



POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 8, Issue 5/12
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**AUGUST
2014**

Vol 8, Issue 5

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**END
POLIO
NOW**

**POLIO
TOTALS**
14 June to
23 Aug 2014
Increase
94 to 146

Pakistan 75 > 115
Afghanistan 4 > 8

Nigeria 3 > 5
Equatorial Guinea
4 > 5

Cameroon 3 > 5

Iraq 2

Ethiopia 1

Somalia 4

Syria 1

**Polio Survivors Network Announce and Thank
The Michael Cornish Charitable Trust for £1,000.00
The Lynn Foundation for £ 500.00**



POST POLIO SYNDROME A Condition Without Boundaries

**25th to 27th June 2014
Amsterdam, The Netherlands**
www.poliocconference.com

All Abstracts published in the Journal of Rehabilitation Medicine
See Page 5 for subject headings and Hilary's Abstract

**Painting the Same Picture can provide Better Clinical Outcomes
By Hilary Boone, Polio Survivors Network.**

Watch those presentations that were filmed - inc. Hilary's
informed-scientist.org/congress/2nd-european-polio-conference



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PICTURES ON FRONT PAGE

2nd European
Polio Conference
Amsterdam
25th to 27th
June 2014

Hilary Boone with
Mrs. Polly O'Lyffe
and
Rotary
International's
Jan Lucas Ket
Governor
2013-2014
District 1580 RI
And
Albertine
Perre-Bulder, M.D.
Rotary
Foundation
Committee Chair
District 1570 RI
The Netherlands

A Lecture in the
Ballroom

The canal behind
the Hotel
Krasnapolsky
Amsterdam

The final sessions
of the Conference
showing all the
logos of the
supporting
organisations

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New Members and Donations received.

New Members

**Margret Embry-Tewes, Robyn Aulmann, Michelle Maher
and Mary Hamnett**

Thank you to all members who have recently renewed.

Thank you to the following for donations given towards our work

June 1st to mid August 2014.

Member donations

Diane Taylor, Maureen Allison, Michael Whitely, Jean Simm,
Susan Freeman, Yvonne Liggins, J Doohan, Stuart Tanfield,
Bridget Langdon, and Jennifer Paulger totalling **£336.50**

Total for 2014 so far is £1,168.50

Grants

£1,000.00 from Michael Cornish Charitable Trust, Lincoln.

£ 500.00 from The Lynn Foundation, Hayward's Heath

See Page 11 and back page for info on Val Scriveners Photo Cards

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Editorial by Hilary Boone

Our Fundraising project has started to prove successful with the very generous donations from the **Michael Cornish Foundation Trust of £1,000** and the **Lynn Foundation of £500**. Huge thanks to both organisations for supporting our work.

I wrote the last Editorial in Canada, the fifth and sixth weeks of our trip, mostly sunshine all the way. Now back in the UK as I type we are experiencing the tail end of Hurricane Bertha. It is strange to have the French doors open but see grey sky and rain that now and then is bouncing inches high on the paved area.

It has been a very full May to July and none of it would have been possible without the help of family and friends as we travelled. We had scheduled in down times to catch up on energy expended and of course - as we all can do, we underestimated how much energy we would use up on some days. We arrived back in the UK from Canada on a Friday early evening and Monday we were off to Hull to catch the Ferry to Amsterdam. Our personal assistants were brilliant all we had to do was rest, and talk. They had done the shopping, prepared the meals and within a few hours the laundry was done and the bags repacked. Wayne drove and taking an overnight ferry was a great idea as we were able to take all the disability equipment we needed in the car. When we got to Hull it was so easy. We handed over our email, were given our tickets and cardboard room keys and within a few minutes were parked next to the lift. Up two floors and our disabled room was just round the corner. The only problem I had was the bed was just that bit too low for me to stand up but the Cool Box was the necessary two inches higher and I was able to move from bed to this and then push myself up with the help of the adjacent table.

Next morning we arrived in Rotterdam and a couple of hours later the Sat Nav had us in Amsterdam. The SatNav said "take the next right" and then "turn right" and thinking this narrow 'alleyway' must be wrong we drove on and saw the SatNav 'recalculate'. We were really surprised how narrow the roads were and driving on the right was not a problem as the other way was in most cases the other side of the canal. Amsterdam was beautiful but bicycles everywhere. Crossing the roads was not easy as they came at you from almost every angle.

The very posh, 5 star Hotel Krasnapolsky was right on the main DAM Square and built in 1866 and stayed in by many famous people. I doubt they had been visited by quite so many folks with a disability at once before and we did encounter a few problems at times getting round on our wheels. The Conference was well attended and the biggest difficulty was trying to decide which of three choices of presentation was the most important for you. See from page 5.

Read the abstracts in the Journal of Rehabilitation Medicine - J Rehabil Med 2014; 46: 568–608
file:///C:/Users/Owner/Downloads/AbstractsPostPolio20.pdf [41 pages]

Princess Beatrix of the Netherlands attended a couple of the Conference presentations in the morning and left after lunch. Late in the afternoon we learned there was a bomb scare in a local department store and the whole of Dam Square had been cordoned off and closed down for quite a few hours. We later learned that discussions between the conference organisers and the police allowed the conference to continue and thankfully nothing was found. In 1956 there was a large outbreak of polio in the Netherlands and an organisation was started. The following year H.R. H. Crown Princess Beatrix became the Patroness and it became the Prinses Beatrix Fonds. In 2012 the name was changed to the Prinses Beatrix Spiersfonds.

It was great to meet Polio Survivors from a variety of PPS Groups not only from Scotland and other countries in Europe but Australia, USA, Canada, Ethiopia, Turkey, India, and the Far East.

PSN PHONE and/or EMAIL PALS

I don't know if members realise but when a group of Polio Survivors get together at conferences, email lists, Facebook groups etc that we chat and share all sorts of things and often laugh till our ribs ache. Talking with someone who understands what it is like to live with the issues of PPS means not having to explain why you can or can't do this or that. We have tried this before shall we try again? Carers or Family members would you like to talk to others in the same position?

MESSAGE FROM OUR CHAIRMAN - Simon Parritt

Electrified and Ready to Roam

We live in challenging times as disabled people as our freedoms and public image is under attack. For polio survivors this increasing marginalising and scrutiny disabled people are subject to comes on top of coming to terms with, and confronting, a level of functional decline that we had hoped would not happen. For those of us who only latterly realised they had had polio and that their increasing problems in everyday life were a result of polio, the shock and psychological struggle is difficult at the best of times as they come to be more fully part of the disabled community.

I mention this as a backdrop to my own recent decision to apply for an electric wheelchair. Only five years ago I could cope, relatively well with the occasional use of being pushed in my manual chair. I have no doubt that electric is the way forward and there are so many advantages, but I still struggle to accept that this is 'where I am now'. It is difficult to always see the positive, however obvious it may seem to others. The truth is that as polio survivors we thrived on denial, ambition and not giving in and ignoring the costs of this because, in the past, to put it bluntly – it worked! However, this denial and bloody mindedness is not the same as accepting limitations and thinking positively about solutions that involve a full and complete acceptance of the identity of being a disabled person.

I think many of us struggle with being a 'disabled person' as an identity. Other minority groups have an advantage in finding not just political but also emotional and psychological strength in identifying with their own group, be that a cultural, ethnic or sexual minority. I try to hold onto the notion that being a disabled person is a core part of who I am and gather strength in identifying with other disabled people as we attempt to exert our right to social inclusion and freedom of access. So my new wheelchair, whenever it actually arrives, represents not just an emotional struggle with my new mobility status, but also an opportunity for me to feel a sense of freedom to roam not just as Simon, the husband, parent, psychologist etc, but also as a representative and member of the disabled community

Simon Parritt, C.Psychol, AFBPsS, MSc, BSc(Hon), BA, CPsSC, MBACP

Chartered Psychologist

HCPC Registered Counselling Psychologist

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Simon Parritt <simon.parritt@poliosurvivorsnetwork.org.uk>

HOT TIPS

1. Use a flannel instead of a towel to dry yourself or hair - you might be surprised how much water one flannel soaks up.
2. Drink plenty of water during the day. Have a look at Hydrate for Health bottles you can attach on your armchair or by your bed. Just pick up a tube instead of the weight of a glass or bottle, www.hydrateforhealth.co.uk
3. Check out the sugar content of fruit juice it can be much higher than you imagine.
4. Spending a long time on the toilet trying to eliminate you know what - try putting your feet up on a small stool as it gets the bowel into a better position. Look at Squatty Potty on Amazon. Maybe you have a grandchild and they have a potty stool?
5. Try asking for help for the heavy part of a job that needs doing and see how much energy you now have to do other stuff
6. Remember breathe out gently when you perform an action, in breath is then automatic and its easier to do the action, www.btbreathingtraining.com [in last newsletter]

Good Article on Post Polio Syndrome for health professionals

Written by Doctors for Doctors

www.patient.co.uk/doctor/post-polio-syndrome



POST POLIO SYNDROME

A Condition Without Boundaries

25th to 27th June 2014
Amsterdam, The Netherlands
[_www.polioconference.com](http://www.polioconference.com)

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[J Rehabil Med 2014; 46: 568–608]

file:///C:/Users/Owner/Downloads/AbstractsPostPolio20.pdf [41 pages]

Diagnostic Criteria for Post-Polio Syndrome.

Stephen Sturman, MBChB - University Hospital Birmingham, Birmingham, UK



Post-polio syndrome (PPS) can only be defined on clinical grounds.

Published criteria from the European Federation of Neurological Societies in 2006 have proven to be workable in clinical practice. These require the following to be fulfilled:

- 1) A prior episode of paralytic poliomyelitis with residual motor neuron loss (which can be confirmed through a typical patient history, a neurologic examination, and, if needed, an electro diagnostic exam);
- 2) 2) A period of neurologic recovery followed by an interval (usually 15 years or more) of neurologic and functional stability;
- 3) 3) A gradual or abrupt onset of new weakness or abnormal muscle fatigue, decreased endurance, muscle atrophy, or generalized fatigue; and
- 4) 4) Exclusion of medical, orthopedic, and neurologic conditions that may be causing the symptoms.

Frequently, however, PPS patients present with co-morbidities and the impact of these requires careful clinical assessment to avoid confusion in diagnosis. This is especially important where investigational techniques and interventions are being assessed in clinical research. The confirmation of the diagnosis of previous polio often raises difficulties especially when patients were minimally affected by the original infection or were left with minimal or negligible long term deficits. This may have significant social and financial implications for patients.

The objective assessment of new weakness, abnormal muscle fatigue, decreased endurance and muscle atrophy all present a significant challenge in the clinic and the use of instruments of measurement and serial assessments is an area for ongoing evaluation.

Determining a threshold at which symptoms become truly indicative of new pathological processes still depends on clinical judgment and has been a controversy surrounding PPS since its earliest description. Efforts to more accurately define this are needed.

Dr. Sturman asked me during a chat at the Conference if any of our members remember having ptosis (drooping of the upper eyelid) at the time of their polio. Maybe you do not remember but maybe you have that issue now. If so then drop us a line or email or ring and we will pass on the information.

Editors Note:- If only I had told the doctors **back in 1989** that since my new weakness and fatigue started after falling that I could **NO** longer swim as fast, **NOR** pull myself out of the water at the deep end of the pool. That I had now **FAILED** my Life-Saving Bronze Medallion and **lost all my jobs as a swimming teacher and lifeguard**. Maybe this would have meant other muscles would have been tested and I would not have spent seven years being told there was nothing wrong with me. **When tests do not confirm your reported symptoms make sure you paint an accurate picture in the mind of the assessing professional.** See next page.

FP 10 - Painting the same picture can provide better clinical outcomes.

[Abstract page 588 in the Journal of Rehabilitation Medicine 2014; 46: 568–608]

file:///C:/Users/Owner/Downloads/AbstractsPostPolio20.pdf

My presentation time was 15 minutes including question time. You can view the presentation at

www.informed-scientist.org/congress/2nd-european-polio-conference

The following is an expansion of my slides and written as a stand alone article.

The most reported issue since 1996 to Polio Survivors Network is the number of months before reported new medical symptoms result in a diagnosis. This usually occurs where you report new weakness in a limb or lessening of an ability to perform a daily living function and can include breathing; sleeping; swallowing; hoarse, lower or reduced level of speech; some visual disturbance, and new pain and fatigue.

Our research shows that the first difficulty is the time allocated for appointments. After some weeks, could be months, of experiencing issues you eventually decide that you need to make an appointment to see your GP to find out why what is happening is happening. If you are like me and spent many years attending medical appointments during your early polio years then a visit to a health professional is the last place you want to be.

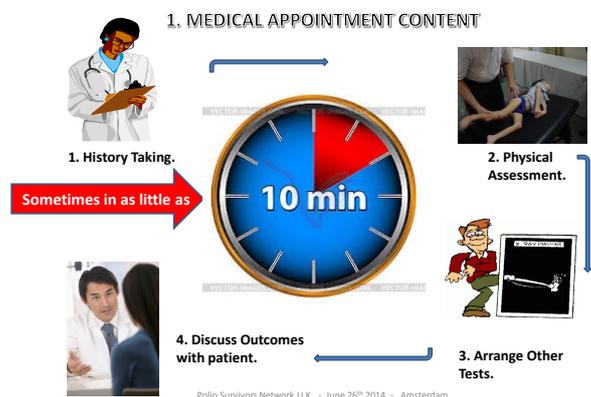
Taking an average appointment where you first seek help for new weakness in your legs.

1. First you are asked some questions about your medical history and your reported new weakness.
2. Next there will be a short examination of your leg muscles to see how strong/weak they are.
3. Then a form or two will be completed to refer you for possibly an x-ray or more tests.
4. Then some advice as to what to do now.

Sometimes in as little as 10 minutes!

Try acting this out with a friend or family member as the doctor and you will see how limited the time is for you to say about your current issues.

Both you and your doctor play important roles in achieving your health goals



The first two minutes of an appointment are often called the

GOLDEN TWO MINUTES.

Polio Survivors Network advice is to set the scene something along the lines of:-

Doctor “Good morning Mr. B.”

Mr. B. “Good morning Doctor Smith.

“Thank you for seeing me about the new and increasing weakness I have been experiencing in my legs over the last six months.”

Make up a sheet for your appointment including

The details of the appointment, place, time and name of professional

Your basic medical details, diagnoses and dates, medications, allergies and intolerances

Reasons for the visit starting with the most important.

Say ‘I have made a copy of my notes for you if you would like one’ [Some do, some don’t]

Take someone with you and prearrange for them to remind you if you forget anything.

The next issue our research found is the way we are asked questions and the way we answer.

If you were asked the following three questions

Can you get up a flight of stairs?
Can you walk?
Can you get yourself a meal?

Yes
Yes
Yes

I am a Polio Survivor.
I have never admitted defeat and I am not going to start now.

could you have answered "Yes" to all of them but be thinking

Asking us "Can you?" is called **CLOSED** questioning.

During the question time a member of the Academic Medical Centre in Amsterdam thanked me for pointing out that we can give CLOSED answers if we are asked 'Can you?' and this would now be included in their training.

We are not helping ourselves and we are not helping the medical professionals assessing us if we don't tell it like it really is. Even if you are asked Can you, it would help if you answered as if you had been asked 'How do you?'

HEALTH PROFESSIONALS, BENEFITS DOCTORS AND SOCIAL SERVICE ASSESSORS

Please ask us "HOW DO WE do actions of daily living?"
and help us tell you like it really is.

HOW DO YOU ...
...get up a flight of stairs?

..walk?

...get yourself
a meal?

Well, I have to go one step at a time, right foot first, pulling myself up with the stair rail, Oh! and stop half way for a rest.

*I have walked since best recovery age 5...
..... but for me walking is using arm crutches and swinging my legs through.*

Because I can no longer chop or peel items
I mostly buy already prepared and frozen food
Pop it in the microwave and wait for the DING!

REMEMBER 'OUR NORM' IS NOT STATIC

"AT BEST RECOVERY I could walk up a flight of stairs normally."
FIVE YEARS AGO I had to change that to right foot first"
"TWO YEARS AGO I had to stop halfway for a rest"
"A YEAR AGO I had to start pulling myself up with the bannister rail as well"
"NOW I am having to move to a bungalow"

Another Issue is Single Action MANUAL MUSCLE TESTING

Between October 1988 when I had a fall that started unexpected new issues of weakness and fatigue and getting a confirmed diagnosis of Post Polio Syndrome in January 1999 I would find myself on the ground and think I had tripped over something. Each time, once I was able to get up again, I would look to see what I had tripped over and each time there was nothing.

In January 1999 I read a recent report on my leg ability that stated that 'the power of my left leg, hip, knee and ankle were normal' which I knew was not true. I had waist down paralytic polio at the age of 5 and I firmly believe through being taken swimming every day in the Mediterranean I regained the ability to walk and do many sports that did not involve running. My left leg, hip to knee remained weak and this had recently been confirmed at the Sports Centre where I worked as a lifeguard. I was unable to lift the exercise bar on a quads exercise machine with this leg and was told 'there is something seriously wrong here'.

How could this neurologist report my left leg was normal, he would not record anything he did not believe to be true. Oh!, I had passed a medical for the Police in 1969 when I could not run... Could there be an issue of validity and reliability with single action Manual Muscle Testing?

Manual Muscle Testing is the procedure for the evaluation of the function and strength of individual muscles and muscle groups based on the effective performance of a movement in relation to the forces of gravity and muscle resistance.

Any health professional using this isolates a muscle or muscle group and tests its action against gravity and a pressure that they apply. If that muscle produces a strong action then the tester usually moves on to the next muscle in line to be tested.

Many of us are able to do some actions once or for a few times before that muscle shows demonstrable weakness. Testing a single/few times can mean that our reported weakness is not corroborated. Plus this form of testing does not test how that muscle or muscle group works as part of a pattern of movement. .

In May 2002 I wrote to Dr's Halstead and Maynard about this and they responded....

Lauro S. Halstead MD - Director of Post-Polio Program NRH, Washington DC, USA.

If done only a single time, it can give an erroneous idea of the true muscle strength and endurance.

Fred Maynard, M.D. President Board of Directors, Post Polio Health International.

You have done a brilliant job of describing a real problem for polio survivors and professionals that is, the limitations of the Manual Muscle Testing

Polio survivors have other muscles that take over or help weaker muscles to achieve actions. Thinking back to the times I had 'tripped over nothing' I remembered that each time I had been carrying a box of craft equipment from my car to a room in a building. I surmised that my back muscles were helping my weak legs and some weakness in my arms and as secondary accessory muscles of breathing were also helping me breathe. Was my brain telling me 'better not drop the box in case something breaks, sorry legs but I cant help you anymore' and my legs would fold and down I would go?

The over-grading of muscles personally experienced and reported to us by our members and by other polio survivors around the world is not just arm and leg muscles but muscles involved with swallowing and breathing [which includes shoulder upper arm and intercostal muscles, the secondary accessory muscles of breathing] which can also affect sleeping. Plus short lived visual disturbances can come from weakness in muscles that move the eyes. .

↓ Single action Manual Muscle Testing does not test repetitive or sustaining power of the muscle.



Polio Survivors Network [firstly as Lincolnshire Post-Polio Network] have been raising issues of the validity and reliability of single action Manual Muscle Testing for 14 years now with the Department of Health through our then M.P. and to other health organisations during surveys and consultations and to health professionals.

This is most often met with the response ‘Health Professionals are aware of this fact and take this into consideration’. However we have many many examples where this is not happening, possibly in some cases due to time constraints of the appointment but this is not fair on patients.

Swallowing assessments. Have you had an assessment and been told there is nothing wrong yet you still experience issues? I had two such assessments but at the third [ten years altogether] I provided a paragraph from a report on the ability of my muscles by my Chiropractor. This stated that if you used a tongue depressor and asked me to repeat saying ‘Ah’ you could see my palatal [swallowing] muscles start to weaken. This was repeated by the ENT Doctor who then tested me a different way and confirmed that I do in fact have problems with swallowing and also a small pocket that tiny pills or crumbly flakes can get caught in causing me to choke and cough. In fact if something makes me burst out laughing I always choke. During my Partners in Policymaking course the tutor passed me a note telling me to beware a moment coming up. Even prepared it was so funny I still choked.

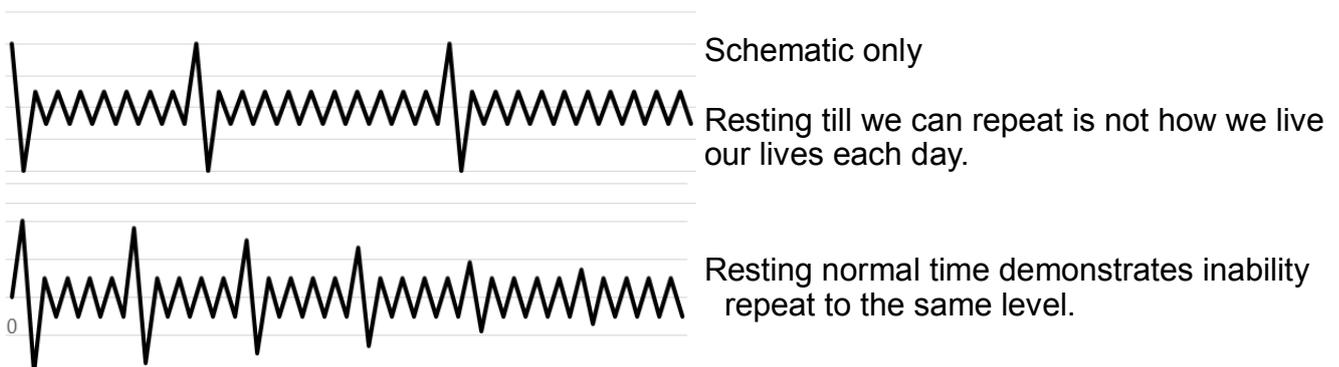
Sleeping positions. Did you use to sleep on one side and turn in your sleep? Do you now sleep on a different side or in a different way? I can no longer sleep on my right side or my back I have to sleep in the recovery position on my left side, with my right leg on a pillow to try and keep my spine straight and with a small fan blowing on my face.

Do you have to wake up now to turn over because of weakness in muscles of turning? Do you find it harder if you sleep in a different bed, say in a hotel or hospital, where the furniture next to the bed that you use to help you turn is not there?

Breathing and Sleeping. Are you having respiratory appointments and assessments and being told that you are fine but you still have issues?

Are you having a Sleep Study but with only a few leads, e.g. an Oximeter on your finger and one lead on your arm? Or did you have in the region of 20 to 22 leads attached, called Channels?

Are you having lung function tests and being asked to repeat each test three times to the same result and because you suffer from fatigue take all the time you need between each repeat?



Do you know if all the results and resting times are recorded on the sheet that goes to the Consultant? Could you like me just have the best result recorded on the Test Result sheets. Maybe no mention of the fact that you rested an increasing number of minutes between each test. My first report shows I fatigued easily but I was still discharged with nothing wrong with me.

Are you being tested supine [flat on your back] and were you able to repeat the test without lifting your head up to bring your neck and shoulder muscles into play. Has anyone else been given a oblong round pillow to put your head on for the supine test? How about when you are asked to hold your breath for ten seconds did you use other muscles to achieve this, e.g. thighs and I was also pushing my feet hard on the floor to comply. Continued overleaf

Eyes - muscles that move the eyes and the pupil.

A number of polio survivors about 12 years ago, including myself, were reporting visual disturbances that were not corroborated by hospital eye tests. The polio survivor in Australia compiled all our information and shared it with an optician friend.

Interestingly he came back with the fact that we needed to get the muscles that move our eyes, e.g. looking from left to right, up and down examined. My reported visual issues had gone through four years of testing with nothing found. On receiving the Australian report I visited my optician and asked for another examination then to read some new information I had received. He readily agreed as this seemed to be interesting. Nothing found on the first examination but after reading the information from Australia he examined me again, testing the movement of my eyes and confirmed that this was my problem. He recommended that instead of moving my eyes that I moved my head instead, e.g. looking in the rear view mirror. This worked.

Another suggestion was to get our pupils reaction to light tested, e.g. when it is very light then your pupil is small but if you go into the dark then your pupil opens to take in more light so you can see. Have you found that if you move from a light room to a dark room that it takes much longer for your eyes to focus now?

REMEMBER - The most important fact here is to make sure you tell any assessing health professional exactly how you perform the actions you are being asked about. I know we are proud that we can still achieve so much but be proud of how you do actions and tell it like it really is.

Note about Manual Muscle Testing by Health Professionals.

My comments are made as polio survivors general experience but I must add that there are many Post Polio Clinics and PPS knowledgeable health professionals around the World and it is likely that they are giving their patients a more comprehensive and probably multi-disciplinary assessment.

During my presentation at the Post-Polio Health International Conference in St. Louis in June 2014, Dr. Carol Vandenakker-Albanese - the Reactor to my presentation - demonstrated on me how as a specialist in post polio that she **modifies** the way she tests our muscles and my current weaknesses were easily demonstrated. My muscles have not been tested this way before.

I had first met her in 1997 at the Atlanta PPS Conference and when I told her that a doctor was questioning that I had even had polio she watched me for the next hour and told me that from the way I moved and performed actions of movement that she was certain I had had polio. After the Daytona Beach PPS Conference I made an appointment with her at her then Miami PPS Clinic and after a mutli-disciplinary assessment she arranged for an MRI and the next day diagnosed Richard with Parkinson's as well as Post Polio Syndrome. She was also the Reactor to my presentation in 2005. She now practices as a Physical Medicine and Rehabilitation specialist at her 2001 established UC Davis Post Polio Clinic in Sacramento, California. She is also on the board of Post-Polio Health International.

Any member or reader of this Newsletter who has any comments to make, good and bad, about the information in this or any other of our newsletters would be gratefully received. We learn so much by sharing information and discussing what we learn.

A UK member reports that at a recent appointment during the recording of her medical history she was asked to list her diagnoses. Having comorbidities she started her list but was stopped and asked, to slow down and start with the first one.

"Polio in 1956" To which the response was 'Well I am sure you are well over that'.



I did a push up today...
well actually I fell down and had to use my arms to get up again off the floor.
That's close enough. Now I need chocolate.

Disability movement has lost one of its greatest personalities and fighters.

Former Chairman of PTU, Holger Kallehuage passed away on 6th June 2014 at the age of 79. He caught polio in 1951 at the age of 16. In 1961 he completed a master's degree and joined the Ministry of Justice as a secretary. In 1973 he was appointed a Judge of the City Court of Copenhagen and became Chairman of the then Polio Association, later named PTU and advocated that people with disabilities have the right to a life like everyone else. From 1983 he was a High Court Judge retiring in 2005. During this time he held a variety of other legal positions and from 1994 to 2008 was deputy to the Parliamentary Ombudsman. He is especially remembered for his work for the UN in 2006 when the Convention adopted equal rights for the disabled in employment and life. He stepped down as Chairman of PTU on 24th May this year a month before the 2nd European Polio Conference when he was to give a presentation.

Holger Kallehuage - An amazing Polio Survivor.

A Life of a Polio Survivor Beginning and Ending as a Respirator User.

Rene Vercoutre from the Netherlands was asked to present in his place.

He caught polio on August 13th 1956. The last ten steps he walked were to the bed. When he woke up an hour and a half later a doctor asked him to move his legs but he could not do this anymore. The next day he was moved to another hospital in the Hague and was soon completely paralysed except for the flexion of his right fingers. He still feel everything. He was then transferred to another department and placed in an iron lung. His life on a respirator had started. But a few days later he again had trouble breathing and was taken to the operating theatre and the next day he woke up with a tracheostomy. I felt good I finally had enough air. I could not talk for a year but I could move on.....



His presentation is online at www.informed-scientist.org/presentation/a-life-of-a-polio-survivor-beginning-and-ending-as-a-respirator-user

Message from Val Scrivener about her Photo Cards sold to help PSN.

The photos below and on the back page of the newsletter give just a taste of the range of topics covered by my Photo cards. When ordering, it is really helpful if you give some idea of the subjects that most appeal to you. The sort of subjects covered include flowers, animals, trains, landscapes, buildings and, of course, cards with a seasonal theme (wintery scenes, Christmas etc.). You may even state that you would like a pack with subjects suitable for men or, as one customer stated, 'no cats please!' - I am more than happy to oblige. Where possible I try, when making up collections, to relate them (in the case of flowers) to the appropriate time of year.

I have, unfortunately, to draw your attention to a price rise. This has been made necessary by the rising price of materials and ink and by the increased cost of postage. I try to work to a shoestring in order to encourage sales - at £4.50 per pack of 5 cards with envelopes you are still getting your cards for under a pound, not an easy thing to be able to do these days so I hope that you will continue to send in more orders (my details are on the back page) - all profits go to PSN.



PLEASE NOTE - The Abstracts printed are the research and work of the authors and are given in this Newsletter to stimulate discussions between you and your health professionals, with other members and polio survivors round the world.

If you have any questions or comments please drop us a line/email, phone if writing is difficult for you. We will combine all information received and contact the authors for a response.

Editors Questions at the end of each Abstract.

WS15 Multidisciplinary One-day Rehabilitation Team evaluation for Post Polio Patients.

Parwin Yari, MD, Anne Carien Beishuizen, PT, Dorien Toor, OT, Liesbeth Eggink, SW

Department of Rehabilitation, Academic Medical Center, Amsterdam, The Netherlands

The AMC serves as the Post-Polio Expert Center for the Netherlands and each year on average 90 new patients are seen for diagnosis and therapy or for advice. Referrals originate from all over the country. Many patients suffer from post-polio syndrome.

Since 2007, the AMC offers a multidisciplinary one-day rehabilitation team evaluation for patients with polio-related complaints. The focus of this day is not on medical diagnosis but on supporting patients in managing their functional problems and physical complaints. The procedure is as follows: After initial screening the rehabilitation specialist together with the patient, decides on participation in this multidisciplinary evaluation. The criterion is that patients must have multiple problems, and questions on how they can better manage their symptoms and increasing disability.

Two weeks before, patients fill in a questionnaire and formulate their questions for the team. These questions guide the multidisciplinary assessment on the day itself, during which a rehabilitation specialist, physical therapist, occupational therapist and social worker see them. Afterwards the team meets to reach a common conclusion on the findings and advice for further therapy. The day ends with a joined meeting of the team with the patient to summarize and discuss findings and advices. The patient is sent a full written report afterwards.

Six weeks later follow-up of advices is checked by phone. The most frequently addressed issues concern the reduction of pain, tiredness and overload, improving fitness, exercise and sport, advice on home and work adjustments, and on the use of walking aids. Social and emotional items most discussed are how to deal with physical complaints, with acceptance, with fear of being dependent and with concerns about the future. Depending on the distance, patients are further treated in the AMC or referred to rehabilitation centers with expertise in neuromuscular diseases in the vicinity of their homes.

Editor's Question - Has your assessment been multi disciplinary/as thorough as this? It would help Polio Survivors Network and the Neurological Alliance research if you could let us know both good and not so good responses. The current NHS financial situation means a huge variation of neurological facilities and services. Lincolnshire has again been referred to as a 'Neurological Black hole' at an NHS Meeting.

IMPORTANT SURVEY - The Neurological Alliance are holding a survey on patients experiences. Link is www.surveymonkey.com/s/neurologicalpatientexperiencesurvey

Deadline to complete is September 15th 2014. Not on the internet and would like to take part give us a ring, it takes about 20 minutes with 25 questions. If we are able to get a paper copy before posting we will add a copy.

Check your local Healthwatch - they might be doing a patient experience survey.

WS1 Management of Bladder and Bowel Symptoms.

Lise Kay, MD, Anne Marie Eriksen, PT

PTU Danish Association of Polio and Accident Victims, Rodovre, Denmark

Bladder and bowel habits are influenced by various factors: neuromuscular function, oral intake, culture, psychology, upbringing, and toilet access. Polio survivors may be challenged in several of these fields and consequently have a special risk of having bladder and bowel symptoms. Polio survivors who experience bladder and bowel symptoms should primarily have a screening to exclude that other diseases are causing the symptoms.

In case of bladder symptoms this would usually imply a urinary test for blood, an ultrasound, and a blood test of PSA (men). For bowel symptoms it usually implies a colonoscopy of the bowel.

When other disease has been excluded, focus can be put on the factors first mentioned.

Initially a patient history should be taken including drinking and toilet habits, diet, and physical challenges at toilet visits. For bladder symptoms a voiding and drinking diary should be fulfilled, together with a standardized questionnaire on bladder symptoms. A physiotherapeutic assessment of the pelvic floor is to be carried out. It includes inspection of the pelvic floor and vaginal palpation of muscle tone both at rest and during contraction. This work-up usually reveals several points for improvement. In many cases incontinence can be eliminated or minimized when structure and changes in toilet-habits, fluid-habits, and training in voluntary use of the pelvic-floor are implied.

Bowel symptoms are generally addressed parallel to bladder symptoms, but may often require support by a laxative. A laxative prevents overextension and thereby facilitates bowel contractions. Laxatives can seldom be misused. Constipation, overextension and the weak contractions are much more risky to bowel function than overuse of laxatives. **Laxatives that function by increasing nerve activity in the bowel are the only exception to this rule.** In severe cases of constipation irrigation of the bowel as self management scheme can be necessary and very seldom different operations may be the last solution.

If symptoms are not relieved by the above, one should consult specialists in urology or gastroenterology, who are experienced in bladder and bowel problems.

Summary and Key points: Toilet habits are influenced by various factors: neuromuscular function, oral intake, culture, psychology, upbringing, and toilet access all which may challenge polio-survivors. If screening does not reveal other disease, improvement can usually be obtained by addressing these factors.

Editors Questions:- These are delicate subjects and maybe not easy to discuss but if we are to help ourselves and sharing information can really help with this, then we need to broach them.

How many of you have problems in this area and if you do have you spoken to your GP about this or asked for an assessment?

Do any of you think your muscle weakness from polio [low motility of items through our guts] has been taken into consideration, or have you just got the 'it's your age'.

Recently raised issue that is getting some 'me too's'. Have you found that sometimes when you go to the toilet that your urine is coming out fine but slowly and no matter how hard you try you cannot use muscles to speed this up? Men have commented that they have to pause mid pee.

How about many years of taking a variety of medications and eating the right foods, drinking the right amount of water yet you still find you are having problems sometimes struggling to eliminate 'moonrocks'?

SL 12 Medication for Comorbidities; effects in Post-Polio Syndrome.

Lise Kay, MD

PTU (The Danish Society of Polio and Accident Victims), Rodovre, Denmark

Effects of medication for comorbidities [presence of one or more disorders] in post-polio syndrome (PPS) have not been evaluated in randomized controlled studies. However, this does not necessarily mean that persons with PPS respond like everyone else to any sort of medication.

Theoretical considerations and experience indicate that in some areas persons with PPS may be at special risk. The acute polio has left polio survivors with fewer nerves in the spinal cord and more central parts of the nervous system (for example centers for regulation of blood pressure, pulse, and sleep). Furthermore the remaining nerves may, to some degree, have a suboptimal function. Consequently, medication acting by interfering with nerve junctions may have a more vigorous effect than normally observed. Various medicines act this way, the most common being in the field of tranquilizers, sleeping medication, anti-depressants, alpha and beta blocking agents, and various medication used for anesthesia.

This does not imply that all polio survivors cannot have the above-mentioned medication; it only means that the medicine should be initiated with a low dose, and the patient carefully followed to adjust the dose in relation to the effect/side effects that turn up.

Some medication may have side effects that are more problematic for polio survivors. For example medicine that is neurotoxic. As polio survivors have fewer nerves, an additional reduction in nerve function may have a much more serious effect, that seen in persons with a normal number of nerve cells. Some types of chemotherapy and of antibiotics have this sort of side effect.

Various medicines have muscle pain and muscle weakness as side effects. The most common are the "statins" taken for elevated cholesterol level. These side effects seem to occur more often in polio survivors, and with more serious results, as it adds to the symptoms they already experience. The side effects usually disappear within weeks after withdrawal. Pravastatin and Rosuvastatin [*1] are reported not to have such side effects. Calcium antagonists used for hypertension and cardiac symptoms may also result in muscle pain and muscle weakness. In conclusion, polio survivors may take almost any form of medicine provided the dose is carefully adjusted, neurotoxic medicine however may give permanent nerve damage and should be avoided as far as possible

Editors note [*1]:- It is important that you read all the side effects of any medication, including the drugs mentioned, and discuss this with your prescribing physician. The medication names mentioned above on checking I still found the following

Pravastatin - muscle problems - some of these muscle problems may be fatal. Seek immediate medical advice if you get unexplained muscle or joint pain, muscle tenderness, muscle weakness or muscle cramps

Rosuvastatin - unexplained muscle pain, tenderness, or weakness and mild muscle pain.

Editors note. Over ten years ago whilst we were in Florida and attended the local Parkinson's Group a speaker, Neurologist Dr. Terry Petrella advised that if at all possible all medications should be started at a quarter dose and titrated up if needed.

Firstly if side effects happen then they are likely to be much much lower.

Secondly a quarter of the recommended starting dose may be enough, or you might need to titrate this up to a half dose. Maybe you need the full dose.

Thirdly. If at all possible only start one medication at once so that you know which medication is helping/not helping/causing side effects.

Polio Survivors Network Medications Card was included a couple of newsletters ago. If you need another card then please drop us a line by letter or email.

Dysphagia [swallowing difficulties] and Dysphonia [problems with voice]

Päivi Tupala, Speech Language Therapist Sunnaas Rehabilitation Hospital, Norway

Swallowing difficulty (dysphagia), problems with voice (dysphonia) and breathing are widely considered to be symptoms attributed to post-polio syndrome (PPS).

It has been estimated that 18 - 29% of polio survivors have daily problems with swallowing and voice. Persons who initially had polio affecting muscles in head and neck are most vulnerable for new/increased difficulties, but many individuals who didn't have swallowing problems before, are experiencing them as a symptom of PPS.

New or increasing muscle weakness and general fatigue are common with PPS. Weakness in muscles contributing to breathing, swallowing, voice production and for instance coughing can lead to difficulty in all or some of the tasks these muscles contribute to.

Swallowing is a result of complex, precise, fast and smooth cooperation of several muscles and nerves. Weakness in these muscles can cause severe inefficiency in swallowing that results often to residue of food in throat after swallowing.

Decreased airway protection can result to coughing, hoarse voice quality and aspiration (food/liquid in the airway). Quality of voice inclusive pitch, strength and voice endurance is also often affected, as the muscles and nerves that control swallowing also control speech and voice.

Therefore it's important that a person with PPS is aware of changes he might experience regarding swallowing and voice. Also professionals should be aware of the importance of regular evaluation of dysphagia and dysphonia in this population.

Clinical evaluation including assessment of oral-motor skills, voice and breathing and mealtime observation is important, as well as a thorough anamnesis [history of your polio] Instrumental examination gives critical information both of the severity and nature of swallowing difficulty, but is also a key to customize treatment and compensatory techniques.

By modifying positioning, eating habits, consistencies and using swallowing techniques can help the person to maintain safe swallowing and to avoid fatigue under meals. The social aspect of dysphagia and ability to communicate is also of great importance for every polio survivor. Therefore everybody who experiences difficulties with swallowing or/ and voice should be assessed at regular intervals.

Editors Questions:-

Have you told your GP or other PPS professional that you have had to change the way you eat. Maybe you pace and rest your eating and drinking, and/or there are foods that you no longer eat [maybe something that needs more chewing, or is very flakey like those delicious oaty biscuits?

Has your voice deepened, or got hoarse after a while. Maybe the volume has got lower and lower or you might have noticed that you speak a few words at a time as you take more breaths?

Maybe you have raised issues and been told that if you did not have bulbar polio then you will not have these issues. Unfortunately this is not the case as many polio survivors, including both myself and my husband have issues with speaking, and swallowing.

Tips that have helped some polio survivors.

1. If you find that you cant swallow the next mouthful you are likely to have tensed up with the why? This raises your shoulders and you cannot swallow with your shoulders up. Try it. Then try taking a big 'sigh' and your shoulders will relax. Then tip your head slightly forward and sometimes slightly leaning head one way or the other can help and swallow.
2. Pace and rest eating and drinking and always have a glass of water handy.
3. Tell your GP and ask to see a Speech Therapist who will help with speaking and swallowing.

Your Newsletter needs your stories, hints, tips and bits

A way of doing something, or aid, that helps you might help someone else. Tell us.

How about a recipe that tastes great on the lips but not on the hips.

CARERS - Are you a Carer and would like to write and tell us how we might help Carers understand what you go through helping us manage our lives.

Articles and items for Post Polio Matters

are always welcome, by post, by email and by phone if writing is not easy for you.

Deadline date for next issue is October 21st 2014

Misconceptions about paralysis by Richard Boone.

A month ago I happened to mention how sensitive my left leg was....., and my Personal Assistant said, 'but I thought it was paralysed'. I said 'it is'.

Much to my surprise he then said 'but they stick pins in people on films and TV programs like Casualty to see if they have any paralysis so I thought you could not feel anything where you were paralysed. I too have often seen this on films and TV programs but it never crossed my mind that people would not realise that polio paralysis was different and it is only our motor nerves that were affected not our sensory ones.

Disabled Toilets.

On our trip round America, Canada and Holland we found a huge variety of layouts and hand rail positions in toilets. Issues that we came across meant every new situation meant working out before you sat down how you might get up again. Thinking about it, it is the same in the UK.

At the Americana Festival near Loughborough we got into a discussion with a lovely couple about things like too low toilet bowls, hand rails in odd places, toilet rolls fitted almost behind you so you have to twist and reach under your left arm to try and jiggle a few pieces off, mirrors that you can only see in if you are seated. Then we got to talking about the very narrow toilets in aircraft.....

The other couple then told us about their flight back from Hawaii. He told us that he took his wife to the toilet area on the plane and looking round was able to unhook an extra panel that made the area bigger. A stewardess then rushed up and asked me "what on earth did I think I was doing?" Amazingly she did not know that this facility was available on this aircraft.

She apologised and helped me get my wife into the toilet and left us to it. On opening the panel and stepping back another stewardess comes from the front of the aircraft and lets rip at me. "How disgusting for two people of your age to go into the toilet together... and is only stopped in her rant by the first stewardess coming from the back of the aircraft explaining that my wife is disabled and I was helping her. He then told us before anyone could say anything else I quickly chipped in and said "We would not make a formal complaint provided we got our 'mile high' badges" ☺

Editors Note:-

Articles from Polio Survivors and Health Professionals Welcome for future issues.

.MOBILITY ROADSHOW SET TO RETURN IN 2015



Mobility Choice is delighted to announce that the next Mobility Roadshow will be held in 2015. The show will take place from 25th – 27th June 2015 at Donington Park, making a welcome return to this popular venue.

19th August 2014 notifications. [excerpts only]

Vitalise survey found that a survey of 100 of Britain's most visited tourist attractions, 52 [almost two thirds 63%] were not fully wheelchair accessible. A quarter had no disabled car parking spaces and just 13% said all their staff had received disability awareness training. The other 48 attractions contacted didn't respond despite repeated approaches from the charity.

www.vitalise.org.uk/about_us/press_office/more-accessibility-now-says-vitalise

UK: Plymouth people on disability benefits will have to use their benefits to pay for social care. | Plymouth Herald News.

Councillors have been accused of discrimination after introducing a policy to make disabled people pay for care out of their benefits.....

The council currently disregards disability allowance when assessing how much people pay towards their care, but from October it will treat 70 per cent of a person's benefits as income. Plymouth City Council has agreed to change the way it provides non residential social care, taking a person's disability benefits into account when assessing how much they pay towards the social services they receive.

www.plymouthherald.co.uk/Plymouth-people-disability-benefits-use-benefits/story-22767010-detail/story.html

PPM Editors Note:- Lincolnshire already takes the low and middle rate care amounts into account for income. Basically, when assessed for social service personal budget you answer questions on a Resource Allocation System form. Your answers, e.g. a), b), c) etc gain increasing points which are turned into funds for the year for you to buy the care you need. Say you are awarded £10,000 p.a. £192 per week. The minimum wage is £6.31 [2013]. You are likely to have to pay more per hour for a personal assistant. You also have to pay tax and national insurance, pay for holidays and cover when away or ill, employment insurance, and soon pensions. You have to comply with employment, health and safety and equality law. We pay HMRC online or you can pay an agency to do all the paperwork out of your funds. You are then financially assessed to see how much you can pay towards this £10,000. The assessment takes into account your income, outgoings and any disability related expenditure [DRE]. This should include anything you have to pay for that you would not if you were not disabled. Your weekly contribution is calculated, e.g. £50 per week leaving social services to pay £142. Both amounts are paid into a special bank account which you use to pay for your care. If you want more info please contact us.

Pakistan: Sindh's 11th polio case of 2014 confirmed | DAWN

Karachi. A one year old child - 10th in Karachi and 11th in Sindh - was confirmed to be the latest victim of the crippling polio virus in the city's Landhi area on Tuesday, officials said..... "The parents have informed us that they got the child vaccinated against polio many times in the past - two times during normal campaigns and eight times during special rounds. However, we'll have to investigate to corroborate whether the parents claim is right, said Dr. Durre Naz Jamal, deputy director of the EPI, Sindh. The officials said that the parents claim about their child's vaccination separated them from a majority of the parents whose refusals led to the crippling of their children. The lack of vaccination was not the reason for Ahmed's fate. In fact there are a few polio cases across Pakistan, including Sindh, that were administered at least one dose but have tested positive for polio.

www.dawn.com/news/1126411/sindhs-11th-polio-case-of-2014-confirmed

Orthotics for Knee InStability

Orthotics for Knee Instability (OKIS): researching the issues

OKIS is a research project about orthotics for knee instability in patients with neuromuscular disease or central nervous system (CNS) disorders.

The National Institute for Health Research (NIHR) identified gaps in the evidence around the use and effectiveness of the various orthotic options for patients with knee instability caused by a neuromuscular disease or CNS disorder. Coupled with research that shows that people often do not use their orthoses, it was clear that good quality evidence could help ensure patients get the best possible service. Our research team were awarded a grant through the NIHR HTA Programme to undertake a research project to start to address these issues.

A key element of the OKIS project is to gather the views of people with a neuromuscular disease or CNS disorder who have been fitted with an orthotic device for knee instability. The types of devices we are interested in include knee-ankle-foot orthoses (KAFO, also known as full leg calliper), ankle-foot orthoses (AFO) and knee orthoses (KO). We plan to carry out one to one interviews and hold some focus groups with patient participants from across the country. We will be asking about their experience of wearing an orthotic device, their treatment goals and what influences whether they wear the orthoses or not.

We also aim to establish what the current referral pathways are, types of devices being used and what is involved in the process of providing patients with an orthotic device for knee instability. To do this we are going to carry out a survey of health care professionals who fit people with orthotic devices for knee instability to find out about the experience, practice and preferences of health professionals in relation to orthotic devices.

Finally, to underpin these information gathering parts of the project, we are looking into what, if any, research has already been done. We are using systematic review methods to identify, quality assess and synthesise existing evidence on the benefits and any harms from using orthotic devices for knee instability in adults with the target conditions.

The project team includes researchers and health professionals from the University of York, Nottingham University, University of Strathclyde, Kingston University and Queen Mary's Hospital Roehampton. The team will pull the elements of the project together and present all the findings in a final report. We will also identify the important issues for future research around the clinical and cost-effectiveness of different types of orthotic management of the knee in people with neuromuscular disease and CNS disorders.

We started the project on 1st April 2014 and have 12 months to complete it. We want everyone interested in this area of work to know about our research so we have created a blog which you can find at <http://kneeorthotics.blogspot.co.uk/> or you can follow us on twitter at [@OKIS_York](https://twitter.com/OKIS_York). The blog contains information about the project and the team and blog posts are being added about our research methods together with progress reports from the researchers and our specialist advisors. If you have any comments or suggestions, we welcome feedback on the project as a whole or individual blog posts either via the blog site or you can email us at kneeorthotics@gmail.com - Alison Booth, Research Fellow, University of York. OKIS Team

Project Lead Dr. Catriona McDonald would like our members to be involved in this project please contact her via email at kneeorthotics@gmail.com or write to her at

**York Trials Unit, Department of Health Sciences, ARCC Building,
University of York, York, YO10 5DD**

Or Phone Project Administrator Sue Collins **01904 321727**

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

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Printing and Website - Elpeeeko Ltd, Lincoln.

 Please contact us if you would like to help with our work 

Membership

Full membership includes voting rights and is available to polio survivors, their partners, families and friends.

Associate membership, no voting rights, is available to patient organisations, health and social care professionals working in the interests of polio survivors £10.00 per year

Membership Fees

UK Individual - £ 12.50 per year

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

Life membership - £ 150.00 or pay by Standing Order £ 5.00 x 30 mo.

We welcome members living in other countries and details will be sent upon request.

Please note the majority of information will be sent via the Internet.

Email:- membership@poliosurvivorsnetwork.org.uk

All Forms are available on our Website, by phoning our helpline or writing to us.

<http://www.poliosurvivorsnetwork.org.uk/joinus.html>

Donations

giftaid it

Donations, small or large, towards our work will always be gratefully received.

SEE BACK PAGE - Val Scrivener is making and selling brilliant photo greetings cards

- Some members send us a few postage stamps
- Some members take their newsletter via the internet saving us printing and posting costs.
 - Others add a donation amount to their yearly cheque, or Standing Order amount.
- Some members send us a donation with some specifying, e.g. for AGM, for Conference. Fund
 - UK Taxpayers can Gift Aid their subscription and donated amounts.

• **NEW CONFERENCE & MEETING FUND**

The Gift Aid scheme. Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year.

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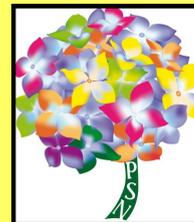
Polio Survivors Network

Lincolnshire Post Polio Network - Registered Charity No. 1064177

Website - www.polfosurvivorsnetwork.org.uk

Email - info@polfosurvivorsnetwork.org.uk

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POST POLIO MATTERS because **WE'RE STILL HERE!**

www.post-polio.org



Traveling Without A Spare

A new book by
WENZEL A. LEFF, MD

A Survivor's Guide to Navigating the Post-Polio Journey

Decades after recovering from polio, many aging Americans grapple with an emergence of new pain, weakness, and fatigue. This unforeseen symphony of symptoms is a central fact of many polio survivors' lives.

In Travelling Without A Spare, retired physician & polio survivor Wenzel A. Leff, explains how polio's initial attack depleted the body's neuromuscular reserves, so that when former polio patients begin to lose cells to the natural process of aging, they find they are truly "travelling without a spare."

I met Dr. Leff at the Post-Polio Health International Conference in St. Louis this year. His grandson was there with him for support. It was great talking to a Doctor who has PPS and knows where you are coming from when you mention issues and symptoms. Other PPSers at the meeting who had read this already recommended it as a good book to share with family and health professionals who did not know a lot about post polio. I have a few copies on order if anyone would like one please contact me, Hilary Boone.

GOOD LIST OF OTHER BOOKS ABOUT THE POLIO EXPERIENCE

<http://www.post-polio.org/edu/aboutpol/books.html>

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[sample cards on back page in each newsletter]

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