

Polio Network Victoria

Polio Perspectives

Vol 21 No 4 Summer 2009



Health and Wellness 'Try Day'

by Mary-ann Liethof

This year's Polio Day proved to be very popular with the 150 people who attended Darebin Arts & Entertainment Centre in Preston on 12th October.

After the morning's key note speakers - Fran Henke, Liz Telford and Shirley Glance - shared their experiences of "Living with Polio in the 21st Century" Wellness Retreat and I gave an overview of the Conference, the Body, Mind and Spirit of 'Wellness' was covered through a variety of interactive 'Try Activities' which included:

- Pain: Cause & Management – jointly facilitated by IA's psychologist, Dr Andrew Sinclair, and Epworth Rehab's Director of Pain Services, Dr Stephen De graaff;
- Writing Your Own Story facilitated by Katherine Ross;
- Seated Yoga & Meditation by Trish Jones, Chiro Yoga
- Exercise Options by Simon Mathieson, Co-ordinator of Polio Services Victoria (PSV);
- Learning to play Boccia with Bocce Victoria;
- Exploring Mobility Aids & Equipment with Mobility Plus;
- Maximising Independence with PSV's OT, Margaret Petkoff and Orthotist, Stephen Hughes;

- Introduction to the Internet with John Wade;
- and Mini Seated Massage Sessions with Kangan-Batman TAFE's Myotherapy students

Feedback from the day included comments like:

- "Excellent venue and organisation."
- "Easy to manage day."
- "I was able to get information about a new orthotic – it had some new designs."
- "It was wonderful to spend the day with people who had also had polio – big family!"
- "Good atmosphere, lively, positive, affordable."
- "A great day, and I don't feel so alone anymore. Good job!"
- From Northern Region's Post Polio Support Group newsletter: "Those who attended report that the day was informative and had items to interest the range of members from the various support groups. A festive highlight was the prizes section, with some substantial goodies going to some lucky winners. For so many the day offers a unique opportunity to catch up with old friends sharing that special bond of being – polio survivors!"

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Polio Network Victoria
Satisfaction Survey



A fitting farewell
June Middleton



Pain management
become an 'expert'



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is published quarterly by
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Peter Willcocks – 9578 5953

PAC MEETING DATES 2009

- | | |
|---------------|----------------|
| • February 26 | • July 30 |
| • March 26 | • August 27 |
| • April 30 | • September 24 |
| • May 28 | • October 29 |
| • June 25 | • November 26 |

USEFUL PHONE NUMBERS

Polio Services Victoria – 9288 3845

Breakdown Service (RACV) – 131 111

Carers Association – 1800 242 636

Centrelink, Disability – 132 717

Centrelink, Aged – 132 300

Council of the Ageing (COTA)

– 1300 135 090

Disabled Motorists (Vic) – 9386 0413

Emergency AH Service – 1800 059 059

Emergency Wheelchair and

Scooter – 9362 6111

Independent Living Centre

– 1800 686 533

Melbourne Mobility Centre

– 1800 735 266

TADVIC – 9853 8655

Victorian Aids and

Equipment Program

– 1800 783 783

Polio Perspectives welcomes articles of interest and reserves the right to edit or reject submissions as it sees fit. Published articles do not necessarily reflect the policies of the organisation. Any information in Polio Perspectives is not intended to be a substitute for professional medical advice.



From the Editor

editor Mary-ann Liethof

This is not only my last newsletter for the year, but the last Polio Perspectives I will be editing for Polio Network Victoria (PNV). If all goes according to plan, my final working day will be Friday 11 December 2009.

I have accepted a 3 day a week position as Coordinator of Peer Support Facilitators with Council of the Ageing (COTA) commencing Thursday 3 December. Of more relevance to the polio community, is that I will be taking up 2 days pw as the National Project Manager for Polio Australia (PA) in January 2010. This follows a small philanthropic grant and a generous donation from one of the network's members, for which we are most grateful.

Although I have been part of a small delegation from PA's Committee of Management lobbying politicians in Canberra for funding, our success in this area dependent on Federal government budget planning. As such, financial backing is still unlikely to come through for some time. However, with this small grant, I can commence the task of setting up an office, continue to identify opportunities and write funding submissions for the numerous projects we have in mind for PA, and co-ordinate the NSW Wellness Retreat in April (see page 11 for details). If required, my email contact at PA is: mary-ann@polioaustralia.org.au

I would like to thank you all for the opportunity to develop my skills and knowledge

during my time with PNV. Working with the post polio community has become more of a vocation for me and I believe the uniqueness of Independence Australia's (IA) service is of paramount importance to PNV's current and future service users. My departure will no doubt provide IA with an opportunity to review the role and functions of the position but it is my fervent hope that the service provided to Victoria's polio survivors continues to be of a high standard.

In the short term, PNV's volunteer, Jill Pickering, will be in the office once a week to check on PNV's telephone and email messages. Jill will be kept advised about relevant IA decisions regarding PNV by Linda Morton, IA's Manager-Service Access. There is also a list of "Useful Phone Numbers" – including members of the Polio Advisory Committee – to the left of this column which should be helpful. And remember, the people best placed to advise you about local services are the Polio Support Groups – contact details on Page 12.

Of course, my role with PA ensures I have continued contact with PNV and IA (being a signatory to PA's Memorandum of Understanding and represented on PA's Committee of Management) and I look forward to building harmonious and effective relationships that will benefit the polio community across Australia.

Other activities covered in this newsletter include feedback from Polio Day and the Services Satisfaction Survey (2009) which was completed by 194 people, and the launch of Knox-Yarra Ranges book "The Calliper Kids".

Wishing you all the best of Seasons Greetings, and many thanks for the memories. •

– Mary-ann Liethof

Year's end is neither an end nor a beginning but a going on, with all the wisdom that experience can instill in us.

Hal Borland

Polio Network Victoria

Service Satisfaction Survey (2009)

Many thanks to all 194 (Victorian) people who completed and sent back the Service Satisfaction Survey, as well as PNV's hard working volunteer, Jill Pickering, for putting it all together. I hope this information will be useful as a guide for the next Coordinator of Polio Network Victoria. A full report will be produced and sent to all Victorian Polio Support Groups and uploaded onto PNV's website in due course.

There are some very interesting polar opinions about 'useful' vs 'not useful' items in the Polio Perspectives magazine, as well PNV's other services. I suppose this all supports the old saying by poet, John Lydgate:

“ You can please some of the people all of the time and all of the people some of the time, but you can't please all of the people all of the time...

The following data is a summary of your feedback. Please note that some questions were left unanswered and some questions could indicate more than one response, which impacts on certain percentage totals.

General Information



- Dates of birth ranged between 1919 and 1967 and nearly everyone became infected with the polio virus between 1926 and 1968
- 82% of respondents were born in Australia
- 8% were born in England, Scotland or Ireland
- 9% from a range of other countries such as China, Germany, Italy, Sri-Lanka, India, Malaysia, Holland, New Zealand, North Africa, Peru, South Africa, Vanuatu, and Vietnam
- 65% of respondents were female

Initial Polio Infection

- 90% of respondents were diagnosed with polio at initial infection
- 60% had lower limb paralysis
- 35% upper arm paralysis
- 15% required respiratory support

Recovery Following Rehabilitation

- 53% residual weakness requiring use of mobility aids/equipment
- 38% some residual weakness but no mobility aids/equipment required
- 7% required personal support for daily activities
- 8% recovered full mobility
- 6% required a wheelchair
- 1% requiring respiratory equipment

Family Response to Polio

- 36% said their polio was openly discussed
- 23% said polio was only discussed when necessary
- 22% said polio was never discussed
- 61% said family was supportive
- 7% said family was not supportive

Living with Late Effects of Polio (LEOP) or Post Polio Syndrome (PPS)

- 30% have not been diagnosed with PPS
- 70% have been diagnosed with PPS
- 93% people believe they are now living with symptoms of LEOP
- 28% have new muscle weakness but no aids required
- 55% use mobility aids/equipment
- 20% use a scooter
- 18% use a wheelchair
- 5% require respiratory equipment
- 41% need house-keeping help
- 18% need personal support for daily activities

Years from Initial Polio Infection to New Symptoms (LEOP/PPS)

- 36% experienced PPS 40-50 years after initial infection
- 24% 30-40 years
- 13% 50-60 years
- 9% 20-30 years
- 6% 15-20 years
- 4% over 60 years

Polio Network Victoria (PNV)

- 39% heard of PNV from Polio Services Victoria (PSV)
- 29% Polio Support Groups
- 17% newspaper articles
- 14% other polio survivors
- 13% friends
- 11% PNV's Community Information Sessions
- 10% other health providers
- 8% Polio Day
- 7% family
- 7% internet / PNV website
- 7% radio
- 7% other
- 3% interstate Polio Networks
- 0% from Service Club talks

Use of Email/Internet to Access Information

- 50% No
- 48% Yes

Of those who used the internet to access PNV services:

- 35% found the PNV website significantly useful
- 28% moderately useful

PNV Services Used

- 84% receive "Polio Perspectives" (assume 100% receive PP as this was how survey was distributed)
- 54% Polio Support Group member
- 51% attended a Polio Day
- 42% accessed information by phone
- 36% attended a Community Information Session
- 30% bought or borrowed resources, i.e. book / film
- 24% used information brochures for Health Professionals
- 21% accessed information on PNV website
- 18% accessed information via PNV email
- 6% other services

Polio Network Victoria

Service Satisfaction Survey (2009)

Degree to which PNV information helped decisions on how to better manage symptoms

- 45% significantly
- 36% moderately
- 11% not at all

Degree to which PNV kept people up to date with PPS information

- 67% significantly
- 25% moderately
- 1.5% not at all

Ways in which PNV has helped people access health services

- 66% via information in Polio Perspectives
- 36% by providing contact details to follow up
- 28% via brochures supplied by PNV

Considered effectiveness of PNV Community Information Sessions to reach wider polio community

- 55% effective
- 33% unsure
- 2% not at all

Considered effectiveness of talks at Service Clubs and schools to reach wider polio community

- 66% effective
- 25% unsure
- 7% not at all

Considered usefulness of information provided in Polio Perspectives

- 57% significantly
- 31% moderately
- 7% not at all
- 56% listed items found **most useful** in Polio Perspectives (as follows)
A compilation of the most recurring comments are:
 - I like the magazine the way it is. I find it all useful
 - International experience regarding treatment
 - Articles on research/new scientific data/future directions
 - World Wide Eradication of Polio figures

- Personal stories; to read people's stories is very inspiring
- How to manage PPS symptoms/ different ways to cope
- Health issues, i.e. articles on symptoms and treatments that work; practical articles on improving lifestyle; articles by polio specialists; Bulbar polio; restless leg syndrome; fatigue; pain management; diet; exercise; surgery
- Questions & Answers
- Noticeboard
- Items/articles which give information I can supply to my GP

- 14% listed items **least useful** in Polio Perspectives (as follows)

- A compilation of these comments are:
- Very technical/scientific info
 - Alternative approaches to treatment
 - Personal stories polio sufferers – depressing
 - Articles on drugs or alternative medicines
 - Descriptions of overseas trips – useless
 - International polio warnings and overseas polio numbers count

Usefulness of the Polio Day Forum for:

- Learning about PPS developments
 - 54% significantly
 - 35% moderately
 - 8% not at all
- Learning about available health/welfare services
 - 50% significantly
 - 37% moderately
 - 9% not at all
- Catching up with friends
 - 38% significantly
 - 29% moderately
 - 27% not at all
- Meeting other polio survivors
 - 52% significantly
 - 29% moderately
 - 10% not at all

DVD's available through PNV, Polio Support Groups and www.youtube.com/PolioNetworkVictoria

- 86% viewed PPS: The Australian Experience
- 56% viewed PPS: Shades of Grey
- 53% felt these films significantly help people with PPS
- 39% moderately
- 3% not at all

If a Polio Support Group member, how useful has it been for:

- Social contact/Meeting others with PPS?
 - 53% significantly
 - 31% moderately
 - 16% not at all
- Exchanging ideas to manage PPS?
 - 51% significantly
 - 33% moderately
 - 12% not at all
- Contributing ideas to others?
 - 43% significantly
 - 30% moderately
 - 18% not at all
- Reducing feelings of isolation?
 - 48% significantly
 - 18% not at all
 - 12% moderately
- Being empowered to contribute other ways?
 - 37% significantly
 - 23% moderately
 - 22% not at all
- 26% provided additional comments regarding 'empowerment' (as follows)
A compilation of these comments are:
 - I have spoken to Year 12 students.
 - As a PAC member I have gained confidence in myself to reignite my involvement in aged care (MS Community Visitors program). I visit other support group members who for reasons of health are unable to attend monthly support group meetings. All this is possible as I am able to gain support and guidance from my peer group and Mary-ann at the PNV and other PAC committee members.
 - Liaising with disability unit at university of Melbourne and participating there with health study for chronic and degenerative conditions in an ageing population.
 - Addressed two school groups using the presentation: *Polio - Forgotten but not gone*.
 - Giving me confidence in taking up positions in other clubs, realising Polio doesn't need to stop me.
 - Providing brochures to community centres and doctors, speaking to clubs and nursing staff. Talking to health professionals and making people aware of what's happening.
 - I try to spread the word about vaccination.
 - Have more confidence in presenting myself. I show polio information to doctors, physios, dentists, friends and family.
 - Encouraging others to speak up.
 - I work in a hospital and the patients see that I walk differently and are eager to learn more about PPS.

Degree to which PNV Information helped people understand symptoms



- 64% significantly
- 27% moderately
- 5% not at all

General comments



How has PNV assisted to improve quality of life?

- 71% provided comments (as follows)
A compilation of the most recurring comments are:
 - It gave me a support person at the start leading to assertiveness in face of unanimous family condemnation. Best source of information about PPS from little hints to titles and reviews at books on Polio. Reliable support from Polio Community Officer.
 - It made me realise I was not going mad as the doctors could not find anything to explain why I was feeling so bad. PNV Community Officer spent ages on the phone talking to me and gave me the numbers of doctors who would understand.
 - Once I learned about PPS and how it was affecting me I was able to find suitable medical assistance e.g. doctor, chiro and physio and control the tiredness and pain also retired sooner than I had planned and this helped enormously.
 - PNV has enabled me to deal with PPS constructively. It is not just the information gained, but the many opportunities it provides to understand my experience through participation with others around our shared issues of growing up with polio.
 - Knowledge and wisdom is powerful and PNV has been a huge blessing to me! Now that I have learned to really pace myself, my quality of life has improved immensely.
 - PNV has made me aware of community resources e.g. orthotists and physios so that if I need support I will know of their availability.
 - I found it difficult to relate to polio in my life because I was never encouraged to accept it as a part of my life. In coming to terms with this and PPS, PNV has given me the information and support to help with this journey. Helped me recognise what was occurring to me when I had put the suffering of polio behind me for so long.
 - (1) I know there is a reason for my pain and weakness and it has a name. (2) I know I must rest more and not fight it. (3) I learn more as I read Polio Perspectives.
 - PNV has helped me in many ways. It has taught me to accept post polio and adjust to my physical problems as they occur. Don't sit in the dark but do something about the problem. Don't be too proud to accept help or

- use a scooter or wheelchair.
- Not at all. The money to produce the magazine would be a great value to me if you would help me with batteries for my electric chair.
- I think I am more aware of what could be PPS and not just ageing (or menopause). Being aware of the 'Pros and Cons' of taking certain medications has been of great importance, i.e. muscle relaxants.
- I had not heard of PPS or the late effects of polio until I met others in PNV. PNV created an awareness of why I was rapidly declining in physical prowess. Now I am aware and have a greater understanding – relieving my stress levels considerably.
- Knowing that I am not alone, after feeling like polio was an 'unclean' word over 50 years. It was never mentioned in my family. Given me skills to improve things.
- Gives me information for my own benefit and some I can share with health care providers to enable them to understand PPS better. Information has been a great help to my GP
- Very moderate impact. It seems it's still mostly up to me to handle the current situation.
- It provides access to management strategies via telephone, brochures, reading material, Polio Perspectives and constantly access a wide range of PPS experienced folk. I would still be struggling with PPS without PNV.

General comments

- 40% provided comments (as follows)
A compilation of the most recurring comments are:
 - Polio Support Groups are great for meeting up with others and sharing new ideas and to have people who understand what you are on about is just awesome. Thankyou for being there.
 - Over the years Polio Services has been a great help to me, especially coming to understand my weakness and disability.
 - My physio told me lately that of all her clients, polio people are the most positive. I took that as a compliment.
 - Managing PPS is much more challenging than living with the effects from the initial infection!
 - PNV should promote better treatment and attract more funding for research.
 - I think the survey fails to give opportunity to point out how important the Polio Community

• 40% provided comments

A compilation of the most recurring comments are:

- Polio Support Groups are great for meeting up with others and sharing new ideas and to have people who understand what you are on about is just awesome. Thankyou for being there.

- Officer role has been and continues to be, in giving each group a strong, reliable, sensitive support to go to when their own resources are wearing thin.
- Had a breakdown 2 years ago due to attitude of my GP. Now have a wonderful GP, supportive group, Polio Perspectives and PNV – Independence Australia does a great job in the community.
- An excellent service to survivors of polio in Australia. Assists Polio Services Victoria regularly and to an excellent standard. (PSV *Physio comments*).
- PNV has been helpful in providing a framework for help with splinting, physio, and general information on assistance that is available.
- I was not able to get a diagnosis until I made contact with PNV and was given a PPS 'specialist' to visit. I cried through most of the assessment as I was so relieved to find someone who understood all I was going through, and knew how to provide positive recommendations to provide comprehensive report to my GP and prescribe a full length calliper for my right leg. This changed my life. I have moved forward since then and still keep in close contact with PNV services to learn of any recent developments in understanding how to best manage PPS.

Numbers using other services offered by Independence Australia

- 14% Yes
- 64% No

Services of interest in the future

- 27% General disability information
- 23% Health Solutions
- 18% In-home support
- 13% Counselling service
- 11% Personal care
- 10% Respite accommodation
- 6% Case management

Noticeboard

Erratum

by Mary-ann Liethof

An error appeared on Page 4 of the Spring 09 edition of Polio Perspectives in the article “Argentina Issues Polio Warning”. The third paragraph referred to “A 15-month toddler [who] was diagnosed with acute flaccid paralysis and gammaglobulinemia . . .”.

Two eminent doctors have since pointed out the following fact: *“Gammaglobulinemia’ should be ‘agammaglobulinemia’. Normal people have gammaglobulin in their blood – this is one of the protective proteins in our blood. ‘Emia’ or in Australia ‘aemia’, just means in the blood. When ‘a’ is in front of a word, it means ‘absent’. The reason the child became ill was because he did not have any gammaglobulin to protect him.”*

Interestingly, this error was actually made in the original report; although it was pointed out that it should have been picked up and amended prior to being reproduced in PP. I apologise for any misunderstanding this omission may have caused.

Disability support takes a large step forward

Media Release – 24 November 2009

NDS strongly welcomes the Prime Minister’s announcement of an inquiry into a national long-term care and support scheme for people with disability.

A no-fault social insurance scheme is needed to replace the current lottery in which many Australians with disability cannot get the support services they need. This problem will intensify as demand for services rises, unless there is systemic reform and increased investment in service provision.

The Productivity Commission will conduct an 18-month inquiry into the costs, benefits and feasibility of a national long-term care and support scheme for people with disability. It will be assisted by an Independent Panel which will ensure that the views of the disability sector are heard.

The Prime Minister described the prospect of such a scheme as “a historic social reform” transforming the way in which disability support services are delivered, funded and administered. Importantly, the inquiry

will consider the complex interactions with aged care, income support and state-based compensation systems.

Many Australians who are born with a disability or acquire a disability through accident or illness face deep uncertainty about whether they’ll get the support services they require. A national long-term care and support scheme would relieve people with disability, family carers and service providers of much frustration and anxiety.

It would be critical in delivering on the Government’s commitment to social inclusion and its ratification of the United Nations Convention on the Rights of Persons with Disabilities.

NDS congratulates the Australian Government on taking this important step and looks forward to having significant input to the Productivity Commission’s inquiry.

Contact: Dr Ken Baker, Chief Executive, National Disability Services, Ph: 02 6283 3200

PolioToday.org

PolioToday.org is the place where polio survivors meet on the web. We are an online community of polio survivors that supports each other, shares history, and educates ourselves and others about living with post-polio syndrome. We invite you to:

- share your unique story with video or text
- learn more about PPS from experts in the field
- watch videos and read stories about fellow polio survivors
- join and create PPS-related discussions with fellow polio survivors

Be a part of this global group and help raise awareness of PPS.

PolioToday.org is published by the Salk Institute for Biological Studies. This website is designed to raise awareness of post-polio syndrome and to be a resource for polio survivors. Dr. Jonas Salk, who developed the first safe and effective polio vaccine, founded the Salk Institute in 1960.



Access Travel Pass

The Access Travel Pass has

been developed for people with a significant permanent disability who travel independently on Victoria’s public transport network and can demonstrate that due to their disability they cannot use ticketing systems.

The Access Travel Pass entitles you to free travel on Victoria’s public transport network, i.e.:

- Melbourne’s metropolitan trains, trams and buses
- V/Line ticketed services (including V/Line Link services within Victoria)
- Urban bus services in regional cities
- Regional services that have a contract or service agreement with the Department of Transport

Free travel passes do not necessarily apply to, and should not be used for CountryLink, Great Southern Railway, airport services and tourist railways. The pass holder should check with the relevant operator before booking or travelling.

To be eligible for the Access Travel Pass you must:

- have a significant permanent disability
- be a permanent Victorian resident
- be able to travel independently on Victoria’s public transport network (without any assistance from a carer or companion)
- be unable to touch on or touch off your myki independently

To apply for an Access Travel Pass you will need to go through an application process to determine eligibility.

Contacts for further information:

Metlink Central Pass Office
Telephone: (03) 9619 1159

Visit Staff: At Southern Cross Station located between Bourke and Little Bourke streets near the bus interchanges.

Website: metlinkmelbourne.com.au
Email: central.passoffice@metlinkmelbourne.com.au

The Role of Vitamin D in Preserving Muscle Strength in Seniors

Source: Tufts University – July 16, 2002
Reviewed: July 16, 2004

The reduced muscle mass and diminished strength that commonly occur in the elderly can have potentially serious consequences, including limited ability to perform activities of daily living, or, worse, falls and debilitating fractures. Helping patients preserve muscle strength may greatly improve their quality of life.

Because muscle weakness is associated with vitamin D deficiency, researchers from the Netherlands reviewed the literature on the relationship between vitamin D deficiency, muscle function, and falls in seniors to explore whether vitamin D

supplementation can improve muscle strength and functional ability. Their review is published in the *American Journal of Clinical Nutrition*.

Supplementation may improve muscle function

Studies have found that seniors with low levels of vitamin D have reduced leg extension power, handgrip strength, ability to climb stairs, and ability to walk distances. Some research shows that supplementation to correct a deficiency leads to improvements in knee extension strength, walking distance, and functional abilities.

Can vitamin D supplementation prevent falls?

On average, one-third of all seniors experience at least one fall per year. Vitamin D deficiency apparently affects the muscles of the lower limbs that are essential for balance and walking. The authors say that there is a correlation between serum vitamin D concentrations and falls, but whether supplementation can reverse the trend remains unclear.

Preserving muscle strength

While the potential role of vitamin D supplementation in preventing falls in seniors remains to be elucidated, supplementation may help preserve muscle strength and functional ability. Because of its critical role in the absorption of calcium, it is of particular importance for seniors with limited exposure to sunlight and inadequate dietary intake. Since vitamin D is toxic in high doses, patients should be advised to take only the recommended dose.

Source: Vitamin D deficiency, muscle function, and falls in elderly people. H. Janssen, M. Samson, H. Verhaar, et al., *Am J Clin Nutr*, 2002, vol. 75, pp. 611-615

Too hot, too cold: TIPS

Silk: Did you know that silk's good absorbency makes it comfortable to wear in warm weather and while active. And its low conductivity keeps warm air close to the skin during cold weather. – Wikipedia

An all-climate fabric, silk is warm and cozy in winter and comfortably cool when temperatures rise. Its natural temperature-regulating properties give silk this paradoxical ability to cool and warm simultaneously. Silk garments can outperform other fabrics in both summer and winter. Silk worn as a second layer warms without being bulky.

Super Hot Hands Portable Hand and Body Warmers: Up to 18 Hours of Heat. Providing you with warmth and the freedom to endure colder climates, these portable hand and body warmers are small disposable packets used to keep your extremities warm and to assist with thermal or insulated clothing. Used by pro athletes, outdoor enthusiasts, skiers, construction workers and those who want safe, convenient concentrated warmth.

Easy to use, simply remove the pouch from outer package, shake to activate contents and within 15 minutes you have an environmentally safe, comfortable heating pouch as warm as 52 – 62°C. For optimal efficiency place the hand and body warmers in gloves, mittens or pockets. Made from natural ingredients: iron powder, water, salt, charcoal and vermiculite.

HeatMax Toastie Toes Foot Warmer: Up to 6 Hours of Heat. Comfortable heating pouch as warm as 38 – 40°C. For optimal efficiency place the foot warmers in your shoe/boot between the bottom of your sock and the insole of your shoe/boot.

It is worth checking with your GP as these warmers are not recommended for people with diabetes. For stockists, try ski, outdoor, adventure, camping, army surplus stores. Some Snowgum stores have Grabber Mycoal hand and toe warmers @ \$5 each pair. Some chemists may also stock similar products. Check on line – www.warmers.com

Heat stress – preventing heat stroke

Heat stress occurs when the body becomes dehydrated and is unable to cool itself enough to maintain a healthy temperature. If left untreated, this can lead to heat stroke, which is a life-threatening medical emergency. Prevention is the best way to avoid heat stroke. Anyone can suffer from heat stroke, but those most at risk are:

- People over 65 years, particularly those living alone or without air-conditioning
- Babies and young children
- Pregnant and nursing mothers
- People who are physically unwell, especially with heart disease or high blood pressure
- People on medications for mental illness

Heat stroke occurs when the core body temperature rises above 40.5°C and the body's internal systems start



to shut down. Normally, sweating helps to maintain a healthy body temperature by increasing heat loss through evaporation. When a person becomes dehydrated, they do not sweat as much, their blood becomes concentrated and organ functioning is impaired. Many organs in the body suffer tissue damage and the body temperature must be reduced quickly. Most people will have profound central nervous system changes such as delirium, coma and seizures. As well as effects on the nervous system, there can be liver, kidney, muscle and heart damage.

Heat stroke may appear similar to heat exhaustion, but the skin may be dry with no sweating and the person's mental condition worsens. They may stagger, appear confused, fit, collapse and become unconscious.

Heat stroke is a medical emergency. Every minute's delay in cooling the person increases the likelihood of permanent injury or death. Apply first aid and seek medical assistance immediately if you or someone you are with shows any sign of heat exhaustion or heat stroke. If someone you are with develops heat stroke:

- Call '000' for an ambulance.
- Get the person to a cool shady area and lay them down.
- Remove clothing and wet skin with water or wrap in wet cloths, fanning continuously.
- Position an unconscious person on their side and clear their airway.
- Monitor the body temperature and continue cooling efforts until the body temperature drops below 38°C.
- Wait for the ambulance to urgently transport the person to hospital, where more intensive cooling and support can be given.
- If medical attention is delayed, seek further instructions from ambulance or hospital emergency staff.
- Nurse on Call Tel. 1300 60 60 24 – for expert health information and advice (24 hours, 7 days).

Source: Disability on Line www.hnb.dhs.vic.gov.au/dsonline/dsarticles.nsf

A fitting farewell to 'our June'

by Mary-ann Liethof



I last wrote about the inspirational June Middleton in the Autumn 09 edition of Polio Perspectives after visiting her and Angel (June's companion dog) at their Thornbury home. This was just prior to June's 83rd birthday and 60th anniversary of contracting polio. At the time, I wrote that June was "as chipper as ever."

In the weeks leading up to Polio Day 09, I rang June to ask if she would be joining us on the day, as she had done in the past. At the time, June mentioned she had been battling a respiratory infection and regretted she wouldn't be able to attend.

On Friday 30 October, the very day I was due to fly out of Australia for two weeks, I learned that June had sadly succumbed. Unfortunately, I was unable to respond to her passing in any meaningful way, although many PNV members kept me informed about the various reports that appeared in the media. I thought the following report written by Robyn Riley summed up what most of us felt about 'our June' and reflected a life well lived.

In memory of June Middleton

by Robyn Riley

Sunday, November 01, 2009

Source: heraldsun.com.au

MELBOURNE woman June Middleton was a special Australian not because she was fantastically talented or because she was driven to succeed, no June Middleton was an inspiration because she was just an ordinary person who fate placed in an extraordinary position and she battled on the best she could.

Ms Middleton personified the very best characteristics that this country boasts: the ability to look adversity in the eye and just give it your best shot. Never complain, never give in. For 60 years Ms Middleton didn't give in. She just got on with living the best she could.

In 1949, when she was an active 22-year-old who loved dancing and bushwalking and was preparing for her wedding day, Ms Middleton became a victim of the dreadful polio epidemic that terrified Australia.

In an interview she recalled that time. "I just felt as though I was getting a bad attack of flu. Sore throat, headaches, stiff neck. I thought I was all right. Battled it out. Went to work one day, expecting to go the next day and I couldn't get out of bed."

Back then there was no vaccine, no warning and often no hope. Polio eventually killed about 1000 Australians and crippled a further 10,000.

Ms Middleton almost died, in fact, doctors held little hope for her. She was placed in an iron lung, a mechanical device that could breathe for her and that is how she spent the remainder of her life.

Ms Middleton had every right to feel sorry for herself; to be angry that she

was imprisoned in an iron lung when she should have been walking down the aisle and starting a family. Her friends said she was not like that.

In an ABC interview in 2006, she was asked by reporter Mick Bunworth if she ever felt sorry for herself or questioned "why me?" "I don't," she told him as she prepared to celebrate her 80th birthday. "I guess that's one of those things that happen and you have to make the best of it."

Although she spent up to 21 hours a day in an iron lung, with the help of her many friends and Red Cross volunteers, Ms Middleton was able to go on outings and even annual holidays. Quite simply, she made the most of every moment.

One of the 120 guests who helped the Carlton football fan celebrate her birthday that year was Harry Newell. He told the ABC that for someone to be in hospital that long and have so many people coming to share her birthday was amazing.

"Cause they love her," he said. "Never once seen her in any sort of 'feel sorry for me' mood. She's just one of those special people." She was indeed.

Ms Middleton died peacefully on Friday morning at a Yooralla-supported residence in Melbourne.

In one of her last interviews she was asked about living with the legacy of polio.

“It was pretty devastating, but then you realise that things are not going to improve so you have to get your act together and... make the most of it and get on with what you've got instead of being miserable about things.”

We could all learn a lesson from June Middleton. •

Become your own 'expert' on Pain Management!

by Dr Andrew Sinclair – Independence Australia Psychologist



At the recent Polio day I was invited by Mary-ann to co-facilitate a workshop with Dr Stephen De graaff on Managing Chronic Pain. I enjoyed the workshop and the opportunity to discuss this complex issue with people living with the unique challenges associated with having had Polio at some point in their lives.

Our workshop was well attended with many participants asking a range of questions about the treatment and management of chronic pain. While many participants were interested in specific medical treatments, there were also many questions from participants for whom medical treatment had been exhausted. In most of the questions I answered, I encouraged participants to become their own 'expert' and seek out information and resources from a wide variety of sources.

This may seem overwhelming at first but when you put all this information together into a chronic pain management action plan, you are well on your way to reducing the impact of pain on your quality of life. Given the complexity of this task, I thought it would be useful to detail some ideas to get you started on developing your own chronic pain action plan.



There are a number of areas to research as you become an 'expert' on your pain. In seeking information, find your own answers to the following questions across these areas:

Physical management of pain

- What medical interventions are available?
 - Surgery
 - Medication
- How can exercise help me?
 - Stretching
 - Activities (e.g. gardening)
- What stress management techniques could I adopt?
 - Relaxation strategies
 - Deep breathing exercise

Psychological Management

- What attitudes and beliefs do I hold that may contribute to my experience of pain?
- Can assertiveness training help me to advocate for myself?
- What behavioural techniques could I adopt to assist in my action plan?

General Information

- How can I improve my sleep hygiene?
- How does my diet affect my pain?
- What support groups are available?

The main goals of pain management that a comprehensive action plan should address are:

- Get basic information about the best methods of controlling your pain
- Decrease level of pain experienced
- Decrease inappropriate use of medical interventions
- Work towards a return to full or partial functioning

Example of a Chronic Pain Action Plan:

GOAL 1:

Get **information** about best methods for controlling pain

- Set up appointment with my doctor to discuss my concerns
- Find out where I can learn stress management (bio-feedback, self-hypnosis)
- Look for support groups/pain management clinics

GOAL 2:

Decrease level of pain – **physical management**

- Start the exercise program right after morning shower
- Take the anti-inflammatory medication

GOAL 3:

Decrease level of pain – **relaxation training**

- Progressive muscular relaxation (twice a day)
- Self hypnosis (when pain intense)
- Mindfulness meditation

GOAL 4:

Decrease level of pain – **psychological management**

- Learn to handle my anger and frustration by confronting negative thoughts and remembering coping thoughts
- Learn to handle my anxiety by confronting any catastrophic thinking
- Learn to say 'No' or set limits

GOAL 5:

Get back to **partial functioning**

- Determine amount of time I can spend gardening before pain levels increase
- Schedule activities regularly

If you would like assistance to develop your own chronic pain action plan please feel free to contact me at Independence Australia's psychology service – Ph: 1300 704 456
Email: Andrew.Sinclair@independenceaustralia.com •

Health and Wellness 'Try Day'

continued from page 1

A warm Independence Australia welcome was made by the new Manager of Community Services, Michael Williams. Jill Burn, Chair of the Polio Advisory Committee, followed up with a welcome from the PAC.

Many thanks go to the additional funding which was provided by the City of Yarra, City of Moreland and City of Darebin Councils, and the Lions Club of Forest Hill who donated a 4-wheel electric scooter to raffle. This was won by the PAC Chair, Jill Burn. Those who stayed until the end of the day were also in the running for 16 fantastic door prizes.

"We're Still Here" is the apt title of the annual campaign being promoted by Post-Polio Health International (PHI) for raising awareness of the late effects of polio within communities around the world.

Our Polio Day is run in conjunction with PHI's campaign and we attracted the interest of a number of local newspapers who printed up stories of polio survivors in their area, as well as a few radio announcements on Magic1278 and one interview with 96.5innerfm's Friday Morning Magazine.

I was also offered the opportunity of doing an awareness raising 'theme day' by the manager of my Curves gym, Kerry. We decided to have a "Wear Orange for Polio Day" on Monday 12th October.

Notices were put up around the gym in the week leading up to the event and, as the women worked their way around the equipment, Kerry and her team got into quite a few discussions about how polio is still found in various parts of the world; the fact that we still need to immunise; and how polio survivors are now living with the late effects of polio. A great effort! •

Shirley Glance



Fran Henke



Liz Telford



Peter Willcocks, Member of the PAC and Co-Convener of the Bayside Polio Support Group made the following observations:

“For me Polio Day was about the phone call I got from Jack H after I got home. He thanked me for encouraging him to attend. Jack met Ron Bell who could walk tall with thanks to the Horton Stance Control and Jill Pickering who explained how to make wheel chair air travel easy. He had a great time and said he learned a lot.

The meeting began with our Shirley (Bayside Support Group Co-Convener), Fran & Liz reliving the challenges that they each overcame during their trip to Warm Springs for the 2009 Post-Polio Wellness Retreat and conference. It struck me how each of them learned about themselves and how they learned to accept help and use equipment. I got a bit teary-eyed hearing how exhausted they became and how, with dejection, they accepted wheelchairs. They felt crippled, horror memories of their polio youth returned. Slowly each of them gained self confidence, energy and relief. They then began to enjoy their freedom without exhaustion. Shirley brought the gift of freedom home with her and rolled through the National Gallery Victoria with her husband enjoying her company, not having to worry about her fatigue. What a great story.

I learned something about myself. The Myotherapy students from the Kangan-Batman TAFE gently massaged my neck and eased my shoulder. My neck was able to turn without restriction and eased the numb pain. The feeling may have only lasted 24 hours or so, but what a feeling. I feel uncomfortable being massaged, but boy was it worth the self imposed embarrassment.

I also attended an open discussion on pain presented by Dr Stephen De graaff (Director of Pain Services at Epworth Rehabilitation) and Dr Andrew Sinclair (Psychologist at Independence Australia). I was sorry that I was unable to attend the Simon Mathieson from Polio Services Victoria's Exercise Session, and I could hear the fun and laughter being had by people next door who were learning how to play Boccia.

I am sure all will have their own experiences from Polio Day but without doubt Post Polio Syndrome was confronted head on and we were reminded of how to enjoy life and move on.”



Curves: Wear Orange for Polio Day



Australia's own 'Wellness Retreat'

by Mary-ann Liethof

Even before we visited Warm Springs, Polio Australia and Post-Polio Network (NSW) Inc. were sending joint proposals to several philanthropic, government and corporate organisations to run our own Wellness Retreat.

The Post-Polio Network (NSW) was recently rewarded with \$10,000 from The Marian & E.H. Flack Trust which provides a good enough starting point to facilitate a 'pilot' Retreat in New South Wales next year.

If this is successful, Polio Australia eventually hopes to secure enough funding to run similar Retreats in each state.



Initial details for the Wellness Retreat are that it will be held from Thursday 15th to Sunday 18th April, 2010 at "St Joseph's Baulkham Hills". Baulkham Hills is only 30 minutes from Sydney CBD and St Joseph's offers extensive conference facilities which include:

- **Large auditorium seating over 100 – fully equipped with AV Technology**
- **10 meeting rooms, many fully equipped with AV Technology**
- **120 seat dining room**
- **guest lounges**
- **swimming pool**
- **art space**
- **library**

Guests can be accommodated in luxurious double, twin or single rooms with ensuite. A few specially designated disabled ensuited rooms are also available; the centre is easily accessible for the mobility impaired.

As this pilot Wellness Retreat is being run in New South Wales, it is anticipated that a large percentage of participants will be from that state. However, there will also be a limited number of places for people from other states who are willing to make



St Joseph's

the journey. Partners/carers are encouraged to attend. An early cost estimation is \$300.00 per person for most of the Wellness Retreat activities, 3 nights accommodation, and all meals.

We anticipate a number of polio-related health professionals will be in attendance including Dr Stephen De graaff (Medical Specialist), Darren Periera (Orthotist), a Physiotherapist, Occupational Therapist, Massage Therapist, and more. •

Details are still being prepared and all future information will be issued from Polio Australia.

If you would like to be sent more information as it becomes available, please complete the form and send it together with a stamped, self addressed envelope to:

**Wellness Retreat
Polio Australia
PO Box 888
Kensington
NSW 1465**



Polio Australia's Wellness Retreat 15 – 18 April, 2010



Please send me more information on the Wellness Retreat.

Name

.....

Address

.....

Postcode

.....

Phone/s

.....

Email

.....

Return to Wellness Retreat, Polio Australia, PO Box 888, Kensington NSW 1465
Please include a stamped, self addressed envelope.

Polio Support Group News

The Calliper Kids

After years of planning, creative fund raising, and much blood, sweat and tears, the Knox-Yarra Ranges Polio Support Group is ready to launch its book "The Calliper Kids – eleven life journeys of polio survivors" and everyone is invited!

This will also be the group's 10th birthday, so it's a double celebration. Details are as follows:

When: Thursday 11 February 2010 at 2.15pm

Where: Ferntree Fully Library, Burwood Highway, Ferntree Gully

RSVP: 18 December to Helen on Ph: 9758 9158
Email: monahan@melbpc.org.au

Wimmera Polio Support Group Calls it a Day

At a meeting held in Horsham on Saturday 5 September, Gordon Reynolds decided it was time for him to step away from the role of Convener. Gordon has been an excellent contact for the Polio Network and support person for the Wimmera Polio Support Group over the last 4 years – and longer. During the meeting, members decided not to continue meeting formally, although they might still get together socially from time to time. Gordon has offered to be a phone contact person for the area on Ph: 5382 7303

Changes to Support Group Contacts in 2009

A number of significant contact changes have been made this year, with many long-standing Presidents/Conveners/Secretaries standing down from their positions and passing on those responsibilities to other members of the group. In many cases, this has been a difficult but necessary decision to make due to significant changes in personal circumstances.

I would particularly like to thank all these people with whom I communicated for so many years, and I encourage the 'new-comers' to continue flying the flag for all polio survivors.

Support Groups are of paramount importance in the provision of understanding, information, and personal experience. And the dedication, time and energy put into running the groups (with no financial remuneration!) is very much appreciated by everyone in the polio community.

You all deserve far more recognition than you'll ever receive – but it's important to know that YOU MAKE A DIFFERENCE! Thankyou. •

Thank you

Polio Support Group Contacts

Ballarat Post Polio Support Group Inc

Meeting: 1st Wed in February, then bi-monthly
Noel Robertson ph: 5332 3172
Margaret Tuddenham ph: 5335 6702
email: mt@netconnect.com.au
Coral Rumler ph: 5342 0629

Bairnsdale Post Polio Support Group

Meeting: 1st Tue in February, then bi-monthly
Margaret Griffiths ph: 5156 7646
email: d-mgriffiths@datafast.net.au

Bayside Polio Support Group (Hampton)

Meeting: 1st Thu of every month
Shirley Glance ph: 9592 8212
Email: howshirl@optusnet.com.au
Peter Willcocks ph: 9578 5953

Bendigo Post Polio Support Group

Meeting: 3rd Sat in February, then bi-monthly
Bob & Dawn Colbourne ph: 5443 8161

Eastern Region Polio Support Group Inc (Box Hill)

Meeting: 3rd Sat of every month
Janice Gordon ph: 9874 5363
Pat Smith ph: 9729 1807
Email: polioeast@gmail.com

Echuca Post Polio Support Group

Ring Group Contact
Di Lauder ph: 5859 6311
Email: di_lauder@yahoo.com.au
Helen Murray ph: 5482 2132

Geelong Polio Support Group

Meeting: 1st Mon of every month
Neil Winter ph: 5241 9592
Owen Bourke ph: 5278 2422
Email: owenpat1@bigpond.com

Hume Polio Self Help Group (Wangaratta)

Meeting: 2nd Saturday of every month
Norah Waghorne ph: 5762 1859
Robyn Aulmann ph: 6032 8199
Email: robynja@bigpond.com

Knox-Yarra Ranges Polio Support Group (Ferntree Gully)

Meeting: 3rd Sat in February, then bi-monthly
Joan Smith ph: 9756 6383
Marlene Wookey ph: 9758 2232
email: joansgra@bigpond.com

Mornington Peninsula Post Polio Support Group

Meeting: 2nd Sat of every month
Dennis & Deirdre Lloyd ph: 5974 3495
email: ddlloyd@aapt.net.au

Northern Region Post Polio Support Group Inc (Coburg)

Meeting: 1st Sat of every month
Rosslyn Pickhaver ph: 9386 0413
Jo McKenna ph: 9308 8440
email: rosslynp@tadaust.org.au

Sale Polio Support Group

Meeting: 1st Fri in February, then bi-monthly
Kathy Glover ph: 5144 3443
email: bastian@dcsi.net.au

Shepparton Post Polio Support Group

Ring Group Contact
Rhonda White ph: 5832 3100
email: Rhonda.White@gvhealth.org.au

South Eastern Region Polio Support Group (Springvale)

Meeting: 2nd Sat of every month
Lyn Bates ph: 9546 5497
email: lyn_bates@bigpond.com

Traralgon Post Polio Support Group

Meeting: 3rd Thu in February, then bi-monthly
Pauline Corrigan ph: 0424 714 720
email: pollyc5@bigpond.com

Warrnambool Polio Support Group Inc.

Meeting: 4th Tue of every month
Bill Hill-Peters ph: 5561 3980
Anne Clapham ph: 5562 5685
email: anne.clapham@yahoo.com



Polio Services Victoria Regional Clinics for 2010

Dates may be subject to change due to venue availability. Contact PSV for updates on **Ph: 9288 3900** or Email: psv@svhm.org.au

- | | |
|--------------------------|------------|
| • Tuesday 23rd February | Rosebud |
| • Tuesday 20th April | Horsham |
| • Tuesday 1st June | Korumburra |
| • Tuesday 27th July | Swan Hill |
| • Tuesday 21st September | Shepparton |
| • Tuesday 16th November | Bendigo |