager (Kew, Victoria Office)

Mary-ann was officially appointed as Polio Australia’s National Program Manager in early January 2010 on a part-time basis following a small philanthropic and private donation. Her hours were increased to full time in January 2011 thanks to a 3 year donation from The Balnaves Foundation. As the only paid employee, Mary-ann is kept busy devising ways of transforming Polio Australia’s program goals into action.

Jill Pickering, Administration and Project Work Volunteer (Kew, Victoria Office)

Jill worked in several roles using her Occupational Therapy skills before retiring in 2000 due to limitations caused by Post-Polio Syndrome. She then volunteered for 10 years at Polio Network Victoria (a service of Independence Australia), prior to commencing volunteer work one day a week with Polio Australia in February 2011. Jill has enjoyed assisting on a variety of projects including the Australian Polio Register and the Health and Wellness Retreats.

Shylie Little, Administration and Bookkeeping Volunteer (Parramatta, New South Wales Office)

In her two volunteer days a week Shylie assists with banking, scheduling payments, bookkeeping, and a myriad administrative tasks which free up time for both Mary-ann and the Management Committee. We are grateful for Shylie’s dedication to polio survivors.

Additional members of the dedicated team of volunteers include:

George Laszuk who provided administrative support including banking and assistance at the Health and Wellness Retreat in Victoria

John Doyle spent many hours entering hundreds of names and details from the Australian Polio Register forms onto a spreadsheet

We also thank the many polio survivors in Australia and around the world who regularly post on Polio Australia’s Facebook page and Twitter.
From the President

2010/11 has certainly been a year of hard work rewarded by many accomplishments. Without the generous donation received from the Balnaves Foundation towards the full-time employment of our National Program Manager, very few of our goals for the year would have been achievable. With Mary-ann Liethof ably managing Polio Australia programs we were able to focus more strategically on our ongoing lobbying efforts in Canberra and on Polio Australia’s future directions.

To contain costs the Management Committee meets regularly by teleconference rather than in person. Our 2010 Annual General Meeting provided the first opportunity since 2007 (when all state Networks agreed to the formation of Polio Australia) for Committee members from all states to gather in person, and we held a very successful meeting at St Joseph’s Centre for Reflective Living in Baulkham Hills. Members are eagerly awaiting the opportunity in November 2011 to come together in Baulkham Hills again, this time focusing on strategic planning in conjunction with our Third Annual General Meeting.

Launching our website was a definite highlight of the year under review. We also successfully applied for a Google Grant which provides pro bono polio-related advertising to drive traffic to our site resulting in us reaching many more polio survivors than might otherwise be possible.

Establishment of an Australian Polio Register has always been considered a vital component of Polio Australia’s work as the ever-present question “what are the numbers?” demands to be answered. The Register was launched in October 2010 although it was not until February 2011 that online registrations became fully operational. Many hundreds of paper forms were received in the meantime; at year end we were nearing completion of formatting around 1,100 registrations for display on our website. As necessary as the Register is, we have always recognised that it needs to be underpinned by a research study into the prevalence of polio in Australia. With support from The Balnaves Foundation, Polio Australia is now able to commission this study and work is expected to commence early in 2012. A second phase of the research is already in the planning stages, aimed at quantifying the economic, social and public health burden of the late effects of polio in Australia. Overall, the study aims to answer the following questions:

- how many polio survivors are there in Australia today?
- how many are likely to be affected by the late effects?
- what is the cost to government and the community of not diagnosing, treating and managing the late effects appropriately?
- what are the savings/benefit to government by putting appropriate services in place now?

It is hoped that the study will assist Polio Australia to attract Federal government program funding to enable the provision, in conjunction with health professionals, of long-overdue support and services to Australia’s tens of thousands of polio survivors.

In the year ahead we are also looking forward in August 2011 to Polio Australia’s participation in a European Conference Post-Polio Syndrome – A Challenge of Today; our second national Polio Awareness Campaign in October 2011; our third Polio Health and Wellness Retreat in April 2012, this time in Queensland; and continuing to work with our Clinical Advisory Group in the development of Best Practice Recommendations for Health Professionals.
From the National Program Manager

Working full time since January 2011 has made all the difference to the effort that can be put into Polio Australia’s program areas.

In February, I was pleased to secure the volunteer services of Jill Pickering, who I have both worked and travelled with previously. Jill comes in to the office once a week, assisting with project and administrative tasks.

Of course, there is the ongoing need to find funding for Polio Australia’s program areas and from July 2010 to June 2011, I submitted 15 grant applications for projects including the 2011 Polio Health and Wellness Retreat, supporting the work of the Clinical Advisory Group, operational funding, October’s Polio Awareness campaign, website development, and conference attendance.

Polio Australia’s annual Health and Wellness Retreat requires substantial planning, coordination and promotion. The Victorian Retreat was held in Mt Eliza and we were very fortunate to secure a wonderful range of presenters, both local and from further afield. A 6 month follow-up questionnaire was sent and completed by the previous years’ participants, which provided valuable insight into the longer term benefits of this self management model. Leading on from this feedback was the opportunity to write an article about the Retreat which was printed in the Health Issues Centre’s "Journal on Chronic Disease Management". The Retreat was also the subject matter of a paper I presented at the 2011 European PPS Conference in Copenhagen.

Considerable time was put into identifying interested health professionals across Australia to become part of Polio Australia’s Clinical Advisory Group to ensure we are progressing with our purpose of “Facilitating the provision of appropriate and consistent health, disability and aged care support services across all states and territories to improve the treatment and management of the late effects of polio.” We were delighted to secure the interest and expertise of 11 health professionals from a variety of disciplines.

It was also important to start spreading the news about Polio Australia and its’ activities, which resulted in the first monthly e-Bulletin, "Reflections", being emailed to 200+ people in October 2010. This was followed up by a quarterly magazine, "Polio Oz News", in June 2011.

Throughout the year I continued to raise awareness of post polio and Polio Australia’s activities by giving talks to a variety of organisations including: Prosthetic & Orthotics students at Latrobe University; the Collective of Self Help Groups seminar; Camberwell and Richmond Rotary Groups; Victoria’s South/East Region, Bayside, and Knox-Yarra Ranges Post Polio Support Groups. May was a busy month, having been invited to speak to 30 members of Toowoomba’s (Queensland) Post Polio Support Group for their 60 Year Anniversary Lunch, as well as addressing 70 of PolioSA’s members in Adelaide by invitation of Trevor Jessop and Brett Howard (pictured above).

Being the only paid employee of Polio Australia certainly keeps me incredibly busy, but I honestly couldn’t think of anywhere I would rather be.
Website Developed and Launched - September 2010

At no cost to Polio Australia the President, Gillian Thomas, and National Program Manager, Mary-ann Liethof, spent untold volunteer hours designing and populating a website for Polio Australia which went ‘live’ in September 2010 - just in time for October’s National Polio Awareness Campaign. It has been progressively improved and promoted, and now shares links with all national and many international Polio Networks.

According to Post-Polio Health International and feedback from other networks and individuals, Polio Australia’s website is now rated as an ‘Excellent’ and world standard polio-related education and information resource.

Australian Polio Register Launched - October 2010

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country.

The polio details received from the many Australians who have already completed the Register can be sorted in various ways; family name, maiden name, given names, birth year, polio year, age at which polio contracted, or location where polio contracted.

With limited resources to promote the Polio Register widely in the community we are nevertheless pleased with the results to date. However, we know there are many more thousands of polio survivors out there. To make the Australian Polio Register truly reflective of the unmet need for polio services throughout Australia, we urge every Australian polio survivor to join the Polio Register. Our strength lies in our numbers.
Polio Awareness Campaign - October 2010

The aim of World Polio Day – Sunday 24th October 2010 - is to increase awareness about the polio virus and to encourage further actions to reduce it from spreading. However, Polio Australia believed it was also a time for us to reflect on those people who contracted polio during the epidemics and are now living with the late effects of polio.

Polio Australia set out to mark World Polio Day as significant for those people who were not able to avoid polio by encouraging people to show their support and “Wear Orange on World Polio Day”. Many did, taking their ‘orange’ photos and uploading them to Polio Australia’s website.

We were very pleased to be offered a professional, pro bono media campaign by GlaxoSmithKline (GSK). GSK allocated members of their Communications team to work with Polio Australia in the development of media materials which incorporated personal accounts from nominated polio survivors around Australia. The GSK team distributed the material to a range of national media outlets and provided a report of media uptake. The team worked as hard as they could to convince media outlets around the country to run our story but found it difficult without a major event/photo opportunity to promote.

However, through another NSW contact, President Gillian Thomas was interviewed by Alan Jones on Sydney Radio 2GB which resulted in additional activity on the Australian Polio Register. Additional radio interviews took place with community radio programs: Brendan Leggett on SWR FM 99.9 at 8:30 am on Saturday, 23 October and John Atkinson on 2NBC FM 90.1 at 4:45 pm on Tuesday 2 November.

"Reflections”: Polio Australia’s Monthly e-Bulletin Launched - October 2010

“Reflections” was launched in October as Polio Australia’s monthly e-Bulletin. The purpose of this free 3-4 page bulletin is to keep people up to date with Polio Australia’s activities, as well as other items which may be of interest to the polio community. “Reflections” is emailed to Australian and international polio networks, interested health professionals, Parliamentary Friends of Polio Survivors, and polio survivors who have signed up to the Australian Polio Register. Recipients are encouraged to forward it on to friends and colleagues who have an interest in the late effects of polio. “Reflections” is only available electronically and is uploaded to Polio Australia’s website.
Clinical Advisory Group (CAG) Teleconference - February 2011

In the second half of 2010, Polio Australia enlisted the expertise of a multi-disciplinary panel of health professionals working together as a Clinical Advisory Group to advise on medical practices and develop criteria for Best Practice Recommendations in Diagnosis and Management for people experiencing the Late Effects of Polio.

It was decided that the CAG would have three teleconference meetings per year, commencing February 2011, with email communication as required. If funding could be found, one face-to-face meeting per annum would also occur at the end of the year.

This work is a bilateral approach to both upskill health professionals and raise awareness of self-management techniques that can be offered to polio patients. CAG recommendations will be based on well researched strategies and standardized for use in clinical settings across Australia. These initiatives are designed to ensure polio patients have access to appropriate health care which can support them maintain independence in the community, and reduce the incidence of admissions into the acute health care system.

Members of Polio Australia’s CAG include:

**Professor Robert Booy**
Head of Clinical Research
National Centre for Immunisation Research & Surveillance
New South Wales

**Dr Diane Bull**
Psychologist & Conjoint Senior Lecturer / Director
The University Of Newcastle / forethought consultancy group
New South Wales

**Dr Wilbur Chan**
Rehabilitation Physician / Pain Medicine Specialist
Division of Rehabilitation
Princess Alexandra Hospital
Queensland

**Anne Duncan**
Outreach Coordinator
Victorian Respiratory Support Service
Heidelberg Repatriation Hospital
Victoria

**Dr Stephen de Graaff**
Rehabilitation Specialist & Director of Pain Services
Epworth Rehabilitation
Victoria

**(Jega) Gnanaletchumy Jegasothy**
Senior Physiotherapist
Late Effects of Disability Clinic
Royal Perth Hospital
Western Australia
By standardising quality information and service provision across Australia, incorporating appropriate diagnosis and management of the Late Effects of Polio, we will ensure that polio survivors have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices. The Clinical Advisory Group’s work will provide a framework for informing health professionals who will, in turn, go on to educate their polio patients in the comprehensive set of management strategies suitable for their complex condition. This intervention will assist in keeping people out of acute care facilities as the result of imprudent practices, thereby reducing healthcare costs.

Victoria’s Polio Health and Wellness Retreat - April 2011
The 2011 Victorian Retreat again showed what could be done with a lot of good will and a small purse. Sixty four participants came from across Australia - 44 polio survivors (34 female/10 male) and 20 carer/family members (6 female/14 male). There were 27 from Victoria, 23 from New South Wales, 7 from Tasmania, 3 from South Australia, 2 from the Australian Capital Territory, and 1 each from Queensland and Western Australia.

The Retreat was held from Thursday 28 April through to Sunday 1 May 2011 at The Melbourne Business School, Mount Eliza, Victoria. Polio Australia was successful in applying for funding from GlaxoSmithKline ($15,000), the Ian Potter Foundation ($10,000), the RE Ross Trust ($7,500), the Elisabeth Murdoch Trust ($1,000) and private donations totalling $1,500. This gave us the financial flexibility to provide the 3-day Retreat at the reduced cost of $450.00 per person/single or $350.00 per person/twin share/double, which included meals, accommodation and all activities. We are most grateful to these funding bodies for their support of the post polio community.
Victoria’s Polio Health and Wellness Retreat - April 2011

The Retreat was based on the successful healthy ‘Body/Mind/Spirit’ format used in NSW in 2010. A number of health professionals familiar with the issues associated with the Late Effects of Polio were involved in facilitating question and answer forums which enabled a broad spectrum of concerns to be raised within a group of people with similar conditions. This format was highly successful insofar as people discussing their own experiences of what has worked for them, supported by the knowledge and expertise of the respective health professionals.

Sessions addressing the ‘Body’ included: an overview of ‘The Polio Body’ by Rehabilitation Specialist, Dr Steve de Graaff, which included how the polio virus affected the motor neurons and its late effects; a scooter demonstration and tryout; aids and equipment options; explaining the roles of the polio survivors’ health ‘team’; exercises for people with limited mobility; respiratory and swallowing difficulties; foot care for polio feet; pain management; bracing; and dietary advice. In addition to these sessions, a range of one-to-one clinical assessments were available, as well as therapeutic services such as massage and acupuncture.

The ‘Mind’ sessions commenced with a presentation from psychologist, Dr Andrew Sinclair which covered ‘emotional health’ and taking care of yourself. This was followed by sessions on: seated yoga; strategies to keep the mind active; the Alexander Technique; early memories of having polio; finding your story; and “what you think is what you get”. The afternoon consisted of a variety of activities such as: photography, cryptic crosswords; bonsai; art; singing; and Mahjong - which were all introduced as techniques to keep the ‘mind’ active.

‘Spiritual Health’ commenced with a personal journey presented by Ms Maureen Anderson, a tutor with the local University of the Third Age. Other sessions included: meditation; life balance; and complementary health.
As there were a number of partners/carers/family members participating, there were scheduled and informal opportunities for people to meet and discuss their own specific concerns.

A group of participants were also treated to a guided 90 minute tour of the historical Mt Eliza Rehabilitation Centre, where many polio survivors received rehabilitation as children.

By way of demonstrating how this Retreat has “changed people’s lives”, a sample of the evaluation comments follows:

“What did I gain from the Retreat? Companionship, support; up until the last few years I had not been one for mixing with people with a disability. Now I see that their knowledge is invaluable to me! See you next year in Queensland.”

We are extremely grateful to all the session facilitators for sharing their expertise, especially as the majority of these presenters provided their time and knowledge at no charge. We also thank the many people who donated door prizes, and the Lions Club of Mordialloc-Mentone who funded the evening entertainment.

As indicated above, the 2012 Polio Health and Wellness Retreat will be held on the Sunshine Coast in Queensland.

"Polio Oz News“, Polio Australia’s quarterly Newsletter, Launched - June 2011
In June 2011, the first free 21 page edition of the quarterly “Polio Oz News” was emailed to approximately 800 individuals and organisations in Australia and overseas, as well as being uploaded to Polio Australia’s website. The content was a balanced mix of reports and presentations from the Polio Health and Wellness Retreat, articles from members of the Clinical Advisory Group, personal accounts, information about polio and disability services, and polio eradication activities. The result was an exponential rise in the number of website hits and numerous positive and encouraging comments from readers, with many asking to reproduce articles in their own newsletters.
In June 2011, Polio Australia’s Parliamentary Delegation made its sixth lobbying visit to Canberra, lead by Dr John Tierney.

Meetings took place with:
- Catherine King MP, Parliamentary Secretary for Health & Ageing (Parliamentary Patron)
- Senator Jan McLucas, Parliamentary Secretary for Disability and Carers
- Senator Mitch Fifield, Shadow Parliamentary Secretary for Disabilities and the Volunteer Sector
- Peter Dutton MP, Shadow Minister for Health & Ageing
- Angela Koutoulos, Senior Adviser to Nicola Roxon MP, Cabinet Minister for Health & Ageing
- Senator Claire Moore, Chair, Senate Standing Committee on Community Affairs

Polio Australia also hosted a Parliamentary Patrons and Friends Luncheon with:
- Senator Claire Moore
- Senator Gary Humphries
- Karen Andrews MP
- Mark Coulton MP (Parliamentary Patron)
- Greg Hunt MP (Parliamentary Patron)

The Delegation provided every Member and Senator with an update of Polio Australia’s activities and ongoing funding issues, particularly as it currently receives no financial support from the Federal Government.

One positive course of action which may result from this visit is a proposed “Inquiry into the Services for Polio Survivors in Australia” by the Standing Committee on Health and Ageing. This hearing would take the form of a roundtable discussion in 2012.

Polio Australia was also invited to participate in an online consultation process regarding priorities for new funds for the Department of Health’s new Chronic Disease Prevention and Service Improvement Fund later in the year.

Polio Australia is grateful for the support provided by our Parliamentary Patrons: Mark Coulton, Jill Hall, Greg Hunt, and Catherine King; as well as the growing number of Parliamentary Friends of Polio Survivors.
The Balnaves Foundation
Just as a 2010 one year grant for operational funding was due to finish, The Balnaves Foundation offered to fund Polio Australia to employ a full-time National Program Manager for three years commencing January 2011. In addition to this funding, The Balnaves Foundation agreed to provide funding for a study into “The Prevalence of Polio in Australia”.

GSK
GlaxoSmithKline continued to be a financial contributor to the Late Effects of Polio Self-Management Residential Program (Retreat) held in Victoria in 2011, in addition to related material. GSK also provided an in-kind contribution to the 2010 Polio Awareness Month media campaign.

Leadership Victoria Skillsbank
Pro bono professional advice regarding Polio Australia’s Strategic Business Plan.

Genuine Print
Genine Thornton from Genuine Print continued to support Polio Australia through the pro bono production of business cards and brochures in 2011.

Jill Pickering
In addition to volunteering, Jill Pickering donated towards the cost of operating expenses during 2010 and 2011.

Dr John Tierney
As a Director of Government Relations Australia, Dr Tierney provided his services on a pro bono basis to lobby Federal Government.

Peter Roebuck (FCA)
Associate Professor Peter Roebuck, Head of the School of Accounting, University of New South Wales, provided pro bono auditing of Polio Australia’s accounts.

Funding Polio Australia
Polio Australia’s Committee of Management is made up of two representatives from each state-based Polio Network and these Networks are our only ‘members’. As most of the state Polio Networks are run by volunteer polio survivors who also require funding to provide services to their members, Polio Australia only receives a small Membership Fee from each of the six Networks.

As indicated above, Polio Australia’s three year grant from The Balnaves Foundation funds employment of the National Program Manager. Polio Australia applies to numerous philanthropic organisations for each individual planned ‘project’. This does not include ‘operational’ funding, so we are very thankful to Jill Pickering whose donation funds the office rental.

Although Polio Australia has been lobbying the Federal Government for funding since 2009, it has received none to date. Without government or membership funding, Polio Australia is constantly seeking to meet its ongoing financial needs through donations and corporate partnerships. Significant contributions are yet to be achieved.
Polio Australia Inc
Who we Supported - 2010/2011

**Ability First**
In 2010/2011, Polio Australia became a member of Ability First Australia, a national body of leading disability organisations working to achieve a fair go for Australians living with a disability. These organisations are amongst Australia’s oldest and most respected charities. All were established from the 1920’s onwards to support children living with the results of polio, cerebral palsy and related conditions.

Ability First Australia’s purpose is to work with our Member organisations to ensure that every Australian living with disabilities, and their families, has access to programs that maximise their potential and create opportunities for them to make their own choices.

**Consumers Health Forum**
Polio Australia is a member of the Consumers Health Forum of Australia (CHF), the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. CHF member organisations reach thousands of Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective. CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.

**National Aids and Equipment Reform Alliance**
Polio Australia has aligned itself with the National Aids and Equipment Reform Alliance (NAERA), a network of organisations which strongly support the establishment of an insurance-based Long Term Disability Care and Support scheme for people with severe and profound disabilities. In the absence of a national aids and equipment policy framework there is currently an inefficient and often ineffective patchwork of over 100 separate equipment schemes operating in Australia with inconsistent patterns of funding and service delivery.

**National Compact Partner**
Polio Australia is a National Compact Partner. The Compact has been developed by the Government in consultation with Australia’s Third Sector – the broad range of not-for-profit organisations that exist to provide services, advance causes, share enthusiasm, preserve traditions or worship together. The Compact is an agreement setting out how the Government and the Sector want to work together to achieve their shared vision.

**National Insurance Disability Scheme (NIDS)**
Polio Australia joined forces with the NDIS campaign, a new support system for people with a disability, their families and carers. It will transform the way services are funded and delivered, ensuring people are better supported and enabling them to have greater choice and control. We promoted the need every Australian to stand up and say that people with a disability, their families and carers in this country deserve better and that it’s time for change. We need every Australian to say that people with a disability, their families and carers are Australians too, and that their hopes and dreams count.