



Polio NZ Inc **POLIO NEWS**

April 2017



Taking a Close Look at DHBs and Post-Polio

By Gordon Jackman
Project Manager

Last year, the Ministry of Health encouraged Polio NZ to talk to every District Health Board (DHB) about their capacity to meet the health needs of polio survivors. Seventeen of the 20 DHBs responded.

While most acknowledged that polio survivors experienced the late effects of polio, *only two said they had clinicians with an interest/expertise in post-polio.*

Some DHBs hoped to “look at a project soon that would provide services for late effects of disability clients which of course would include LEOp survivors.”

Others offered to include information on the LEOp on their website and to host presentations to clinical staff. Only two DHBs could quantify how many polio patients were on their records.

From experience, we know that it is almost impossible to get DHBs to meet our needs in a coordinated way and that any progress is often temporary.

We would like to see each DHB develop a clinical pathway for people with the late effects of polio or post-



polio syndrome; have key clinical experts; a rehabilitation referral service; a smooth patient journey, and educational opportunities for all health professionals.

For this to happen, we think somebody in the DHB should be responsible for establishing a clinical pathway. They would have to understand our needs; how these needs are being met within the DHB and what gaps exist in service.

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PolioNZ Inc.

Polio NZ is an incorporated society dedicated to seeking support for people who have had poliomyelitis. It does this through information sharing and where possible, assistance to Polio Society members and their families, whether or not they are experiencing problems at present.

The Society's Board of Management meets regularly, either in person or by teleconference, and the annual general meeting of members is usually held in September or October.

Polio News is published three times a year (usually April, August and November) and sent to all members.

Contributions are welcomed and the deadline for copy is the 5th of the month before publication. Ideally, it should be received well before that date.

Disclaimers: Opinions expressed in the newsletter are those of the writers and not necessarily those of the Society.

This newsletter is not intended to provide medical advice. For decisions about health matters, first consult your health professional.

Similarly, no brand name product mentioned in this newsletter has any formal endorsement by Polio NZ.

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GP Survey – *Continued from Page One*

Where there is a polio clinic in the region, we would encourage a relationship with that clinic, to use the assessment expertise and work with them implementing rehabilitation plans.

They would need to identify clinicians who have an interest and or experience in working with people with polio; and potential key clinicians in all disciplines and areas such as identifying post-polio syndrome which is often misdiagnosed as other conditions by GPs unfamiliar with the condition.

There is a real need for orthotists to be able to work with physiotherapists (PTs) so that clients can successfully use their orthoses long term.

There is also a funding issue with chronic patients who need sophisticated gait analysis and in some cases high tech, blade runner type orthoses. We need a facility to apply for extra funding for chronic orthotic users on a case by case basis. We need PT input.

Maintaining muscle strength and endurance needs a careful exercise programme that helps reduce decline in functionality. This requires a detailed muscle function assessment by an experienced physiotherapist. The use of hydrotherapy and fatigue management programmes can be beneficial.

We also need specialised clinics – many polios have sleep apnoea; many have respiratory challenges, especially if on ventilator in the initial phase. The onset of post-polio symptoms may require home adaptations, equipment modifications or installation and lifestyle modifications. Seating and wheelchair provision may be needed as many will have postural and trunk deformities.

Needs Assessment and Coordination (NASC) evaluation may be needed for additional home help and support.

Most polio survivors were pre-schoolers and separated from families from months to years so Post-Traumatic Stress Disorder (PTSD) is common. These issues may need to be dealt with for rehabilitation plans to be successful.

Anaesthetists may need further education, as many polio survivors react strongly to anaesthetics and are more sensitive to pain, requiring special care and attention.

Many have orthopaedic issues if they have had one paralysed, shorter limb their whole lives, so their other side develops osteoarthritis, and they have joint replacements secondary to asymmetrical gait

So far, only the Christchurch DHB has appointed anyone to oversee the development of a Polio clinical pathway and coordinate all the relevant departments to deliver integrated services.

The Robots Are Coming!

According to the Oz Polio News, “robots” are being enlisted for the fight against polio in the United States of America.

The enlisting is being done by the US Centers for Disease Control (CDC) which tests blood samples for virus and antibodies. In the past, between 20,000 and 30,000 samples were processed during a two-decade period.

But in just one year, the robots, in the form of automated laboratory machines, tested 100,000 samples. Not only were they faster, but they produced more accurate and higher quality test results.

First Meeting Focuses on Strategic Plan

By Barry Holland
President, Polio NZ

The Board of Management gathered in Hamilton on the weekend of February 25-26 to review the Strategic Plan.

Our discussions reaffirmed the action plan that Gordon Jackman is working to and we expressed deep appreciation for his contribution.

The draft revised version of the Strategic Plan was expected to be confirmed by the Board at its March meeting and made available on our web site from early April.

The plan has the purpose of reaching every Polio Survivor in New Zealand rather than simply seeing us become a large membership organisation.

It seeks to strengthen our role as a catalyst and facilitator to support polio Survivors and ensure they get the services and support they need to live enriched lives.

I welcomed Board members to what was our first "face to face" meeting of the year and thanked them for making the effort to be there.

Being there in person meant there was an opportunity for all of us to put our thoughts into the discussions without being shackled by the time constraints of the normal telephone conferences.

I congratulated Gordon for securing the funding for the epidemiology study. This is an important study for a number of reasons, but for Polio NZ it should give us the necessary data to better push our case to the health professionals.

As well, the more data we have, the more ammunition we have when exploring extra funding avenues.

More funding will inevitably be needed to achieve the goals in our strategic plan, so I reiterate my call for all of us to keep a sharp lookout for any trusts, charities, and potential donors who may want to assist us.

For instance, one area where funding is very tight is orthotics.

We'll certainly need help here, because there are signs the two workshops held last year have re-energised orthotists and prosthetists and may have prompted them to think outside the square a little and be a bit more innovative when it comes to what can be done for aching and twisted limbs.

A week ago I had the pleasure of representing Polio NZ at the Rotary Foundation's centennial celebration. It was held on a beautiful, fine Sunday at Ellerslie racecourse and was essentially a family fun day, with all sorts of activities for the children.

Somewhat understandably, Polio was the main theme and I was invited along to say a few words about Rotary's involvement with Polio through the years – in particular our thoughts on their eradication programme and their initiative as one of the instigators in setting up the Crippled Children's Society in New Zealand.

It was also a chance for me to create awareness of just how New Zealand victims of polio from last century are coping with the late effects of the disease and also to get a plug in for the importance of parents continuing to inoculate their children against the disease. I ended the celebrations with the symbolic "letting off "of 100 helium balloons.

Gordon Making News in Pakistan

Project manager Gordon Jackman appears to have taken Pakistan's polio world by storm.

He was supposed to be home in time to file a report by this issue's deadline, but had to send his story from Karachi.

Gordon was there to be a guest speaker at a conference organised by the Pakistan Paediatric Association (PPA) and the National Institute of Child Health (NICH).

"Still in Karachi," he reported, apologetically. "Very productive time.

"It looks like the formation of Polio Pakistan, where there are approximately 830,000 polio survivors, will start. "Rehabilitation will also become a priority alongside the elimination of Polio, however this will become an enormous task."

Gordon hit the headlines when he gambolled down a hotel corridor in his polio braces.

The *Dawn* newspaper witnessed his efforts, telling readers of the 61-year-old teacher affected by polio who "travelled all the way from New Zealand to provide a beacon of hope for many polio children and grown-ups affected by the same disease."

Said Gordon : "I want to extend just a single message to polio-affected children and adults that they should never give up.

"Don't give up. You can also have such wings and you can lead a normal life like me."

Duncan Fund Guidelines

The Duncan Fund programme of Polio NZ Inc. is made possible because of generous donations from the Sir Thomas and Lady Duncan Trust. Its purpose is to assist in addressing the needs of those living with the long-term effects of polio, for which no other funding is available.

The qualifying criteria for this assistance are as follows:

- The applicant is living with the long-term effects of having had polio.
- The applicant is in good standing as a member of Polio NZ Inc. (having paid their \$10 per year sub).
- The applicant shall produce evidence or otherwise convince the Duncan Committee that the purpose of their application is necessary in the management of their post-polio condition.
- Other avenues for funding need to be investigated before applying to the Duncan Fund. The Fund is for where there is no other funding available, or possibly where alternative funding would take too long as to make it impractical.
- The purpose of the grant must be for the personal benefit of the applicant in managing the effects of polio.
- The terms of the grant shall be determined by the Duncan Fund Committee of Polio NZ Inc. The Committee may decide to approve partial or full funding of the application. The approval or denial of any application is at the sole discretion of the Board of Polio NZ Inc.

An application form for the Duncan Fund can be requested from:

**The Secretary, Polio NZ Inc.,
PO Box 791 New Plymouth 4340
or e-mail : secretary@polio.org.nz**

Another Step For Orthotics

An orthotics course held at QE Health, Rotorua last year saw eight polio survivors fitted with new tri-planar orthotic devices, reports Project Manager, Gordon Jackman.

Marmaduke Loke from California's Dynamic Bracing Solutions introduced the braces which are designed to position the foot and ankle to restore the leg's natural balance while walking.

As the course was the first of its kind here, the orthotist had to start with the basics using gait analysis in three dimensions (tri-planar gait analysis), to cast the ankle in the correct position.

Braces were fabricated out of carbon fibre, but without the capacity to give the foot a spring when hitting the ground and lifting off.

Learning to use the static braces has been challenging for our polio survivors, Gordon reports. They say you have great balance while standing, but walking on anything other than a flat surface is difficult.

Users say that it takes about six months to become comfortable and confident in the braces. First, you must overcome a lifetime of habitually walking with a compensatory limp – the brain finds it difficult to realign the gait into a smooth and balanced motion.

At the same time, the muscles must adjust to a new sequence of contracting and resting and this can be quite uncomfortable and tiring at first.

A new Dynamics Solutions brace could cost anything from \$15,000 to \$25,000



Above left: Turbo Texas Plastic Brace, under \$1000; Above right: Marmaduke's Static Brace; Above: DPE Dynamic Brace, \$4000.

“By contrast, Darren Pereira from NeuroMuscular Orthotics in Melbourne ran an Auckland workshop on his DPE braces, and he made me one as a demonstration,” said Gordon.

“They're based on the Marmaduke Loke-developed tri-planar orthotics but use a modular system with a carbon fibre spring that bolts onto the brace. The angles can be adjusted as one gets used to it, but it is bulkier and less dynamic than Marmaduke's braces.

“I have been wearing it now for three months and I'm not only getting used to it but also enjoying using it. I installed parallel bars and a full-length mirror to practice using my new brace.

“The most difficult thing I've learned is to swing my hips so that I don't sway from side to side as I have done for most

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(Orthotics Continued)

of my life. They (the braces) would cost around \$4000 and the components are available in New Zealand.”

Gordon said some local orthotists were using or had adapted the concept to achieve a lower cost using special plastic materials.

“Ask your orthotist to contact us for more information,” he said.

New Clinic Service Gathers Support

A national support service for people living with neuromuscular conditions, initially the late effects of polio, and the health professionals who treat and support them is becoming a reality.

The Sir Thomas and Lady Duncan Trust has established the Duncan Foundation to empower people with these conditions to live to their physical potential.

The Foundation knows that confidence in diagnosis, treatment and rehabilitation is the goal of both clinician and patient.

By providing resources and a network of knowledgeable and experienced therapists, the Foundation aims to make education and best practice treatment easily available.

This involves setting up a “Virtual Centre of Excellence” or online hub of resources and information for best-practice treatment, rehabilitation and support of neuromuscular conditions.

It will offer the latest evidence-based research, education, clinical support and assessment tools.

In Auckland, Julie Rope of Rope Neuro has moved in with the Orthotic Centre in Penrose and is continuing to assess polio survivors there.

In Christchurch, Jessie Snowden of On the Go Physio has seen several people.

However, at this stage Julie, Jessie, staff at Rotorua’s QE Health, and Polio NZ are focusing on developing resources to deliver integrated rehabilitation plans, including physiotherapy, exercise programmes, fatigue management, hydrotherapy, orthotic management, and more.

This requires forming relationships with providers in each place.

We are also working with the St Vincent’s Polio Clinic in Melbourne, the only public health clinic in Australia, to learn from their experience and help develop our resources.

It’s early days, but we’re making progress — *Gordon Jackman*.

Are You Ready For Retreat 2017?

Expressions of interest are being sought from people wishing to attend Polio NZ’s 2017 Retreat at Rotorua.

The Retreat will be held from Friday, October 6 to Sunday, October 8. and will have a programme revamped in line with suggestions made in a survey after the highly successful 2016 Retreat.

Once again the Polio NZ AGM will be included in the Retreat.

For \$250 per person, participants will gain accommodation at QE Health for two nights, all meals and admission to most activities.

Attendance will be limited to 45 and beds will be allocated on a “first-come first-served” basis.

For more information, write to Polio NZ Inc. Retreat and AGM at PO Box 791, Taranaki Mail Centre, New Plymouth 4340, or e-mail Sue Griffin, vp@polio.org.nz

How Post-polio Fatigue Can Change Your Mind

By Mavis J. Matheson, M.D.

One of the most frustrating late effects of polio for me was the awareness that I could not concentrate and feeling that I wasn't thinking clearly anymore.

For many of us who have compensated for our physical limitations through intellectual pursuits this is terrifying. Is it not bad enough that our bodies are giving out? Must we undergo the indignity of losing our minds as well?

Studies show that despite marked impairments of attention, polio survivors are within the high normal or superior range on measures of higher-level cognitive processes and IQ.

They also show that if we allow ourselves to become fatigued we do lose our ability to focus our attention and to rapidly process complex information requiring 23 to 67 per cent more time to complete tasks requiring sustained attention and vigilance than did polio survivors with no fatigue or mild fatigue.

Polio survivors experience two kinds of fatigue. One is physical tiredness and decreased endurance. The other and often more distressing is "brain fatigue".

Brain fatigue describes problems with attention, alertness and thinking. Between 70 per cent and 96 per cent of polio survivors reporting fatigue complained of problems with concentration, memory, attention, word

finding, staying awake, and thinking clearly.

Tests indicate that an impairment of selective attention (related to damage because of polio) results in feelings of fatigue and cognitive problems.

The poliovirus damages the anterior horn cells of the spinal cord and parts of the brain stem. Findings indicate that poliovirus consistently and often severely damaged the brain areas known as the Reticular Activating System.

These are responsible for activating the part of the brain involved in maintaining voluntary attention, memory, spontaneous interest, initiative and the capacity for effort and work, and for preventing feelings of fatigue. This is the area that keeps us awake and allows us to focus.

Polio survivors report that they are most disabled by fatigue – exhaustion, passivity and an aversion to continued effort that generates an avoidance of mental and physical activity.

Treasurer's Report

Discussions at the Polio NZ Board of Management meeting in Hamilton on February 25-26 reaffirmed the Strategic Plan and expressed deep appreciation of project manager Gordon Jackman's contribution, said treasurer Carl Pascoe.

The draft revised version of the Strategic Plan was to be confirmed by the Board at its March meeting and then become available on the Polio NZ website from early April.

Carl reports that the plan has a strong focus on reaching every Polio Survivor and strengthening Polio NZ's role as a catalyst and facilitator to help polio survivors get the services and support they need to live enriched lives.

News that stalwart JB Munro had been made a life member of Polio NZ was greeted with universal acclaim at the time. But you can't have too much of a good thing! This later tribute is based on an article written by Board member Susan Kerr.



JB Munro, QSO

JB was granted his award at the Annual General Meeting for Polio NZ Inc on Wednesday, October 21, 2015, at the Thorndon Hotel in Wellington.

The previous evening, on the eve of Parliamentary celebrations for World Polio Day, Anthony Scott, District Governor of Rotary District 9940, spoke of the part Rotary had played in all but eradicating the scourge of polio. He also made special mention of JB, recalling his loyal support of Rotary over the years.

In Polio NZ, JB served as an executive officer for 13 years in the capacity of secretary and treasurer and later as vice-president.

"I discovered that JB first joined Rotary with the Dunedin Club in 1963," said Susan. "He was a foundation member of the Mosgiel Club. After his retirement from paid employment, he became Vice-Chair of Rotary NZ World

Community Service Ltd, and President of the Rotary Club of Mosgiel."

Susan said the first time she decided to attend a Polio NZ AGM was in about 2006 in Wellington.

"One of the first people who talked to me, in a bar where everyone seemed to know someone, except me, was JB, who for some reason decided to shoulder tap me to join the board.

"He had a grin from ear to ear, and that is how I remember him – as an encourager. He encouraged me to do what I would not have been confident to do by myself."

The Polio NZ newsletter which followed his retirement from the Board in October, 2014, described him as "indomitable" and his service as "stalwart". The article detailed his life so far and all that he had crammed into it after what seemed a less than promising start as a tiny polio survivor who was adopted out at the age of nine and was teased at school as a teenager with a caliper.

After school he initially found employment with the Vacuum Oil Company of Invercargill, but his real interest was in working for youth and that is where he became an encourager of people in earnest.

He was secretary for the YMCA in Invercargill, Australia, and Dunedin between 1958 and 1968, having married his wife Val [Valmai Sharfe] in 1962. It was during this time that he developed his abiding passion for working for intellectually handicapped children and adults. He became the Southland administrator for IHC New Zealand from 1968 to 1973.

JB felt that he could make an even better contribution towards making a difference by entering politics and

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(JB Munro, QSO – from Page 9)

served for six years as a City Councillor in Invercargill followed by three years as Member of Parliament for Invercargill.

He championed the drafting of the Disabled Person's Community Welfare Act which was passed into law in October, 1975. The Act set the standards for access to buildings, recognised work opportunities for people with disabilities and gave support to their families.

Whilst in Parliament, JB was also Chairman of the New Zealand Paraplegic Trust Appeal which raised enough money to finance the 1974 Commonwealth Paraplegic games.

In 1977, JB was appointed National Secretary of IHC and in 1998 he retired from the position of CEO. He was made a Life Member of that organisation too and in 2014 was inducted into the Attitude Hall of Fame for lifelong service to the disability community.

His other honours include The Abbeyfield International Royal Patron's Award (2010). This is presented to one person per year from across the world. The Certificate is signed by HRH the Prince of Wales and is accompanied by a lapel badge incorporating the emblem of the Prince of Wales Feathers.

Space does not allow me to write further of all you have achieved, JB. We look forward to reading your memoirs.

Thanks for all your work for us, and encouragement.

See you soon JB! Ka kite ano.

- For those who haven't guessed as much, JB's adoptive brother was Bert Munro of *The World's Fastest Indian* movie fame! We think our Munro is a star too!—
Editor.

Educating GP's on the Late Effects Of Polio

By Gordon Jackman

The two complaints about GPs that I hear most often from polio survivors are: "My GP didn't know anything about post-polio" and "My GP believes polio has no late effects and it's just ageing".

Well progress is being made.

I'm working with Auckland University Professors Warrick Bagg and Shanthi Amertatunga to develop a disability and enablement teaching topic for medical students for the 2018 year.

Dr Lisa Lack, National Clinical Lead GP at the Royal NZ College of General Practitioners, will include information about polio and post-polio in the curriculum.

Webinars will be available to students and the next GP Pulse magazine will cover Post-Polio Syndrome and the late effects of polio. I'll also address their conference in July.

Talks with Professor Tim Wilkinson, Director of the Otago Medical School about including post-polio and ageing in disability studies may also result in students researching alongside the Christchurch DHB.

All in the early stages now, these initiatives will help lead to a new generation of GPs who understand the late effects of polio.



We Want to Hear From You!

Everyone is supposed to have at least one book inside them, but Board member Susan Kerr says it's not necessary to go to that extreme. She'd settle for a few letters and has volunteered to edit the column!! She says:

Polio News would love to hear from you, our many readers. We would welcome ideas about what you would like to read about in Polio News and the difficulties you are experiencing – anything at all that you would like to share with other readers.

I like to think of January as a time of new beginnings and resolutions to become more positive.

However, the 'flu dragged me down and a week later I fell yet again – just when I thought I wouldn't – and my bruised ribs were painful, every time I coughed.

February brought much warmer weather here in Picton and I longed to be able to go swimming on the Foreshore, but it's far too difficult to get into the sea on crutches.

Many cruise ships have filled the town with tourists and one thing I enjoy is sipping coffee in town and listening to the different languages and pretending I too am on holiday.

Marlborough doesn't seem to have enough Polio survivors keen to have a support group. Maybe there are other areas which are in the same position? However, the newsletter is another way for us to keep in touch. Whatever is on your mind, please write to us at:

Susan Kerr, 32 Seaview Crescent, Picton 7220, or e-mail: susanvrm@clear.net.nz

Letters should be no longer than 150 words and we may be edited for length, sense and good taste.

Please include name, address and phone number.

Write to us !

Around the Regions

Waikato

An ice-cream party for the Waikato Polio Support Group was held on a beautiful summer day under the cool shade of a huge tree in the Morris's back yard.

People from Thames, Hamilton and nine National board members from around NZ enjoyed a pleasant afternoon listening to short talks from national president Barry Holland, project manager Gordon Jackman, and neuro-rehab therapist Julie Rope.

John Forbes oversaw the programme and Lynda oversaw the serving of the ice-cream. It was a happy occasion which lingered into the late afternoon.

Manawatu

By the time this is being read, the Manawatu-Wanganui group should have held another successful luncheon meeting at Coffee on the Square in Feilding.

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Nelson Trio Joined India's Polio Struggle

Three Nelson Rotarians who travelled to India earlier this year to join a group helping the fight against polio, returned home amazed by what they discovered.

They included Whakatū Rotary Club president-elect Karen Stade, past-president Kristine Marriott and club member Belinda Wheatley.

The trio left New Zealand on New Year's Eve bound for Agra in India's north where they joined a party of 50 Rotarians from 10 countries and saw first-hand how Rotary International's polio vaccination campaign operates.

"When we heard about it in September last year we were planning our own October polio fundraiser," said Karen Stade. "We looked at each other and agreed, 'we're going to India no matter what.'"

There they built a personalised tour around the weekend Rotary Keep India Polio-Free Mega Campaign which was hosted by 11 Agra Rotary Clubs.

Although India was declared polio-free in 2014, polio is still found in neighbouring Pakistan and Afghanistan, posing a potential for re-infection, they said in an article which appeared in the *Nelson Leader* newspaper.

They joined other international Rotarians in vaccinating children ranging in age from newborns to five-year-olds in poor rural schools and villages.

"This programme was a wonderful opportunity to join Indian health workers



Karen Stade administers polio drops to a baby in India.

to administer the polio drops ourselves," said Karen.

"We felt humbled knowing the children we vaccinated that day will not be crippled or paralysed by polio. The world is so close to eliminating polio and we are proud to have played a small role in helping to achieve this ultimate goal."

For Nelson Marlborough District Health Board employees Marriott and Wheatley, the Mega Campaign was an opportunity to join an international public health programme.

Karen Stade said India was an amazing country.

"We have returned home with our eyes widened as to the possibilities and opportunities for future participation in other worthwhile international projects."

Around the Regions

(Manawatu Continued)

The meeting was scheduled for 1pm on March 25 [after our deadline] and organiser Raylee Murphy was hoping for a good turnout in the private room hired for the occasion.

Earlier, she said the group appeared to be going through a period when some people had become reluctant to leave home.

"We need to get together," she said. "We gain so much when we are able to share experiences."