Polio NZ Inc

POLIO NEWS

DECEMBER 2015

World Polio Day at Parliament 2015

Polio New Zealand, Rotary and CCS Disability Action were hosted at a World Polio Day event on Oct 20th 2015 at the of Parliament's Beehive. The event was also well attended by members of all three groups and associated colleagues plus 17 MPs from across the political spectrum. The hosts were Catherine Delahunty from the Green Party, Paul Foster Bell from National and Barbara Stewart from New Zealand First.

Barry Holland spoke lucidly (see page 3) for Polio New Zealand about the importance of the global "End Polio Now" campaign and how support is also needed for the polio survivors of the world, including the estimated 5,000 in this country. Polio New Zealand is stepping up its advocacy for polio survivors who need to be recognised and have their health needs addressed.

Anthony Scott spoke passionately (see page 6) for Rotary about their extraordinary global campaign which has helped to eradicate one strain of polio and has seen a huge global reduction in the other strains. Only a few countries are seeing new cases of polio and they are in areas where violence and war are preventing vaccination.

David Matthews of CCS Disability gave a great speech (see page 12) about the vital need for an inclusive society which values all people and meets all needs.

It is hoped that the event was the beginning of a new era of cooperation between the three groups and also a chance to raise the awareness of a number of MPs, most of whom were unaware of the number of New Zealanders currently affected by polio. We look forward to further collective action to support polio survivors and ensure they recover the political recognition and practical support everyone deserves

Catherine Delahunty

Paul Foster Bell

Barbara Stewart

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 or October.

Polio News is published three times a year (usually April, July 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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Polio NZ wishes Rosemarie Smith and her husband Maurice Barker all the best as Maurice recovers from a significant stroke. Our thoughts are with you.

Gordon has put the Newsletter together so apologies for the amateur layout. Many thanks to Penny Humphreys, Jeanette Aldridge and Susan Kerr for your contributions and assistance. Thanks also to David Sercombe of the Karori Rotary Club for the photos of the Parliamentary event

Barry Holland's address to Polio reception, 20th October 2015 at Parliament

We are gathered here tonight to celebrate World Polio Day for three reasons. The first is that the world, thanks in large part to our friends in Rotary, is very close to eliminating polio in the wild. One of the three wild strains, strain B, is already extinct. Africa has been declared free from polo for a year and so has India. The last remaining wild infectious strains are in war torn Afghanistan and Pakistan, and just lately in the Ukraine and there is real hope, despite the conflict, that these will be extinct by 2018. The hardest part is always just before the end so now is the time to increase the support for 'End Polio Now"

The second reason is to remember that 80 years ago Rotary funded the Crippled Children's Society to deal with the Polio epidemics that terrified the country and be thankful for all the good work that they did and are still doing.

The third reason, from polio New Zealand's perspective is to announce that "We are still Here" all people who have survived polio – a disease that most think has disappeared from NZ, but "We're still here". We don't know how many there are of us, so we are about to do a thorough epidemiology study with AUT – we think it is over 5000 of us who caught it in NZ before 1961, that last year of multiple infections. We do know that there are also quite a few polio survivors who have immigrated and many of them are quite a bit younger. Most of us have led very active lives despite of or as a result of having polio. However we now find that many of us are having to live with the late effects of polio, or Post Polio Syndrome, as it is sometimes known, where the original symptoms are coming back to haunt us in varying degrees.

The biggest hurdle is ironically a symptom of medical success, because what we find is that very few doctors, physiotherapists and other professions now have any training in dealing with the late effects of polio. Rather than use it or lose it, we have to pace ourselves in a very controlled manner, to retain our functionality. We need very specialised orthotics to keep mobile and sadly very often we don't get this.

As a neuromuscular disease we react differently to anesthetics and pain killers and this knowledge is not widely disseminated through the medical profession and the list goes on.

However being the experienced survivors that we are we have a plan. What we need in New Zealand is a dedicated centre of excellence devoted to those with long term neuro muscular disabilities, of which polio is one, who are also coping with the effects of aging. Australia has two such clinics, one in Sydney and one in Perth, and there are many in North America and Europe, but we do not. We need a place or places, preferable at least one in the South Island and three in the North Island where we can go to get an expert assessment of our condition, get an appropriate supported program to enable us to live independent and full lives in our homes for as long as possible. We believe this will be not only good for us, but save the government and DHBs the expenses associated with rest home care and unnecessary medical cost.

We believe there needs to be an in depth inquiry, possibly by the health select committee, into the needs of the long term neuro muscular disabled and ageing as the combination presents unique challenges and requires specialist knowledge and experience. There is no dedicated program in this country to the needs of people who have survived a life time of disability, people who still deserve the best quality of life possible in their old age, rather than being left to die off so that the problem goes away.

Polio New Zealand is currently exploring the concept of a clinic with the Ministry of Health, AUT, Massey university, QE hospital in

THE INTERNATIONAL PREVALENCE OF POLIO: A SYSTEMATIC REVIEW

Notes from funding application - see Programme Manager's report - page 14

"The battle against polio will not be won until the global community can assure those who live with the disabling consequences of polio that their needs will be met and resources will be made available to enable them to function fully and freely in the societies in which they live - now and in the decades to come."

Grocea et al., 2014

In New Zealand (NZ), accurate estimates of the prevalence of polio and improved understanding of the needs of those with previous polio will be of considerable significance for informing; 1) the growth of Polio NZ Inc services; 2) optimum planning of resources/ services and support at regional and national levels; and 3) to increase awareness of polio prevalence and outcomes in NZ. The absence of reliable NZ prevalence and outcome data means that it is challenging to determine and ensure that that the services and supports available map onto the needs of people living post-polio.

In the absence of evidence-based figures around prevalence, it will continue to be difficult for organizations such as Polio NZ Inc to effectively advocate for polio survivors. It is difficult to credibly engage with government agencies on behalf of constituencies with little evidence base to draw upon. Determining national and regional prevalence estimates will provide a solid base from which to inform the planning of services and resource allocation for people with polio. To the best of our knowledge, there are no international population-based prevalence studies of polio conducted worldwide. Undertaking a systematic review of the international prevalence of polio survivors to inform estimated rates within in NZ and will provide a sound platform from which to seek funding for a prevalence study in NZ.

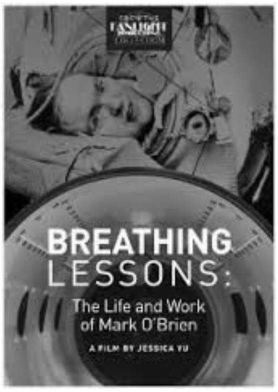
p. 177 Grocea, N. **E.,** Banks, L. M., & Steinc, M. A. (2014). Surviving polio in a post-polio world. *Social Science and Medicine, 107,* 171-178. doi:10.1016/ j.socscimed.2014.02.024

Rotorua and other neuro muscular organisations and so far we have had a very positive response. We can contribute considerable expertise because of our international connections, to provide training and share knowledge with the clinicians who will run our clinic in New Zealand. We are not at the stage yet to present any formal proposals to either the Government or DHB, as we have some work yet to do but we would like to start the conversation as ***we are still here***, we are not going away any time soon and we believe that what would be good for us would benefit many others with disabilities in the years too come.

Breathing Lessons

A Documentary Review

By Penny Humphreys



"The two mythologies about disabled people break down to: one, we can't do anything; or two, we can do everything. But the truth is, we're just human." So states Mark O'Brien, American poet, journalist, writer and disability advocate.

Mark O'Brien (31/7/49 – 4/7/99) is the subject of Jessica Yu's documentary, a 35 minute stunning and intimate insight into O'Brien's struggles and triumphs . His struggles to initially survive, to have autonomy in expression, in independent living, in his relationships and in expressing his sexuality.

Polio left O'Brien paralysed apart from a muscle in his foot, hand and neck. Reliant on an iron lung or portable breathing equipment, he strived to elevate his physical self through poetry and writing, both of which are skillfully woven in his own voice throughout the film.

I was mesmerised by this artful watch – it is real, poignant and at times, raw. A truly moving and thought provoking representation of O'Brien who through his honest representations of his deepest thoughts and needs, addresses the issues central to us all as human beings but especially as human beings with disabilities.

Please take the time to view the documentary http://www.snagfilms.com/films/title/breathing_lessons and perhaps follow it up with Cheryl Cohen Greene's Ted Talk https://www.youtube.com/watch?v=gds2RvmCBKE. Cheryl explains her work as a sex surrogate and devotes much of her talk to her work with O'Brien and the profound influence he had on her.

Life Membership awarded to JB Munro, QSO.

By Susan Kerr

At the Annual General Meeting for Polio NZ Inc a motion was unanimously supported in favour of conferring Life Membership on JB Munro (JB). In so doing, JB is acknowledged for the many years of service that he dedicated to the organization, as an Executive Officer for 13 years in the capacity of Secretary and Treasurer and towards the end of his Board career, as Vice President. .

The previous evening, at the Parliamentary celebrations for the forthcoming 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. JB was unable to be present at either of the two days, but Anthony made special mention of him at the event remembering his loyal support of Rotary and all the work he had done over the years.

I discovered that JB first joined Rotary with the Dunedin Club in 1963. 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.

The first time I 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 teased at school as a teenager with a caliper, and after several attempts could not achieve School Certificate.

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 began working as 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 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.

He felt that he could make a better contribution towards making a difference by entering politics and served for six years as a City Councilor in Invercargill followed by three years as Member of Parliament for Invercargill. He lobbied for the drafting of the *Disabled Person’s Community Welfare Act* which was passed into law in October 1975 and set the standards for access to buildings, recognized 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 retired from the position of CEO . He was made a Life Member, and in 2014 was inducted into the Attitude Hall of Fame for lifelong service to the disability community.

Other honours include (2010) The Abbeyfield International Royal Patron's Award. 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 biography by Dr Hilary Stace. Thanks for all your work for us, and encouragement. See you soon JB! *Ka kite ano.*

Anthony Scott, Immediate Past District Governor, Rotary International District 9940, New Zealand address to Polio reception, Parliament, 20 October 2015

I am here as a representative of tens of millions of Rotarians around the world who have raised money and worked over the past 30 years on the great mission to eradicate polio. Many here tonight have personally put those drops of life saving vaccine onto the tongues of youngsters in India and other countries.

We have a remarkable set of anniversaries to celebrate tonight. They also remind us to look forward, because the work is not yet done.

It starts with polio, a scourge that has been around thousands of years.

The anniversary we celebrate first is the formation of Rotary, 110 years ago this year, in Chicago, USA. Of course, none of the four men who formed that first club had any inkling that Rotary and polio would one day be so connected. They did not even know they were forming the world's first service club. Their focus was creating trusting fellowship amongst business leaders, and fostering business and personal integrity.

Yet within ten years a club in Ohio had formed a Rotary Crippled Children's Committee to help children and their families affected by polio. That's our second anniversary. Like Rotary itself, that idea quickly spread around the Rotary world.

New Zealand's first Rotary club was established in Wellington in 1921. The first big project was funding the building of Wellington's Karitane Hospital. The next big push was to establish the New Zealand Crippled Children's Society. That becomes our third anniversary tonight: 80 years.

Our fourth anniversary: the last polio epidemic in New Zealand was 1955-56 – 60 years ago. And our fifth anniversary: 50 years since New Zealand's last recorded case of polio, in 1965.

Those last two anniversaries are due to the development of the Salk vaccine in 1955, and the Sabin oral vaccine in 1960. We celebrate those anniversaries tonight as well.

But as polio was eliminated from New Zealand and increasingly the rich west, it still remained a scourge to most of the world. And, in the age of the jet plane, polio was just a plane ride away.

So 30 years ago, in 1985, Rotary globally took on what many described as an impossible dream – to eradicate polio from the face of the earth. If it could be done with smallpox, why not with polio?

In 1985, an impossible dream; 30 years on, we are "this close".Nigeria was recently declared polio free after a year without a single case. This time last year, the world had 359 cases across 9 countries. Today, 48 cases in two countries – 36 in Pakistan and 12 in Afghanistan.

So, there are many milestones to celebrate tonight. They are impressive statistics but the drive has always been about the people.

I want to mention one person in particular, which is so appropriate to meeting in this place. In 1972, a polio survivor called JB Munro came here as MP for Invercargill. He was here only 3 years but in that time he played a major role in developing rights for disabled people. JB's legacy is the Disabled Person's Community Welfare Act, 1975. That Act, 40 years ago, deserves celebration alongside all the other anniversaries tonight.

As a Rotarian from that first club in New Zealand, I know that Rotary has a tradition of establishing, nurturing and then letting go groups such as CCS Disability Action. CCS has long been in charge of its own destiny. I suspect that the many Rotary clubs and many individual Rotarians currently involved with CCS may not know of the history, so it is good to see this partnership re-formed.

Fewer and fewer New Zealanders have direct experience of polio. Polio NZ Inc is a reminder that while only 48 people in the world have contracted polio this year, millions still suffer its effects; and that those affected people in our communities need a strong and continuing voice

Anthony Scott continued….

and the active support of all of us.

Sometimes I hear people ask why so much effort is going into eradicating the final pools of polio, in far-off countries. It costs tens and probably hundreds of millions of dollars, and surely we have better things of greater urgency closer to home on which to focus our time and money. I won't offer a cost-benefit argument or econometric analysis. It can be done, but I want to speak to you as a father.

In 2008, a student at a Melbourne university went back home to Pakistan for holidays. When he returned to Melbourne, he had a fever. Thankfully, the doctor recognised the signs of polio. All the passengers on that flight were urgently contacted and precautions taken.

My daughter goes to the Australian Tennis Open in Melbourne. She could have been in the seat next to him on the tram, at the stadium, at a café. Polio is only a plane ride away. So that young man's health, and the health of his family and wider community in Pakistan, is as crucial to me as is the health of my daughter. We are all linked. That link, however, is not just about fear of contracting a dread disease – it is a linkage born of our common humanity. He and his community deserve to be free of this fear as, largely, are we. That linkage was the driving force for Rotary, from the start.

The profound concern for our common humanity has impelled everyday examples of courage. I cannot imagine the courage it takes to go out into areas where you know that fellow polio workers have been killed to prevent them delivering those vital two drops. More than 70 polio workers have been killed in the past four years. Yet, they continue to serve.

So tonight we celebrate 80 years of CCS Disability Action serving New Zealand; 60 years since the Salk vaccine and 55 years since the Sabin vaccine; 50 years since New Zealand's last polio case; 40 years since the landmark Disabled Persons Community Welfare Act; and 30 years since Rotary committed to eradicating polio from the world.

We can celebrate that New Zealand has achieved the goal here. Tonight, we renew our commitment to making that dream become real for our brothers and sisters elsewhere in the world, and to supporting the polio-affected community here.

Thank you, everyone here and to the organisations that you represent, for all that you have done and the inspiration you are. Rotary is proud to have had an impossible dream, to have played a part alongside many others in helping it come true, and we will continue to play a role for as long as it takes.

Can you help?

Julia Squire from the Wairarapa support group asks: Next year I will be having a hip replacement in my good right leg. My left leg is completely paralysed and I wear calipers on my left leg. Has anyone out there had this experience and if so how did you cope and have you any pointers that aided you recovery? Was there anything that you were able to communicate to hospital staff that made them understand the issues that you faced? Please reply to gjackman@clear.net.nz so we can pass it along to Julie and publish in the next Polio News as this is a situation that many of us may face in the future.

Gratitude Corner

"To educate yourself for the feeling of gratitude means to take nothing for granted, but to always seek out and value the kind that will stand behind the action. Nothing that is done for you is a matter of course. Everything originates in a will for the good, which is directed at you. Train yourself never to put off the word or action for the expression of gratitude."— Albert Schweitzer

Highlighting conference speakers

Carol Vandenakker-Albanese

Physical Medicine & Rehabilitation, University of California-Davis
Medical Centre, USA

Dr. Vandenakker Albanese has clinical interests in diagnosis and non-operative care of spine conditions and problems related to sequelae of polio. She speaks locally, nationally and internationally on topics related to spine care and the management of polio-related conditions. Dr. Vandenakker-Albanese is well-known for her expertise in post-polio syndrome and established the UC Davis Post-Polio Clinic in 2001. She serves on the Board of Directors and the medical advisory board for Post-Polio Health International as well as several local post-polio support groups. Dr. Vandenakker-Albanese reviews manuscripts for multiple medical journals and has authored several book chapters and peer-reviewed journal publications on topics relating to aging with disability, and rehabilitation of spine and post-polio conditions. As the department's Mentoring Director, Residency Program Director and as a Faculty Mentor for the medical school, she promotes quality medical education and fosters professional development.

To get an idea of the kinds of services a Late effects of Polio clinic might offer have a look at Carols exellent video at:http://www.polioplace.org/comprehensive-post-polio-management or visit http://www.postpolionetwork.ca/pdf/vandenakker_presentation_20152.pdf

Thinking of going to Sydney? Keep an eye on the 2016 Australasia-Pacific Post-Polio Conference webpages: vvvvw.poliohealth.org.au/conference-sydney-2016/

EDITORIAL HIGH by Penny Humphreys

Speaking of Gratitude

Mark O'Brien, American poet, journalist, writer, disability advocate and polio survivor is accredited with the following quote, *"The two mythologies about disabled people break down to: one, we can't do anything; or two, we can do everything. But the truth is, we're just human."* So very true and being human we need others, we are social beings who thrive in communion with others of our species and progress in cooperative enabling relationships.

In October Polio NZ reached out to commune with our historic enabling partners; those of Rotary and CCS. Initiated as much by the 80th anniversary of CCS (Crippled Children's Society as we knew it), and Polio NZ Inc. Board's desire to raise the profile of polio survivors in this country, the drinks and nibbles event in Parliament was a night to behold. Rotarians, CSS and Polio NZ representatives spoke eloquently as did Members of Parliament from most of the parties. And there could be no mistake that the subject of polio was to the fore. Polio of the past, polio internationally and New Zealand polio survivors needs going forward. Pledges of interest and help from the movers and shakers be they at the political helm, from within the charitable service or advocacy agency. The good will toward polio people in this country is nothing less than amazing.

Polio survivors might not be able to '*do everything*', but what is recognised is that with those and numerous other cooperative and collaborative relationships, together, we can achieve great things. It might not happen quickly but an assessment system for long term neuromuscular conditions will I believe eventuate within this decade.

Drinks and nibbles October 20th was for me, '*polio pride*' in action. I felt uplifted, acknowledged, elated and perhaps for the first time, indeed for the first time, able to 'live' fully in the 'I had polio' moment. Somewhat at peace, not needing to prove anything and, feeling an acceptance like never before, that was a night to indeed be grateful for and one that will live on in my memory.

Book Reviews By **Mary Ellen Warren**

The Polio Paradox

I wish I had read this book 10 years ago. The Polio Paradox, by Richard Bruno, is not an easy read, is some 350 pages. And it is not the latest news, having been published in 2002. But it contains comprehensive information that will help you answer those "what if", "what about" and "why" questions that you have about post polio syndrome. It has changed my life in two major ways. I will be eating more protein, particularly at breakfast. I will be paying closer attention to anaesthetics. My dentist has already come on board and said he is now prepared to treat me based on post polio syndrome parameters. And so bring on that root canal. Or as the old saying goes, "what you prepare for never happens".

Mind Over Muscle

Denial that is me. I was loaned a copy of Mind Over Muscle, Surviving Polio in New Zealand by Karen Butterworth. It sat on the edge of my desk for 6 months unopened. Then I gave it a go and got through 79 pages. And then I gave up, it was too painful. Although the post polio survivor's stories are full of grace and positivity, the description of the respirators and callipers and ambulance rides brought back memories that were too difficult for me to take. On the other hand the book was an easy read for my husband, he was pleased to find it filled in some missing bits about polio and indirectly about me. So get a copy if it isn't a great read for you it may be very important for someone dear to you.

Hawkes Bay September Meet

Ten polios and partners attended our lunch and talk at Mary Doyle Retirement Home, Havelock North on 17 September 2015. We fondly remembered Bruce Welby who passed away suddenly. Penny Humphreys and David Hodgkinson spoke at his funeral on behalf of the group. We will keep in touch with Bruce's family and attempt to fill the important role Bruce played in keeping polio top of mind with Napier Rotary.

Penny Humphreys updated us on the National Boards activities including plans to gift copies of Managing Muscles and Mobility to the DHB and provided a heads up on the Australasia-Pacific Post-Polio Conference 2016.

Jenny MacQueen provided a copy of the Western Australian polio newsletter. She is pleased to have a GP who trained in Egypt and has had experience with polio first hand.

Our speaker was Dr Phillip Baker, neurologist with our DHB. In 1989 the NZ Medical Journal published Mr Baker study of 20 clients presenting with polio. Mr Baker provided an overview of his study with additional findings of studies by the Mayo Clinic and in Brazil.

Some points by Dr Baker:

1) Our strength does decline with late effects of polio
2) We need to be cautious with anaesthetics especially paralytic drugs

What we can do about it:

1) Not to 'overdo it'
2) Exercise in a non-fatiguing way
3) Ensure ventilation at night
4) Possible consideration of anti-inflammatory drugs

The next meeting of the Hawkes Bay group is Saturday 12th December. A pot luck end of year lunch at MaryEllen and John Warren's home. All welcome.

The Christchurch Post Polio Support Group

On World Polio Day a group of 6 of us spent the day at the South City Mall with a display of brochures on Polio. We had a lot of interested people approach us, some had never heard of Polio. Two nurses were among the ones that took information, one from England and told us she had been studying about Polio and the other one was at CPIT here and was doing an assignment on it and needed information and peoples experience's with it. She later rang me for my Life With Polio which I sent thru to her.

Then on Friday the 30th October Alison Walshe and myself went to the Burwood Hospital and presented the book The Late Effects of Polio Managing Muscles and Mobility to Nicola Rooney the head of the Physio Department and they were delighted to receive it. A photo and an article went into *The Mail* which has proved to be a success, as I have had a number of people ring me about it wanting to order a copy, get more info about Polio and to join our group - was well worth the effort.

The 14th-21st November 13 of us went on our yearly Hamner Retreat. We thoroughly enjoyed the delightful therapeutic pools and a relaxing time was had by all.

Dr Phillip Baker

News Briefs

Cell Phone Technology in the Fight against Polio

Conflicts and earthquakes had been distracting vaccine efforts but with a push against the Taliban in North Waziristan and collaborative commitments to the vaccine program from security and health agencies, the Pakistan army and telecommunication providers, families previously unreachable are being vaccinated.

As a result of the armies activities in the North Waziristan area more than 100,000 families were evacuated. They were stopped at roadside checkpoints and required to take a drop of polio vaccine. When later registered at refugee camps they were given free SIM cards for their phones. Used to alert families to cash assistance, health officials also used the cards to track clusters of resettlement, setting up polio eradication centres in the areas.

Pakistan has reported 40 new polio cases this year, compared with about 240 at this time last year. Pakistani officials say they believe they are on track to vaccinate nearly all children younger than 5 by next summer.

Meanwhile in Afghanistan vaccinators have been unable to reach 30,000 to 60,000 children because security has worsened in eastern provinces, in part because Pakistan's military's drive of militants across the border. So far this year, 13 new polio cases have been reported in Afghanistan, a slight increase over last year's figures.

Ukraine undertakes Mass Vaccination Program

A nationwide vaccination campaign was launched 21 October following the September announcement of a 10 month and 4 year old child having contracted polio in south west Ukranine.

The World Health Organisation (WHO) is assessing the risk and potential routes of virus transmission within and beyond the borders of Ukraine. The risk of further spread within the country is deemed to be high due to low polio vaccine coverage. The campaign will initially target 2.85 million children under the age of 6, followed by two additional rounds, with one targeting 4.75 million children up to 10 years.

WHO currently considers that the risk of international spread from Ukraine is low but notes that the infected area shares borders with Hungary, Poland, Romania and Slovakia. The WHO continues to closely monitor the situation.

Human Faeces and the Eradication of Polio

The eradication of polio from a country may start with mass immunisation of infants and children but it is ongoing surveillance that is keeping the lid on the disease. In an article entitled. *'Africa's Year Without Polio: The unglamorous but effective global search for every last trace of a terrible disease'* by Jay Wenger, the reader begins to understand the significance of surveillance, both in confirming polio in the paralysed child and detecting where the virus is lurking within the environment.

The excrement of the infected child contains the polio virus which can in turn infect other children. However, as only an average of 1 in 200 people infected with polio exhibit symptoms, the other 199 will still be excreting live virus into the environment. Using this vital indicator of virus activity, the global polio program has established extensive networks dedicated to collecting and testing stool samples, both from children showing signs of paralysis and from community sewage systems.

Environmental surveillance has proven tremendously valuable. In 2014, polio was found in the sewage system in Brazil during the World Cup. In 2013, this practice helped Israel's surveillance system locate polio circulating in the country's sewage for the first time in more than a decade. If undetected, small blips like these can lead to outbreaks. When spotted in advance, health workers have the chance to respond quickly with immunization campaigns.

For the full article enter the following on the Google search bar.

http://www.slate.com/articles/health_and_science/medical_examiner/2015/08/no_new_polio_in_africa_for_one_year_gates_epidemiologist_on_vaccines_and.2.html

David Matthews, CEO CCS Disability Action address to Polio reception, 20 October 2015 at Parliament

Greetings to you all. Thank you for the opportunity to say a few words at this celebration event for World Polio Day. Today we are commemorating many things; a national organisation that has been around for 80 years; the inspiration of our Rotary founders who decided to take action to address issues for a group of people (young children with disabilities) that they felt were not getting a fair go; the hard work and dedication of Polio New Zealand who are providing support for people who have had poliomyelitis through information sharing and other forms of assistance to members and their families.

I want to acknowledge those who organised this event and all those who have attended. Thank you for being here with us today to reminisce about the past 80 years, celebrate about today and provide encouragement for the work ahead. Yes there is a great deal to celebrate to day – much to be proud of.

I want to firstly say what an honour it is to be leading this organisation at this time. A time when we are seeing at last some positive signs of progress in the lives of disabled people yet at the same time we know there is still much, much more to be done. Today is something special – the chance to connect with two other organisations, share stories about past achievements and commit ourselves to even greater achievements in the future.

The story of our founding is a great one. It reminds us what happens when an organisation, in this case Rotary, decided that they wanted to do something for a group of people (children with poliomyelitis) who they felt were not getting a fair go. They could have spent time and energy trying to convince Government to do more or, as they decided to do, get on and do something themselves. Hence in 1935 they decided to set up a network of branches of what was called the Crippled Children's Society and within two years it had gone nationwide – a tremendous achievement.

Rotary was also behind an early example of direct action on behalf of disabled people. A number of Rotary wives who were concerned that young children were being denied an education by concerned school principals. Decided that they would literally push these children to school and demand they received an education – and they did!

CCS Disability Action is in good heart and despite all the uncertainties that sit around our changing sector, funding challenges and the lack of clarity around government policy directions and our place in them, I am confident we have the talent, energy and resolve at all levels of this organisation to continue to make a real difference for disabled people and their families. We also have the will, talent and experience to bring about real change in communities.

We would like to be around for another 80 years but only if there are still unmet needs. We have only got to where we are today by sheer hard work; by being determined to be at the forefront of change, by evolving to meet the needs of disabled people as well as government requirements, by investing our precious resources in innovative practice and by being staunch about our values and principles. We will never ever accept anything less than a fully inclusive New Zealand in all aspects of life. That is what we stand for.

So what will we see when we have reached this goal?

- Children with disabilities can go to their
- local school or local early-childhood Centre without any fuss or barriers in their way
- Disabled students transition from school to the next phase of their life with a plan and challenging goals
- That disabled people are expected to work

David Matthews continued…..

and if this is not possible at the time, to engage in meaningful activities not just in their community but with their community.

- Disabled people can live in the home setting of their choice and not someone else's home or someone else's decision.
- All our public buildings are accessible and homes are designed with the changing needs of a person built into the core design

The older disabled people have access to the same choices as in their younger years

At the end of the day, it all boils down to attitude. We can make the built environment more user friendly, we can put in place support systems to remove barriers and we can develop individualised programmes of support – all this will help but unless people understand the fundamental rights of all people having a fair go and what this means on a daily basis, then the impact of accessible buildings, support and individualised programmes will have limited benefits. This is our great challenge going forward for the next 80 years.

Therefore I am looking forward to a renewed partnership between CCS Disability Action, Rotary and Polio NZ. A partnership that has the potential to challenge limiting attitudes and to create even better lives for disabled people and their families and one that can make this wonderful country of ours a better place for everyone.

Thank you again for inviting me here today.

2006 NZPPS Conference

A room of strangers
fear prickles my mind
doubt drains confidence
I only need
one voice
one hand
one smile

In other rooms
I have sat silently
while others stood and
talked
I have limped and lurched
while boys sniggered behind
pain and fatigue
have caged the bright butterfly within

But here I am
soon among friends
I recognize the kinship
that binds us as one
and unshackles our shining
spirits.

© Susan Kerr 2006

Gisborne support Group

Gisborne Group members meet four times a year to share experiences and hear from a wide variety of guest speakers including the St Johns, Tairawhiti Aging Trust, and Gisborne Pen Pushers Writers Group as well as local lawyer, coroner and councillor, Alan Hall, who did not allow congenital spasticity and cataracts to prevent him from contributing hugely to our community. Gordon Jackman also updated us on new work being done by Polio NZ.

Being able to refer medical staff to good research on the PNZ and Polio Australia websites has been really useful for local members undergoing procedures like surgery. It is great to have easy access to respected sites that have practical advice. Our members are not up to participating greatly in national activities but we do appreciate the work being done by the Board of Management.

We had a stall at a Community Group Festival and attracted considerable interest with our 'Name the Famous Polio' competition, but no new members. Gisborne Herald articles, including a feature item to mark World Polio Day 2015, have also attracted lots of positive feedback but nobody in need of group help. Anyone wanting information about the Gisborne Group should contact Jill Hudson, phone 06-868 5056

Programme Manager's Report

Since starting work as programme Manager for Polio NZ in November I have been busy on the top priority of the strategic plan, namely the establishment of centre of excellence or clinic for the late effects of polio (and possibly other neuromuscular skeletal long term conditions) and aging. We have been successful in the first stage of this project with the approval by the Sir Thomas and Lady Duncan trust of a study by Professor Valery Feigin, Dr Kelly Jones and Dr Alice Theadom, AUT University to 1) provide a systematic review of the literature on prevalence of polio worldwide, 2) Use findings from the systematic review to estimate prevalence of polio in NZ and 3) Use findings to inform a grant application for a full study examining a) prevalence of polio, b) outcomes of polio, and c) the needs of those directly impacted by polio and their family members in NZ. This study will start in February 2016 and give Polio NZ a solid basis for any negotiations in the setting up of a clinic in New Zealand.

I have met with Dr Sally Lark, Campus Leader School of Sport & Exercise and Research Director for Vascular Rehabilitation Clinic Services at Massey University, about the possibility of setting up a pilot clinic for the late effect of polio as part of Massey's clinical teaching establishment. This process will take about a year to go through the planning and approval process, and while there are no guarantees we will learn a lot by giving it a go. Sally is preparing a funding proposal for research into "Whole Body Vibration", (a technique developed to keep astronauts fit in space), and wellbeing for the late effects of polio as they have found it very beneficial for those with Parkinson's disease. Ten minutes on a WBV machine is supposed to be equal to a hours moderate exercise and has been found to be beneficial for the elderly who find prolonged exercise difficult. Watch this space.

I had a meeting with officials at the Ministry of Health to present our statement of intent for the clinic and received a very positive hearing and some very good advice and information. As a result next year I will be asking all DHBs about their capacity to meet the needs of people with the late effects of polio, what they consider they are required to provide and what gaps exist in their annual plans. The MoH have offered to meet with polio NZ with all their relevant officials in the new year to discuss the results and look at ways to provide for our needs. They are also very interested in the outcome of our survey on Orthotics, so I will be contacting every support group in the new years to complete that project. Again nothing concrete promised as yet by the MoH but I felt they genuinely understood our issues and would support Polio NZ's efforts to remedy the situation.

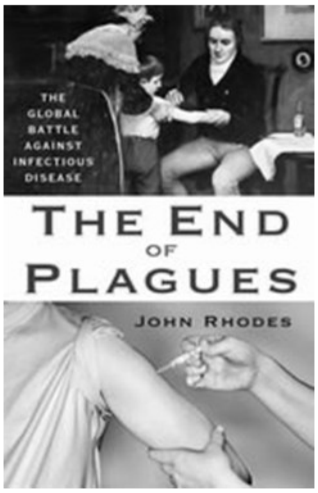
I have also met with Anthony Scott and Michael Fagg of Rotary and David Mathews of CCS Disability action to cement the relationship we formed at the parliamentary celebrations around world polio day and we have agreed to actively look at ways we can work together in the future.

Polio NZ has received an invitation from John MacFarlane, President of the European Polio Union to join with them in the formation of a World Polio Survivors Alliance with the aim of establishing a worldwide virtual centre of excellence and a training facility for post polio clinicians in the UK, This came from a call from polio Survivors, medical personnel and associated disciplines to form an overarching body that could tackle issues affecting them on a world-wide basis. We will be meeting with John at the Sydney conference and look forward to collaborating on this project. It feels like the stars are aligning and I look forward to continuing in the work next year.

I wish you all the best for the festive season, hope you enjoy time with friends and family and feel in the best possible spirits for the year to come.

Book Review

‘The End of Plagues’ by John Rhodes



Spanning three centuries, **The End of Plagues** weaves together the discovery of vaccination, the birth and growth of immunology, and the fight to eradicate the world's most feared diseases. From Edward Jenner's discovery of vaccination in 1796, to the early nineteenth-century foundling voyages in which chains of orphans, vaccinated one by one, were sent to colonies around the globe, to the development of polio vaccines and the stockpiling of smallpox as a biological weapon in the Cold War, distinguished immunologist John Rhodes charts our fight against these plagues, and shows how vaccinations gave humanity the upper hand. Today, aid groups including the Bill and Melinda Gates Foundation and the World Health Organization have made the eradication of polio a priority, and Rhodes takes us behind the scenes to witness how soon we may be celebrating this goal.

For more information on this book visit http://www.post-polio.org.uk/theendofplagues.html

The Duncan Fund

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 Fund 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

POLIO NZ INC AGM 2015

Thanks to departing board members: Many thanks Ruth Hall from the Christchurch Polio support group for her many years service on the Board and in particular the organisation of the 25th jubilee in Christchurch. We wish Ruth all the best and will be staying in close contact with her and the Christchurch Group. Many thanks as well to John Forbes who has served as our Kaumatua and valued representative from the Waikato. John has indicated his willingness to continue to support Polio NZ wherever he can; and we intend to take him up on this and we wish him well in his busy life.

and welcome to the new:

We are very fortunate to have **Judy Lawley** from West Auckland join the Board. Having served as a Councilor in local government and Chair of many Trusts and Committees for many years, Judy has strong networks, including Rotary and Members of Parliament. Judy's strengths in analytical and strategic thinking and business experience will be invaluable to Polio NZ

Judy Lawley

We welcome **Susan Kerr** from Blenheim back to the Board having taken a break for a few years to rest and recuperate after serving for four years while she was also a director of IPPSO International Post-Polio Organisation. With the delightful disposition of a musician and a poet, Susan brings practical secretarial skills, writing, and an enthusiasm for social networking – a regular presence on Polio New Zealand Facebook and other international polio sites.

Susan Kerr

Brian Robinson from Nelson has been a member of Polio New Zealand for about 10 years and has been coordinator for the Nelson area for the last 3 years. This is his first year on the Board. Brian has been effective in raising awareness about polio by getting articles in local media and with the support of his family, Brian is keen to help the Board promote other awareness raising events and activities.

Brian Robinson

Heather Hopson has been a member of Polio NZ for the past 12 years and this is her first year on the Board. She has worked in sole charge office administration for 30 years handling everything from payroll to answering the phone. Heather has been a volunteer at Citizens Advice for 7 years. She is a strong advocate for *the "We Are Still Here"* campaign.

Heather Hopson

Stephen Griffiths from Auckland was born in England where he contracted polio at 18 months old. He's been in New Zealand for 40 years and like most Kiwis he loves the sea. Now living in Auckland with his family, Steve has been running his own business (Tileworks) for the last 22 years. With an ambitious programme in front of the Board in his first year, Steve's head for business will be a great asset.

Stephen Griffiths

Many thanks to **Barry Holland**, President, **Sue Griffen**, Vice President, **Jeannette Aldridge**, Secretary, **Dianne Mathews**, Treasurer, and **Penny Humphreys** who have all volunteered to serve on the board for another year.

Nancy Blackstock (pictured here with Mayor of New Plymouth Andrew Judd) served on the Board from 2013 to 2015 with one year as Vice President. Nancy stood down from the Board at the 2015 AGM but has taken on the role of Chair of the Duncan Fund Committee.

Nancy Blackstock