



# Annual Report July 2011-June 2012

National Patron: Dr John Tierney PhD, OAM, Federal Senator for NSW 1991 - 2005

# Photos taken at the Health and Wellness Retreat in Queensland

## Our Vision

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



## Our Mission

Polio Australia is committed to standardising quality polio information and service provision across Australia for polio survivors.



## **Our Values**

are encompassed in the following statement:

As the national peak body, Polio Australia represents the needs of the post-polio community and works with passion and professionalism to educate, advocate and achieve recognition for polio survivors.

# 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 coordination 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.



# Our Committee of Management



Gillian Thomas NSW President



Arthur Dobson TAS Vice-President



Tessa Jupp WA Secretary



Neil Von Schill NSW Treasurer



**Brett Howard SA** 



Trevor Jessop SA



Jenny Jones WA



Michael Judson VIC



John Mayo QLD



**Margaret Peel QLD** 



Jen Sykes VIC



Billie Thow TAS

## Our strategic priorities

Αt 2011 its Annual General Meeting and Strategic Planning (right), Polio Meeting Australia's Committee of decided Management on four priorities to work towards over the next three years.



## **Priority One**

Capacity Building: Securing a stable income stream to support Polio Australia and our key program areas into the future

## **Priority Two**

**Education:** Promoting enhanced knowledge and management of the Late Effects of Polio across the Health and Community sectors

## **Priority Three**

**Health Service Promotion:** Lobbying and advocating for recognition of and appropriate service provision for Australia's polio survivors

## **Priority Four**

**Collaboration:** Working with and supporting state-based Polio Networks by producing resources and standardising polio information for use by the Networks and their members

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

Post-Polio Network (NSW) Inc

Spinal Injuries Association Inc (QLD)

Post Polio Support Group of SA Inc

Post Polio Network - Tasmania Inc

Polio Network Victoria (a service of Independence Australia)

Post Polio Network of WA Inc

Special thanks to these Committee of Management members



**Leonie Swift VIC**Retired at Nov 2011 AGM



John Tierney NSW Stood in for Neil von Schill from Jan 2012

# Supporting our key programs areas into the future

Priority One Capacity Building

## Polio Australia receives no funding through membership or from government sources.

Apart from a generous 3 year donation from the Balnaves Foundation which pays for our National Program Manager, we only receive irregular philanthropic funding for specific 'projects' such as the Health and Wellness Retreats.

Jill Pickering, polio survivor and volunteer at Polio Australia, provides an annual donation to pay the office rental. In 2011/2012 Jill also donated towards a financing consultancy.

In order to secure a stable income stream to support our key program areas into the future, four strategies have been identified:

- Establish a community investors' Polio Support Circle
- 2. Utilise Parliamentary Friends of Polio Survivors
- 3. Continue to pursue Federal Government Funding
- 4. Explore all philanthropic funding opportunities

Strategies 1 and 2 are continuing to be explored.

In addressing Strategy 3, Polio Australia submitted two applications to the Department of Health and Ageing (DoHA) in December 2011:

- Chronic Disease Prevention and Service Improvement Fund for "The Prevention, Early Intervention and Management of the Late Effects of Polio"; and the
- Health System Capacity Development Fund for "The Late Effects of Polio Best Practice Clinical Recommendation Modules".

Neither application was successful and no further funding rounds are scheduled to date.

During the 2011-12 financial year, Strategy 4 has yielded funding from:

- GlaxoSmithKline, who once again contributed to the Late Effects of Polio Self-Management Residential Program (Retreat), this time held in Queensland in April 2012, in addition to sponsoring Canadian polio survivor, Ramesh Ferris's visit to Melbourne (from Sydney). GSK also provided in-kind contribution to the 2011 Polio Awareness Month media campaign;
- Marian & EH Flack Trust, who also contributed to the annual Retreat for the second time; and
- James N Kirby Foundation, who provided funding towards the production of a Clinical Practice Module.



Hamish and Neil Balnaves with Gillian Thomas

## Our key programs

Priorities Two, Three and Four

## Australian Polio Register

# Please help us by registering now!

The Australian Polio Register is a vital component of Polio Australia's work as the everpresent question, "what are the numbers?" demands to be answered. These registrations help support our case when lobbying the government for support.

## **Priority 2**

- Best Practice Clinical Modules for Health Professionals
- 2. Fact Sheets for Consumers
- 3. Annual Polio Health and Wellness Retreats
- 4. Three Day International / Asia-Pacific Post Polio Syndrome Conference
- Annual Polio Awareness Month October

## **Priority 3**

- 1.Research
- 2. Polio Clinics
- 3. National Policy Development

## Priority 4

- 1. Resourcing the Polio Community
- 2. Standardising Information



# Promoting enhanced knowledge

Priority Two Education

## Personal Reflections of Polio Australia's 2012 Health and Wellness Retreat

by Bernard Peasley

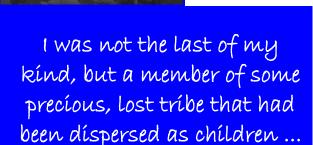
Angela and I came to Marcoola to learn more about PPS and the techniques I need in order to manage my emerging late effects of polio.

Polio Australia's 2012 Health and Wellness Retreat at Marcoola Beach was the second gathering of polio survivors in the past 12 months that made me realize how far removed I have been from the world of my childhood polio. I contracted polio as an infant in 1952 and was quarantined from my family for 3 months. I was returned to them bound into a Double Thomas splint, where I remained until I was 4 years old, even though my only paralyzed muscles were the left shoulder, bicep and deltoid.

After my physiotherapy finally ceased at 9 years of age, I did not meet another polio survivor for the next 36 years, when I attended a Polio Network Victoria (PNV) Stress Reduction Workshop in 1997.

Another 14 years passed before I met more polio survivors at the Post Polio Victoria (PPV) public meeting in the Northcote Town Hall in August last year.

There I found myself among 65 polio survivors who had travelled to that place across 55-65 years of life with the aftereffects of their polio. Like me, they had converged to share their stories, and to find ways of dealing with emerging symptoms of Post Polio Syndrome (PPS) and the Late Effects of Polio (LEOP). I am still trying to make sense of the unexpected emotional impact of that day.



The Retreat for me was like finding myself in a jungle clearing and being joined by weary travellers, wandering in from distant places, and discovering that I was not the last of my kind, but a member of some precious, lost tribe that had been dispersed as children, but had come together to share its common history and accumulated wisdom to continue its survival.

The strongest feeling I had during the Retreat was one of belonging and understanding. There seemed to be a common relief among the participants I spoke to that they did not need to explain themselves, nor their aids, to anyone else in the gathering.

For me it was a very positive experience. I felt fully connected with a community of aware, sensitive, humble and caring people with wonderful senses of humour. And I was privileged to be asked to record the three days through candid photographs of presenters and participants alike. A photographer could not hope for more wonderful subjects.



#### Reflections on the Retreat

**by Angela Gill**, Partner of Bernard Peasley

When Bernard first suggested that I might like to join him at this three-day Retreat I was ambivalent, thinking that it would probably not be relevant to me. I initially thought that I would feel like an impostor and a fraud, turning up to a Retreat for people dealing with Post-Polio Syndrome (PPS) and the late effects of polio (LEOP), and that I would be perceived as an intruder. How wrong I was!

Bernard assured me that the Retreat was specifically designed for "polios" and their partners, so after a wee bit more hesitation, I decided to join him.

Initially, when we first looked at the Retreat's range of sessions, it was a challenge deciding what to attend, everything looked so interesting. We decided not to go to the same sessions and that worked really well for us, and at the end of each day, we shared what we had learnt from the day's sessions.

As a partner of a polio survivor, I learned a lot, met heaps of wonderful people, shed some tears and had many hearty laughs! I look forward to doing it all again next year! In the "Partnering Polio" session we shared experiences and thoughts with other nonpolio people who are living with and supporting those with PPS and LEOP some of them have been doing this for a very long time. For most of us, we were fully aware that our partners had experienced polio as children, however polio was not a factor in our blossoming courtships all those years ago. As we all agreed, there were plenty of other things that attracted us to our future spouses! Now, as our polio-survivor mates face the increasingly unpleasant and unexpected symptoms of PPS and LEOP, we, as their partners and supporters, are also coming to terms with the prospect of possible lifestyle changes ahead. For me, this session was very reassuring and very humbling!



Angela Gill second from left

# Lobbying and advocating for recognition

Priority Three
Health Service Promotion

## Discussion Paper on the Late Effects of Polio/Post-Polio Syndrome (excerpt)

House of Representatives Standing Committee on Health and Ageing

"The Health and Ageing Committee, which I Chair, expressed interest in learning more about LEOP/PPS and its impact on polio survivors, their families and carers. Accordingly, on 30 March 2012 the Committee held a roundtable discussion in Melbourne. Participants at the roundtable included representatives of Polio Australia and associated statebased post-polio networks. between them provide support and advocacy for Australia's polio survivors. A roundtable participants number of identified themselves as polio survivors directly affected by LEOP/PPS. roundtable also included representation from health professionals involved with the treatment and clinical management of LEOP/PPS, as well as a representative of the Australian Government Depart of Health and Ageing. The roundtable discussions have formed the basis of the Committee's discussion paper, which I trust adequately reflects the range and scope of issues considered.

On behalf of the Committee I wish to thank all of the roundtable participants. The commitment of participants to providing support and advocacy for polio survivors was evident. In particular the Committee appreciates the contribution made by those directly affected by LEOP/ PPS. Despite struggling by the end of the day with LEOP/PPS associated fatigue, the knowledge and experience of this individuals provided group Committee with invaluable insights. The Committee also acknowledges and thanks the observers who attended the including day's proceedings, polio survivors, their family members and carers."



## Steve Georganas MP Chair

"It was evident to the Committee that Polio Australia and the state-based polio networks are a cohesive and unified group dedicated to improving the lives of polio survivors, their families and carers."

## The House of Representatives Standing Committee on Health and Ageing:

(I-r) The Hon Steve Irons MP – Deputy Chair, House of Representatives Standing Committee on Health and Ageing; The Hon Steve Georgenes MP - Chair, House of Representatives Standing Committee on Health and Ageing; Dr Alison Clegg – Secretary, House of Representatives Standing Committee on Health and Ageing; The Hon Mark Coulton MP – Member, House of Representatives Standing Committee on Health and Ageing; The Hon Jill Hall MP – Member, House of Representatives Standing Committee on Health and Ageing

# Supporting state-based polio networks

Priority Four Collaboration

During the year, Polio Australia's National Program Manager, Mary-ann Liethof, worked together with Polio NSW, Polio SA, and Post-Polio Victoria to deliver a range of presentations and activities for their members.

At Polio NSW's AGM in November, members were keen to hear about Mary-ann's attendance and new ideas gleaned from the European Post Polio Conference in Copenhagen held in September 2011.

It was at the Copenhagen Conference that Post-Polio Victoria's (PPV) President, Liz Telford, devised a plan to bring Indian-born/Canadian-raised polio survivor and advocate for polio eradication, Ramesh Ferris, to Victoria when he was due to visit Sydney for a Rotary Conference in March 2012. Ramesh was a popular speaker at several meetings coordinated jointly by Polio Australia and PPV. His expenses were covered by GlaxoSmithKline.

With the 2013 Retreat being scheduled to run in Adelaide, Mary-ann was invited to speak to members of Polio SA to explore their ideas on preferred activities and local presenters.



Mary-ann Liethof speaking to Post-Polio Victoria members



# The year at a glance

	We are constantly applying for 'project funding' to try to finance these programs - most of which are ultimately achieved through goodwill
July 2011	After almost a year of toil, Polio Australia's President, Gillian Thomas, proudly unveiled the new online Australian Polio Register.
August	National Program Manager, Mary-ann Liethof, attended the European Conference on Post Polio Syndrome in Copenhagen and gave a presentation on Polio Australia's Health and Wellness Retreats.
September	Mary-ann wrote a daily blog about the European conference and uploaded it to Polio Australia's website, as well as sharing information in the Spring edition of "Polio Oz News".
October	Polio Awareness Month campaign and promotion of The Global Poverty  Project's "The End of Polio" campaign and concert in Perth on 28 Oct, with stories of Australian polio survivors included on their website.
November	Polio Australia held its annual face-to-face Annual General Meeting in Sydney and developed a Strategic Plan for 2012-2014. Mary-ann spoke at Polio NSW's AGM.
December	Summer Edition of "Polio Oz News" was produced and distributed to the growing email list.
January	Polio Australia's National Patron, Dr John Tierney, was awarded an  Order of Australia Medal on Australia Day for services to parliament, education and the community.
February	Prepared for March! As well as the Roundtable forum (below), Mary-ann worked with Liz Telford, Post-Polio Victoria, and GlaxoSmithKline to arrange several speaking engagements for Ramesh Ferris during his visit in March.
March	Polio Australia participated in the House of Representatives Standing Committee for Health and Ageing Roundtable discussion into the needs of people living with the Late Effects of Polio / Post-Polio Syndrome. Produced and distributed Autumn Edition of "Polio Oz News".
April	Conducted Polio Health and Wellness Retreat on the Sunshine Coast, Queensland, for 73 participants.
May	Guided project work being done by two University of SA physiotherapy students for the 2013 Health and Wellness Retreat in South Australia.
June 2012	Release of the "Discussion Paper On the Late Effects of Polio/Post-Polio Syndrome". Produced and distributed Winter Edition of "Polio Oz News".

# Pictorial highlights



Roundtable Discussion in March 2012



#### Daily Danish Doings - Mary-ann Liethof's Copenhagen Blog

Polio Australia's National Program Manager will be blogging and uploading photographs here on a daily basis to bring readers up to date with her attendance at the **European Conference: Post-Polio Syndrome – A Challenge of Today** and the outcome from meetings she has arranged while in Copenhagen.







Session participants at Polio Health and Wellness Retreat, Qld, in April 2012



Ramesh Ferris talking to staff at GlaxoSmithKline in March 2012



# Presidents Report

## by Gillian Thomas

Even a casual look through this Annual Report will reveal just how much has been achieved for our nation's polio survivors by Polio Australia over the last twelve months. Readers unfamiliar with Polio Australia's operations may be surprised to learn that these achievements derive from the hard work of one person, our sole staff member and National Program Mary-ann Liethof, albeit Manage, supported by volunteers on the Management Committee, on the Clinical Advisory Group, in our Kew Office, and further afield. Many of Polio Australia's volunteers are polio survivors who are themselves experiencing the debilitating late effects of the disease. All our volunteers live otherwise busy lives yet collectively they still find the time to pour thousands of hours of effort into our organisation and its work. Without Maryann's drive, energy and passion behind us, however, we would certainly not have achieved as much as we have with the limited resources at our disposal and I publicly acknowledge here her efforts over the past year.

We cannot rest on our laurels while there is obviously still so much to do, and we are keenly aware of the need to finance the employment of staff on a secure, long-term basis to ensure our programs continue. In the year ahead we will again seek funding for additional staff to support Mary-ann as she progresses the implementation of our Strategic Plan. Our Canberra lobbying activities led by Dr John Tierney are succeeding wonderfully in raising the profile of both Polio Australia and this country's many tens of thousands of polio survivors. To date, though, this heightened profile and the growing awareness of the unique needs of polio survivors have not resulted in any Federal Government financing at all, let alone stable, ongoing funding for our operations.

Until sufficient and secure financing is available to Polio Australia, what might be possible to achieve can never be fully realised. It is important to understand that unlike the range of consumer-based and other organisations which represent the interests of many health

conditions and disabilities nationally, Polio Australia is the "only game in town". We are not competing with other bodies for a piece of the Federal Government's "polio pie" – there are no other national polio organisations, and such a pie simply does not exist. We instead must compete for a piece of the overall "health/disability pie" in an environment where generic, rather than specialist, services are favoured and those organisations and conditions already receiving funding often appear to have the upper hand. Polio survivors need and deserve nationally consistent specialist services and Polio Australia will continue to battle until we achieve this.

While we are continuing to actively pursue Federal Government funding, at the end of the reporting period we were also about to embark on a financing consultancy aimed at identifying and bringing on board passionate and committed individuals and organisations with an interest in polio to assist us to build our capacity over the ensuing twelve months.

In the year ahead we are also looking forward to the development and launch of an online resource for health professionals "The Late Effects of Polio: Introduction to Clinical Practice"; our "We're Still Here!" national Polio Awareness Campaign; and our fourth Polio Health and Wellness Retreat, this time in South Australia.



# National Program Manager's Report

## by Mary-ann Liethof

People often ask me if I, or anyone in my family, had polio. When I answer "no", the next question is invariably "So what's your interest in working with polio survivors?".

As a Community Development Worker, I have worked with many different types of community groups over the years, spanning both health and disability. I consider 2004 to be a fortunate year for me when I applied for and was successful in securing a job as Polio Community Officer with Polio Network Victoria, (a service of Independence Australia). During the 5 years I was working with the 15 Post Polio Support Groups, and other members of the post-polio community, I went from knowing virtually nothing about polio and its late effects, to learning quite a bit indeed.

But I would have to say that the most important thing I have learned relates to the collective 'nature' of Australia's polio survivors, most of whom share a similar history stemming from the epidemics of last century, prior to vaccination. Many of the people I meet have developed a keen sense of independence and resilience, and in spite of needing increasing assistance as the late effects of polio kick in, these veterans are required to continue their battle, not only with their bodies, but with a system that fails to recognise their plight.

This injustice is exactly what inspires my passion and provides me with the drive to work with the post-polio community. I believe I am incredibly lucky to have found a role and 'community' that I can really relate to and, where (unfortunately) so little is being done, I can't help but make some kind of positive contribution.

This year has been filled with activities that I could participate in and share, not only with polio survivors and their families, but also with a range of health professionals, who now know much more about the late effects of polio!

The European Conference on Post-Polio Syndrome in Copenhagen was a fantastic experience. I learned more about new research being done in Europe, networked with a number of very knowledgeable people, and presented on our Polio Health and Wellness Retreats. The Retreat



The European Conference on Post-Polio Syndrome in Copenhagen

concept attracted quite a bit of interest. This Conference also inspired some thought about hosting a future Conference in Australia, especially for the Asia/Pacific region - funds forthcoming, of course.

A highlight insofar as recognition is concerned, is participating in the Roundtable Discussion which resulted in three key Recommendations, all of which require the involvement of Polio Australia. Unfortunately, there has been no financial commitment to follow-up and actually realise these Recommendations. It should be noted that the other members at the Roundtable were:

## • Dr Stephen de Graaff

Rehabilitation Specialist and Director of Pain Services, Epworth Rehabilitation

#### Arthur Dobson

Vice President, Polio Australia, and Secretary, Post Polio Network-Tasmania

#### Blaise Doran

Physiotherapist and Co-ordinator of Polio Services Victoria

## Brett Howard

Committee of Management Member, Polio Australia, and President, Polio SA

## • Dr Margaret Peel

Committee of Management Member, Polio Australia, and Secretary, Brisbane Post Polio Support Group

#### • Elizabeth Telford

President, Post Polio Victoria

#### • Gillian Thomas

President of both Polio Australia and Polio NSW

## • Dr John Tierney

National Patron, Polio Australia

In the forthcoming year, I very much look forward to fruit being yielded from all the passion-fueled time and labour which Gillian, I and Polio Australia's Committee of Management have been investing!

## Our supporters and friends



#### **Balnaves Foundation**

3 years funding for full-time National Program Manager (Jan 2011 to Dec 2013)



## GlaxoSmithKline Australia

- Financial contributor to the 2012 Late Effects of Polio Self-Management Residential Program (Polio Health and Wellness Retreat)
- Financial contributor towards Late Effects of Polio education events
- In-kind contribution to the 2011 Polio Awareness Month media campaign

## The Marian and EH Flack Trust

Financial contributor to the 2012 Late Effects of Polio Self-Management Residential Program (Polio Health and Wellness Retreat)

## **Jill Pickering**

Personal donations towards the cost of operating expenses for 2011 and 2012

## **Dr John Tierney OAM**

Pro bono Federal Government lobbying from 2008 – ongoing

## **Audrey Clarke**

Donated money raised in Sydney's City2Surf fun-run in 2011

## **General Donations**

- Barbara Burnett
- Rohan Clark
- Andrew Clarke
- Ross Clarke
- Sarah Collins
- Duncan Conor
- Sarah Croft
- Margaret Cutcliffe
- Ruth Harrower

- Michelle Itzstein
- David Miller
- Veronica Schmidt
- Heather & David Shirley
- Joy Shore
- Gwen Skinner
- Liz Telford
- Fay Wheeler
- Matthew Woodland

## 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

#### **Genuine Print**

Genine Callahan provided pro bono production of business cards, brochures and Polio Awareness Month Posters in 2011 Matt Freer provided pro bono graphic design of website banner in 2011

## Rob Foster (UK) and Michael Simpson (USA)

Pro bono assistance with website in 2011 and 2012

## **Our Parliamentary Patrons**

- The Hon Mark Coulton MP
- The Hon Jill Hall MP
- The Hon Greg Hunt MP
- The Hon Catherine King MP









## The Hon Kim C Beazley AC

Australia's Ambassador to the United States of America and polio survivor

## **Clinical Advisory Group**

- Professor Robert Booy NSW
- Anne Duncan Vic
- Dr Stephen de Graaff Vic
- (Jega) Gnanaletchumy Jegasothy WA
- Phil Ladlow Tas
- Natasha Layton Vic
- Melissa McConaghy NSW
- Dr Peter Nolan QLD
- Darren Pereira Vic and NSW
- Dr Nigel Quadros SA
- Dr Mary Westbrook NSW

# Special thank you

In addition to those mentioned below, the nature of not-for-profit charities is that there are numerous people and organisations quietly providing support in many, many ways, and we sincerely thank each and every one of you for your contribution.

## **Volunteers**



**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, Polio NSW 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.

We couldn't do it without you!

We want to thank the Australian National University's Associate Professor David Harley and Masters Student, Bhaval Chandaria (far right), for meeting with Polio members of Australia to discuss a into the study incidence of polio in Bhaval Australia. produced a Report entitled "Poliomyelitis Survivors in Australia 2012" which is yet to be released.



## Our Social Network 'Champions'





Ella Gaffney (left) from Mudgee in New South Wales, and Lyn Glover (right) from the Gold Coast in Queensland have been regular contributors to Polio Australia's Facebook and Twitter pages, so we thought we'd make it official and appoint these two social butterflies as our social network 'Champions'. Ella and Lyn have been busy keeping Polio Australia's Twitter followers and Facebook visitors up-to-date with the latest news, as well as whatever snippets they find of interest which they share with our wider social network.

Thanks Lyn and Ella

— keep up the good work!

Lee O'Connell, Physiotherapist at MS Australia and Lecturer at University of SA, recruited and supervised fourth year Physiotherapy students, Vivienne



Maxwell and Alex Daniel for their project which surveyed the needs of Polio SA members in relation to the 2013 Polio Health and Wellness Retreat being held in Adelaide. They also explored possible venues, session presenters, and funding sources, resulting in the production of a substantial report. A great example of the future of our allied health therapists!