

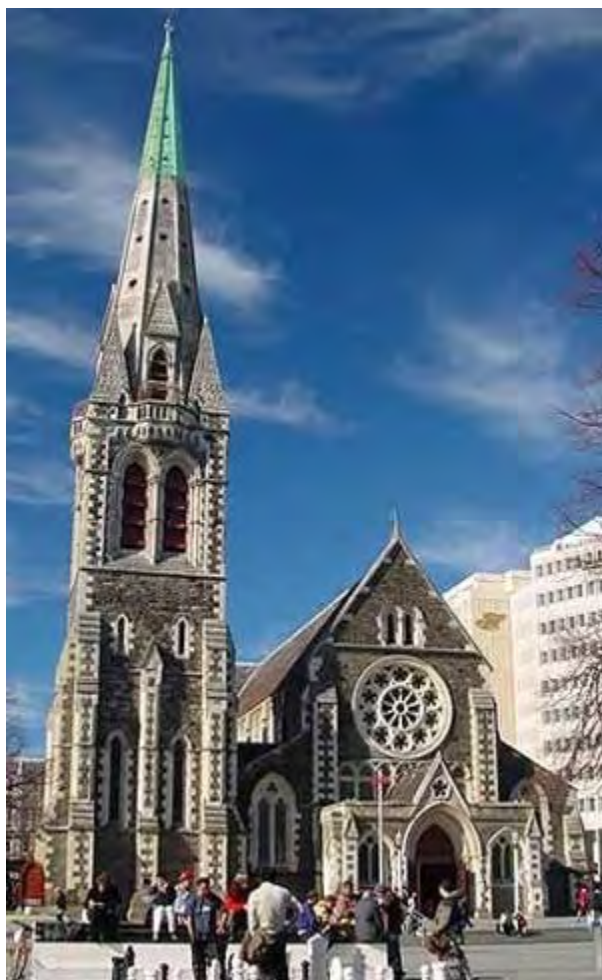


Polio News

Post Polio Support Society NZ (Inc)

March 2011

Christchurch



Our thoughts and prayers are with people of Christchurch at this time.



Scribble

To be crippled
To sit in a twist
Unable to be straight.

To reach out and topple over into the
bend.
No balance at all.

Scoliosis
The mark of polio
Uneven as a scribble
No way to unwind and rest.

Anon

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Christchurch: Before and After the Earthquake



I was sent "Before and After" photos showing thirteen buildings in the city. They clearly show the devastation. I publish this pair to exhort PPSSers to help Christchurch in whatever way we can. Ed.

Post Polio Syndrome

Post-polio syndrome (PPS, or post-poliomyelitis syndrome or post-polio sequelae) is a condition that affects approximately 25–50% of people who have previously contracted poliomyelitis - a viral infection of the nervous system - after the initial infection. Typically the symptoms appear 15–30 years after recovery from the original paralytic attack, at an age of 35 to 60.

Symptoms include acute or increased muscular weakness, pain in the muscles, and fatigue. The same symptoms may also occur years after a non-paralytic polio (NPP) infection.

The precise mechanism that causes PPS is unknown. It shares many features with the post-viral chronic fatigue syndrome, but unlike that disorder it tends to be progressive, and as such can cause a tangible loss of muscle strength.

Treatment is primarily limited to adequate rest, conservation of available energy, and supportive measures, such as leg braces and energy-saving devices such as powered wheelchairs, analgesia (pain relief) and sleep aids

After a period of prolonged stability individuals who had been infected and recovered from polio begin to experience new signs and symptoms, characterised by muscular atrophy (decreased muscle mass), weakness, pain and fatigue in limbs that were originally affected or in limbs that didn't seem to have been affected at the time of the initial polio illness.

PPS is a very slowly progressing condition marked by periods of stability followed by new declines in the ability to carry out usual daily activities. Most patients become aware of their decreased capacity to carry out daily routines due to

significant changes in mobility, decreasing upper limb function and lung capability.

Fatigue is often the most disabling symptom; even slight exertion often produces disabling fatigue and can also intensify other symptoms. Problems breathing or swallowing, sleep-related breathing disorders, such as sleep apnea and decreased tolerance for cold temperatures are other notable symptoms.

Increased activity during intervening healthy years between the original infection and onset of PPS can amplify the symptoms. Thus, contracting poliomyelitis at a young age can result in particularly disabling PPS symptoms.

Waikato Telephone Survey

Waikato PPS made a telephone survey of members about medical professionalism. 47 members commented on 58 of their medical providers

A summary of results:

-There were 19 providers who were sympathetic, supportive or helpful towards PPS
-There were 17 providers who were not helpful or thought that PPS was not relevant
-There were 5 providers who looked at the brochures and had some degree of understanding
-There were 5 Locums who gave no comments or discussion about PPS

But perhaps the **more significant outcome** from the phone survey is that it was actually our support group in action. Many who are not able to attend meetings appreciated being contacted, and several were referred to other services they were not aware of.

Scribble

An American female polio survivor wrote the poem on this edition's front cover. The author prefers to remain anonymous. She had polio at age two and she suffered significant paralytic damage from the neck down. Like so many severely damaged polios, she spent much of her childhood trying to walk with two braces and crutches. She was unable to attend school away from home until her high school years. She eventually earned an undergraduate and masters degrees and worked until Post-Polio Syndrome (PPS) ended her career. She had no choice but to commit to a wheelchair as a teenager and a power chair as an adult woman. For years she drove her own van equipped with hand controls. PPS has taken its toll on her. She is essentially quadriplegic.

As a result of polio, she has scoliosis. Recently when she was sitting in her bed, she fell over because of her weakened back muscles and could not get upright again. During this time of helplessness, she thought of the words for her poem. She was successful in getting one of the lift straps under her chin and with some struggle, was able to return to a sitting position. In regard to the poem, she explained,

"The poem poured out of me because the minutes before I was unable to sit up - I kept falling over to the right. I felt like a corkscrew. The left side of my back has no muscles, so those on the right, when used, pull me over."

Much has been written about the pain, new weakness, and fatigue of PPS. Much has been written about the changes in lifestyle that PPS demands and much has been written about the various modalities of treatment and recommendations to help PPSers. I have written my share of articles on these topics. Many polio

survivors, who were fortunate to achieve good recoveries, now have to deal with PPS. Many writers refer to these PPSers as "passers" because for so many years they "passed as normal." From my perspective the "passers" conquered polio, but were caught off guard by PPS and were often misjudged by medical professionals because they had no visible marks of polio.

Dr Richard Bruno says ...

Work Smarter, Not Harder

Many polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs, their muscle weakness will go away.

The opposite is true: The more you overuse your muscles, the more strength you lose. Muscles affected by polio lost at least 60 percent of their motor neurons; even limbs you thought were not affected by polio lost about 40 percent.

Most disturbing is that polio survivors with new muscle weakness lose on average seven percent of their motor neurons per year, while survivors with severe weakness can lose up to 50 percent per year!

Forget about "use it or lose it." You need to "conserve it to preserve it." Stretching may help pain, and non-fatiguing exercise for specific muscles can prevent you from losing the strength you have after you get a brace. But polio survivors need to work smarter, not harder. Remember the Golden Rule for polio survivors: If anything causes fatigue, weakness or pain, don't do it. Or do lots less of it.

Conference 2011

ANNUAL GENERAL MEETING

and

CONFERENCE

NEW PLYMOUTH

Friday August 12 from mid afternoon until early evening

Saturday August 13 all day and into the night

Sunday August 14th morning

Hosted by Taranaki Post Polio Support Group

By email

*Subject: RE: Chch members
28 Feb 2011*

Thanks Julia and Edith for your enquiry regarding our members in Christchurch. I have spoken with our colleague Ruth Hall who is also President of the Chch society and she is OK although they have no water or electricity and have tonnes of sand for anyone wishing to build sandcastles. Their house is badly damaged and is in a neighbourhood badly affected with liquefaction. Many houses in the area have been or will be written off. (Including my son's.)

Some of the Chch members have been hit very hard, one member's house has been written off and he and his wife are shifting to Wellington. Secretary Joan who lived in Sumner has gone to live with family and George Ross was actually thrown from his chair at 12.51 pm last Tuesday. Because the telephones are not working in several areas Ruth has not been able to "have a roll call done" as yet. What a tragedy it is for so many!!
JB

Shirley does it again.

Our Board member Shirley Hazlewood has again been honoured with two awards in Eltham, Taranaki.

Shirley was a semi-finalist in the Kiwibank New Zealander of the Year awards for 2011, which she was nominated for because of her work with the Taranaki Post Polio Support Group and with DPA.

She was also the regional winner of the Local Heroes Award, and she will go to Palmerston North in March to receive this honour.

Congratulations Shirley!



From the President's Chair

Wow!!!! What a challenge we all face with another earthquake in Christchurch. We wonder what we can do to help our members. Some are staying "put". Others are moving out of the area for a while. Others are picking up the broken pieces and getting on with life - typical polio determination! For some it might be all too much, and we trust care and appropriate help is being made available. We send our best wishes to all.

Our Board has been very active in advocacy on behalf of you, our members.

Anne Mace, vice president, who has the portfolio of Orthotics, presented our recommendations to the operations manager of Orthotic Centre NZ Ltd. Still more work remains to be done on this vital project. On March 19 Anne is representing us with a stand at the Neurological Foundation's "Brain Day" in Auckland.

Dr Liz Falkner and I were part of a team advocating for the expansion of QE Health services to include all polios throughout NZ. At this stage it looks like a huge task but Dr Liz is investigating a pathway to see what can be done for our members.

While I was in Wellington I had a meeting with the Office of Disability Issues to update the director on the concerns of our Society. My summary of that meeting is on another page.

From the 12th to 20th of March I will be visiting 6 support groups in the lower North Island. The purpose is mainly to encourage these groups and find out how to strengthen them. Diane Mathews will travel with me to as many meetings as possible and will do the follow-up needed.

Shirley Hazlewood and her team have started on plans for our AGM and Conference to be held in New Plymouth in August.

She is also to be congratulated on receiving several civic awards for her tireless volunteer and community work.

Our questionnaire data revealed very few Maori are members of our Society. The polio virus didn't discriminate who it attacked and John Forbes' Board portfolio is to continue bringing awareness of Post Polio Syndrome to his people.

New Board member Ruth Hall has worked with JB to find a home for our aging library of Polio books which is now deposited in the Allan Bean Centre in Christchurch. Well, I suppose it is still there after the earthquake! Ruth has survived both quakes and has participated in our board teleconference for which we are thankful.

JB continues to support each board member with advice and finance - as needed, and wisdom from his long years of involvement in the disability sector. His role is invaluable.

March already, and so much has been achieved this year. Still more to come.

From my wheelie friendly chair



Edith
0800 476 546
info@postpolio.org.nz

Regional Events

Nelson

Top of the South

Hi everybody,

Best wishes to all out there for our new year and we hope you all enjoyed your Christmas and your holiday time. It was a busy time at our house and we have certainly had some hot days as we go on with summer.

There is nothing that I have to report on except that we enjoyed our Christmas gathering and were pleased at quite a large group as our numbers are dwindling and some are no longer able to come. To our Nelson members I say keep as well as you can and do let Rex or me know if we can help in any way. Take care everyone.

Rex Wastney and Jenny Kissane.

Christchurch

Note: This report arrived before the devastating earthquake of 22nd Feb. Ed

This month's report just has to begin with a word about the weather. Those who like the warmth have had a summer to remember and a chance to forget the earthquake blues. Our end-of-year activities went with a swing, especially the Xmas dinner which drew the usual strong attendance. Our first monthly meeting for 2011 is due as I write (mid February) and already an outing has been held, a film event at a local theatre. The next big event looks like being a mystery bus trip in April and that is bound to get us out and about as bus trips are always popular.

Members will this month be contributing details of their experiences with their orthotics providers in response to the request in the last (November) issue of this newsletter. It will be interesting to see the results published in due course.

George Ross



Members of the Christchurch group exploring a well kept woolshed during a recent bus outing

Northland

Hullo again.

Another year is well on its way again. We hope it is a good one for you all. We have just had our first meeting for 2011 with a most interesting speaker from Rotary, Sandra Mckersey, who along with her husband, daughter, son in law and a friend, participated in the New York marathon in November, which raised \$13,000 towards the Rotary's worldwide "End Polio Now" immunisation campaign!!

As well as talking about the Marathon experience Sandra told us about the immunisation program in India where a vast network of volunteers and Rotarians administer the Polio Drops vaccine (which immunises against the 3 strains of polio) to every child from the remotest towns and villages to the biggest cities. 200 million children were immunised in one day which seems utterly incredible to us! In Pakistan the war was stopped for "Immunisation day" only! What a wonderful effort the Rotary clubs throughout the world are making in their campaign to End Polio forever!

Sandra was very interested to hear about our Polio experiences and about how the late effects of polio can catch us up again in our later years.

Our next meeting will be on Wednesday 13th April. Please phone me (09 4352168) or Dorothy (09 4370271) for details.

Best wishes to all

Ruth Inglis.

What a dollar can buy

\$60	100 children immunized against polio
\$100	200 posters promoting immunization
\$250	500 aprons to identify health workers, volunteers, and vaccinators
\$500	4,000 finger markers to identify children immunized
\$1,000	700 vaccine carriers

Questionnaire Bytes

Some further statistics from the Questionnaire, submitted by Anne Mace.

- 34% have shortness of breath during activity such as bed making
- 16% have shortness of breath during talking
- 14% have difficulty breathing through their nose
- 24% experience difficulty with swallowing
- 9% wake short of breath
- 25% wake with a start for no reason
- 57% have restless sleep
- 45% suffer from restless legs at night
- 24% have some form of permanent paralysis
- 53% have noticed increasing muscle weakness over the past few months
- 62% have notice increasing muscle weakness over the past 5 -10 years
- 32% experience muscle twitching
- 43% get cramps. Dr de Graff mentioned at a recent conference that magnesium, or preferably magnesium and zinc tablets, available from the supermarket, can considerably reduce incidences of cramp.

Keep mobile,
enjoy life,
pace yourself,
and always keep smiling.

About Us

The Post Polio Support Society of 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.

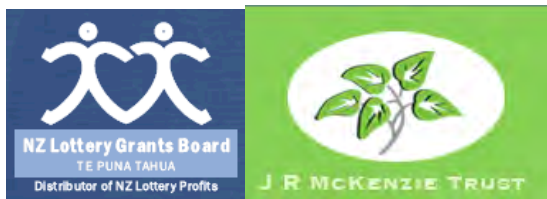
The Society's Board of Management meets regularly either physically or by telephone conference, and the annual general meeting of members is held in September.

The Society's newsletter, **Polio News**, is published four times a year (March, May, August, and November) and is sent to all members.

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

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

Acknowledgement: This newsletter has been paid for by a grant from the Lottery Grants Board and the JR McKenzie Trust, to whom the Society expresses its thanks.



Editorial

The whole country is focussed on Christchurch and the catastrophic event that has happened there.

My own connections with the City are strong. I am a graduate from the University of Canterbury, met my wife and got married while a student, and our daughter was born there. We still have a handful of friends living in Christchurch, and as you imagine, it is difficult to find information about their well being. Some are safe, others we have heard nothing from in spite of our emails. (We are staying off the phone to keep those channels clear for emergency services.)

So are we ready for an event like that? Do we have enough water, food, blankets, batteries, radios, torches, etc in storage? Twenty years ago I had these things assembled together in a safe place; but having moved six times since then it has fallen off the list of priorities.

As polios, how prepared are we to see that our uniquely special needs are covered? What provision do we need to take to ensure our mobility is facilitated? A few hours forethought may make a huge difference in such an event. Survivability is often proportional to preparedness – that's a quote from NZ Search and Rescue.

So let's get behind the effort to help Canterbury; and at the same time take stock of our own needs should disaster overtake us.

FYI: monetary donations can be made through many banks. My bank, for instance, has a link on its internet site where cash can be sent directly to the Salvation Army in Christchurch.

Immunisation Levels in NZ

Once again NZ is confronted by its lack of comprehensive immunisation. How easily could this read *polio* instead of *measles*?

From NZ Herald
17 Feb 2011

Fifteen people in the Auckland region are now confirmed to have measles since an Emirates flight arrived in Auckland from Brisbane in mid-January.

Eight cases were confirmed following the flight arrival but a number of the subsequent cases had occurred in the community without any obvious infection source, Auckland Regional Public Health Service (ARPHS) medical officer of health Richard Hoskins said.

Dr Hoskins said measles was a serious and highly infectious disease which needed to be taken seriously.

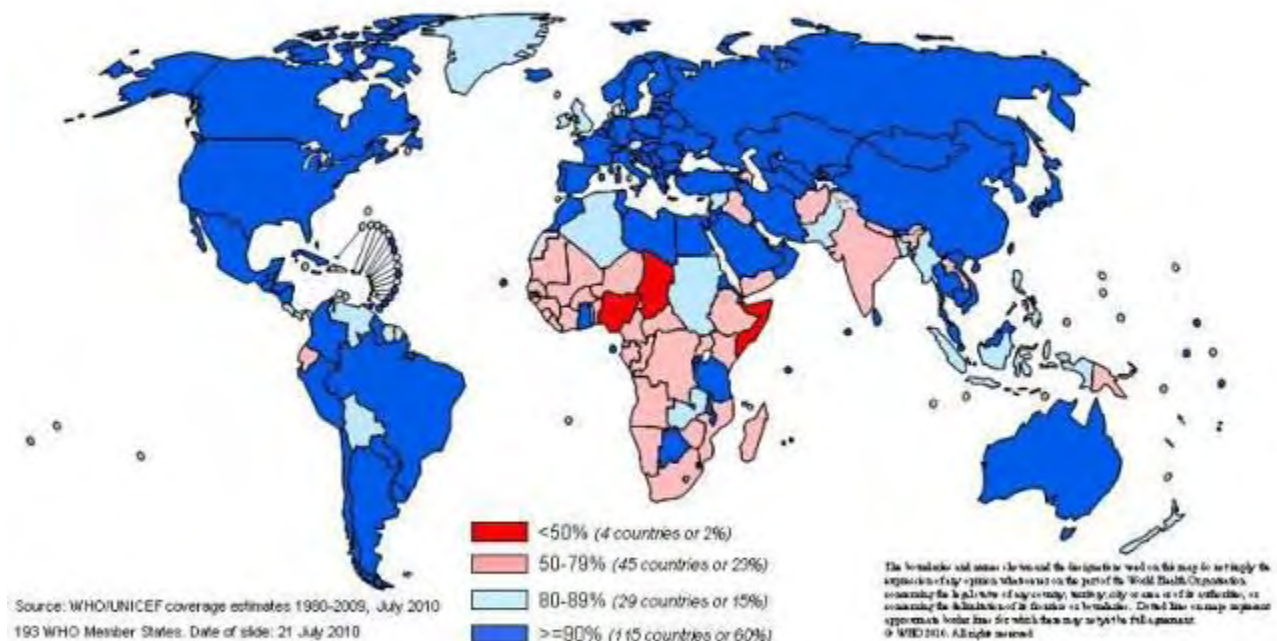
"This disease spreads easily through the air, especially from coughing and sneezing," he said.

"It commonly causes ear infections and pneumonia, and may lead to other serious complications and can, in some cases, be fatal."

From the WHO site:

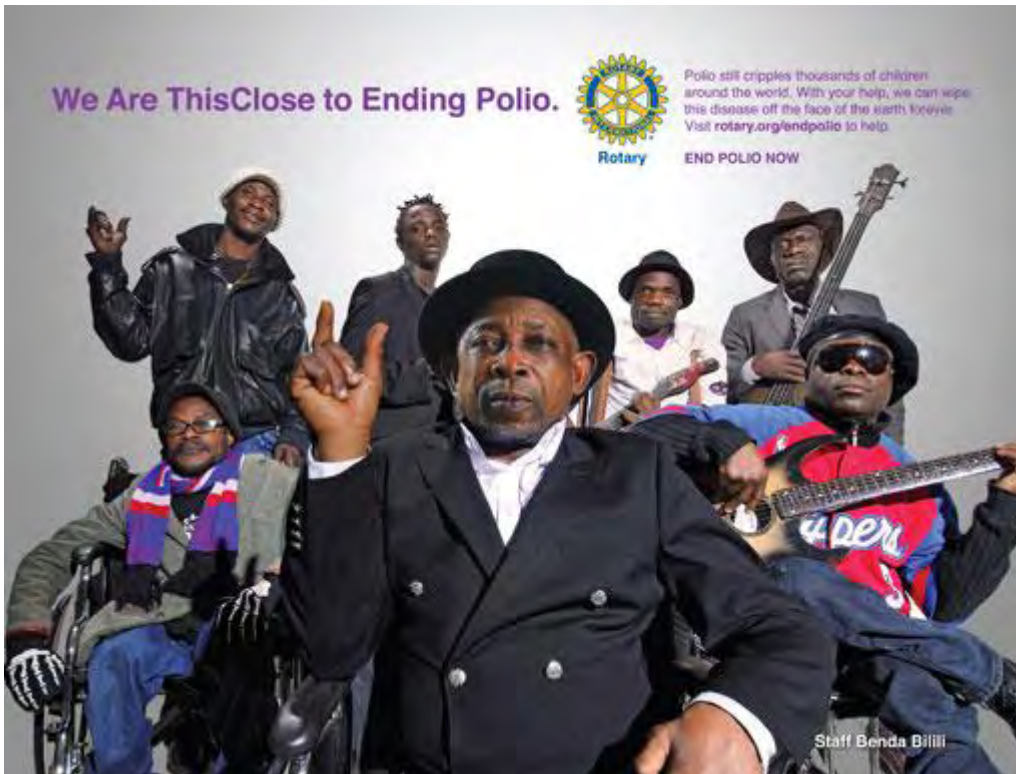
Measles is one of the most readily transmitted communicable diseases and probably the best known and most deadly of all childhood rash/fever illnesses

Immunization coverage with measles containing vaccines in infants, 2009



ThisClose Rotary Campaign

Staff Benda Bilili



A Congolese soukous band largely composed of polio survivors, Staff Benda Bilili describes the impact of the disease in the group's signature song, "Polio." The band received a 2009 WOMEX (World Music Expo) Artist Award for World Music



Bill Gates

Bill Gates is cofounder of Microsoft and cochair of the Bill & Melinda Gates Foundation, along with Melinda Gates and William Gates Sr. The Gates Foundation strives to expand opportunities for the world's most disadvantaged people by collaborating with grantees and partners.

The Gates Foundation is working closely with Rotary International in the fight to eradicate polio. It recently awarded US\$355 million in challenge grants to Rotary, which has pledged to raise \$200 million in response. The resulting \$555 million will support critically needed polio eradication activities.

The Journey of Hope

The Journey of Hope (Cycling NZ for PolioPlus) is now over. On 24 November 2010 Xaver Hausner, a Rotary Ambassadorial Scholar from Germany who was hosted by the Rotary Club of Pencarrow (District 9940), and his friend and flatmate, Oliver Macindoe, left Cape Reinga on a 3360 kilometer journey to Bluff. Along the way they and the supporting Rotary clubs of New Zealand raised money and profile for the ongoing campaign to eradicate polio world-wide.

Post Polio Support Society says Thank you

16 January 2011

Congratulations and thank you to Xaver and Oliver and support team, for raising the huge amount of money and awareness to help eradicate polio. The impact of your tour will be felt overseas and in NZ for a long time to come.

On behalf of people who had polio in NZ before the vaccination was developed and who now live with the after effects of getting polio, I want to say thank you a thousand times.

Much appreciation,
President Edith Morris
Post Polio Support Society of NZ (Inc)



Polio Epidemic in Congo

United Nations officials have called for an immediate ceasefire in the Democratic Republic of Congo (DRC) to allow vaccinations to reach millions of children threatened by a sudden epidemic of polio.

The aggressive return of the contagious paralyzing virus comes just five years after it was declared eradicated in most of the world.

It marks a major setback in the race to make polio only the third disease, after smallpox and the cattle virus rinderpest, to be eradicated.

After an outbreak this year of so-called wild poliovirus, the first round of an unprecedented vaccination campaign aimed at 72 million children under 5 was launched in 15 African countries in November.

But vaccination teams have struggled to reach children in war zones, such as eastern DRC, where government forces, the Rwandan army and militias are fighting.

"We are calling on all parties to the conflict to respect the vaccination days and cease fighting," said Pierrette Vu Thi, who represents Unicef, the United Nations children's fund, in the DRC. "All children have the same right to health."

According to the charitable organisation Rotary International, one of the main supporters of the African vaccination effort, up to 800 suspected cases of polio have been found in the past six months in 12 African countries.

As soon as we have one case of polio, we consider that we are dealing with an epidemic," said Andre Kasogo, a Unicef immunisation officer in the DRC. "Polio is highly contagious. One person can pass the virus to 200 others."

The World Health Organisation puts the number of confirmed cases of polio in Africa this year at only 139, but spokesman Rod Curtis said: "Determining numbers is complex. Multiple factors, such as the Republic of Congo not having seen polio for 10 years, or adults dying before being able to provide stool samples, mean that a significant number of early cases in the outbreak did not provide diagnostic specimens."

Poliomyelitis appears via a fever which kills some victims and subsides of its own accord in others.

Days or weeks later some survivors wake up paralysed, often in one leg and in the arm on the opposite side of the body

Gillian Gorick recalls her time nursing polio patients

PHOTO of Gillian and also photo with caption: The so-called iron lung was a cylindrical steel drum which artificially maintained respiration. A person's head and neck remained free but the rest of the body lay in the sealed air tight compartment, with a tight rubber seal around the neck to ensure no air could enter.

As a child Gillian Gorick would tip the dressing table mirror, lie on the bed, gaze up and pretend to be a polio patient encased in an iron lung (see photo,) whose only view of the world was via a small mirror suspended above the face. This creative play eventually launched Gillian into a nursing career, firstly - in 1945 - as an orthopaedic nurse at the Royal Cripples Hospital (RCH), Birmingham, UK and later as a physiotherapist caring for patients some of whom had polio (dubbed 'the crippler').

It wasn't until 1946 that the post-war Labour Government introduced free

health care: the National Health system. Prior to this, the RCH was supported by donations of money and kind: sixpences were welcome, sacks of potatoes from farmers and even Cadbury's was a prominent benefactor as plaques on cots and beds testified.

In 1948 Gillian, as a student physiotherapist, found herself caring for young polio patients who had been transferred to the RCH - stiff and suffering pressure sores - from Fever Hospitals which catered for anyone contracting the highly infectious diseases: measles, scarlet fever, typhoid, diphtheria and polio all killer viruses before the advent of immunisation. At the RCH, the children's contact with relatives was confined to one hour a week.

Gillian arrived in NZ in 1957 with a trunk containing plastic splints, a novelty in a country where metal and leather straps were still in use. She recalls being told of the impact of the virulent polio epidemics of the early 50s. So great were the numbers of polio patients that army marquees had been pitched on the Waikato Hospital's lawns whilst nurses walked on duck boards to tend their patients.

Gillian and fellow physiotherapists employed the once controversial Sister Kenny techniques for treating the limbs of polio survivors. This revolutionary treatment rejected immobilisation of affected limbs in favour of a) the application of hot packs to alleviate the pain in joints and muscles to facilitate movement plus b) a regimen of passive, assisted, active and resistance exercises.

Gillian recalls cutting bails of soft pink wool material (used in the manufacture of men's longjohns!) into pieces, boiling them in a small steriliser and once spin dried, shaking them to remove the trapped steam. A person was employed to wrap the hot packs around patients'

affected limbs with physios following to stretch and exercise tight muscles and joints. The Orthotics team, she says, were an inventive lot, creating splints to maintain optimum positioning of limbs in anticipation of regained mobility, eg behind the knee joints, on the ankle to prevent 'dropped foot' (gravity pulls the foot down, causing 'dropped foot'). Whether patients continued to use these aids after leaving hospital, says, Gillian, was a matter of choice.

Of the patients in Gillian's charge, 18 were children under 18 months of age. Two of these had received an initial inoculation (the Salk vaccine had been introduced in 1955 and the Sabin vaccine in 1958), and made a 95% recovery incurring only mild muscle weakness; the others were more severely affected. All were helped out of bed to play with toys to help in their recuperation. Callipers, splints and crutches were provided by the hospital.

The Crippled Children's Society's Field Officers, says Gillian, were wonderful. Families living remotely (sometimes a horse ride, rowing boat and bus trip away!) had difficulty getting to hospital appointments so the Field Officers would visit them in their own homes.

*Kathy Walsh
Outburst Magazine
CCS Disability Action*



Finding those who had polio

There may be several thousands who had Polio in the epidemics and have not yet heard of how we can assist them with Post Polio Syndrome material. The Society wants to reach out and find them. We have produced a handout postcard with a tear-off reply section, for distribution at events like the "Brain Day" or send to friends we know.



The postcard has a brief description of Post Polio Syndrome, and directions to our web site and our national free-phone 0800-476-546. The reply section has a list of questions with check boxes to find out how we can best help.

In the near future supplies will be sent to each support group. If you have a project or event where you might need larger quantities, please phone and ask.

From the Board we would like to thank Noel Morris for designing and overseeing the printing of the postcards.



Orthotics Update

March 2011

Written by Anne Mace
anne@specialneedscoaching.co.nz

Subsequent to a meeting with Vaughan Sampson, CEO of Orthotics New Zealand I am happy to give you the following update.

If your Orthotics supplier is Orthotics New Zealand, then the following information applies to you.

You should not have to wait longer than 3 weeks between your phone call and your appointment. If it is longer, it is very important that you let me know.

When you receive your orthotic device you should receive a form to gauge your satisfaction with the service you have received. It is vital that you fill this form in whether you are satisfied or not happy, so that they can gauge their service performance from your comments.

A complaints form is available at all reception desks. You won't be offered it; you will have to ask for it.

You should automatically be given a follow up appointment at the time of receiving your orthoses to review the performance of the device. If you are not, please ask for your follow up appointment and let me know that it did not happen automatically.

It is vital that we communicate our needs to them. They consider us to have a chronic condition but an acute need which they sometimes need to be reminded of.

Understandably their priority is to serve paediatric and trauma clients first.

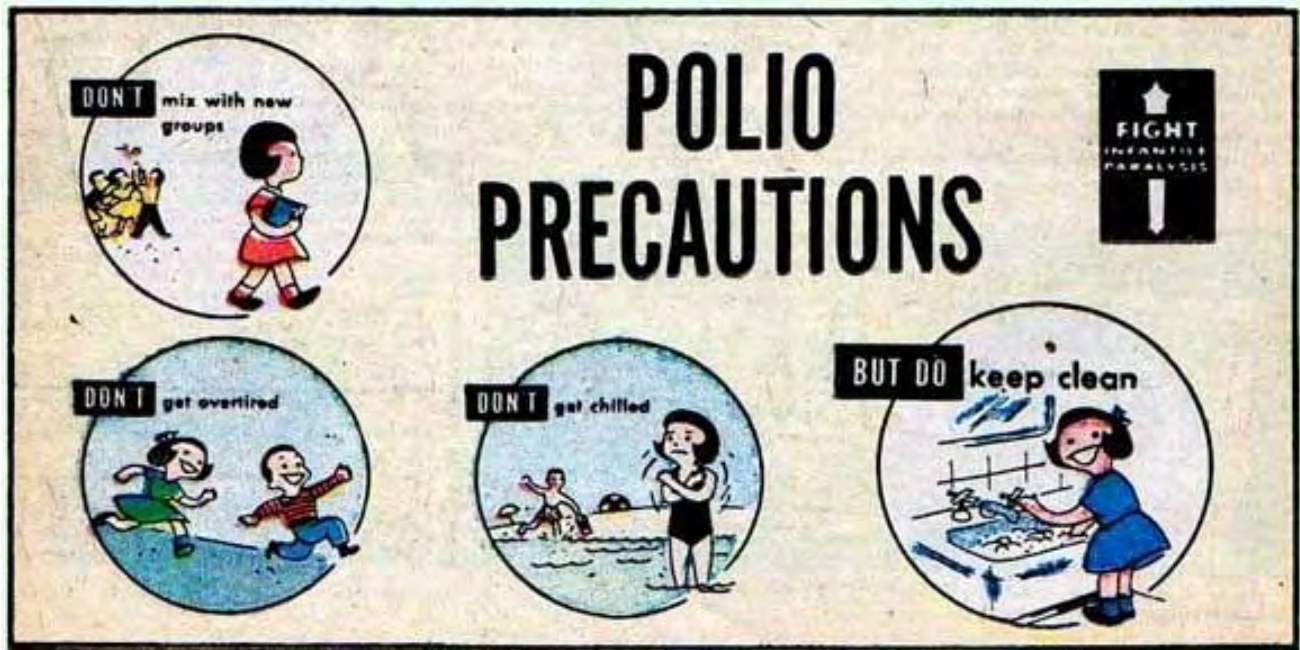
Orthotics NZ tend to make orthotic devices for chronic conditions like Post

Polio, as they have made them in the past as they know they work. If you need something changed it is up to you to ask for the change.

If you are offered an "off the shelf" model remember its use has been adopted because it can be satisfactorily adjusted or adapted to your needs, but you will have to ask for the modifications to be made.

We have lodged complaints with Orthotics NZ on your behalf, now we need to monitor the situation to note progress or no progress. Therefore PLEASE email me your comments good and bad, along with the name and location of your provider so that we can continue to work on your behalf to change the situation to our benefit.





If only it was so easy – no one really knew the answers.

Directory

Information about membership and local support groups

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