



The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**
Volume 5 - Issue 11 — December 2006

WebSite - <http://www.lincolnshirepostpolio.org.uk>

Hamish,
our youngest member aged 9,
moving 'without' and 'with his bits'



AGM

September 9th 2006

Back Row, Robin Butler,
Middle Row, Denise Carlyle,
Speaker Helen Kent,
Sheila Dunnett,
Ros Sinclair, Pauline Butler,
Front Row, Hilary Boone,
Mary Kinane, Barbara Taverner
and Silkie



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Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.

Lincolnshire Post-Polio Network,
69 Woodvale Avenue, Lincoln, LN6 3RD, UK
Tel: +44 01522 888601 Fax : +44 0870 1600840
[Do not dial first 0 if ringing from outside the UK]

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Renewal dates are the first of the Months of Feb, Apr, Jun, Aug, Oct, Dec.

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Next LincPIN Newsletter - March 2007

Articles for publication 5th February by post or - newsletter@lincolnshirepostpolio.org.uk

Management Committee

Chair - Mary Kinane - mary.kinane@lincolnshirepostpolio.org.uk

Secretary- Hilary Boone - hilary.boone@lincolnshirepostpolio.org.uk

Treasurer - Denise Carlyle - denise.carlyle@lincolnshirepostpolio.org.uk

Committee Member - Di Newman - di.newman@lincolnshirepostpolio.org.uk

Committee/Email List Facilitator - M. McCreddie - mary.mccreadie@lincolnshirepostpolio.org.uk

Operations Team

Membership Secretary - Robin Butler - robin.butler@lincolnshirepostpolio.org.uk

Phone Team - Di Brennand (Leader), Pat Hollingworth, Margaret Edmonds, Judy Barter

Administrative Support - Sheila Dunnett, Barry & Olivia Branston

Internet Services Administration - Chris Salter - netadmin@lincolnshirepostpolio.org.uk

Editorial by Hilary Boone.

Yesterday, 31st October we were out in T shirts and it felt really warm and was 18C [65F]. Today is November 1st and it's a lovely sunny day with not a cloud in the sky but it's only 9C [48F] today and we have put the central heating on during the day for the first time this year.

This newsletter is again full of information on Post Polio issues. **Mary Kinane, Chair**, reports on our Annual General Meeting and other meetings she has attended. Next, our youngest member, Hamish aged 9 today, '**Happy Birthday Hamish**', tells his story. If any reader has any idea how to help this delightful young man achieve his dreams then please get in touch.

Page 12 is where you need to take a deep breath and relax your shoulders before reading although we can tell you now that whilst this seemed disastrous at first it has certainly brought PPS into the headlines and the outcome is looking more promising. The lead author **Dr. Eric Sorenson** has responded that 'we do have valid criticisms' regarding the **15 year Mayo Study** and we now await his response to 22 specific questions. Unfortunately he has responded that he does not have time to answer the questions. We will not be leaving it there and will report what happens in the next newsletter. A big thank you to members **Marcia Falconer, Eddie Bollenbach, Ruth Bridgens, Mary Westbrook** and to **Mavis Matheson** for sharing their responses to the Study. Mavis, who I met at a PPS Conference in Toronto, shares with us her latest after dinner speech on page 23.

Mary McCreadie reports on some of the subjects discussed on our members email list.

We have received notification of two PPS conferences in 2007, I will be in Florida so have booked for the Miami conference and member **Jann Hartman** has confirmed she is attending and going on the Cruise. If you are going to attend either Conference then do let us know. N.B. Unless money is donated to the LincsPPN towards Conference attendance we pay our own costs.

March 29th to 31st 2007 - Como, Italy by the **Associazione Nazionale Polio e Sindrome Postpolio**. Sessions will be conducted by physicians dealing with polio and post polio. Also on March 31st The European Polio Association will meet to discuss various proposals that the group can undertake at local and national level. See www.postpolio.it

April 9th to 11th 2007 - Miami Florida by the **Post Polio Association of South Florida & The International Post Polio Support Organisation** 'Partnering for a Better Tomorrow' at the Radisson Hotel, Miami Downtown. The Boca Raton PPS Group have organised a 7 day Caribbean Cruise to follow the Conference. Details of the Conference and Cruise can be found at <http://www.post-polio.org/PPConfApr9-11.pdf>

Margaret E Backman PhD sent information on her new book, The Post-Polio Experience, I bought a downloadable version for \$6 and I found it very informative. We need to ensure we allow our family and friends to tell us how they feel about the way PPS has changed our/their expectations.

Viola Pahl in Canada, who long time readers of the LincPIN will remember, has moved to a residential home and whilst downsizing decided to donate some copies of her books to the LincsPPN. Viola thank you so much, and we look forward to printing some of your story of your new home in the next issue. Not only is it informative but makes you smile as well.

Also in the next issue - member **Robin Brierley** shares with us his inspiring fictional based on fact story of a child getting polio. Remember when visiting your past, which can also be triggered by smells, pictures and reading about someone else, it can make you very emotional, often totally unexpected. You are not alone in this and whilst 'opening the box on the past' is tough the majority will tell you that it has helped them move on. Send us your stories and/or photos.

STOP PRESS. Congratulations to Phone Team Member Pat Hollingworth on her engagement to Terry Bevington on 4th November.

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Message from the Chair

It has been a busy period for Committee Members. Our AGM was held in Lincoln on September 9th with 33 attending. Unfortunately the caretaker who was to have opened up the Memorial Hall for us could not be found and I would like to thank Sheila Dunnett and Barbara Taverner for sorting out a nearby venue in a very short time. The Trustees of the venue have apologised, refunded our money, and offered us free use of the premises next year, should we so wish.

Voted in were myself, Mary Kinane (Chair), Denise Carlyle (Treasurer), Hilary Boone (Secretary), Diane Newman and Mary McCreadie as Committee Members. Thanks went to all our Operations Team volunteers for all their hard work this year. We do not have any paid staff - all the work is done on a voluntary basis. Member Ros Sinclair, also a British Polio Fellowship Trustee gave us a short update on their work and how greater co-operation was planned between our two organisations. We feel that this is a welcome development, especially for our UK members. It was decided to hold next year's AGM in early September; the date will be published in the next newsletter.

Member Dr Sally Sennitt, the Medical Director of Kingfisher Healthcare, a medical devices company based in Belgium, was our first speaker. She came to introduce herself, the company and the work they are doing with microcurrent in the treatment of fatigue in chronic illnesses and in particular PPS. They are producing hand held devices that deliver microcurrent, (very low electric currents) a fascinating and promising technology which has until now, never been fully developed for use in specific diseases or symptoms.

The philosophy of Kingfisher Healthcare is to develop products optimised for a particular use (e.g. fatigue, wound healing) that have been proven in clinical studies; assisting individuals to manage their own conditions safely and effectively.

Unlike TENS, microcurrent does not trigger any nerve activity and cannot contribute to muscle overuse. The devices support physiological processes at cellular level, amongst others by stimulating the body's own cells to produce more ATP, the energy source for all cell processes. This allows the cells to carry out their normal processes faster and more effectively hence more energy, faster healing and recovery etc.

A study in a group of PPS patients in Belgium, the Netherlands and the USA, has shown very promising results with a statistically significant increase in stamina of 43% and a 36% reduction in fatigue over a period of 3 months. Dr Sennitt presented the results and after a searching and informative question session asked for volunteers to join the UK branch of the study. Many of you did and we will let you know the results in due course. Dr Sennitt's medical background is in anaesthesiology, a welcome addition to our knowledge base.

We then had a lovely buffet lunch and time to chat. Our Main speaker for the afternoon was Helen Kent, BS, RRT and owner of Progressive Medical in California. Helen told us that patients with neuromuscular conditions need to have some simple respiratory tests included as part of their yearly assessment. This will give an early indication of possible respiratory issues and results should be reviewed on a regular basis.

Helen tested 21 of our members during the day. The tests consisted of Maximum Inspiratory Pressure (MIP or PiMax) Maximum Expiratory Pressure and Forced Vital Capacity. Helen advised all those with MIP's lower than -60cm H₂O to ask their General Practitioners to refer them to a Respiratory Consultant for further testing.

[Two quotes from “Hypoventilation? Obstructive Sleep Apnoea? Different Tests, Different Treatment” by Judith R Fischer, MSLS, Editor Ventilator-Assisted Living - see full article in LincPIN Newsletter, March 2006. ‘*Hypoventilation. Generally, in people with neuromuscular disorders who are having breathing problems, the main problem is hypoventilation (under ventilation) - not breathing deeply and/or often enough. Muscle weakness, scoliosis and/or chest wall stiffness make it difficult or impossible to fully inflate the lungs.*’ AND ‘*A result of <50% predicted FVC or a MIP <60cm H2O may signal that it’s time to get some assistance with breathing.*’] The results were **4 at -50, 6 at -40, 1 at -35, 1 at -30, 5 at -25, 1 at -20, 1 at -15 and 2 at -10, all cm H2O**. All 21 were lower than -60cm H2O [note that where a negative scale is used for MIP, e.g. -60 instead of 60, -50 is lower than -60 and -10 is lower than -50]. The San Francisco PPS Group Testing results were 22 of 25 had MIP’s lower than -60cm H2O. Two of our members attending were already using Bi-level Night Time Ventilation and they and their partners confirmed that all four lives were greatly improved by this.

I would like thank Member John DeAth who arranged a dinner in Jesus College for the Kents and Boones to meet Professor John Stradling, Consultant in Respiratory Medicine at Oxford. They report ‘A wonderful meal in awesome surroundings with very lively conversation regarding PPS and respiratory issues.’ A big THANK YOU to Helen and her husband who re-scheduled their holiday itinerary to spend a few days in England, so that she could speak at our AGM and do the respiratory tests for members.

We were very pleased to welcome Graham Ball (Chief Executive) and Mike Egan (Trustee) of the British Polio Fellowship (BPF) who joined us in the afternoon. Denise, Hilary, Richard and myself, all BPF members, attended their AGM two weeks later in Walsall.

As a further step towards our collaboration with the BPF, I attended the inaugural meeting of the BPF's Expert Panel in London in October. Two other members, Dr. Ros Sinclair and Dr. Ruth Bridgens are polio survivors and BPF and LincsPPN members. There are other specialists in research, rehabilitation, neurology and respiratory medicine. In preparation for the next meeting in January, each member will be putting forward what they consider to be important issues which need addressing. The opening remarks by the Panel's Chair - Bert Massie CBE - that we were there 'to make a difference' to polio survivors will, I hope, continue to guide us

Denise Carlyle and I were invited to give a presentation on self-assessment at the Scottish Post Polio Network's AGM near Glasgow, also in October, so it has been a very busy month. Our presentation was well received (this was based on the material developed by Hilary Boone and ourselves for the PHI Conference at St Louis, MO in 2005); afterwards we had quite a few requests for copies of the self-assessment forms which we ran out of on the day! Other speakers included a very accessible session by Billy Cassidy, qualified Self-Management Tutor: “Managing Life with Post Polio Syndrome” and a talk by Dr Christopher Roy, Consultant in Rehabilitation Medicine, Southern General Hospital, Glasgow. Both Billy and Dr Roy live with a disability themselves and I thought that their approaches were both informative and down to earth. We hope to have more on these in the next issue.

On behalf of the Committee I wish you all a safe, warm and peaceful winter.

Best wishes, Mary Kinane, Chairperson. mary.kinane@lincolnshirepostpolio.org.uk

Our youngest member says: I'm Hamish, I am 9 years old and

I had polio at 9 weeks old from my vaccine. I have to be in a wheelchair nearly all the time.

In my walker I have to wear my spinal jacket and legs splints. Mummy puts me in my walker lying down on the floor, she then lifts me up, to standing. I move my hips forward and backwards and side to side to move the footplates so I can walk. I also move my arms. I like to stand up, it also gives me a good stretch, but if I'm in for more than an hour my legs really hurt and its painful when I come out and bend my legs. I think I will need a new swivel walker soon as I'm growing taller.

I love swimming as I'm free as I don't wear my bits [See photo front page]. I would love a swimming pool at home to swim in every day. I went to Florida by myself with 7 other disabled children, it was fantastic. I want to go again.

I go to Shirwell School and I have lots of friends. I have one sister, Christina and two brothers, Michael and Joshua and a dog called Phloxy.

I just wish I could walk. That's all I can say. Hamish

Note from Dad:- [picture on front page]

The swivel walker was designed by the same person who designed the Spitfire in WWII. He designed it to help injured pilots and the concept is that the footplates are angled just like an airplane wings. As weight is transferred to one footplate the other lifts off the floor and can be swung forward by twisting the body or hips. Transferring body weight to the opposite side enables the other footplate to be moved forward. There is a spring loaded strut connecting the front of the two footplates keeping them parallel for stability. This works very well but only on flat firm surfaces.

Hamish's Story. [Editors note:- all information is in the public domain]

Hamish was born on 1 November 1997 in Barnstaple, North Devon. His family had moved to England from Johannesburg in South Africa just 4 months earlier. Hamish's Granny lived in Croyde which is a seaside village 8 miles from Barnstaple and when his parents decided to move back to the UK Granny's house became home for a while.

At the time of his birth Hamish's siblings were Christina aged 7, Michael aged 5 and Joshua aged just 18 month old. All was well and six weeks after his birth the family moved into a small house they had managed to buy in Braunton.

At about 4 weeks old Jacqui, Hamish's Mum, noticed a pimple like spot form on one buttock right next to his anus. This became hard and was obviously tender to the touch. After a couple of weeks it formed a head and then while changing him one day the head came off and the spot appeared to clear away. At the same time another spot appeared on the opposite buttock but this one seemed to get bigger and more tender.

Just before Hamish was 8 weeks old this spot had become so large that it was more like a lump and was obviously becoming very uncomfortable. This was so much so that on the Sunday before he was due his 8 week vaccinations Jacqui called the emergency doctor to seek advice.

Have you ever tried to explain to an emergency Doctor on a cold winters Sunday

morning that your 8 week old baby has a spot on his bottom and that he is very uncomfortable and that you think there is something wrong without sounding like a paranoid mother who is wasting the Doctor's time? The end result was that it was agreed that as Hamish was due his vaccinations in the morning as he would be going to the Health Centre it would be best for this to be addressed there.

The next day was 28 December and as a result the whole family were together due to the holidays. David, Hamish's father, as well as Jacqui and all the children took Hamish to the Health Visitor at the Health Centre where he was weighed and measured. The Health Visitor, when told about the lump, wanted a Doctor to examine it. She went off to call the duty Doctor, Dr Grey, and returned looking sheepish with a prescription for a local topical antibiotic cream. Jacqui was told to apply the cream and if there was not improvement in a couple of days then to come back.

Both David and Jacqui asked if they should still take Hamish to the Nurse for his vaccinations. The health visitor indicated that this would be fine.

When the family took Hamish in to see Nurse Dalimore she asked if Hamish had any problems. She was told about the lump on his bottom and shown the prescription that had just been given. Nurse Dalimore immediately decided to examine him. When she saw the lump she insisted that a Doctor come and examine Hamish. Off she went and then came back saying that Dr Grey was unavailable and that Dr Bradford would come as soon as he was finished with his current patient.

The whole family waited in the surgery until Dr Bradford came through. He looked at the lump, decided to squeeze it and take a swab for analysis and prescribed an oral antibiotic. He said that if there was no improvement in the next two to three days Hamish should be brought back.

David then asked if it would be safe to proceed with the vaccinations. Dr Bradford replied in a dismissive tone that the lump was at one end that the vaccinations were at the other and therefore there was no problem going ahead. With that he left the room and Nurse Dalimore proceeded with the vaccinations. As she gave Hamish the Oral Polio Vaccine she reminded his parents to wash their hands after changing his nappy as the polio vaccine was live and was passed through the bowels for a couple of weeks after vaccination. With that the family left and went home. Both David and Jacqui commented in the car afterwards to each other about the strange expression Dr Bradford had used regarding one end and the other.

By Wednesday evening the lump had increased in size and was more uncomfortable than ever. Most of Wednesday night Hamish cried and could not sleep.

The next morning, being New Years day 1998 this lump was big red swollen and looked really angry. Jacqui once again called the emergency Doctor who this time told her to bring Hamish straight in to the clinic. She examined Hamish and sent Jacqui, David and Hamish directly to the children's ward at the local hospital.

There Hamish was examined by the surgeon on duty who contacted the consultant surgeon and then advised that the perianal abscess needed to be lanced and drained under a general anaesthetic immediately as there was a serious risk of septicaemia.

This was done and after the procedure had been carried out there was a hole ½ inch wide by ½ inch long and ¼ inch deep. Bearing in mind that Hamish was only 22 ½ inches long this was quite a crater. It was very difficult to dress the wound and over the next few days each time Hamish had a bowel movement the wound was filled the faeces.

Over the next few days Hamish responded well and seemed to be more comfortable but by the Thursday, being a week after surgery, he developed a high temperature and was extremely irritable. On the Friday morning Jacqui took him back to the Doctors and Dr Pearce told her to take him straight to the Hospital as he suspected Meningitis.

Hamish was admitted on the Friday and by that evening he was diagnosed with Meningitis. On Saturday he began to develop twitching movements but on Saturday night he seemed to sleep right through the night. On Sunday morning Jacqui told the Nurse that he had slept through and was still asleep. The Nurse examined Hamish and discovered that he was unconscious. He remained in this state for a few days and was totally floppy. The only way you could lift him was on a pillow. Hamish was then diagnosed with encephalitis which it was thought was causing the state of semi consciousness.

Fortunately the paediatrician who was caring for Hamish left no option unexplored and after a week of tests and debates with the virologist Dr Bosley diagnosed Vaccine Associated Paralytic Poliomyelitis. (VAPP).

Hamish spent the next month in hospital and when he was discharged he had to be carried home on a pillow. He had lost all movement, his voice and had a very weak sucking ability.

Very slowly over the next few weeks little movements appeared to return. First his hips could be felt moving slightly and then his right fingers began to move. What was surprising was that improvements were noticed and continued to appear for the next three years.

Hamish is now nearly 9 years old and due to the vast quantity of live polio virus that went into his system through the wound site, bypassing any normal body defence mechanisms, he remains severely physically disabled. His legs are true polio legs and his shoulders are very weak. His upper arms are severely affected and his left hand does not function. He has a double scoliosis with the lower curve last measured at 68 Degrees.

Despite all this Hamish is a true polio survivor. He is charming, bright, determined and a real joy to know. He is fast becoming a whiz on a computer as Hilary has learnt from experience.

Hamish's parents were told by a number of medical professionals that Hamish should never have been vaccinated at the time. It was negligent of Dr Bradford to proceed with the vaccination when Hamish was unwell and that this needed to be taken further.

On this advice the case was referred to a specialist London Clinical negligence firm of Solicitors. The solicitors were first contacted in 1998 and six years later, having explored all aspects of the circumstances of the vaccination, the case was heard in the high court in London. During the trial it came to light that Dr Bradford had not taken any notes of the consultation and that he and Nurse Dalimore had concocted

a story that Jacqui and David were concerned about Hamish's hips at the time of the vaccination and that the lump was not an issue. Furthermore Dr Bradford had diagnosed a reoccurring perianal abscess but never told Hamish's parent of this diagnosis or that he had never seen this before in his life but he accepted the only treatment of a perianal abscess was lancing and draining under general anaesthetic.

Dr Bradford did not mention that there was a risk that Hamish would require surgery within the next few days. His argument for not disclosing this was because he thought Hamish may not be brought back for his vaccinations if he was not vaccinated that day.

Dr Bradford relied very heavily on the government advice given in the guide to vaccinations commonly know as the Green Book. This book states that surgery is not a contra indication to vaccination with the oral polio virus. This advice is in direct contrast to the advice given out during the wild polio epidemics in the 40's to 60's when doctors were advised to postpone all tonsil and adenoid operations when wild polio was around. This is also in direct contrast to the published Strebel study proving what is known as provocation polio.

After a 5 day hearing in the high court the Judge ruled in Hamish's favour and he had won. Whilst damages had not been discussed it was reported that due to the extreme nature of his polio Hamish would be due to receive damages of around £5,000,000 in order to provide the right level of care he would need for the rest of his life.

Whilst Dr Bradford was being sued he was protected by the Medical Protection Society (MPS) who defended his side of the case. This meant that Dr Bradford would not be affected financially should he lose and even though he was found to have provided a level of care below that of a competent medical practitioner he personally would not be affected at all.

The MPS appealed the decision of the judge. The appeal was allowed and a year later there was a hearing in the Court of Appeal in London before three Appeal Court Judges. This process was most disappointing as of the two days allocated the MPS were allowed total free rain for the first day to present a picture which was totally out of kilter with reality. Unsurprisingly the appeal was won on the grounds of foreseeability in that Dr Bradford could not have foreseen Hamish contracting polio.

The Appeal Court judgement stated that: *The maximum any competent GP could have foreseen was that if Hamish had an adverse reaction to the vaccination he would have a greater degree of discomfort as a result of possible surgery and not that of contracting VAPP.*

So after 8 years of David and Jacqui having to relive, over and over again, the tragic day that they watched Hamish be crippled because they accepted the doctors answer to their questioning him being vaccinated that day, it came down to this.

When Hamish was vaccinated the virus used was live and as it is excreted for a few weeks advice must be given. The nurse cautioned us 'to wash our hands after nappy changing as polio can be caught from the excreted virus'. However, the judges deemed the GP could not foresee that Hamish might contract polio when he most likely will need to have his perianal abscess lanced within a few days which will be flooded with live polio virus every bowel movement.

The other great lesson being learnt is that all the knowledge and experience gained over the past 60 years for the treatment and rehabilitation of polio victims has been thrown out as “polio does not occur anymore”. Compared to all the reports read on intense physiotherapy and hard work done in the '50 and '60 Hamish's rehabilitation has been left to his Mum to do because the medical professionals “Don't know what we can do as polio is untreatable”.

David and Jacqui will now spend the rest of their lives paying for Hamish's care because they allowed Hamish to be vaccinated that day believing that a doctor and the Department of Health won't get it wrong.

David Thompson <dlt42@btinternet.com>

Editors Notes:-

1. On the 10th August 2004, The Chief Medical Officer, the Chief Nursing Officer and the Chief Pharmaceutical Officer issued the New Vaccinations for the Childhood Immunisation Programme. Paragraph 2. 'The risk of polio infection being brought into the UK is now very low. This is because polio has been eliminated from large parts of the world due to the success of the global vaccination programme. JCV1 has recommended that a switch can be made from live oral polio vaccine (OPV), which provides good individual and community protection, to inactivated polio vaccine (IPV), which provides effective individual protection. **Also, IPV does not carry any risk of causing vaccine associated paralytic polio, that occurred very rarely with OPV.'**

2. Quotes from the current Green Book, a publicly available document on immunisations against infections disease. Poliomyelitis. The disease...

- A. The virus replicates in the gut and has a high affinity for nervous tissue. Spread occurs by way of the bloodstream to susceptible tissues or by way of retrograde axonal transport to the central nervous system
- B. Transmission is through contact with the faeces or pharyngeal secretions of an infected person. The incubation period ranges from three to 21 days. Polio virus replicates for longer periods and it can be excreted for three to six weeks in faeces and two weeks in saliva. (Gelfand et al, 1957). Cases are most infectious immediately before, and one to two weeks after, onset of paralytic disease. (Sutter et al, 2004)....
- C. Routine immunisation with inactivated poliomyelitis vaccine (IPV—Salk) was introduced in 1956. This was replaced by live attenuated oral vaccine (OPV – Sabin) in 1962... Following the introduction of polio immunisation, cases fell rapidly to very low levels. The last outbreak of indigenous poliomyelitis was in the late 1970's. The last case of natural polio infection acquired in the UK was in 1984. Between 1985 and 2002, a total of 41 cases of paralytic polio have been reported in the UK. (Figure 4.2) Thirty cases were vaccine-associated paralytic polio (VAPP); six cases had wild virus infection acquired overseas; and a further five cases, all occurring before 1993, the source of infection was unknown but wild virus was not detected. (From the chart in 1997 there were two cases of polio recorded, one for vaccine recipient and one for vaccine contact.)

- D. Precautions. Minor illnesses without fever or systemic upset are not valid reasons to postpone immunisation. If an individual is acutely unwell, immunisation may be postponed until they have fully recovered. This is to avoid wrongly attributing any new symptoms or the progression of symptoms to the vaccine.

<http://80.168.38.66/files/gbpolio.pdf>

Under Information for Travellers.

A. Contraindications specific to OPV[1] Current GI upset.

- B. Adverse events. OPV[1] Paralysis temporally associated with vaccination, termed Vaccine Associated Paralytic Poliomyelitis (VAPP) has been reported rarely in vaccine recipients or contacts of vaccine recipients. The risk of VAPP is higher after the first dose of OPV than after the subsequent doses, ranging from 1 case per 1.4 million to 1 case per 2.4 million first doses administered.

<http://www.nathnac.org/travel/factsheets/poliovaccine.htm>

Hilary Boone asks readers... Do you think the judgement was correct?

I first met Hamish when he was about two years old. I have seen him grow up to be a strong willed, determined, very intelligent young man with a wicked sense of humour. At five years of age he mastered the track mouse on my laptop, something he had not seen before, and in about two minutes was looking through the photos on my computer. A swimming pool fund has been started with a generous donation from David's firm. Any suggestions as to how we can help enable him to enjoy movement 'without his bits' would be welcome.

Tricks that we use to achieve actions by Mary McCreadie.

There's no doubt about it, things can get complicated when you have PPS – especially when bits of you don't work as well as they should. Hilary and I were talking today, free video phone via Skype on our computers, about how we carry things – like a carrier bag with a little bit of shopping in it. Simple, you say. Just pick it up and walk off with it.

Yes, but I only have my fairly feeble left arm to use, as the right one is busy with my elbow-crutch. If I try and carry a bag as one normally would, my grip gives way and the bag hits the deck..... and I stand there like a lemon, watching my tomatoes (or whatever) roll down the road! My strategy is to get my hand and forearm right through the handles of the bag, and then grab the collar of my coat, locking my arm into position. That way, I can usually manage to at least get the shopping into the house before disaster strikes.

Hilary, who is also using stronger right arm for cane or arm crutch, has a different approach. She also puts her arm right through the handles of the carrier, but she then hooks her thumb into the waistband of her trousers, and hopes to goodness that the elastic is strong enough to counterbalance the weight of the shopping!

Ah well, each to their own..... But why not write and tell us all more about your lives and the tricks and ways you have devised to do actions.

What works for one might just be the tip that someone else needs.

**Three Press Releases from 21st to 26th August 2006
Relating to a medical article from the Mayo Clinic, Rochester, MN, U.S.A.**

'Survivors of childhood polio do well decades later as they age' [21.10.2006 - [a]

'Polio Survivors faring well' [24.10.2006 - [b]

'No polio effects' in later life' [26.10.2006 - [c]

The initial statement [a], on the 21st August 2006, was the announcement by the Newsbureau of the Mayo Clinic in Rochester, Minnesota, of the research findings reported in an article in the Journal of the Peripheral Nervous System, 'Electrophysiological findings in a cohort of old polio survivors' by Eric J. Sorenson, Jasper R. Daube, and Anthony J. Windebank.[1] This was taken up by other journalists and reported by HealthDay on 24th August [b] and then BBC NewsHealth on 26th August. [c]

Here is a quoted response from Dr. Sorenson from each of the Press Releases:-

- a. *"Other researchers have suggested that polio is a more aggressive condition later in life, but we've actually found it to be relatively benign," says Eric Sorenson, M.D., Mayo Clinic neurologist and lead study researcher. "Our results suggest that polio survivors may not age any differently than those in the normal population -- they're not doing too badly compared to their peers. This tells us that the cause for the decline in muscle strength in polio survivors may be aging alone."*
- b. He added that the findings should be comforting to people worried about polio-related decline later in life. *"Though the likelihood is high that patients who have had childhood polio will complain of weakness later in life, they can expect years of stability without the need for major lifestyle modifications."*
- c. *"Our results suggest that polio survivors may not age any differently than those in the normal population - they're not doing too badly compared to their peers."* He added that the findings should be comforting to people worried about polio-related decline later in life.

BBC NewsHealth [c] made some modifications to their initial press release following an email from one of our members daughters. The email and response follow.

Dear Mr Herrmann,

In response to the "'No Polio effects' in later life" article (26 August 2006, <http://news.bbc.co.uk/1/hi/health/4799725.stm>), I would like to say that after contracting and recovering from polio, my mother lead a full life, with little disability, the referred to 'period of stability'. Thirty years down the line she began to experience progressive muscle weakness and pain in her forties, and was in an electric wheelchair by her fifties.

I do not call this 'normal ageing' or 'not doing too badly compared to her peers' - her peers are playing sports, going on holidays, working full-time and doing housework or gardening. My mother has had to give up all these things, and much more, including her art. She lacks the muscle strength and stamina throughout her body, she experiences muscle pain in her arms and shoulders, and even her breathing is affected through weakness of the diaphragm and intercostal muscles.

My mother's experiences are not unique - She is in contact with many other people across the world who had polio earlier in life and are now experiencing disability greatly out of proportion to their age, and the severity of their initial acute poliomyelitis viral infection. The Post-Polio Syndrome (PPS) community in Britain and the USA has been fighting to get diagnosed, to have the condition recognised, to get the disability benefits they deserve, and to feel supported and believed, all whilst experiencing declining health and finding their world getting smaller and smaller. A research report such as that of the Mayo clinic could potentially damage the progress that they have made so far.

Anybody who knows anything about research will understand that 50 people living around the Mayo clinic is not a statistically representative sample of world-wide polio-sufferers, and that the Mayo clinic's findings can only apply to people who had polio in that small region of America. It is likely that most of those people had the same strain of polio, which perhaps may turn out to cause fewer post-polio symptoms than other strains. To imply that PPS does not affect any polio victims is not a conclusion that can be drawn from such a limited study.

'Benign' is a wholly inappropriate word for this condition, which is progressive. The fact that it is so poorly researched and understood, means that those with PPS face an uncertain future, with no prognosis, and little treatment. For the Mayo clinic now to state that this life-devastating condition doesn't exist, is just cruel and I think that the BBC has a duty to present the other side of this issue, rather than just reporting on a factually dubious and non-representative study.

Do I need to point out that if I had followed fifty people in my home town of Brighton who had had cancer, but survived, and then I published a report that said, "cancer doesn't kill", I would be drawing an equally crass conclusion?

Let's have some responsible journalism. Yours sincerely [Anne Wood's daughter]

Richard Warry replied:- Steve Herrman passed your letter dated 1 September on to me, as editor of the health index of the BBC News website. First please may I thank you for your message - and interest in the site. I apologise for any offence the piece caused you, but believe it to be a fair representation of the research.

That said, in light of your comments, the introduction has been changed to read "many people" rather than "most people", and extra paragraphs have been added to highlight your concern that the sample was small and not necessarily representative.

My reporter did run this past a leading polio organisation, which was very positive about the study, and so I don't think it fair to suggest that the research was presented uncritically. [Editors note—Post-Polio Health International]

Neither do I think it fair to suggest that the piece intimates that post-polio syndrome does not exist. In fact, it explicitly states that people who were most badly affected when originally infected are most likely to experience problems in later life.

Please may I assure you that every effort is made to ensure only responsible journalism appears on the site.

Kind regards, Richard Warry

Health desk BBC News website T: 0208 576 9610 news.bbc.co.uk/1/hi/health/

Readers attending our AGM, and/or subscribed to our Polio and Post Polio News Service and/or our Members Email List will already know that this caused a huge response from Polio Survivors worldwide.

I can well imagine your comments as you read this article. Take a deep breath, let it out slowly and relax those shoulders. Now read on. A huge amount of time has gone into reviewing all the related medical articles, writing, rewriting following peer reviews, and preparing the final documents for uploading to the Website. We would welcome comments from anyone reading this newsletter, and that includes your family and friends and health professionals.

The information in the medical article [1] had been extrapolated from a 15 year study of polio survivors in Olmsted County, Minnesota, that had been ongoing since the early 1980's. In February 1996 The Lancet printed a review by McCarthy of the 1996 Windebank et al article 'Lack of progression of neurological deficit in survivors of paralytic polio: a 5-year prospective population-based study. [2] with the title

'Study throws doubt on Post Polio Syndrome.' [February 1996 – [3]

Within weeks polio survivors were reporting that doctors were now telling them that PPS did not exist. Rebuttals were written to this article and Helena Edwards of the Leicestershire Polio Network pulled them together under the title 'The Mayo, The Lancet and the Revolting Polios', which can be read in the Online Library on our Website. [4] This was also published in the May 1997 LincPIN. [5]

Rebuttals to the main article in question were written by members Dr. Marcia Falconer and Professor Eddie Bollenbach [full article starts page 18 - [11]. Dr. Mary Westbrook in New South Wales, Australia reported this and wrote a rebuttal in their August newsletter [excerpt page 21 - [12]. Other rebuttals followed from Dr. Mavis Matheson [excerpt page 21 - [13], by member Dr. Ruth Bridgen [excerpt page 21 - [14]. I have also written an article [summary of some of the issues starting below - [15] but did not confine myself to this article, I looked at all other medical articles that related to studying polio survivors in Olmsted County. [1,2,4,6,7,8,9,10]

I was one of the Polio Survivors told in 1996 by my neurologist that 'he had just read an article in a medical journal that showed it had now been found that PPS did not exist'. I was therefore delighted when Mary McCreadie suggested the following as the title for my article,

'Polio Survivors throw doubt on Study' [September 2006 – [15]

I sent the article to Dr. Eric Sorenson with a covering letter. He replied '***Many of the points you raised are valid criticisms'*** and made general comments ending with '***I am sorry if our work has provided you or your colleagues difficulty or distress, none was intended.'***[18] I replied with a list of very detailed questions but before I go any further I need to start at the beginning.....

The Mayo Clinic in Rochester, Olmsted County, Minnesota, U.S.A., are in the unique situation of having all medical records for the county since 1907. These were data based in 1938 using a coded diagnosis for easy retrieval.

In the early 1980's the new problems being experienced by polio survivors presenting to clinics began to be discussed at conference level. The Mayo Clinic

decided to do a population based study to see if the results from the patients currently presenting could be generalized to the total population at risk.

The retrieved information from the database showed that '*608 people had been diagnosed with acute poliomyelitis between 1935 and 1960*'. Based on the definition of paralytic poliomyelitis and a further clarification of the word paralytic in the *National Conference on Recommended Practices for the Control of Poliomyelitis, Ann Arbor, MI, 1949, personal communication* it was decided that '*300 met the criteria for paralytic poliomyelitis. The remaining 308 were either nonparalyzed or they had such brief paralysis that they did not fulfil the requirements.*'

Mary Codd et al, in a preliminary report in 1984, [6] reported that 316 polio survivors had been recorded as being diagnosed with acute poliomyelitis in **Rochester** between 1935 and 1955. 201 were classified as having had paralytic polio and 115 non paralytic polio. Just over 50% of all cases occurred in 1952. 23 died at the acute phase and 7 since then and 23 remain untraced. Questionnaires were sent out and 125 completed questionnaires returned. 97 reporting no symptoms and 28 reporting new symptoms that had started between 12 and 35 years with a mean of 25 years since their polio. The questionnaire was supplemented by a detailed telephone interview for those who indicated deterioration since their maximal functional recovery from polio.**[28 quoted above]** In this interview, the subjects were questioned about excessive fatigue, decreased endurance, extent of muscle weakness, fasciculations, muscle cramps, muscle and joint pain, atrophy, contractions and deformity. Activities of daily living and increased needs for walking aids, wheelchair, personal and ventilatory assistance were discussed. In addition, patients were asked about intercurrent illness, surgical procedures, falls and fractures.

Based on these responses it was decided to expand the survey to include all residents of Olmsted County who had paralytic polio between 1935 and 1959. A 15 year study of 50 people was planned. Anthony J Windebank M.D. was the lead medical professional at the inception and at five years and Eric J Sorenson M.D. at fifteen years.

Our initial response is - as it has been since the Lancet article in 1996 - 'Do the cohort of 50 fully represent the polio population as a whole'? Following a presentation at St. Thomas Hospital in London by Dr. Windebank on the results of the first five years study [2], I asked "*How many of the 50 did sport?*" Dr. Windebank replied that "*one man could manage three holes of golf.*" When I asked, '*No swimmers, athletes, rugby referees, people in the police or armed forces?*' he emphatically replied, '*these people had paralytic polio*'. I replied, '*so did the people I am talking about, including myself. They all had paralytic polio and some were even in iron lungs*'. The seminar restarted and Dr. Windebank did not answer a follow-up letter.

I now go back to the medical article in question [1] and the statement made by Sorenson et al '**Fifty representative subjects were randomly chosen from 298 patients**' which leapt out of the page. Light-heartedly we ask you to imagine a cartoon depicting a cemetery where the 53 polio survivors that died at the time of polio and since then are lying in their graves, with finger bones crossed, hoping that they are not going to be randomly chosen '*for detailed historical, functional, psychological, clinical and electrophysiologic examination.*' Quoting from the 1991

Inception article *'Of the 300 polio survivors identified, 30 (10%) died at the time of polio and 23 in subsequent years. 2 remain untraced.'* 300 minus 53 leaving a possible 247 if the 2 untraced were found and 245 if not.

In the 1991 article [8] Windebank reports *'From the 247 survivors' '58 subjects were called in to recruit 50'. 'Fifty survivors who lived **closest to Rochester** were selected for the study. This group was likely to stay in the area and be available for follow-up study.'* Later in the article Windebank stated *'There may be a tendency for more handicapped residents to remain geographically closer to our clinic.'* and *'These subjects were not seeking medical attention; they were invited to participate on the basis of their having had polio.'* So you can see that randomly chosen is not an accurate statement.

I extrapolated phrases and numbers from each of The Study's articles onto a large chart. I found other apparent anomalies and points that I felt needed raising with the authors of The Study. The following are some I am taking up with Dr. Sorenson.

1. In the 1991 [8] article In Table 2 they compare some statistics between the 50 chosen and the 197 not chosen (50 + 197 is 247). The age at polio and then 34/35 years later is given for the 50 (1.5 to 36) (35 to 71) and for the 197 (1 to 47) (35 to 76). Age 47 + 35 years is 82 not 76.
2. The mean age of polio survivors at the time of polio starts at **9 years** in 1984,[6] increases to **13 years** from the 50 involved in the study [8,2,10] and to **15 years** from the 38 remaining in the latest article.[1] As polio was originally called infantile paralysis, do you think 13 and 15 as the mean (average age) seems high?
3. Comparing figures at the three points of the study, Inception, [8] 5 years [2] and 15 years. [9]
 - a. At inception 32 of the 50 are reported as having symptoms, 18 did not. [8]
 - b. At the five year point the figure with symptoms reduces to 30. Windebank reports *'Of the original cohort of 50 subjects, 46 returned to complete the studies. Of the four who did not return, two completed the symptom questionnaire and two reported by phone that they were doing well. No data were analyzed from the two subjects interviewed by telephone.'* One therefore assumes that this is why the number is reduced to 30. However, in the next paragraph he states that *'23 individuals had at least one of the complaints at the first and second evaluation, 12 had no complaints at either evaluation, 7 had complaints at the first but not at the second [this is the only mention of this fact, no explanation is forthcoming] six had no complaints at the first evaluation but did have a complaint at the second.'* [2] 23 plus 6 with complaints is 29 not 30. 12 plus 7 without complaints is 19. 29 plus 19 are a total of 48. (Figures on table and words do not match)
 - c. At fifteen years out of 38 remaining in the study, 31 had symptoms and 7 did not. [9]
4. We know from the 1991 Inception article [8] that *'Creatine Kinase levels were increased in 10 of the 50 subjects...all of these subjects had new symptoms'* and *'All of the subjects with increased CK values also had significant residual weakness and atrophy'*. In discussion they also stated *'Of note, equally weak subjects without new symptoms did not have increased CK levels, and there were no subjects with a normal examination who had abnormal CK levels.'*

There is no mention of CK testing at the five or fifteen year points of the study.

5. Functional testing - Some tests for diabetic neuropathy were chosen to test polio survivors function. To test function of the legs the **only** test was a timed test to walk 100 feet. To test arms the tests were standard timed pegboard tests of placement and displacement, pin and collar manipulation and screw manipulation. Do you think these four tests were an appropriate choice to test functional change in polio survivors?
6. Windebank decided to compare the maximal score for complaints in polio survivors to those with ALS [8] (Amyotrophic lateral sclerosis or Lou Gehrig's Disease or MND - Motor Neurone Disease). Survival from diagnosis of ALS is rated as 2 to 5 years. The combined score for ALS is 10 to 20 (early disease) and 20 to 40 (late disease). The combined score for the polio survivors at the inception of the study was 8. However remember these subjects were not seeking medical attention and had been diagnosed with polio between 30 and 50 years earlier. Do you think comparing Polio with ALS is appropriate?
7. The questionnaire covered 337 items, so initially one would expect this to give a considerable amount of information. Unfortunately all the questions were ticking boxes. Here is a sample. A - Independently and with ease. B - Only by using adaptive equipment. C - Completely unable to do this.

Excerpt of 337 item questionnaire.	COULD			CAN		
	A	B	C	A	B	C
1. Manage a small flight of stairs (10 steps)						
2. Get in and out of bed						
3. Sit down/get up from a chair						
4. Manage to bathe or shower						
5. Dress and Groom myself						
6. Feed myself						
7. Carry out home activities (cooking, laundry, cleaning etc)						
8. Go out shopping.						

As most of our readers know, Polio Survivors will gladly answer 'Yes' to 'Can you' because we are proud of what we achieve. Ask us 'How do you' and hear a huge variety of answers, which tells a different story.

Take question 3. Sitting down and getting up from a chair. There is no mention of height of chair or if it is a dining chair with or without arms, or a lounge chair. My answer would change depending on which chair. Also using my arms to push myself up I don't think is using adaptive equipment so therefore my only option is to say that I do this independently and with ease which is not accurate.

How do you answer question 7 when (*cooking, laundry and cleaning etc*) are combined? Leaning against work surfaces, holding on with one hand whilst you use the other, sliding saucepans instead of lifting them, using a slotted spoon to

list the veg out of the water, vacuuming a different room each day instead of doing them all each day as you used to, etc., How would you answer this, and do you think the way you do this is using adaptive equipment?

When you add this to the first rebuttal of the article [1] by Members Marcia Falconer, PhD and Professor Edward Bollenbach [11] published on 27th August 2006 on our Polio and Post Polio News Service.

Examining a Controversial PPS Publication by M. Falconer and E. Bollenbach.

Recently a controversial article, "Electrophysiological findings in a cohort of old polio survivors" by Sorenson, Daube and Windebank was published in the Journal of the Peripheral Nervous System, volume 11, pages 241-246, September 2006. The findings in this article are the subject of heated discussion in the PPS world. Below we examine this article.

A scientific article usually is divided into parts; an abstract, which gives a brief overview of the article; the introduction, where related findings are discussed; the methods, which tell how the work was done; the results, which tell what was found in the study and the discussion in which the results are put into context with previous findings. In this final section the authors can speculate on wider implications of their findings.

The discussion section is often the source of intellectual debate. On occasion this debate can be vigorous, particularly when data from different studies point toward very different conclusions. Science would not be science if it was not exciting and controversial. We can expect scientists to have honest disagreements about methods, results and especially the discussion section of a paper. Unfortunately the debate is sometimes removed from the scientific arena to the public one when the popular press, or the internet, seizes upon an idea or a statement in the article.

This appears to be the case in the article by Sorenson et. al. In particular, one statement in the discussion section has been sensationalized. The statement is: "This suggests that the most likely cause for the decline in our polio survivors is aging alone." It is easy to understand why this sentence was highlighted. Taken out of context, this statement can infer that Post-Polio Syndrome (PPS) does not exist. It can even be interpreted, incorrectly, to mean that people with PPS are no worse off than their similarly aged peers with all this implies. Taken within the context of the reported data, the statement does not mean any of this.

This study is based upon two electrophysiological studies with the results explained using statistical methods and models. It is complex for the layperson to read and understand but it was not designed for the general reader. It is designed to pass specific data to people working in the field who are conversant with the methods and the interpretations of this data. We present here a less technical, but still scientifically accurate, summary of the main points in this paper.

In this study, the muscle strength and symptoms of 38 people with a history of prior paralytic polio were studied at 5 year intervals for 15 years. Innervation to two muscle groups, the thenar muscle at the base of the thumb and the digitorum brevis muscle on the sole of the foot, was examined using two electrophysiological measurements. One technique, CMAP (compound muscle action potential), examines the maximum amount of muscle contraction that can be achieved. The second technique, MUNE, (motor unit number estimate) provides information about

the number of motor units in that muscle. A motor unit is a group of muscle fibers for which the message to contract is carried by a single neuron coming from the anterior horn of the spinal column. Both techniques indicate the functionality of the nerve that is tested.

The underlying cause of Post-Polio Syndrome remains unknown. Current theories include chronic inflammation of the spinal cord and die-back of recovered neurons from overuse. The "die-back hypothesis" suggests that fragile neuronal sprouts (which reinnervate muscles after the loss of neurons during acute polio) die because of metabolic stress caused by overuse. These two suggested origins for PPS are not necessarily contradictory but rather examples of different levels of observation; one at the tissue level, the other at the cellular level.

31 of the 38 people in the Sorenson study indicated they have PPS and experienced progressive muscle weakness during the 15 year period. 7 did not have PPS symptoms and did not experience this. It was found that the amount a muscle could contract (CMAP measurements) declined equally in people with PPS symptoms and people without symptoms. The number of motor units that could be activated (MUNE measurements) declined in both groups, but, oddly, there was a greater decline in people who did not report new muscle weakness! Since increasing weakness is associated with increasing loss of nerve connections to motor units, clarification or discussion of this unexpected result would be good.

A significant flaw in this article is the use of results derived from another study with different methods. It is acceptable to discuss and compare results from different studies. It is not acceptable to use the results of others to replace missing elements of your own study. This is particularly true when different methods were used to obtain the results. The authors did exactly this in the most provocative part of the publication. Because this study does not have a 'normal control group', the authors took the results from another, undefined study, with different methodology, to get data about people who did not have polio. They then compared the results from their electrophysiology study on polio survivors with the results from this undocumented study. By doing this, their comparison of the effects of aging in polio survivors and normal people is meaningless.

It is clear that the statements causing most concern to people with PPS are the ones least supported by the evidence. Unfortunately, these statements also are the ones most likely to be picked up and sensationalized. They are, in the authors' own words, "...the similarity of our results suggests that our polio cohort did not age any differently than a normal population. This suggests that the most likely cause for the decline in our polio survivors is aging alone." To make a statement with such import, the data that supports it must be impeccable. It is not. Without appropriate data the conclusion is unfounded and inflammatory.

Saying that "the most likely cause for the decline in our polio survivors is aging alone" invites many questions. For example, all polio survivors age, but not all polio survivors report an accelerated decline. What about them? What about young people, from the less developed world where polio is still endemic? They are reporting symptoms of PPS and they are not at the point where age causes loss of neurons. To ascribe aging as the main cause of PPS new muscle weakness ignores the other severe problem of PPS – central fatigue – which has no obvious connection to aging.

Indeed, to say that the decline is due to aging alone also suggests that the aging process is the root cause of PPS. This is a gigantic leap and ignores documented differences between similar aged polio survivors who have PPS and those who do not. Specifically, the profile of proinflammatory cytokines is significantly different in the two groups (Gonzalez et. al. J. Neurol. Sci. [2002] 205: 9-13), as is the presence or absence of poliovirus fragments in cerebrospinal fluid (Leparc-Goffart et. al. J Clin Microbiol [1996] 34: 2023-2026). Neither of these is typical of an aging population.

In addition, the Sorenson et. al. citation of work by McComas et. al. is perplexing. McComas disagrees about aging being the most likely cause of new weakness. Indeed, actually says the opposite. To quote from McComas et. al. "...denervation progresses in patients with prior poliomyelitis ...and ...this progression is more rapid than that occurring in normal aging." (McComas et. al. Brain [1977] 120, 1415-1421).

The data in the current study shows that people with prior polio lost motor units at 3% per year. In the McComas article people with prior polio lost motor units at the rate of 6.7% per year and people without prior polio lost motor units at half this rate. Sorenson et. al. then say that "The rate of decline in our polio cohort was approximately the same as the normal population in the McComas study but about half that in their polio patients." It is not clear why this statement is included. It appears the authors are saying that the decline in the polio group in their study is the same as the decline in the normal population of the McComas study and this supports their contention that PPS weakness is due to normal aging. However they are comparing apples and oranges – results from two different studies. Moreover, the two studies came to diametrically opposed conclusions about PPS weakness and aging.

Another controversial part of the article is the suggestion by Sorenson et. al. that there are two models to explain new muscle weakness in PPS. One is "linear loss" where the loss of neurons (and hence of strength) is a constant rate of decline for everyone as happens in normal aging. The other model is "proportional decline" where the loss is related to the amount of damage from acute polio. In the discussion, the authors say that the proportional model best explains their findings. However the authors also say that neither model closely fits their data! This strongly suggests that neither model is correct. Therefore, the pattern for new muscle weakness is not related to a slow general loss (as is found in everybody with aging) and it is not (solely) related to the amount of original paralysis. There are other rate laws which could describe the way new muscle weakness is appearing. It might have been illustrative if these had been explored. It appears that the model preferred by the authors does not support their hypothesis that muscle weakness (loss) is related to normal aging (the first model).

Sorenson et. al. tell us that "The large degree of variation seen in both models may be a reflection of the underlying variation known to occur with most MUNE techniques available currently." This means that the method used to obtain this data may not be adequate for the job asked of it. In other words, be a bit sceptical about the results.

On a different topic, the authors say that "There was no association between the magnitude of decline in either the summated CMAP amplitude or the summated

MUNE and the presence of symptomatic progression." One interpretation of this data is that a decline in the function of the two muscles they tested does not correlate with symptoms of new muscle weakness elsewhere in the body. If there is a significant relationship between the muscles tested and those generally reported as becoming weaker, this should be demonstrated or referenced.

This article is controversial not because of its actual findings, but because of the interpretation of its findings. The authors were poorly served by reviewers whose job was to point out all of the inconsistencies described above. This article has many statements that are not supported by the evidence. Unfortunately the popular press found a critical one and sensationalized it.

Address Correspondence to marcia.falconer@lincolnshirepostpolio.org.uk and eddie.bollenbach@lincolnshirepostpolio.org.uk

Also take into account the additional rebuttals in date order

In Post Polio Network (NSW) Inc's Newsletter Issue 71, August 2006. Dr. Mary Westbrook titles her rebuttal 'Inaccurate Mayo Clinic News Release Threatens Polio Survivors' Wellbeing and Healthcare; and ends her article with the paragraph,

'Thus it is clear that this recent research suffers from several significant limitations. The sample was small in size and did not identify those with PPS and those without PPS. The measures failed to include important symptoms of PPS and these often have the most negative influence on survivors' quality of life. The spin placed on the results by the Mayo Clinic News Release is inconsistent with the study's results. The release ignores, and is contrary to, findings from a very large body of rigorous research into the late effects of polio, many examples of such research can be found in Silver and Gawne's recent book [17]. The greatest concern for polio survivors is the potential damage that this media release may cause in undermining their family and social support and increasing the risk that health professionals may dismiss their symptoms or prescribe inappropriate treatments. Post-polio support groups frequently witness how such happenings can have very detrimental effects on polio survivors wellbeing.' [12]

In "MUNE data review", Dr. Mavis Matheson discusses significant inconsistencies in the math. "I've reviewed the article and if the math is done correctly, one gets entirely different results." [13]

In another article "**The Mayo Clinic haunts postpolio patients again**", member, **Dr Ruth Bridgens** discusses a number of aspects including the cohort's applicability to the wider population of polio survivors, the limitations of the measures chosen and the interpretation of their findings. [14]

4th November 2006. Dr. Sorenson has just replied to my letter and list of questions stating 'I am sorry but I am unable to dedicate all the time necessary to respond individually to the detailed correspondence you provided. If you wish to share my previous responses I have no objection to that. Unfortunately I am not able to come to Jacksonville while you will be in the States. I would be happy to meet with you if we could arrange a mutually acceptable time.'

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 13. Dr. Mary Westbrook. PhD, AM Post Polio Network [New South Wales] Inc. Network News – Issue 71, August 2006. http://www.post-polionetwork.org.au/news/Mayo_Research.pdf
 14. Dr. Mavis Matheson. MUNE data review.
<http://www.lincolnshirepostpolio.org.uk/downloads/extra/munedatareview.pdf>
 15. Dr. Ruth Bridgens. The Mayo Clinic haunts postpolio patients again.
<http://www.lincolnshirepostpolio.org.uk/downloads/extra/mayohauntsagain.pdf>
 16. Hilary Boone. Study throws doubt on Post Polio Syndrome.
<http://www.lincolnshirepostpolio.org.uk/downloads/extra/poliosurvivorsdoubtstudy.pdf>
 17. Silver JK, MD and Gawne AC, MD. Postpolio Syndrome published by Hanley & Belfus, 323 pages. www.elsevierhealth.com
 18. Dr. Eric Sorenson. Polio and Post-Polio News Item. [Part VI - The Authors response]
<http://mt.lincolnshirepostpolio.org.uk/archives/pandpp-news/001995.html>

Another medical article of Interest to those of us who have Memory Problems. We will endeavour to get more information for the next newsletter.

23rd October 2006—The Mayo Clinic in Rochester, Minnesota, U.S.A.

Mayo Clinic Study suggests that a Central Nervous System Viral Infection can lead to Memory Deficits in later life. The study was published in the November issue of *Neurobiology of Disease* and explores the implications of picornavirus infections. The authors of the study are Charles L Howe, Ph.D, a Mayo Clinic neuroscientist and Eric J Buenz, Ph.D, a recent graduate of the molecular neuroscience program at Mayo Graduate School.

How I Cook the Turkey, A Thanksgiving Story **By Dr. Mavis Matheson - mavis.matheson@accesscomm.ca**

Thanksgiving is over here but Christmas won't be far behind. Turkey dinner is the traditional meal on special occasions. When I tell fellow polio survivors I still make the turkey dinner for holidays they are impressed. They say "I just don't have the energy any more." Using my cooking methods, anyone can make the festive dinner. An aside about side dishes - DELEGATE - It doesn't matter if you insist your guests bring everything else, she who cooks the turkey, cooks the dinner. I MAKE SURE EVERYONE UNDERSTANDS THIS. I cook the turkey.

About a week before the holiday, turkeys go on sale. I'm not strong enough to actually lift a frozen turkey so I need some help. After their first experience of lifting the third, fourth and fifth turkey out of the freezer for me to reject, the store clerks eyes glaze over and they scatter when they see me coming. I have to flush them out of the foliage in the produce department to get their help. Family members know they will be eating the bird so they have a vested interest in helping me pick the best one. I find by rotating the job, each family member has time to forget the experience of his last turkey expedition. After we choose the bird, he puts it in the shopping cart, lifts it on to the checkout counter, loads it into the car, carries it from the car to the freezer and puts it in the freezer. My turkey rests in the freezer until I am ready to prepare it.

When I am working in the kitchen, I dress the part. The day before the big feast, I thaw the turkey. I put the plug in the sink. I get someone to lift the turkey out of the freezer, and put it in the sink. I run cold water over the turkey and let it sit until it thaws. This takes me about 12 hours. Once the turkey is thawed, I call for someone to lift the turkey into a bowl and put it into the fridge until it is time to get it ready for the oven.

My son loves stuffing so I get him to cut the bread into squares, chop the celery and dice the onions. I put the bread and herbs and spices together. I set the stove to 325 degrees. I get my partner to lift the turkey out of the fridge, take off the wrapper, clean off the bird and put it on the roasting pan. I spoon in the stuffing. He turns the bird over so I can stuff both ends.

My partner puts the roaster into the oven. It takes me 5 to 6 hours to cook the turkey. Two or three times during the cooking process, he lifts the turkey out of the oven and tips the pan so I can get at the drippings. I baste my turkey. He returns the pan to the oven. My partner takes the turkey out of the oven so I can remove the cover for the last half hour of cooking. He returns it to the oven. When it is done, he removes it from the oven again.

I allow the turkey to sit on the cutting board for 10 minutes before carving. My partner puts it on a serving platter and puts the platter on my kitchen trolley cart. I triumphantly push it into the dining room. I savor my turkey and my family's admiration.

Because I cooked the meal, my family cleans up. They cut the meat off the turkey, put the leftovers in the fridge, boil up the bones for soup, and clean the kitchen while I have another coffee. I know it all seems like a lot of work but your friends and family will appreciate it. Cooking the turkey for your feast, it's a good thing.

Dr. Mavis Matheson lives with her partner, Adam and two sons in Regina, Saskatchewan, Canada.

<http://nonprofits.accesscomm.ca/polio/Mavis.htm>

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POLIO: A VIRUS' STRUGGLE
A Graphic Novella
By James Weldon
<http://www.scq.ubc.ca/?p=45>

This is a heads-up to those friends who haven't experienced it yet, and an explanation to those friends and family who have. Most of you have read the scare-mail about the person whose kidneys were stolen while he was passed out. Well, read on. While the kidney story was an urban legend, this one is not. It's happening every day.

My thighs were stolen from me during the night a few years ago. It was just that quick. I went to sleep in my body and woke up with someone else's thighs. The new ones had the texture of cooked oatmeal. Who would have done such a cruel thing to legs that had been mine for years? Whose thighs were these and what happened to mine? I spent the entire summer looking for my thighs. Finally, hurt and angry, I resigned myself to living out my life in jeans and Sheer Energy pantyhose.

Then, just when my guard was down, the thieves struck again. My butt was next. I knew it was the same gang, because they took pains to match my new rear end (although they attached rather poorly at least three inches lower than my original) to the thighs they stuck me with earlier. Now, my rear complemented my legs, lump for lump. Frantic, I prayed that long skirts would stay in fashion.

It was two years ago when I realized my arms had been switched. One morning I was fixing my hair and I watched horrified but fascinated as the flesh of my upper arms swung to and fro with the motion of the hairbrush.

This was really getting scary. My body was being replaced one section at a time. How clever and fiendish.

Age? Age had nothing to do with it. Age is supposed to creep up, unnoticed, something like maturity. NO, I was being attacked repeatedly and without warning. In despair, I gave up my T-shirts. What could they do to me next?

My poor neck disappeared more quickly than the Thanksgiving turkey the replacement one resembles.

That's why I decided to tell my story. I can't take on the medical profession by myself. Women of the world, wake up and smell the coffee. That really isn't plastic that those surgeons are using. You KNOW where they are getting those replacement parts, don't you? The next time you suspect someone has had a face "lifted", look again. Was it lifted from you? I think I finally found my thighs, and I hope that Cindy Crawford paid a really good price for them!

This is not a hoax. This is happening to women in every town every night. Warn your friends. P.S. I must say that last year I thought someone had stolen my breasts. I was lying in bed and they were gone! As I jumped out of bed I was relieved to see that they had just been hiding in my armpits as I slept. Now I keep them hidden in my waistband.

**See If You Can Figure Out
What These Words Have In Common.**

**Assess -- Banana
Dresser -- Grammar
Potato -- Revive
Uneven -- Voodoo**

Answer on bottom of page 27.

The Post-Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families

Margaret Backman, Ph.D., a Clinical Psychologist in New York City, has written numerous articles and given presentations on the psychological aspects of post-polio. She has now published a book based on her more than 25 years of experience with those who had polio.

Today many polio survivors find themselves with new symptoms reminiscent of the earlier days when they first had polio-- these new symptoms trigger frightening memories that had long been repressed, along with anxieties about what the future holds.

In *The Post-Polio Experience* Dr. Backman, examines polio survivors' psychological reactions to their earlier experiences and to their current struggles with the late effects of polio. Topics include:

- o Understanding the early years
- o Issues of abandonment and anxiety, loss and bereavement
- o Facing the future
- o The Polio Personality: Does it exist?
- o Role changes from the perspective of significant others

The book also includes practical guidelines for survivors on:

- o Coping with the emotional and interpersonal aspects of PPS
- o Giving and receiving help, gracefully
- o Managing stress and depression
- o Negotiating relationships with family and friends
- o Developing a positive self-concept
- o Improving doctor-patient communication

Family and friends will also find the **The Post-Polio Experience** of interest. In the book they learn how to deal with the changing roles that they and the survivor now face and gain insight into their own needs, which interact and sometimes conflict with the polio survivor's needs.

Mental health providers, physicians, and other health professionals gain a better understanding of their patients' psychological reactions to Post-Polio Syndrome--paving the way for more effective treatment. An entire chapter is specifically written for physicians to aid them in their interactions with polio survivors.

The following from page 130 was suggested by Margaret Backman to reproduce in this Newsletter.

Table 4 - Communicating with Significant Others.

Survivors say:

“When I say I’m tired, I mean it.” “Don’t overestimate what I can do.”

Significant others say:

“Consider me too.”

“When you see I’m busy give me time to finish what I am doing.”

“Thank me once in a while.”

POSITIVE BEHAVIOURS:

Think about what you really want, and how you can make it happen...

.... In a positive way.

The Post-Polio Experience can be purchased through the publisher: www.iuniverse.com, or 1-800-288-4677, Ext. 501. The book is also available through Amazon.com, Barnesandnoble.com, and through special order at Barnes and Noble bookstores. The cost is \$18.95, plus shipping and sales tax, where applicable. U.K. www.amazon.co.uk the cost is £10.91 and available for Free Delivery on orders over £15.

What's been happening on the E-Mail Forum

It doesn't seem to matter what the problem or question, there is always *someone* on the e-mail list who is able to help! In the last few months, we've discussed quite a variety of subjects – everything from the BBC through to Incapacity Benefit, and many points in between. Here's just a small selection of what we've been talking about:

Incapacity benefit forms. “A few days ago I received an IB form in the post. I have been on this benefit since 2001, and wonder why they have decided to send me another form now (to be honest, I had a few minutes of blind panic). Once I had calmed down, I rang jobcentreplus and asked why I had been sent it, but I just got a lot of waffle and stonewalling - the upshot being that if I didn't go through all the rigmarole and return the form I'd lose the benefit. Has anyone had a similar experience recently?”

“**This** happened to me a couple of years ago and I was told that it was a routine check to see how my condition had changed. I think their concern is that some people succeed in claiming IB then their condition improves and they do not notify the authorities.”

“**...current IB** can be reviewed by DWP at any time but I don't have any info on how often or for what specific reasons.

Disability Rights Handbook - <http://www.disabilityalliance.org/drh31.htm>

Absolutely everything you need to know including how to fill out forms. It costs £13.50 for people on benefit but is worth it (it's updated every year). It's also supplied as a CD-ROM but that's more expensive.”

“**I got** help from my local council's Care and Repair department. Every council has something of this nature, and it might be well to contact yours and ask. These departments aren't always called the same thing, so you'll have to explain to the receptionist what you mean! They are well versed in completing IB application forms, DLA and IS....you could also ask the BPF for help.”

“**Travel insurance; if you need it where is the best deal?**”

“**I have** used my Banks Holiday Insurance. I get 30 days free insurance and then have to pay for days on top of that. There are no questions asked, nothing to fill in. All they ask when I ring is for the date of leaving and the date of returning and work out the extra amount that I have to pay.”

“**This is** a) not from personal experience, just from a search in response to a similar question on another list, b) "cover is for Medically or Physically disadvantaged people up to the age of 60 years inclusive" and c) possibly more expensive than Saga.

<http://www.ourway.co.uk/pre-existing.htm>”

“**I've just** had a quote from Saga, for insurance for a week in the USA. £40.20 – which covers me for absolutely everything, including re-patriation. PPS didn't seem to be a problem at all - although if I had breathing problems, then I assume the price would go up”

“**What hobbies do you all have?**”

“**I am** a singer and singing has been my main hobby most of my life, in amateur operatic societies, choirs and for 7 years we had our own semi-pro folk group which was enormous fun.”

“**I have** found that having a "project" or two in hand at all times is a good cure for moods that lead to depression.”

“I go to a day centre for disabled people... I find it very gratifying and it helps me get out of the four walls twice a week. I get to meet all kinds of people and the other people that go on the same days I do are always smiling and joking.”

“If gardening is an interest there is a charity called 'THRIFT' who help disadvantaged people.

“I did a computer course several years ago and that was free but our local place has been closed due to redevelopment and cut-backs.”

“I play speed chess on the internet which depending on the time allows me to be beaten (mostly) by any nationality in the world and more recently I've started taking up digital photography.”

“I've learnt to play bridge and now play socially but also play on line.”

“Should we, as disabled people, receive free TV Licences?”

“One way to avoid paying the TV licence is to live with someone over a certain age...I think it's 75...? Perhaps you could persuade a Golden Oldie to move in with you.”

“We all complain about discrimination against disabled people. If we received free TV licences, wouldn't that be discrimination?”

“We pay our licence monthly by direct debit. It makes it easier and doesn't come as a shock at the time of the licence renewal.”

Thank you to everyone who contributes to the e-mail discussions - your input is absolutely invaluable. As with any e-mail group, we know that we have some 'lurkers'! (This is not a rude expression, just a term to describe those who like to read but perhaps don't feel ready to contribute.) What you have to say is important to us all, and we'd love to hear from you!

If you would like to join the e-mail list, please send an e-mail to join-pnl@lincolnshirepostpolio.org.uk (please include your full name in the email).

Those of you who are not on the Internet can write to our main address or you could phone the Polio Survivor on duty this week [message on 01522 888601 as to who is on duty]. The more we share information and stories the more we learn.

Have you ever written a Limerick?

Well by chance we came across this site OEDILF—the Oxford English Dictionary In Limerick Form. ‘The OEDILF Project, our online Limerictionary, is proud to present the work of writers living in more than a dozen countries.’ At the moment you can write Limericks from pre-A to Cd. Your Limericks are reviewed by Editors with suggestions of how you can improve them and they progress through New to Tentative to Approved. Hilary has submitted seven so far and here is the one she wrote for the word assessment.

**Neuromuscular patients complain,
Lack of testing repeat or sustain,
Can grade muscles much higher,
With results that are dire:**

"Change assessment points, that's our campaign".

© Hilary Boone, Oct 2006.

For more information go to <http://www.oedilf.com/db/Lim.php>

Answer from Page 24. Put the first letter of each word at the end and read backwards. Same word.

First meeting of South Western Members

I did not actually know anybody locally with PPS. There are no easily reached groups or meetings to join in my area, and one tends to feel very much 'the only one'. Attending the Lincolnshire PPN AGM, taught me that being with a group of people who accept you as you are – without the sideways glances that say 'I wonder what's the matter with her' - or the feeling that others are having to make special arrangements for you, is both energising and liberating.

22nd September saw the very first, and decidedly impromptu meeting of some of our members in the South West. Hilary and Richard had decided to take a few days break in Bristol which seemed an ideal opportunity to have a little get-together.

I contacted as many members in the area as possible, to let them know that we would be at the Central Travelodge in Anchor Road from 11.00a.m. onwards, and that they would be very welcome to join us. I have to admit, I was a bit concerned that we hadn't given people enough notice – but I needn't have worried – it was a wonderful turn-out!

The manager of the hotel was a delightful man, who seemed to be quite happy for us to take over his café-bar and provided free coffee for us all. As the hotel didn't serve food at lunch-time, he allowed us to 'picnic' on sandwiches bought from M & S across the road from the hotel. It's surprising how hungry one gets just laughing and talking!

This was essentially a social occasion – a chance to put faces to names, meet people who are going through the same difficulties, and swap ideas on how to overcome various problems. But perhaps the most important thing about socialising in this way, is that it underlines the fact that we are NOT alone. And even if we're spread out geographically, we can occasionally meet, chat, laugh and learn.

The photo below shows just a few of the gang - sadly we just couldn't get everyone in shot :



Left to Right are Shirley Rose, Dinah Foweraker, Paul Stanton, Hilary Boone, Vic Oliver, John and Pat Thomas. Not shown in the picture, but very much with us were Richard Boone, Bridget and Derek Langdon, David Rose (who took the picture— thanks David!) and Linda, daughter of

Member Kay Preece [they caught polio at the same time] who couldn't be with us.

I'd like to thank everyone who turned up, and made the whole thing such fun! Many of you travelled quite a distance to be with us, and it was much appreciated. I'm hoping very much that we can have more get-togethers like this, and do please note that *everyone* is welcome, no matter where they live! The weather and time of year are somewhat against us just now, but it won't be long before Spring arrives, and we can arrange to meet again.

If anyone has any ideas about where they would like to meet, or ideas for things to do, please let me know! The Exeter area, with an overnight hotel stay, has been suggested.

[If you would like to meet up with others in your area then email me or write to me c/o our main address and I will do what I can to help facilitate meetings in other areas.]

Mary McCreadie mary.mccreadie@lincolnshirepostpolio.org.uk