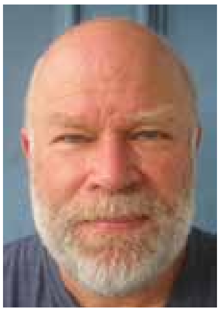
Polio NZ Inc

POLIO NEWS

April 2015

New Strategic Plan Ready for Action



Polio NZ board member and plan author Gordon Jackman reports on progress.

At last year's Polio NZ conference in Christchurch, members gave a clear picture of what they would like the Polio NZ board to achieve in the next few years.

In response, the board has prepared and adopted a strategic plan which it is now putting into a program of action.

Here's a brief overview of what priorities and what actions are underway to get things moving.

The program is divided into four areas:

- support for all people in New Zealand who have survived polio
- health service provision
- education
- capacity building

Support The board will continue to support all members through Polio News plus a new Polio NZ Facebook page for internet-savy polio survivors, family and friends. Each support group in the country now has a dedicated board member who will personally keep in contact with the group leader so we can get more immediate feedback and keep people informed of current developments.

The theme of this edition is gratitude. The new science of happiness and contentment is now showing that counting one's blessings is indeed healthful. Read more inside, then spread thankfulness around. It's good for you.

National Register A register of polio survivors is being created in addition to our membership base so that we can get a better idea of how many there are in New Zealand today. This will give us more weight when advocating for improved services.

Mind, Body and Soul Retreat Our first retreat will be in Hamilton 6-9 August. Initial plans are for sessions on physiotherapy, occupational therapy, coping with daily tasks, pain control, acupuncture, and creativity with massage. Massage and hot pool will be available. More details next edition.

(continued on page 6)

Member input opportunity

The Polio NZ Board will hold its April meeting in Wellington on the 28th. The agenda includes a significant session on the Strategic Plan, plans for this year's AGM on October 21 including a march to Parliament to show "We're Still Here!" and Walk with Me! on October 21 or 22.

All members welcome at an open session 1–2:30pm. Venue not yet confirmed, but anyone interested in attending phone 0800 476 546 or email secretary@polio.org.nz to find out where to go.

Polio NZ Inc

About Us

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.

Polio News is published four times a year (usually March, May, August and November) and sent to all members.

Contributions are welcome and the deadline for copy is the 15th of the month before publication.

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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"Behavioural psychology: the science of pulling habits out of rats."
(Douglas Busch, quoted in The Cynics' Dictionary)

BRIEF: Shirley Hazlewood QSM, president and coordinator of the Taranaki Post Polio Support Group (not affiliated to Polio NZ) has given notice of retirement after 22 years service to her community. The Opunake & Coastal News carried a story in which she explained membership has dwindled and aged, and it's now hard to get funding for such a group.

The story paid tribute to Shirley's dedication, her work creating social opportunities for people with disabilities, and also to her lifelong love of horses – she runs a Horse Ornament Museum in her home. She is continuing as president of the Taranaki Disabled Persons Assembly.

About the President – Barry Holland

Barry has been busy in advocacy for Polio NZ so we gave him a month off from writing for the newsletter and asked Penny Humphreys to write a profile instead. She found a man quietly determined about the task he has taken on.

Barry was elected President at Conference 2014, following some 50 years' experience in radio, television, marketing and advertising and in governance roles with community groups like the Auckland Racing Club.

These skills will be capitalized on as he leads the board as media front man, responding to issues and raising the society's national profile.

Barry contracted polio at age three and spent nine months in Auckland Hospital then another three in the Wilson Home. He considers himself fortunate having been primarily affected in the right leg but still able to run and physically compete during school years.

He developed a demanding career in broadcasting and got on with life without much thought of polio. There was the occasional fall when out running with the children (he and wife Carolyn have three) but it was not until his late 40's that he noticed odd occurrences such as not being able to 'step up'.

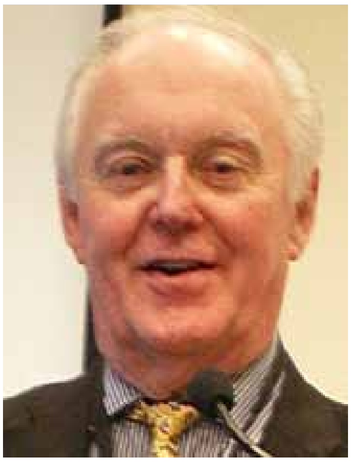
Listening to a radio interview on the late effects of polio, he put two and two together. He began acknowledging some increased weakness or other symptoms that until then had been just annoying. He was falling more regularly and people would ask if he was managing ok.

Barry is now aware his faithful and previously reliable left leg is beginning to complain about having worked twice as hard all these years, and his gait is definitely changing.

"It just has to be managed," he says philosophically. But he is determined that others should be aware of the issues and be supported in coming to terms with and managing the late effects of polio.

This includes the professionals who support the many thousands of polio survivors in similar and worse situations than his own.

At the board's first planning meeting in New Plymouth Barry inspired members with his mild-mannered and determined way. He spoke with passion about the need to work to break down the barriers people report. He has supported board members in the development of Polio NZ's Strategic Plan with its short, medium and long term objectives.



Barry Holland

Issues particularly important to him are individualized assessment processes; plans to manage weakness, pain and diminishing physical capacities and also sorting out the many problems reported with orthotics.

Barry appreciates that assistance in the home, (which promotes self-sufficiency and greater comfort) is a limited resource and he sees Polio NZ as having a role in advocating for 'needs-based' provision.

He is encouraging board members to think creatively to continue work in strengthening Polio NZ's relationships with various health professionals and resource organizations. He also acknowledges the need to explore 'teaming up' with organizations of like physical presentations and needs, to advance our aims and strengthen arguments for funding. One such example is the development of clinics addressing the impacts of aging on everyone with long-term neuromuscular conditions.

"The population of polio survivors, whilst aging, is not going away and we need to be a force at all sorts of levels across New Zealand society," Barry says.

Barry says he's had a great career.

"I've met wonderful people and have seen lots of the world."

He remains involved and busy tutoring young people eager to enter broadcasting and is in demand as a world tour organizer for groups wanting that 'special experience'.

It is evident that he is equally passionate about doing his bit to make the lot of those with the late effects of polio easier.

"Polios must never give up on life. It is a challenge to do what we do, but with acceptance and the following of logical advice and supports, we can manage together."

He is delighted with the commitment shown by board members and firmly believes that Polio NZ is in for an interesting and promising year. •

Gratitude a key to happiness

Penny Humphreys

How about writing a brief article on how evidenced based research can improve one's health? The challenge was laid at my novice feet by our Polio News Editor and in typical polio persona I readily accepted! So, what have I deciphered from the glorious annals of the all-knowing Google?

Various philosophies, including those of religious thought, have long recommended giving thanks and being grateful for what one has. And research is evidencing that an approach to life along these lines can lead to many personal and wider benefits.

Psychologist Robert Emmons is one such pioneering evidenced-based researcher. He's involved in what is referred to as 'positive psychology' or studies that identify health-promoting behavior and the pleasures of life.

These approaches are relatively rare as the focus in psychology is more often on illness and emotional problems.

In his book *Thanks! How the New Science of Gratitude Can Make You Happier* (2007) Emmons reports using traditional methods with participants divided into three groups.

One group recorded five things they were grateful for in the preceding week, the next recorded five negative events and the third or control group, five things that had affected them in some way.

When results were analyzed, the gratitude group were found to be feeling better about their lives, were more optimistic about the future and reported fewer health problems than all other participants.

It's not happy people who are thankful – it's thankful people who are happy.

Repeat studies concluded that daily writing led to an even greater overall benefit than weekly gratitude practice.

Another study into the effects of practicing gratitude on health looked at people recovering from heart attacks. Gratitude appeared to have a protective effect against subsequent attacks. Those in the gratitude group saw benefits and gains from having had the heart attack and they became more appreciative of life in general.

Many similar studies across diverse age groups, nationalities and situations, all demonstrate significantly improved mental and physical wellbeing from the daily practice of gratitude.

Of particular interest to post-polio people is a study overseen by Emmons exclusively with people contending with the effects of neuromuscular diseases, several of whom had PPS. Those using daily gratitude journals reported more satisfaction with their lives and greater optimism for the future than the control group.

They also reported getting more sleep, spending less time awake before falling asleep and feeling more refreshed in the morning.

The research challenges thinking that each person has a 'set point' for happiness or that a person may have a 'genetically determined' level of happiness. Emmons suggests we can move our 'set point' upward to some degree and that this is enough to have a measurable effect on our outlook and our health. Well worth trialing I would suggest!

A daily Gratitude Journal is one of ten starter activities Emmons recommends. If you would like to read about these activities and bring increased gratitude and its effects into your life see the polio NZ Facebook page for the links or ask me (through the secretary) for copies of these articles to be sent to you. After all, who doesn't want to feel more loving, forgiving, joyful, enthusiastic and optimistic about our futures, while having our family and friends reporting us happier and more pleasant to be around!

The Greater Good Science Center is offering a free on-line Science of Happiness course, zeroing in on "a fundamental finding from positive psychology: that happiness is inextricably linked to having strong social ties and contributing to something bigger than yourself—the greater good." Enrol before May.

Thank You Dr Salk – Polio Vaccine Hero

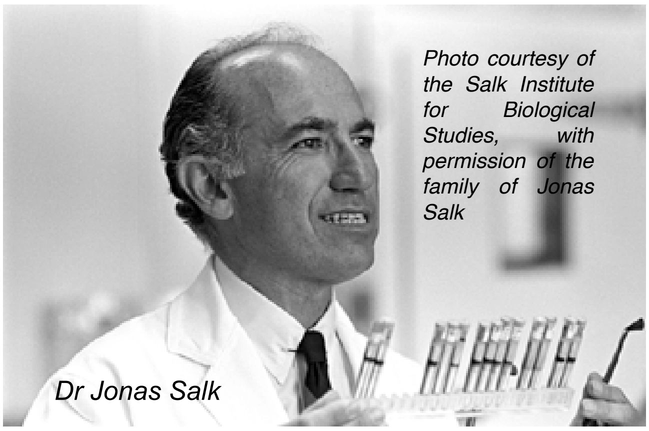


Photo courtesy of the Salk Institute for Biological Studies, with permission of the family of Jonas Salk

Dr Jonas Salk

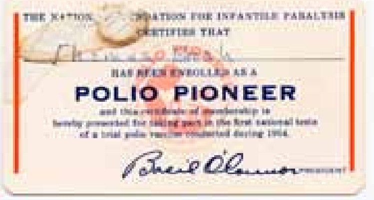
On the 60-year anniversary of the first official announcement of an effective polio vaccine, Edith Morris pays tribute to polio vaccine hero Jonas Salk.

The long-awaited vaccine was declared "safe, effective and potent" on the 12th of April 1955 in America.

Huge banner headlines read: "Salk's Vaccine Works, Polio Routed! Vaccine Triumph Ends Polio Threat."

Can we imagine the rapturous joy, excitement and pure relief that one of the most crippling and terrifying diseases could now be conquered?

In the US, radio, TV, newspapers, public address systems in schools, factories and workplaces, and ringing church bells shouted out across the nation that the Salk vaccine was successful. Huge crowds went wild as they gathered in the streets and around wireless sets to absorb this historic announcement. That day was also appropriately the 10th anniversary of the death of America's polio president F D Roosevelt.



CERTIFIES THAT

POLIO PIONEER

The Polio Health International website has a history corner, which currently refers to the 1954 field trials for the vaccine, with 1.8 million schoolchildren receiving either the vaccine, a placebo, or acting as a control. They received these 'Polio Pioneer' cards and were acutely aware of the significance of participating in a grand scientific experiment to benefit humanity. •

In the last two years before the vaccine, polio cases in the US numbered more than 45,000, but by 1962 the number was down to 910, and in 1994 US was declared polio free.

Here in New Zealand the records of how many contracted polio are not so clear or accurate. Between 1915 and the last polio epidemic in 1961 an estimated 10,000 people were registered, however many others went unreported.

The first batch of Salk polio vaccines arrived here in April 1956. A small group of eight and nine-year-old school children were the first to be immunised. In 2000 New Zealand was declared polio free and this once-feared, dreaded disease has almost disappeared from our national psyche, thanks to Jonas Salk and Albert Sabin.

The development of the polio vaccine by Jonas Salk and his team of researchers is one of the greatest medical breakthroughs in modern times, in my opinion.

I contracted polio at the age of six months in 1945 (ten years before the vaccine) and live with the after-effects of a lifetime of polio damage to my body. The emotional harm of isolation, hospitalisation, rejection and the super-human effort of trying to live a so-called "normal" life with polio have left their marks too.

Yet when I look at my family and hug my grandson Jonas, what else can I say but "Thank you Jonas Salk. My family need never be touched by polio."

In this modern era, there is absolutely no reason for anyone to be infected with the polio virus. It is so important to keep vaccination levels up in New Zealand because low levels could mean that a polio epidemic is only a plane ride away. •

Edith Morris with that triumphant 1955 headline.

The action plan

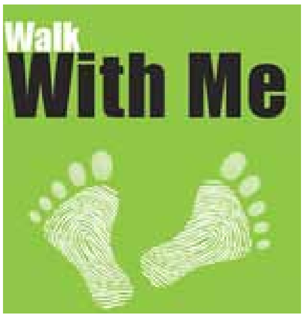
continued from p 1

Orthotic services These were a concern for many at the conference, and we have started work with the Health and Rehabilitation Research Institute at the School of Research and Occupational studies, AUT University, to do a thorough survey on orthotics issues and needs of all our members. This will give us solid information to engage with the DHBs and the orthotics profession to improve services to us.

Assessment and treatment We are also talking to AUT about training physiotherapists in polio assessment and treatment. Establishing a clinic devoted to those with long term disabilities and issues of aging is at the top of our priorities, similar to the "Late Effects of Disability Clinic" in Perth Western Australia. To this end we have started talking with Massey University in Palmerston North, other disability organisations and with G Jegasothy [Jega] to develop our initial proposal for the clinic.

Education The Polio NZ board is working with Rotary and CCS (formerly Crippled Children) to hold the first New Zealand "Walk with Me" fundraiser. See last December's Polio News for the story on the Australian model for high-profile event featuring people of all disabilities and their need to be fully included in our communities.

This will be in Wellington on World Polio Day, 24 October.



The Polio NZ board is excited about implementing the strategic plan and looks forward to working with the wider membership to improve the lives of all polio survivors in New Zealand.

On World Polio Day we will also stage a "We're Still Here" event on the steps of Parliament. This will highlight the need for a "Late Effects of Disability Clinic" and also that there are still thousands of polio survivors in New Zealand today whose specific needs have largely been forgotten by the health system.

Put yourself in the picture. We need as many of us as possible on Parliament's steps on 24 October to show that indeed "WE'RE STILL HERE". All the better if the future photo shows a wheelchair fleet storming the steps (like Myrtle the tractor...)

Other projects in the pipeline include an education programme in schools, updating Polio NZ's resources, developing a media strategy and list of sympathetic journalists and joining the steering committee organising Polio Australia's 2016 Australasia-Pacific Post-Polio Conference: Life Stage Matters – Australia's first international post-polio conference. •

Obituary

Joan Radburnd

Polio NZ lost a stalwart member with the death of Joan Radburnd (nee Crosbie) in Christchurch on 9 January after a short illness.

Joan Radburnd 1931-2015

Joan was born in Dannevirke to share-milking parents and had a younger brother. The family moved to Christchurch during her childhood and Joan trained as a tailor; a trade that provided her with employment for much of her life, including owning a tailoring business.

New Year's Eve 1956 at 25 years of age and with three small boys, Joan contracted polio. She was in hospital for four months and treated with hot packs and physiotherapy. She managed to stand at three months, and was sent home a month later with continued exercises and a back brace that she wore most of her life.

Joan managed her mobility well but over latter years became more reliant on mobility aides.

Her family reflected on growing up with a full-time working mother who sewed, knitted, kept house and baked – notably the best cream horns and chocolate éclairs. They were hardly aware that she contended with the effects of polio in their earlier days. She was a determined can-do person, or as her youngest son Gary put it, "She had a tough life, but she always worked it out and got round any obstacle."

Joan was always involved in the community, especially her sons' cycling club and as treasurer of the Sumner Senior Citizens. She was a founder of the Post-Polio Support group in Christchurch, serving as president, treasurer and secretary on numerous occasions over the group's 26 years, and as organiser of the popular annual week-long retreats to Hamner Springs.

During 2000-04 Joan served on the Polio NZ board. Ray Wilson, president some of this time said Joan served extremely well, and despite her mobility difficulties, she would readily travel in support of meetings away from her area. He remembered Joan's husband, Tom,as being right behind her, supporting her in many respects.

"She was a lady able to put her point across, a capacity that earned her respect from other board members," Ray said.

Fellow board member JB Munro recalled Joan as a forthright, conscientious and reliable person, always available to assist in what was needed to be done.

Joan's long association with Polio NZ was acknowledged at the 25th Conference in October when along with other foundation members, she assisted with cutting the cake.

In 2004 the Christchurch City Council recognized Joan's volunteer efforts with a Community Award. The citation reads:

"In recognition of (her) outstanding contribution to the general wellbeing of the community."

Son Gary recalled how proud his mother was on receiving this deserved recognition.

Joan is survived by her four sons, seven grandchildren and seven great grandchildren. She has left a lasting legacy in the manner in which she gave so willingly in the service of others or as Ruth Hall, President of the Christchurch Support Group testified at Joan's funeral:

"Even as her disability got worse and her health deteriorated, Joan was always willing to help and advise. That meant so much to us."

May she rest in peace. •

Another scrap of wisdom from the science of happiness: Your brain reacts to emoticons as if they were real faces, according to a study reported in the journal Social Neuroscience.

Thank you Ray

here's a story just for you

While we're on the subject of gratitude... apologies are due to Ray Willoughby who diligently organised that highly popular classic car tour of at the Christchurch conference. His name got hidden behind one of those photos of happy passengers in the last newsletter.

So here, in tribute to Ray and all the volunteer car owners and drivers, is a piece about a vehicle oddity worthy of Top Gear. But it possibly hasn't got there yet because it was officially classed as a mobility device, not a vehicle.

It's the British Invacar, a generic name (like Electrolux for vacuum cleaners) for what was basically a three-wheeled motorbike encased in a light-weight body. It has a long history and models were built by different firms under contract to the National Health – most famously by the same company who produced a car at the other end of the spectrum, the Shelby Cobra.

Drivers had them 'dispensed' like an orthotic through the health system, not the motor trade, and maintained under lucrative contract, (the high cost of which was part of their eventual demise.)

They were hugely popular for many years, providing mobility and independence. And envied. One motor history writer recalls how in the days before corporate boxes, Invacar owners were the envy of all at sports events, sitting under cover from the elements and in a prime position near the goal line.

Invacars were inherently unstable, and required careful driving, though that apparently didn't deter skilled speedsters.

As technology improved the ease of fitting out production line cars to meet individual disability needs, the Invacar fell out of favour. Reasons included the lack of passenger capacity and their high visibility (all the same ice blue) which some advocates held to be discriminatory. The Invacar was recalled and outlawed in 2003, though a few escaped the crusher, and are greatly prized.

There's lots of funny stories and memories to be found through Google. •

EDITORIAL HIGH HORSE

The editor packed up her life into banana boxes, climbed on her horse and took to the road for the best part of summer.

The sunny photo below was taken at Mavora Lakes, a DOC camping ground where you can truly take your horse (real or notional), your dog, your caravan or tent and your just-sold-up-and-moved-out-of-the-house stress. Then recuperate. Others might write 'chill out', but that's not what we cold-blooded people do of course.

It was a lovely interlude, especially watching dogs run free and happy together; and fortunately few dirt bikes or even sandflies.

Not an easy office though without power or internet, so now it's back at the desk, finding all the essentials in the banana boxes, and getting connected again.

Help in pulling this newsletter together has therefore been especially gratefully received, notably from Penny Humphreys.

We were up to the minute in choosing 'gratitude' as a theme – so did North & South magazine for its February edition. (Look for it at your library.)

Gratitude also goes to all those who sent historic copies of Polio News. That particular banana box is still in store, but it seems like we're well on the way to assembling a complete editorial collection. What was striking in glancing through back copies was the quality of material, and its continuing relevance. But also the repetition.

There has to be a better way of keeping relevant material easily accessible. That's a project that will take legs (or wheels) under the new strategic plan. Any skilled indexer out there?

Meantime, apologies for lateness. Though this might be the start of moving to just three printed newsletters a year, plus other forms of electronic communication. •

Cold feet & nose woes

More from the 'thanks for telling us why, but can't you get on with finding a cure' school of research.

As if having chilly feet or a cold nose isn't uncomfortable enough in itself, researchers now report it increases the risk of catching viruses.

Cardiff University's Common Cold Center director, Dr Ron Eccles, has been looking at data on the subject for more than 25 years.

Many of us carry cold and flu germs in our noses already without getting sick, he says.

However, when our feet get cold, our entire body temperature drops and leaves us susceptible to developing a full-blown cold or flu.

Chilling the feet causes the blood vessels in the nose to constrict. It's a protective reflex action which slows down the loss of heat from the body, to try to keep you warm.

The skin goes white, the inside of the nose and throat goes white and blood flow to the nose is reduced. The white cells that fight infection are found in the blood, so then there are fewer white cells to fight the virus.

Being cold also slows down the movement of the cilia – the hairs in the nose that filter dirt and germs – allowing the virus to get into the body.

US researchers report the germ that commonly causes a cold finds it easier to breed at (33°C) – the sort of temperature typically found inside a cold nose – than at the (37°C) found deep inside the body.

Read More: Google 'Research Shows Keeping Feet Warm Can Dodge A Cold' (and reach for your bunny slippers)

And as for the cold nose.. the internet abounds in free knit, crochet or sewing patterns for nose warmers; woolly, furry, fleecey; with or without animal ears, nose and whiskers or trim moustache adornment. See Pinterest post on our Facebook page for inspiration and send us a photo of your efforts. You're never too old to be a foxy lady (or gentleman.)

They will be ever so gratefully received.

Now where's that possum roadkill... •

Grateful to QE Health

Former Polio News editor Mervyn Dykes of Palmerston North praises Queen Elizabeth Health hospital in Rotorua.

Readers may recall two articles Mervyn wrote about the effects of stress on those with Post Polio Syndrome.

He had been badly affected by PPS himself after the trauma caused by the sudden death of his younger son.

At one point he was barely able to walk and had lost much of his ability to focus. He found it hard to read a book or even write a short letter.

Then he was referred to QE Health and went twice. He found it enormously beneficial both then and now and is still shouting its praises.

"It's great, simply great," he says. "Everything went crazy so quickly that at one point I thought my life might as well be over."

"During the first visit they helped me manage my physical symptoms and in the second they concentrated on the mental aspects of stress."

"Although I had lost my ability to write and several projects had foundered, they turned me around and I cannot speak too highly of them. They are more than worthy of our support."

And the benefits have continued. Since returning from QE Health in 2013, Mervyn has completed the stalled book and nearly finished another. He has also launched a series of small regional history books about the Manawatu – the first two of which were published this year. A third is now under way.

"I still get tired easily. I get cranky. I am still sore most of the time and I have other post-polio symptoms," he said. "But I am working again and I have my future back." •

Keeping a gratitude journal

Write down and record what you are grateful for, and then when you need to reaffirm your good lot in life, look back on the journal. Remember the bad. If you do not remind yourself of what it was like to be sick, unemployed or heartbroken, you will be less likely to appreciate health, your job or your relationship. – Robert Emmons.

Duncan Fund Report

Over the last few years the Sir Thomas and Lady Duncan Trust has given Polio NZ a generous total $175,000 to assist polio survivors in managing their lives as they age and contend with the late effects of long-term disability. Here, summarised, is the latest report to the Trust of how the money has been used and how Polio NZ sees the wider situation on meeting needs.

The Duncan fund is prolonging independence and enhancing the quality of life of many. So far 92 people have had help, with $107,470 distributed (an average of $25,000 per year.)

The grants have covered:

- Alterations to the home and assistive devices for the home (42%). More than half of that amount was spent on bathroom alterations, also kitchens and other building modifications, and small household equipment
- Transport and mobility equipment (25%) notably wheelchair batteries.
- Rehabiltation programmes (15%)
- Seating (10%)
- Respirators and alarms (5%)
- Footwear and orthotics. (3%)

Official funding criteria misfit

We have been prudent with the funds by examining each application in relation to funding available through the Ministry of Health and the Ministry of Social Development.

The criteria for such funding is often too restrictive to be optimal. The ministry’s need to prioritise the most needy does not account for the polio survivor’s need to conserve his or her motor neurons in polio-affected muscles. For example, a person whose legs are affected by polio may be able to continue walking on crutches for years longer if they use a ramp instead of steps. But the MOH criteria for funding a ramp requires that the person is no longer capable of using steps at all. For a polio-affected person to continue using steps until they cannot do so will certainly mean that they will end up needing a wheelchair much sooner than if they had been using a ramp.

We can confidently report that the money provided by the Duncan Fund is prolonging the independence of people who have had polio and enhancing the quality of life of many individuals.

Similarly, the funding of a wheelchair for a polio person who is still able to get about on crutches or with a stick(s), does not meet Ministry criteria. Rather than being proactive and funding prudent use of a chair when someone is fatigued, the policy makes them keep on getting around using their aids, which will result in a greater decline.

There are many examples where funding criteria don’t taking into account the late-effects of polio and where we have thankfully been able to assist due to the Duncan Fund.

Critical gap in available services

The lack of access to health professionals familiar with the research into the late-effects of polio or even an understanding of the original damage done by the polio virus, remains the greatest struggle for polio survivors living in New Zealand.

Thirty-plus years of research into the late effects of polio shows that before embarking on any rehabilitation programme, a full-body muscle assessment must be done to clearly determine which muscles can and should be exercised – and which should not, to ensure the person’s condition is not worsened.

We have anecdotal evidence that many of those who had polio have had to shorten their working life (with consequent loss of independence) much sooner than would have been necessary had they been attended to by those with appropriate knowledge and understanding.

Application forms for grants from the Duncan Fund are available from Polio NZ secretary or treasurer.

Contact details on p.2.

Services available elsewhere

Recognising that the damage done by the polio virus included critical areas of the brain, clinics have been established elsewhere, (Europe, the United States and Western Australia) that take a holistic and collaborative approach to the management of the late effects of polio.

Neurologists, physiotherapists, occupational therapists, psychologists, nutritionists, sleep and respiratory specialists are all available in the assessment and ongoing management process.

The programme begins with a full-body muscle assessment and a rehabilitation programme is designed for each individual based on the results. Such insights ensure muscle groups weakened by polio are not over-worked, protecting vulnerable motor neurons.

This process is repeated every five years so a body of knowledge is developed on the progress of the individual. This also contributes to research regarding long-term neuro-muscular disability.

Seeking an assessment clinic

One of the principal reasons for the formation of the organisation that became Polio NZ Inc. was to establish such a clinic in New Zealand.

It has facilitated 25 years of conferences with presentations from international experts on the late effects of polio. These researchers and practitioners have made it very clear that there is a great deal that can be done to slow the process of degeneration caused by the late-effects of polio.

Past presidents of Polio NZ have spent many hundreds of hours making submissions and meeting with successive Ministers of Health. Despite many promises, nothing has eventuated.

(Note: The Board recognises that Rotorua's QE Health does offer a programme that some members find beneficial, but it does not yet offer the individualised full body assessment that is best international practise.)

The current Polio NZ Board has re-examined this situation and is actively engaged in research and preparation for a business case to establish a late-effects of disability clinic here.

There is an encouraging level of skill and energy represented in the board, particularly the three new members, Gordon Jackman, Sue Griffith, and Penny Humphreys, supporting President Barry Holland.

In the last few months the board has made good progress in determining the key stakeholders and initiating conversations with those in education institutions that will be able to assist with the required research. This includes pending discussions with Massey University with regard to the utilization of the Sir Thomas and Lady Duncan Scholarship for neuro-muscular research, and engagement with students at AUT in Auckland.

Clinic relevant to others

New Zealand will conceivably remain polio-free into the future and in a couple more decades the treatment of those who had polio will no longer be needed. However, there will always be a need for a facility that specialises in the care of those with long-term disability such as cerebral palsy and muscular-skeletal injury.

Future with the Duncan Fund

Polio NZ will gratefully continue to administer the Duncan Fund for the support of individual applicants.

The committee's report calls the Duncan trustees' attention the development of Polio NZ's Strategic Plan. In time this will significantly change the circumstance of everyone in New Zealand living with the late effects of polio – and ultimately all who are aging with and experiencing the late effects of neuro-muscular disabilities in general. •

Members of the Duncan Fund Committee are JB Munro (chair), Jeannette Aldridge and Diane Mathews)

At present the New Zealand public health system does not recognise that aging with long-term disability requires specialist attention beyond the disabilities caused by aging itself. As a result, people aging with life-long disability in New Zealand are seriously neglected often resulting in unnecessarily severe conditions which if addressed in a timely fashion, could be managed or even avoided.

Hawke's Bay Support Group

by co-convenor Mary Ellen Warren

Eleven polios and friends at our March meeting heard the latest news from the Polio NZ Board, with Penny Humphreys our designated board member to enable information flow back and forth.

Regarding the national Strategic Plan, we thought it useful for polio to link into research on aging, and look forward to hearing more about the pilot retreat and activities planned for World Polio Day in October.

Wine, conversation, and lunch followed. Thanks to our hostess Jean Lane and the staff of Mary Doyle café.

I gave a mini presentation on self-advocacy using my celiac condition as an example of how sometimes we must say no thanks when we call it quits with a doctor, or make things inconvenient for family. Thanks are due to businesses like Air New Zealand that accommodate health needs with good will.

The internet has pluses and minuses. The US Post Polio Facebook group had users making use of the site for business purposes in the guise of friendship!

But I do recommend the British National Health System. Their site called Choices, "developed to help you make choices about your health" is very much in keeping with self advocacy and the Strategic Plan. (see www.nhs.uk and search on 'polio')

However my number one self-advocacy recommendation is to encourage use of support groups such as Polio NZ, who provide a forum for sharing practical information and inspiration.

Polio NZ has a Facebook page...

...and you don't have to be a FB member to look at it.

It's a public page open to anyone to read. You just can't post to it without joining.

It states: *This Facebook page is for polio survivors, their family, friends and supporters to share information and ideas and connect with other polio survivors.*

We also hope that anyone who had polio in the past register with Polio NZ so that we can better understand how many polio survivors there are in New Zealand and so better advocate for us.

Rotary raffle for Polio Plus:

NZ $5 note signed by Sir Edmund Hillary in collector pack

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