



Polio News

Post Polio Support Society NZ (Inc)

November 2009

Conference 09 – Brainy Stuff and Food for Thought



Prof Richard Faull shows us his brains



Maggie shows us how to age gracefully



Brains in hand, on the table, and screen



Maggie threatens to take Frank home



Bob Hillier explains how ODI can help



Questions from the floor

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Conference 09: Professor Richard Faull



Professor Richard Faull came from Tikirangi, just out of Waitara. It was a very small place. Richard shared that his parents had very straight forward views on life, and so imparted to him a strong set of values. Because his parents owned the local store Richard had to deliver groceries as a boy. Through this task he learned to serve the community and to care for people. Richard told us it is important to communicate with people, and to look after others.

He saw a human brain for the first time as a third year medical student, and became fascinated with it. He spent a year working with rat brains in relationship to Parkinson's disease, and had seven papers published.

Professor Faull has spent a long time investigating Huntington's disease. This disease is caused by a gene, and half of the children of an affected parent will develop the disease. Sufferers usually die within 15 years of the onset of symptoms. Professor Faull has developed such a good relationship with the Huntington's community that families willingly donate the brains of victims for his research into the disease.

Professor Richard Faull is an acknowledged world-expert on the

anatomy of the human brain. His research group has made invaluable contributions to our knowledge of the chemical anatomy of the basal ganglia, mechanisms of cell death and genetics of Huntington's disease. It has shown the potential of transplanted neurons to reverse the damage seen in animal models of neurological diseases.

His research was among the first to show that that the diseased adult human brain tries to repair itself by making new replacement brain cells (neurogenesis).

This discovery holds great promise for the development of new treatments for neurodegenerative diseases, such as Parkinson's, Alzheimer's, Huntington's, stroke and epilepsy, which affect one in five New Zealanders. It may also have future benefits for polio survivors.

More information about Professor Faull's work is available at <http://www.scoop.co.nz/stories/GE0702/S00036.htm>

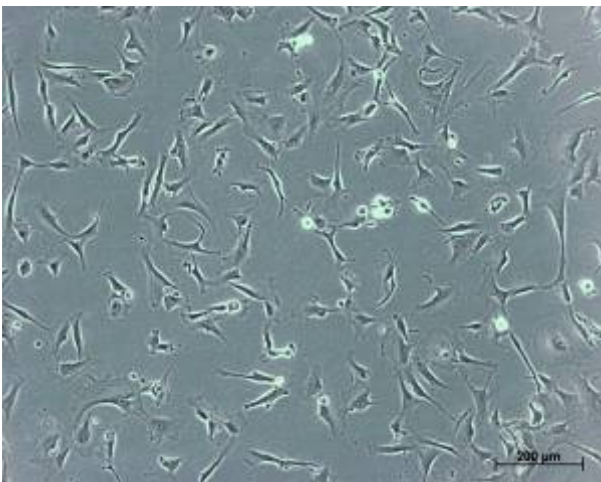
From Prof Faull's presentation

Neurodegenerative Diseases

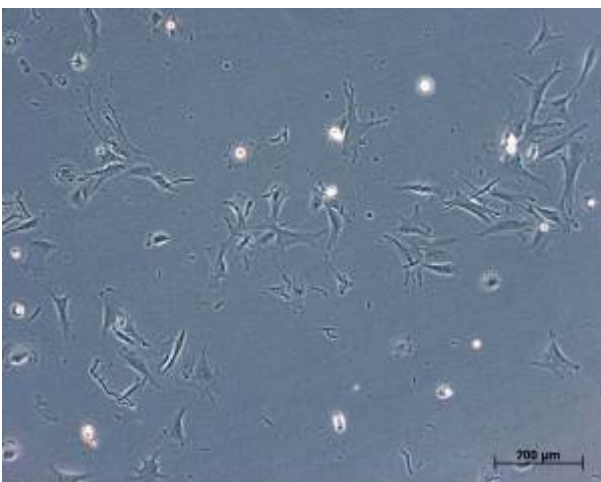
These diseases are major health problems. They include

- Alzheimer's Disease
- Parkinson's Disease
- Huntington's Disease
- Epilepsy
- Motor neuron Disease
- Polio

Each disease is characterised by a specific pattern of cell death affecting different regions of the brain.



Healthy brain cells.



Brain cells dying due to Alzheimer's Disease.

General conclusions from Professor Faull's world leading research:

1. The adult Human Brain makes new brain cells. This is called **neurogenesis**, and is an extremely exciting discovery!
2. The human brain can repair itself just like all other organs in the human body.
3. Animal studies suggest that enhanced and stimulating environments, and physical exercise, result in increased numbers of new brain cells.

A Joke

An elderly couple had been experiencing declining memories, so they decided to take a power memory class where one is taught to remember things by association.

A few days after the class, the old man was outside talking with his neighbour about how much the class helped him.

"What was the name of the Instructor?" asked the neighbour.

"Oh, ummmm, let's see," the old man pondered. "You know that flower, you know, the one that smells really nice but has those prickly thorns, what's that flower's name?"

"A rose?" asked the neighbour.

"Yes, that's it," replied the old man. He then turned toward his house and shouted, "Hey, Rose, what's the name of the Instructor we took the memory class from?"

From the President's Chair

I was re-elected to be your president again and it is my honour to continue in this role. Thank you for your trust in me, and I will do my best. Of course I am surrounded by a skilful board of management who were wholeheartedly re-elected too. Laura Ladkin was unable to stand for re-election, but what an amazing contribution she has given to the board. She continues as the Waikato co-ordinator. **Thank you Laura.** A new face on our board is John Forbes. He adds youth and enthusiasm to our leadership, and we welcome his input over the coming year.



John



Laura

In my opinion the conference was a friendly, relaxed one with a variety of speakers to please everyone. Although it was smallish, it is our aim to increase the number of participants by maybe holding future conferences every second year. Elsewhere in this issue there are reports about the AGM and Conference for you to enjoy. A set of DVDs is available for you and your support groups to purchase.

Some of the challenges facing us as polios and as a society are in the areas of:

- funding locally (support groups) and nationally (the society)
- improvements to footwear and callipers through the various DHBs and orthotic service providers. We are in the process of collecting concerns from the various regions, so if you are unhappy about the quality of your

orthotics, or the time taken to provide services and repairs, or unexpected increases in costs, or any other issues, please contact us.

- wishing to increase our membership as we recognise the gradual decline of numbers and finances. We feel there are many polios yet to be contacted and helped. Several new members have joined after viewing our website:

www.postpolio.org.nz

WE ARE STILL HERE!!

My best wishes for a Blessed Christmas and a Happy New Year 2010.

From my wheelie friendly chair

Edith



Conference 09: Philippa Werry



Philippa Werry masterfully presented her literary work to conference attendees. She said she usually talks to children's groups, for example in schools. In her experience most children know nothing about polio.

At conference she said she felt like she was amongst experts.



Philippa enthralled us all when reading from her novel "Enemy at the Gate".

Philippa told us the background to the book, and explained the developmental processes needed to produce such a story. These included such things as:

1. Selecting the time in history
2. Selecting the geographical location
3. Determining the characters

4. Deciding the viewpoint of the story teller (ie who is relating the narrative). Philippa explained the difficulties associated with trying to use different characters as the story teller.
5. Working out the back story – those things that are not directly described in the story but which are implicit in it.
6. The huge amount of historical research needed to give the time and place settings authenticity.

The story Philippa wrote was set in the summer of '36 / '37, when there was a polio epidemic in NZ. This determined the point in history, which coincided with the Great Depression. Hence the logical choice of characters involved a poor family. Philippa gave the family five children, and placed them in Lyall Bay, Wellington. She assigned the story telling to one of the brothers.

The time setting meant that these events were also taking place:

- Wallis Simpson and King Edward VIII
- Amelia Earhart
- Dion quins
- Introduction of school milk
- Jack Lovelock, Olympic medalist

In her research Philippa found out lots of things about that era. For instance it was believed that the polio bugs entered through back of neck and was connected to the sun – so hats had to be worn. This was probably because often the first sign was a severe headache based in back of neck.

Philippa explained how the story has to drive the book, and how the time and place settings need to be in the background. She went on to say once all these things are in place then the author has to spend an enormous amount of time writing.



Philippa answers questions

Latest Polio Case

Nov 23, India

Loopholes in the polio immunisation programme in Himachal Pradesh seemed to have led to a fresh case of polio detected in a two-year-old child of a migrant family from Uttar Pradesh. The boy, who stayed in Nalagarh slum of Solan, was never covered under the National Immunisation Days (NID), the only immunisation programme followed in the state.

The case was detected on November 17, when the child was in his home town Badaun in Uttar Pradesh, a few days after his family left Himachal, said Director Health Services Nagesh Sharma. The

At this stage Philippa read an excerpt. Everyone in the room was transfixed as the reading progressed. When she finished there were a number of tear-filled eyes in the room. We really were touched by the powerful description of what polio meant to families and its impact on them. And I suspect each of us was relating that back to our own childhood.

Since the book was published Philippa said there has been a huge response from readers. Many of the readers have had a story to tell of their own encounters with polio, either directly or through another family member's illness.

The book signing was a huge success. We all felt that Philippa had an empathy with us that not many folk do.

More information is available at:

<http://www.wheelers.co.nz/books/9781869438135-enemy-at-the-gate/>

<http://www.bookcouncil.org.nz/Writers/Profiles/Werry,%20Philippa>

child was staying in Himachal when he contracted the polio virus, which travels through faeco-oral route. His home was located in a cluster of nearly 11 slums in the industrial area with poor sanitation. After the condition of the child deteriorated, his parents took him to Badaun.

“It is still to be found out whether other children living in these slums were also left out in the NIDs,” said Dr G P Dwivedi, WHO representative for National Polio Surveillance Project in Himachal. The affected child was never administered polio vaccine and was now detected with P3 type polio virus, he added.

Conference 09: Jo Maling, Wellington Disability Info Centre



Jo Maling pulled a whole pile of aids out of her trundle bag. Note the huge pile on the table between her and JB.

Disability Information Service Centre

The Centre's mission is to provide information and aids to those needing them. Jo Maling worked with the Wellington centre, but there are others in the country. Go to Enable NZ at www.weka.net.nz to see all the centres.

What an amazing bag of devices Jo showed us. Here is a non-exhaustive list:

Jar, bottle openers, Book rest, shower aid (sponge on stick), easy reach, new easy reach, dressing stick, merino wear possum socks and gloves, antigrip socks, sock aid, fat pen for those who have difficulty gripping, straps for walking sticks, clips for sides of walking sticks, lumbar roll, another pen – uses the right muscles and easier to grip, uni-feet for the bottom of a walking stick, Tap turner (aka potato turner); fold down walking stick – can go in hand bag, or brief case, Jar opener, cutlery large handle fork

which bends, spork, Nelson knife, grips for cutlery, gloves, peelers, long shoe horn, reflex carving knife, knob turner, hot water bottles, ginger nuts, tap turners.

Free mobility scooters can be hired at the Wellington city council (you leave your credit card with the council as bond).

A web site for the service is being created. A postal service for the purchase of items is available.



JB thanks Jo at the end of the highly informative "show and tell" session

Conference 09: Board of Management Election



Board of Management - Elected 2009

Back row: Anne Mace, Diane Mathews, JB Munro secretary/treasurer, John Forbes, Des Crabb vice president

Front row: Susan Kerr, Edith Morris president, Shirley Hazlewood

Absent: Susan Barber

An Overview of Conference

The AGM and National Conference held in September was a friendly and informative one with delegate attending from North and South. Quite a smallish conference but full of variety as the presenters covered a wide range of Polio related topics.

- ✓ A representative from the Office Of Disability Issues spoke on their role within Government. Lively discussion followed.
- ✓ Professor Richard Faull presented his research on the brain. An enthralling session.
- ✓ The AGM resulted in the re-election of Edith Morris as president and a full board of management remains in place with a new member John Forbes added.

- ✓ The after dinner speaker Maggie Jack entertained us with her humour about the delicate matter of incontinence.
- ✓ Philippa Werry spoke about and read from her newly released book "Enemy at the Gate" to a very hushed audience. Most relived their own experiences of polio and lined up for her book signing.
- ✓ Jo Maling demonstrated useful appliances and gadgets provided through the Disability Information Service Centre in Wellington.
- ✓ A remit about the quality of service provided by DHB's Orthotic department was discussed with frustration being expressed by most.
- ✓ Susan Kerr, a board of management member, reported on the International Conference in America, which she attended earlier in the year. She also gave brief results of

the New Zealand wide questionnaire which continues to be collated and analysed.

- ✓ The editor of Polio News, David Whyte gave a glimpse of his life in his "Polio Reflections."
- ✓ The Conference closed with an address by Dr Liz Falkner, the medical advisor to our society.

Conference Dinner

Maggie Jack, from the Bay of Plenty, is a very accomplished speaker, Physiotherapist, businesswoman, and Toastmistress. She was our guest speaker.



Maggie gave us some serious advice, packaged extremely humorously, on how to deal with aging and incontinence. This is a surprisingly common problem, and can be brought on by too much straining – over-lifting, polio, stroke, medication, surgery, childbirth, constipation etc.

Strengthening the pelvic floor is the first line of defence, and she had us all practising this.



Then it was techniques for holding everything in.

Finally in her advice to "pad up and play on" Maggie spoke about how to live a full life by using incontinence products that are readily available.

Good food.
Great company.
Outstanding speaker.

Equipment on Display



Mobility scooters on display for conference members to view and trial.

Conference on DVD

If you want a video of Conference '09 DVD recordings can be ordered from <http://www.faithnet.co.nz/tapes/pps09.html>

Regional Events

Nelson

Hi everybody.

First of all I give my apologies for missing a message in the last newsletter but hope to do better this time!

Our Get-Well thoughts go out to several who are ailing and in distress; can we help in any way?

A particular thought goes to Pauline and Norm Hennessy who, following Pauline's previous distress, have now suffered an accident in the Lewis Pass whilst returning home to Nelson from Christchurch. Pauline is slowly recovering in Darfield Hospital so may it not be too long before she is able to return home to Nelson. Lots of love from all up here!

Rex has the DVD "Warm Springs" concerning the life of President Roosevelt and his battle with polio and post-polio. Anyone who would like to view this [approx 2 hours] please let Rex or me know and we can organise a viewing either in a group or you may borrow if you have the viewing facilities. [Our phone numbers are below.]

It's that time of year again and we look to our Christmas luncheon. Where has this year gone to? For ease of access we again go to the Brightwater Motor Inn.

Christmas luncheon:

Saturday, 28th November, 12.30 pm.

Brightwater Motor Inn.

RSVP to Rex or me by 24th November to confirm your attendance.

Rex on 5477043 or Jenny on 5451030

Rex wished me to mention how informative and interesting the conference was, it is quite sad that some of us are no longer able to attend. We look forward to resulting notes.

A very happy Christmas to one and all out there and may 2010 keep us all ticking over and doing the best that we can. Good health is the biggest gift of all.

Regards from Rex and Jenny.

Christchurch

So much has happened and is happening here in Christchurch as the end of the year approaches, that Christmas may seem like an anti-climax. Even as I write a bunch of stalwarts from our group are experiencing the hot spring facilities at Hanmer on what has become an annual adventure. There'll be some stories to tell when they return, I'm sure.

A recent day trip to Ashburton by wheelchair bus was very popular and an opportunity to renew contacts with South Canterbury members. Curiosity drew a number of us to visit the Christchurch Mail Centre on a recent occasion to learn the intricacies of mail sorting and to sample the lunch menu at the staff café.

Yet to come before year's end are a safari to Orana Wildlife Park and, of course, a night out for a Christmas meal at our usual venue, Cashmere Club. Two of our committee members attended the National Annual General Meeting last September and reported back to us on the proceedings. They spoke highly of the material presented.

We wish you all a very happy Christmas.

George Ross

Northland

Hullo everyone.

The year is racing along again and end of the year activities will soon be upon us again!

Our group welcomed President Edith, husband Noel and Sister Rose to our A.G.M. in August, and we all enjoyed hearing Edith's message and sharing a very nice meal together at the Kamo Hotel.

A trip north to visit some of our post polio members in Kerikeri and beyond took place this week. Six of our Whangarei members travelled by mini bus to Kerikeri, where we met at the lovely home of Audrey and Mike. A further six members plus spouses joined us from the far north region.

Peggy told us about her recent trip to Wellington for Conference. She was impressed by the fellowship and friendliness of everyone there and gained much from the speakers who took part.

Another local woman at our Kerikeri meeting spoke to us about the benefits to be gained from Bowen therapy!

Good discussion took place between members about various topics of interest to us all including problems with orthotics and the difficulties and delays some of us have had in getting help in obtaining orthotic equipment.

After a delicious shared lunch and a bit of fund raising with a raffle and a trading table, we made our way back to Whangarei vowing to repeat the enjoyable day up North! (We found that hiring a minivan and driver was an excellent way for us to travel!

Our next meeting on 11th of November will be the last for 2009!

Until next time Best Wishes to you all from all of us.

Ruth Inglis.

Otago

The Otago Group is finding a cafe a very welcoming place to hold meetings. The Cafe Doulos allows us the end of the room all to ourselves as well as supplying us with delicious muffins, scones and coffee.

At our October meeting JB gave us an overview of the National Conference and I added an extra perspective to parts of the report. I found Professor Faull an enthusiastic communicator who must be an inspiration to his students.

And after hearing Philippa Werry's reading, we have added two of her books to our small library. As usual, one of the main highs of the Conference was meeting, talking to and comparing notes with, folk from other parts of the country. Thank you to all the organisers for their work.

Back to our August meeting - We met in the CCS Rooms because our speaker, David Horne, needed to use a screen and he took us on his "intrepid journey" to Timbuktu. Once an impressive city it is now ruins of clay.

We are planning a bus trip to Waihemo Lodge at Palmerston for our end of year dinner, a date which seems to be approaching at an alarming rate. Best wishes for the Christmas break from the South.

Diane Jackson.

Waikato Disability Expo



Jack and John show the spirit of polio survivors



Laura and John staff the exhibition

Our Waikato support group had a Post Polio stand at the Waikato Health and Disability Expo. Our display looked very clear and fresh after a re-make and re-design by Noel and Edith, and our new banner certainly added interest.

A DVD from Jega's talks at last year's Polio conference played non stop and a variety of pamphlets were distributed to the public and other stall holders.

There were about 70 other stalls with around 2,000 visitors passing through the Expo over two days. Our stand was staffed by friendly polio members ready to answer inquiries. Jack Norton and John Forbes did most of the "manning" of the

stand with Laura Ladkin and Jean Coe coming for stints. Edith hovered around here and there as needed, and did some radio MC and interview slots for Community Radio Hamilton.

One passer by yelled out "Polio, what's polio doing here? I thought it was done away with". Edith yelled back, "But we are still here. We are not done away with". And that's the point of being at the Expo year by year, to have a presence and to pass on information.

Thanks to all those sitting at the stand, to Noel for setting up the display boards.



Edith conducts an interview at expo

Editorial

What an Event

Conference was outstanding. It was a highly informative, entertaining, and extremely well planned event. Congratulations must go to the organisers; and sincere thanks to all contributors and participants.

Professor Richard Faull's comment about the large amount of mental acuity present in the room reminded me that Polios are a high achieving lot. I am sure we all relate to that! I remember well that no concession was made and that the expectation was that I kept up in whatever activity was undertaken. It makes for a great deal of resilience. But it also becomes counterproductive when post-polio syndrome appears. The need to slow down is difficult to acknowledge when life has always been full on. Dr Bruno's article in this edition speaks to that.

Philippa Werry's excerpt from her book "Enemy at the Gate" gave us food for thought about how our parents must have felt when the diagnosis of polio was made. It put a particularly human perspective on the way polio intruded on, and totally disrupted, normal family life. I think parents were the unsung heroes of that era. When I left home to attend university in 1970 my father told me, "Just remember son your mother and I have put in a huge effort to ensure you can walk. Don't undo the work we've done by being daft." He was wise enough to recognise that at eighteen I thought I was bullet-proof! He wasn't looking for thanks, he just had my best at heart.

I am sure that all of our parents put in a huge effort to get us to where we are.

Cheers, David

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.



Ramping up for Mobility

Dollar signs started it. Like \$600 to \$700 for a smallish ramp that might get my powerchair into the back of my smallish wagon. The alternative wasn't hard to find -- a \$100 sheet of structural ply from my friendly ITM store. The man even cut it in two, so I could get it home in the back of the wagon -- lengthwise, with a handsaw. I stashed one half-sheet in the garage, awaiting some other project. Darned handy stuff, thick plywood.

Here's how I made a pair of ramps that make it easy to load my powerchair into the back of our Toyota Carib (Corolla family) wagon:



Powerchair on the ramps

First get your plywood. You'll need the long half of a 2400 by 1200mm sheet of 18mm-thick CD-grade exterior ply. This will give you two 200mm wide ramps, each with 50mm upstanding edgings glued and screwed into the sides of each ramp. If you have a bench saw, cutting the sheet to length and then into

six lengths (four at 50mm wide, two at 200mm wide) will be easy and should give you good straight edges.

My ramps are 1600mm long, since this is the maximum length I can carry in the wagon with both front seats still in use. The slope is about right. They sit neatly on top of the plastic bumper and deliver the powerchair wheels level with the tailgate sill.



Once I had the pieces cut I rounded off the top edges of the side pieces with coarse sandpaper and curved the ends down close to where they'd join the ramp centre pieces. Then I drilled and countersunk nine holes for 35mm long-thread screws in each side piece, made sure the edges of the ramp pieces were smooth and glued each side piece in place with polyurethane glue -- which expands mightily, filling any little gaps but oozing out a real mess if you overdo it; a 3mm bead of glue right along the centre of the ramp edge is about right, then put the screws in carefully. A power-driver helps.

Once the glue is dry you can clean up any rough bits with coarse sandpaper. I filled a couple of surface knot-holes with auto filler. Paint with acrylic primer-undercoat and then two acrylic topcoats. Sprinkle some grit on the first coat while it is wet then dust off before the second coat. I used SRG (skid resistant grit) from Resene -- inexpensive and it works well. I can ease the powerchair up and down the ramp even if it is wet.

New NZ PPSS Banners



Under-ramp fillets that provide a good footing on the bumper.

Two little safety add-ons: At the bottom of each ramp I rasped a taper to make a flat surface where it meets the ground then glued a piece of flattened bike-tyre tread across to prevent sliding on firm surfaces – I never use the ramps on gravel. And at the top, where the ramp sits on the bumper, I made up two fillets of tapered wood to give flat pressure points – another anti-slip feature – and screwed them in place. It's possible to provide even greater security by devising a strap for each ramp hooked over a suitable bracket on the floor of the wagon.

All this took me a couple of days and involved quite a bit of fiddling, but the result works well and the out-of-pocket cost was about \$75, not counting the half-sheet of plywood that I have left over and the paint, which I had on hand.

Jim Webber



PPSS NZ has designed two new display banners for you to use at public events like Expos, Library displays, seminars on disability, and other events.

They can be borrowed.

Contact Edith: Freephone 0800-476-546

Emotional Stress in Polio Survivors and Post-Polio Sequelae

By Richard Bruno PhD

Emotional stress is the second most frequent cause of Post Polio Syndrome (PPS) symptoms, causing fatigue in 61% of polio survivors, muscle pain in 51% and muscle weakness in 45% (*Bruno & Frick, 1987; Bruno, et al., 1991*). Polio Survivors report other symptoms of chronic stress, including trouble falling asleep because "their minds are racing" in 58%, frequent feelings of anxiety (49%) and a frequency of ulcers that is 80% higher than in the general population (*Bruno & Frick 1987; Bruno 1995*).

There appear to be two sources of Polio Survivors' stress:

1. having had Polio
2. having PPS.

Stress and Polio

Three North American surveys and two clinical studies of more than 2,200 Polio Survivors found 23% more "Type A" behaviour - being hard driving, time conscious, pressured and over-achieving - as compared to those without disabilities or those who have Spina-Bifida, a physical disability apparent at birth (*Bruno & Frick, 1987; Bruno, et al, 1991; Creange & Bruno, 1987, Frick, 1997*). It should not be a surprise that Polio Survivors also have more years of education, work more hours of overtime and take fewer sick days than do non-disabled workers (*Bruno, et al., 1991; Bruno & Frick, 1987; 1989; Lomborg, 1993*).

"Type A" behaviour seems to have developed in Polio Survivors as an attempt to prevent abuse (*Bruno & Frick, 1989*). Polio Survivors who were emotionally, physically or sexually abused as a result of their Polio related disability are at least 15% more sensitive to the criticism of others and more ready to believe that they are failures than Polio Survivors who had not been abused or those without disabilities (*Frick, 1987*). The more sensitive Polio Survivors are to criticism and failure, the more "Type A" they are, and less likely they are to agree to complete or even

begin Post Polio treatment programme (*Bruno, 1995b; Bruno & Frick, 1995; Frick, 1997*).

Whether or not Type A Behaviour actually did protect against criticism, failure or abuse, it has taken a heavy toll on Polio Survivors. Post polio fatigue and muscle pain are more common in "Type A" Polio Survivors, as are trouble in falling asleep, frequent headaches, neck pain, back pain, or muscle spasm (*Bruno & Frick, 1987; Schanke, 1998*). "Type A" Polio Survivors are less likely to agree to be evaluated for Post Polio Syndrome and are less willing to take rest breaks during the day to treat Post Polio Syndrome (*Creange & Bruno, 1997; Frick, 1997*).

What's more, many Polio Survivors' stress response system is compromised. Polio Survivors with fatigue do not release enough ACTH in response to stress (*Bruno, et al. 1995b*). ACTH is a hormone produced by a part of the brain damaged by the Polio virus that activates the brain and turns on the body's stress "breaking" system (*Bodian, 1949*). Polio Survivors with fatigue are less able to activate their brain and concentrate when they need it most, that is when under stress.

Distress and PPS

Unexpected and disabling Post Polio symptoms occurring in the prime of life are understandably a cause of distress (*Frick, 1985; Frick & Bruno, 1986*). And Polio Survivors do have "significant psychological distress" and symptoms of depression (*Bruno & Frick, 1991; Conrady, et al., 1989*). Interestingly distress and depression are not caused by Post Polio Syndrome symptoms themselves, but when new symptoms cause the loss of functional abilities necessary to work, socialise and participate in family life, or when Polio Survivors believe that their Post Polio Syndrome symptoms are beyond their control and will progress (*Schanke, 1997; Kemp, et al., 1997; Conrady, et al., 1989, Diard, et al., 1994; Mullins, et al., 1995; Kirsh, et al., 1989; Peterson, et al., 1989*).

Depression is more common in Polio Survivors who have less social and family support to help them deal with functional loss (Tate, et al., 1994). A lack of family support is also related to Polio Survivors not completing or even beginning a treatment for Post Polio Syndrome (Creange & Bruno, 1994). Using crutches or a wheelchair is associated with Polio Survivors feeling inadequate as family members, while embarrassment about having an obvious disability is associated with the refusal to use assistive devices necessary to treat PPS (Creange & Bruno, 1997; Bruno & Frick, 1987).

Both stress and distress must be addressed if Polio Survivors are to make the lifestyle changes and use assistive devices necessary to manage Post Polio Syndrome.

It is recommended that all patients of post-polio receive a psychological assessment as

well as individual and group psychotherapy to teach “more effective coping behaviours decrease Type A Behaviour and help deal with past abuse and feelings of inadequacy, embarrassment and sensitivity to criticism, and failure to prevent Polio Survivors from treating their Post Polio Syndrome (Bruno & Frick, 1991; Conrady, et al., 1989; Tate, et al., 1994).

Richard L. Bruno, PhD is chairperson of the International Post-Polio Task Force and Director of The Post-Polio Institute and The International Centre for Post-Polio Education and Research at Englewood (New Jersey, USA) Hospital and Medical Centre.

Reprinted from Forward Motion, Florida, USA, June, 2007

Directory

Information about membership and local support groups

Free phone 0800 4 POLIO (0800 476 546)

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Informal interactions and networking at Conference 2009

We Are Twenty Years Old!

Here is a reprint of the Minutes of the inaugural meeting that started the ball rolling twenty years ago.

MINUTES OF THE MEETING OF THE POST POLIO SUPPORT GROUP STEERING COMMITTEE, HELD AT THE REHABILITATION LEAGUE, NAPIER, ON SUNDAY 5th DECEMBER 1989

PRESENT: Phillipa Morrison, Les Hewitt, Bryan Cox, Yvonne Cox, Shayne Parks, George Walton, Jo Walton, John Caulton.

COMPOSITION OF STEERING GROUP – elected at the Polio Conference as follows:

Phillipa Morrison (President) Bryan Cox (Secretary) Shayne Parks (Treasurer) John Caulton, George Walton. It was decided at this meeting to co-opt the following onto the steering committee: Les Hewitt and Lois Campbell.

It was agreed that the areas of responsibility would be as follows: P Morrison - Newsletter
Bryan Cox – Correspondence Shayne Parks - All Financial matters
John Caulton - The rules of the new Society (in conjunction with Alan McAllen)
George Walton - Liaison among committee members Lois Campbell - International Portfolio

MATTERS ARISING FROM CONFERENCE:

- (a) That “private people” can get footwear from the hospital on request.
- (b) That lectures be arranged for the medical fraternity on the post polio syndrome
- (c) That a newsletter be sent out containing the proposed rules of the new society as soon as possible so people can write in with their concerns.
- (d) That John Caulton collect in submissions concerning the draft of the society rules and that he work with Alan McAllen on an updated version for presentation to the registrar as soon as possible.

PUBLICITY: It was agreed that publicity of the post polio syndrome be left until the society is officially formed

CLINIC : It was agreed that this steering committee keep a watching brief on the formation of a clinic by Disler and Dean.

MINISTERIAL QUERIES: It was reported by P. Morrison that the appropriate ministers of the crown had been written to regarding: (a) How the amalgamation of ACC and the Benefit system will affect those people with PPS. (b) How the area health boards will accommodate the needs of people suffering from PPS.

TRAVEL FUND : There was discussion on how a travel fund could be set up to help people attend future conferences. Suggestions were to approach Social Welfare and to seek sponsorship. No decisions were made.

DONATION: It was decided to ask all members to send in a donation of \$10 to cover the costs of the steering committee over the next nine months.

Next meeting: Rehabilitation League on Jan 29th 1990 at 2pm unless necessary to bring it forward.

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