



POST POLIO MATTERS

The Polio Survivors Network Newsletter - Volume 8, Issue 1
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

**AUGUST
2013**

Vol 8, Issue 1

**P.S.N.
Annual
General
Meeting
September
14th 2013
Lincoln**

**2014
Post Polio
Conferences**

**Post-Polio Health
International
St. Louis, USA
31 May - 3rd June**

**European
Polio Union
25 to 27 June
Amsterdam**

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**WE'RE
STILL
HERE!**

October 6-12, 2013
www.post-polio.org

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Post Polio
Library



POLIO CASES to 31st July 2013 now 170

AFGHANISTAN Endemic

Cases this year

3

Last notified case
5th June 2013

NIGERIA Endemic

Cases this year

40

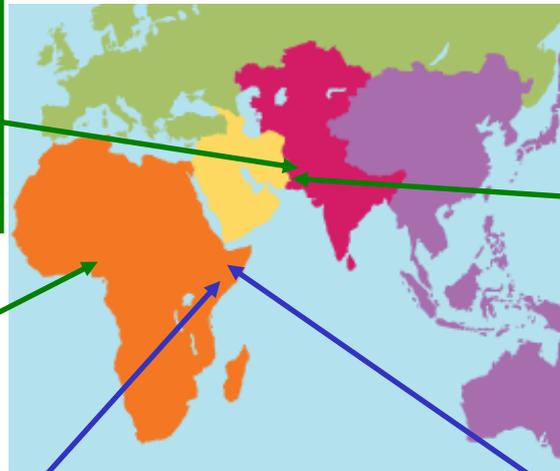
Last notified case
9th July 2013

PAKISTAN Endemic

Cases this year

22

Last notified case
3rd July 2013



KENYA - Non endemic

First reported cases since July 2011

May 9th to 31st July 2013

10 reported cases

SOMALIA - Non endemic

First reported cases since 2007

April 18th to 31st July 2013

95 reported cases

ISRAEL - Wild Polio Virus found in Routine Sewage Sampling

Since February 2013 **Wild polio virus** has been detected in routine sewage sampling in ten sites in southern Israel. Tests by laboratories abroad provided "indications there are between 1,000 to 2,000 carriers of the virus who are not sick themselves". **4th August 2013**. Israel Health Minister, Yael German launches mass vaccination campaign that will take a month to vaccinate 200,000 children, under the age of 9, with a weakened active polio virus between Kiryat Gat and Mitzpeh Ramon in southern Israel. Israel's last case of polio was in **1988**.

Member Professor Eddie Bollenbach reports:-

This month's Scientific American tells the story of polio eradication efforts and setbacks. Polio vaccine workers are attacking spots where wild polio is endemic but these areas and other areas pose new problems for the eradication effort. We had polio in Nigeria, Pakistan, and Afghanistan then suddenly we have several cases in Somalia. It is characterized as a game of Whack-a-Mole. Something that is adding to the problem are chronic excretors of polio which originated from the Sabin live vaccine of mutated virus. It seems people with immune deficiency sometimes after vaccination excrete for an extended period of time with the chance of the virus mutating back to the virulent paralyzing virus. It is rare and the excretors may not even know their immunity is compromised but add millions of virus particles to sewage. In Israel they found virulent virus from excretors but were unable to identify the individuals who were excreting. This buttresses the conviction that babies, even in the developed world, stay up to date regarding vaccines in babies. eddiepps@gmail.com

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**See
Editorial**

**NAIDEX
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2013**

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2013**

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Welcome: to New Member Dinah Bass

Thank you to all members who have recently renewed and to all those who have made donations towards our work.

L, Forsyth, M. Allison, M. Whitley, S. Freeman, Y. Liggins
J. Doohan, S. Tanfield, V. Gabriel, D. Bass. D. Ives, C. Colfer,
A. Johnson, Mablethorpe Computer Supplies.

£ 940.00 donated so far this year.

Val Scriveners Card Sales £ 30.00

Help our funds by ordering - info on back page.

We have no paid employees.

**Donations & offers of time, no matter how small,
towards our work are always welcome.**

This publication is provided as a service to those seeking such information and is not intended as a substitute for professional medical care. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Polio Survivors Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

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Editorial by Hilary Boone

I have to start with some sad news - due to the unexpected illness of developer of the GENIE wheelchair, Bob Hester, [Easycare Products Limited} the company has now gone into liquidation. This has left us without warranty for the wheelchair we bought in March 2013. We have someone looking into the warranty issue for the manufacturers parts used on the chair and thank Paul Stanfield for his help in the last few days. PLEASE note that had we not paid the deposit by cheque and the remainder by bank transfer but used our Credit Card we could have had some help to cover this situation. Advice is to pay for any item between £100 and £30,000 with your credit card - Section 75 refers - then the Credit Card company are equally liable if the company goes bust or the item is faulty. This does not apply to Debit Cards.

We could have done without this added stress to managing our lives. I can hear you saying why didn't we ask for a wheelchair assessment? Well we have on at least three occasions in the last two years with nothing being arranged for us. Plus we were told that there were still NO electric NHS wheelchair vouchers for Lincolnshire. We visited Naidex and the Mobility Roadshow each year and met Bob Hester and his GENIE wheelchair each time and were impressed with all the extra bits that had been thought of. We had a home demonstration, personal measurements taken, and we ordered the chair (not available on the Motability Scheme)

5 weeks ago we visited Lincolnshire NHS Wheelchair Services who helped us out with a small problem we had with our own wheelchair for which we were grateful. We learned that there had been electric wheelchair vouchers for about 18 months now, but too late for us. There are times each month when Richard cannot get to places in his electric chair but could with his PA in a manual so we asked for an assessment. Forms were sent to our GP and having heard nothing after four weeks I rang Wheelchair Services to be told that yes they had received the request and they would send us an appointment but it wont be till November!!!

We try to manage our own conditions as much as possible. Lets face it a doctors office or hospital is the last place any of us want to be. In Lincolnshire services for people with neurological conditions are very poor compared to the counties around us. Lincolnshire Neurological Alliance formed in January 1998 and report that until 2003 Lincolnshire did not have a resident neurologist for its over 634,300+ population. Every couple of years there has been a change in boundary/names/trusts/etc and with that a change of staff. Surveys and consultations have taken place with recommendations and even commissioning dates for the next couple of years.. But sadly there is no money, little has been commissioned and the campaigns for better services have to start again with yet a new group of staff members. For the last two years its been 'things are on hold till the new GP Commissioning Groups take over in April 2013', and still we wait for the promised meeting to have round the table talks with the staff on the ground to see where improvements can be made that will benefit staff, users and carers, and save the waste of NHS money that our members report.

How about letting us know what is happening in your area of the country. Have you found health professionals who are helping you manage your polio life? Have you had assessments for your physical ability/mobility equipment/orthotics/wheelchairs/respiratory/swallowing/etc? If you have then why not tell us the good and sadly also the bad bits so we can update the Neurological Alliance now we have a New National Clinical Director for Neurological Conditions. [See page 18]

giftaid it

If you pay UK Income Tax
did you return your form to Gillian?

Polio Survivors Network - Meetings

If you have any matters you would like us to discuss at our meetings please get in touch via
hilary.boone@poliosurvivorsnetwork.org.uk
or Tel: 01522 888601 or write to us at Polio Survivors Network PO Box 954, Lincoln LN5 5ER

MESSAGE from Polio Survivors Network's Chair

As I take over as Chair of PSN, I reflect upon what has been achieved in the past and where we need to go in the future. Many polio survivors are, in this country, largely growing older and have been living with the effects of polio for some years. Many others have only realized relatively recently that their symptoms and problems stem from having had polio way back in the past. This may be a greater number than has been thought.

However, we are a small group in terms of membership but potentially relevant to a much larger number of polio survivors, many who even now may not realize that they have PPS. One of our aims is to educate and inform health professionals about polio and its effects but also to reach out and recruit more polio survivors as members.

The other issue that struck me whilst reading the newsletter was the article about 'coping styles'. I think we need to realize that many of these models are based upon a need to classify and label and, whilst useful for reflection, most people do not fit neatly into boxes but fall between and within multiple models. As a Counselling Psychologist, I am by the very philosophy of my training and beliefs, wary of diagnostic labels. I prefer to think of individual's own life stories and individual histories as a guide to understanding.

I mention this, as we also need to realize that many of our issues and requirements are shared with others with neurological and chronic conditions. We need to avoid thinking of ourselves as unique in being 'polio survivors' as we can benefit from what others experience and what works for them. As the very good 'letter' from Dr. Rob makes clear, it is our knowledge of ourselves and our condition and our desire for a shared and equal but different relationship with our medics that makes us special patients and to some, challenging.

I do hope that some of you will feel able to email me with anything that you feel we should be doing for you as members, be that personally or as a general issue you feel strongly about.

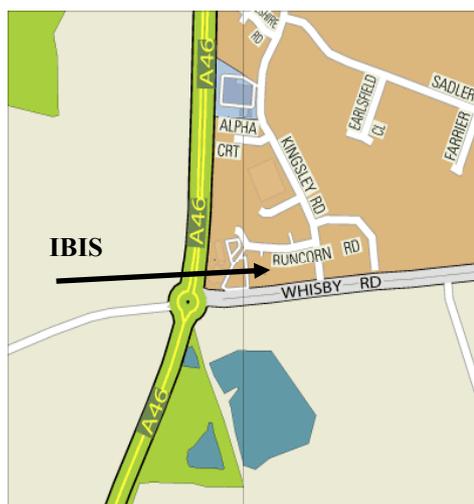
Simon Parritt, Chair

simon.parritt@poliosurvivorsnetwork.org.uk

POLIO SURVIVORS NETWORK - ANNUAL GENERAL MEETING.

SEPTEMBER 14TH 2013, 10.30 a.m. for 11.00 a.m. start.

AT THE IBIS HOTEL, RUNCORN ROAD, A46 OFF WHISBY ROAD
LN6 3QZ - LINCOLN



In our MAY newsletter that was posted to members we included an address label and asked that you return the AGM slip enclosed to let us know if you were or were not able to join us on this day.

For those members that received the newsletter by email we asked you to let us know by email.

We are doing the same this issue and look forward to hearing from more members. We will provide more information to all who respond that they are coming.

Take the opportunity to suggest items to ask us questions about PPS issues, tell us your story, send us tips for coping for future newsletters. We look forward to hearing from you.

“Hello” by Millie Lill, from Polio Perspectives, August 2013

Listen up, Brain. We body parts have had a **meeting** and we want to bring a few things to your attention. You don't know everything, you know. As Left Leg of this conglomeration, I would appreciate it if you would keep from insinuating that I'm worthless. If I weren't here, even damaged as I am, you would topple over. The polio virus did a number on me, I admit that. And, OK, I'm not pretty. I won't lie, I know that I'm skinnier than Right Leg, but look how hard I've tried to be everything you want in a leg. It is not my fault that I was left with so few motor neurons that I can barely function.

And I'm Right Leg. I've been hauling this whole body around since we were four years old. I'm doing pretty good, I think. I believe a few less Twinkies and Pepsi might be helpful. I'm not Super Leg, you know!

This is Back, here. There are times when I realize I'm giving you more grief than you can handle. Sorry about that. You have to realize that with Left Leg being less useful...hold on, Left Leg, I did not say useless! I just mean that with your not being your old self (there, is that better?) there's a bit of a twist on me and I can't help complaining about it. I agree about the Twinkies, by the way.

Right Arm speaking. Sorry about dropping your grandmother's crystal bowl the other day. I did help you sweep it up. However, we need to talk about those crutches. I'm just not meant to do the work that Legs were designed for. Left Arm and our Hands have just about had it. It's no wonder we are losing our grip! We think you should at least try to have a little consideration for us. Polio zapped us, too. Not as bad as Legs, but still, we also lost a lot of neurons and we've worked very hard to help you get places and do things.

This is your Right Hip talking. With the difference in length between Right Leg and Left Leg and the slight twist in Back, life is not wonderful for me and Left Hip. Sometimes the scoliosis twists us till we are almost dizzy. We would definitely vote for fewer Twinkies, too.

So, as spokespart, for this body, I, Left Leg, have some suggestions. One is to try really hard to eat healthier. Come on, it's hard enough to drag you around without your gaining even more weight. Another suggestion is that you show a little appreciation for us. We've worked really hard for you for a very long time, under conditions that would make a lesser body give up the ghost. It hurts our feelings when you stand in front of the mirror and disparage us. "Oh, look how crooked I stand. I list to port and I fall so easily." You complain that we aren't pretty. Well, excuse me, but it wasn't our fault, really that you look like this. Blame it on Polio, he's the Bad Guy. He tried to kill you, but we didn't let him. He tried to make your life sad and lonely, but we didn't let that happen.

OK, lecture over. You can go back to what you were doing. No, not that exercise bike! Don't you ever listen? Conserve to Preserve. Pace. Give it up, Spanky, you are never going to be an athlete, but you can have a good life anyhow. Most athletes abuse their bodies even more than you do, and many of them have to retire at an early age from working too hard.

What's that you say, Brain? You couldn't live without us? Darn right and don't you forget it!

<http://postpoliobrangers.com/newsletter>



www.postpolioinfo.com

207 pages \$3.99 / £ 2.69 bought via PayPal

Hot Water, Orange Juice 'n' Kids... is the long-awaited collection of Millie Malone Lill's columns from "Gleanings," the newsletter of the Nebraska Polio Survivors Association, and "Polio Perspectives," her online newsletter. Lill's unique insights about life and about disability are mixed with humor and great wit, the spoonful of sugar that help the medicine go down with a laugh, a knowing nod and the occasional tear

"Millie's writing? In a word, spectacular! In eight words: incredibly insightful, wonderfully witty, marvellously moving, fabulously funny." **Dr. Richard L. Bruno, Chairperson, International Post-Polio Task Force**

Recognizing typical coping styles of Polio Survivors can improve Re-Rehabilitation. A Commentary¹

Frederick M. Maynard,² MD and Sunny Roller, MA

Am. J. Phys. Med. Rehabil. Vol. 70, No. 2, April 1991

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Key Words: Psychological Coping Behaviour Adaptions, Poliomyelitis, Rehabilitation, Post-Polio



www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/maynard/coping_styles.html

During the past ten years [Editors note:- 22 years ago and relevant today] many polio survivors in the U.S. have actively been seeking professional help for a wide range of new physical problems, commonly referred to as the late effects of polio. Often these persons require re-rehabilitation in order to continue their accustomed social roles.[1] In our experience at the Post-Polio Program of the University of Michigan Medical Center, we have come to recognize among polio survivors three distinct patterns of emotional reaction to the need for re-rehabilitation. These patterns appear to result from characteristic styles of living with a chronic disability. We propose a model for categorizing polio survivors that is based on our observations. Although it is limited by overgeneralization, we have found that polio survivors themselves have verbally validated our proposed categories at many post-polio conferences. A 1963 study of children with polio and their families also describes early coping behaviors that are compatible with our model.[2]

The model designates polio survivors as Passers, Minimizers and Identifiers. These labels characterize typical attitudes and behaviors that were adopted in order to cope with long-term mild, moderate or severe disability. Passers had a disability that was so mild it could be easily hidden in casual social interactions. They could pass for nondisabled. Minimizers had a moderate disability that was readily recognized by other people. They often used visible adaptive equipment or had to do physical tasks differently in order to optimally function. They typically minimized the importance of their physical differences. Identifiers were severely disabled by acute polio. They generally needed wheelchairs for independent mobility. Some also used respiratory equipment. They needed to fully identify with their disability in order to make major lifestyle adaptations and successfully cope. A closer look at each group's coping style is presented in order to clarify the typical patterns of emotional reaction that occur when polio survivors experience disabling late effects.

Passers worked directly to hide their long-term disability. Many of their acquaintances probably did not know they were disabled in any way. Although intimate family members and friends may have known, on the whole Passers became psychologically invested in hiding their disability from other people. Even today, they do not like to have to explain it or to talk about it. They don't want to think of themselves as having a disability. By using denial, they have been able to put their disability out of existence mentally and physically and to create an image that completely fools the casual onlooker. Passers may hide a paralyzed hand by keeping it constantly in a pants pocket or cover slightly imperfect body parts with stylistically camouflaging clothing. Passing is a coping style that requires constant vigilance and attention to the nondisabled disguise. Good Passers believe they cannot "blow their cover" or they might get stigmatized as part of society's disabled minority.

We administered an attitudes survey to 100 polio survivors and discovered that Passers were the group who were most distressed in having to adjust to the late effects of polio. They were more likely to be emotionally overwhelmed by the physical changes from the late effects than any of their post-polio counterparts. It is important for helping professionals to know that among post-polio people, it is the Passers who have the greatest resistance to making, and the most emotional difficulty in accepting, some of the relatively minor lifestyle adaptations that are needed to cope with the late effects of polio. Passers who are confronted with post-polio sequelae [Editors note:- after effect of a disease] often have their self-image threatened because they cannot pass any longer. Their disability has become undeniable and suddenly they must give in to it. They may become frightened because they do not know how far it will progress. Typical thoughts may

include: "Wearing a brace could lead to using two crutches, and a year later to a wheelchair, or who knows what after that... and now that the disability is obvious, what will other people think...?"

When confronted with polio's late effects, Passers often must alter their self-perceptions and lifestyle in order to continue successful coping. Their former coping style may no longer be effective and new attitudes and behaviors must be learned. Clinically, Passers can often be fully rehabilitated because their new disabilities are less severe. They can be reassured that modern orthotics, such as plastic braces, can be nicely worn under clothing and completely hidden under shoes. Passers may require an unexpected amount of understanding, patience and empathetic support from health care professionals because of strong emotional reactions that are not only triggered by the impending public nature of their new disability, but also by memories of past polio-related experiences.[3] When their disability progresses from mild to moderate, they become undeniably disabled for the first time. This can be a harsh reality for them to finally face, accept and adapt to.

Minimizers are post-polio people who have had a moderate disability that was always apparent to themselves and to others. They have coped with polio's first effects by minimizing the negative and accentuating the positive. Minimizers may say, "So what if I use braces and crutches and I can't walk in a normal fashion, look at all the other things I can do." Minimizers have adapted by de-emphasizing physical pain, deformity and functional shortcomings. Many have pursued intellectual vocations and avocations in place of more physical or athletic activities. They often have been high achievers who have pushed themselves to their limits. Minimizers have learned how to tune out their bodies in order to ignore physical imperfections, a process called "devaluing physique." [4] This practical approach to living with an obvious physical disability has often been helpful for effective coping in a society which emphasizes physical beauty and prowess. However, Minimizers are often so adept at this form of denial that they recognize polio's late effects only when physical symptoms become unbearable and insurmountable. In order to survive and function at peak capacity they may have learned to use minimizing as a defense mechanism to such an extent that they are quite insensitive to their own pain, sadness, weakness and anger. This perception can occasionally generalize to become an insensitivity to similar conditions and feelings in other people, including persons with a more severe disability.

When asked to respond to the survey statement, "I feel uncomfortable around other disabled people," Minimizers endorsed it more than the other groups. We found that they often had negative attitudes about severely disabled individuals as a group, particularly wheelchair users. Therefore, they may feel that to personally begin using a wheelchair signals joining a social group that they have previously devalued and/or implies defeat, helplessness and not fighting vigorously enough against polio's disabling effects. Minimizers sometimes admit to difficulty being socially linked with someone in a wheelchair because the very association might somehow generate their own need to use one. It is useful for professionals to recognize these phobic-like reactions when they occur and employ techniques for helping Minimizers change their perceptions of wheelchairs and wheelchair users. Indeed, these post-polio patients are the most likely to physically benefit from beginning to use a wheelchair.

Minimizers may have difficulty verbally describing new physical symptoms because they are skilled at ignoring and/or denying such problems. They need coaching and encouragement to fully focus on their body sensations and reactions and to become what might be called "wise hypochondriacs." Health care providers must listen closely to Minimizers for the slightest mention of new medical problems and give them permission to elaborate. Minimizers most commonly feel guilty about causing others, including health care professionals, inconvenience related to their new disabilities. Additionally, they are likely to have intense angry feelings about having to deal with new disabilities and re-rehabilitation.[5]

In spite of many negative emotional reactions, Minimizers know how to set goals and achieve them with persistence and determination. The astute health care professional will encourage and help empower the Minimizer to use these qualities to refocus on what is important in

life; to take another look at how to be successful; to set new goals and achieve them in new ways. Health care professionals must be patient in helping Minimizers work through understandable resistance, fears and anger with re-rehabilitation. They must respect, remember and sometimes remind Minimizers that they are experienced copers who have a well-proven capacity to adapt effectively.

Identifiers are post-polio people who have usually been sufficiently disabled since their acute polio to require wheelchairs for mobility. They have needed to more fully integrate their disability into their self-image in order to create successful and meaningful lives. Through identifying with others having physical disabilities, they have gained the strength to tolerate social prejudices and architectural barriers. Not surprisingly, many became disabled rights activists and helped start the independent living movement. Among the three groups sampled through the attitudes survey, Identifiers most strongly endorsed the statement, "high achievement is a requirement for survival as a disabled person." They also most intensely believed that taking an active role in the disabled rights movement was necessary to their future well-being in society, and that fully acknowledging their disability will help them cope with it more effectively.

With the onset of polio's late effects many Identifiers confront the loss of their independence. The smallest functional forfeiture can be extremely distressing to a person who has been chronically severely disabled. If breathing function becomes significantly impaired, death may be a realistic threat. For Identifiers who have had to work diligently to learn to feed themselves and perform other simple self-care activities, independence in daily living activities may be one of the most important accomplishments of their lives. Therefore, if post-polio sequelae threaten a decline in strength, they can be expected to appear extremely distressed. Effective helping professionals need to anticipate the Identifier's concerns and recognize that his/her intense interest in autonomy and control of his/her environment is not pathologic. Identifiers have needed to develop a heightened concern about physical independence and about personal choice with how required help is given in order to attain high self-esteem and survive with their severe disability. When their freedom to control their life activities is threatened by new physical limitations or even by temporary dependency imposed by a hospital setting, Identifiers may experience a threat to their whole life and purpose for living. This reaction often leaves Identifiers vulnerable to other's false perceptions of them as being overly controlling, difficult and demanding people. In reality, they simply know what they need and are not too timid to ask for it. The informed health care professional will accept this and will do everything possible to let them continue to feel, and actually be, in charge of what happens to them.

Passers, Minimizers and Identifiers each adopted a characteristic coping style in the past that worked to create some of our generation's most successful and resilient survivors of physically disabling illness. The onset of new post-polio problems can present a challenge to their previously successful methods of coping and create significant emotional distress and pain. Health care professionals need to be aware of polio survivors' typical past coping styles and of their need to employ different tactics for coping during the re-rehabilitation process. They can point out to polio survivors that it is possible to find opportunity in their time of change. Passers can "come out of the closet," relax and enjoy a little more freedom with their very acceptable natural physiques and identities. Minimizers can also be empowered to live life with a greater sense of wholeness through more fully recognizing, accepting and integrating all aspects of their bodies. By relinquishing their struggle for physical independence and accepting new personal and technological assistance, Identifiers can gain the time and energy to develop new pursuits and cultivate other realms of interest. It is in this honest and supportive spirit of healthy transition that successful re-rehabilitation can occur for the ever-adapting group of polio survivors.

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AMERICAN JOURNAL OF PHYSICAL MEDICINE & REHABILITATION

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Editors Note: It would be interesting to know what members think about this article. What were you? Did you fit in one category or more. Please write or email and let us know. Any member who finds this difficult and would prefer to phone, ring and if the ansaphone comes on leave your name and phone number and I will call you back.

I was a Passer, I did not know anyone else who had Polio and nearly everyone I knew had no idea that I had polio as a child. After the operations on my feet at age 11/12 I started to achieve in sports that did not involve running and if anyone had asked me until I found PPS existed I would have said "I had polio", past tense. My electric scooter was delivered on my 50th birthday in 1997 sixteen months after I found PPS existed and now my disability was visible.

Members and anyone else reading this why not write/email us and tell us your story.

Disabled Jokes from Tetraplegicliving.com Penn is 43, a tetraplegic living in Devon.

A website with some good articles about what has and has not worked for him.

- a) A bloke is showing two young American girls around London and they come to a Pelican crossing. He presses the button and the pedestrian signal goes 'bleep-bleep-bleep-bleep' "Whats that for?" asked one of the girls. "Oh that's just to let the blind know that the lights have changed" said the bloke. "My Gaad" she said, really shocked, "in the States we don't even let them drive..."
- b) My girlfriend said she was leaving me due to my obsession with the 60's group The Monkees. I thought she was joking and then I saw her face.....
- c) Last night I was sitting on the sofa watching TV when I heard my wife's voice from the kitchen, 'what would you like for dinner my love, chicken, beef or lamb?' I said, 'Thank you, I'll have chicken please' She replied, 'You're having soup you fat b****d, I was talking to the cat!'
- d) Hi, you're through to the Incontinence Hotline...Can you hold, please?

Complaints to Councils.

- I wish to report that tiles are missing from the outside toilet roof. I think it was bad wind the other night that blew them off.
- My lavatory seat is cracked, where do I stand?
- I am writing on behalf of my sink, which is coming away from the wall.
- ..50% of the walls are damp, 50% have crumbling plaster and the rest are plain filthy.
- The toilet is blocked and we cannot bath the children until it is cleared.
- Our lavatory seat is broken in half and is now in three pieces.

MUSINGS OF A DISTRACTABLE MIND

Thoughts of an odd, but not harmful primary care physician.

A Letter to Patients with Chronic Disease

by Dr. Rob Lamberts, July 14th 2010

Dear Patients:

You have it very hard, much harder than most people understand. Having sat for 16 years listening to the stories, seeing the tiredness in your eyes, hearing you try to describe the indescribable, I have come to understand that I too can't understand what your lives are like. How do you answer the question, "how do you feel?" when you've forgotten what "normal" feels like? How do you deal with all of the people who think you are exaggerating your pain, your emotions, your fatigue? How do you decide when to believe them or when to trust your own body? How do you cope with living a life that won't let you forget about your frailty, your limits, your mortality?

I can't imagine.

But I do bring something to the table that you may not know. I do have information that you can't really understand because of your unique perspective, your battered world. There is something that you need to understand that, while it won't undo your pain, make your fatigue go away, or lift your emotions, it will help you. It's information without which you bring yourself more pain than you need suffer; it's a truth that is a key to getting the help you need much easier than you have in the past. It may not seem important, but trust me, it is.

You scare doctors.

No, I am not talking about the fear of disease, pain, or death. I am not talking about doctors being afraid of the limits of their knowledge. I am talking about your understanding of a fact that everyone else seems to miss, a fact that many doctors hide from: we are normal, fallible people who happen to doctor for a job. We are not special. In fact, many of us are very insecure, wanting to feel the affirmation of people who get better, hearing the praise of those we help. We want to cure disease, to save lives, to be the helping hand, the right person in the right place at the right time.

But chronic unsolvable disease stands square in our way. You don't get better, and it makes many of us frustrated, and it makes some of us mad at you. We don't want to face things we can't fix because it shows our limits. We want the miraculous, and you deny us that chance.

And since this is the perspective you have when you see doctors, your view of them is quite different. You see us getting frustrated. You see us when we feel like giving up. When we take care of you, we have to leave behind the illusion of control, of power over disease. We get angry, feel insecure, and want to move on to a patient who we can fix, save, or impress. You are the rock that proves how easily the ship can be sunk. So your view of doctors is quite different.

Then there is the fact that you also possess something that is usually our domain: knowledge. You know more about your disease than many of us do – most of us do. Your MS, rheumatoid arthritis, end-stage kidney disease, Cushing's disease, bipolar disorder, chronic pain disorder, brittle diabetes, or disabling psychiatric disorder – your defining pain - is something most of us don't regularly encounter. It's something most of us try to avoid. So you possess deep understanding of something that many doctors don't possess. Even doctors who specialize in your disorder don't share the kind of knowledge you can only get through living with a disease. It's like a parent's knowledge of their child versus that of a pediatrician. They may have breadth of knowledge, but you have depth of knowledge that no doctor can possess.

So when you approach a doctor – especially one you've never met before – you come with a knowledge of your disease that they don't have, and a knowledge of the doctor's limitations that few other patients have. You see why you scare doctors? It's not your fault that you do, but

ignoring this fact will limit the help you can only get from them. I know this because, just like you know your disease better than any doctor, I know what being a doctor feels like more than any patient could ever understand. You encounter doctors intermittently (more than you wish, perhaps); I live as a doctor continuously.

So let me be so bold as to give you advice on dealing with doctors. There are some things you can do to make things easier, and others that can sabotage any hope of a good relationship:

1. Don't come on too strong – yes, you have to advocate for yourself, but remember that doctors are used to being in control. All of the other patients come into the room with immediate respect, but your understanding has torn down the doctor-god illusion. That's a good thing in the long-run, but few doctors want to be greeted with that reality from the start. Your goal with any doctor is to build a partnership of trust that goes both ways, and coming on too strong at the start can hurt your chances of ever having that.
2. Show respect – I say this one carefully, because there are certainly some doctors who don't treat patients with respect – especially ones like you with chronic disease. These doctors should be avoided. But most of us are not like that; we really want to help people and try to treat them well. But we have worked very hard to earn our position; it was not bestowed by fiat or family tree. Just as you want to be listened to, so do we.
3. Keep your eggs in only a few baskets – find a good primary care doctor and a couple of specialists you trust. Don't expect a new doctor to figure things out quickly. It takes me years of repeated visits to really understand many of my chronic disease patients. The best care happens when a doctor understands the patient and the patient understands the doctor. This can only happen over time. Heck, I struggle even seeing the chronically sick patients for other doctors in my practice. There is something very powerful in having understanding built over time.
4. Use the ER only when absolutely needed – Emergency room physicians will always struggle with you. Just expect that. Their job is to decide if you need to be hospitalized, if you need emergency treatment, or if you can go home. They might not fix your pain, and certainly won't try to fully understand you. That's not their job. They went into their specialty to fix problems quickly and move on, not manage chronic disease. The same goes for any doctor you see for a short time: they will try to get done with you as quickly as possible.
5. Don't avoid doctors – one of the most frustrating things for me is when a complicated patient comes in after a long absence with a huge list of problems they want me to address. I can't work that way, and I don't think many doctors can. Each visit should address only a few problems at a time, otherwise things get confused and more mistakes are made. It's OK to keep a list of your own problems so things don't get left out – I actually like getting those lists, as long as people don't expect me to handle all of the problems. It helps me to prioritize with them.
6. Don't put up with the jerks – unless you have no choice (in the ER, for example), you should keep looking until you find the right doctor(s) for you. Some docs are not cut out for chronic disease, while some of us like the long-term relationship. Don't feel you have to put up with docs who don't listen or minimize your problems. At the minimum, you should be able to find a doctor who doesn't totally suck.
7. Forgive us – Sometimes I forget about important things in my patients' lives. Sometimes I don't know you've had surgery or that your sister comes to see me as well. Sometimes I avoid people because I don't want to admit my limitations. Be patient with me – I usually know when I've messed up, and if you know me well I don't mind being reminded. Well, maybe I mind it a little.

You know better than anyone that we docs are just people – with all the stupidity, inconsistency, and fallibility that goes with that – who happen to doctor for a living. I hope this helps, and I really hope you get the help you need. It does suck that you have your problem; I just hope this perhaps decreases that suckishness a little bit.

Sincerely, Dr. Rob

continued overleaf

*Post Script: This post has generated a huge amount of conversation and interest (as witnessed by the large number of comments!). I very much appreciate the dialogue it has spawned both here and across the web. I've subsequently written follow-up posts explaining my thoughts in more detail – largely in response to the comments here. One of them discusses in more detail my own experiences as a doctor and the second talks of the importance of **knowing and being known**. Reading these will give you a better picture of my thought process and perspective on this.*

Dr. Rob [Doctor-Rob.org main website]

<http://more-distractable.org/2010/07/14/a-letter-to-patients-with-chronic-disease/>

Excerpt from **Knowing and Being Known** referred to in paragraph above.

If you build a relationship that is non-adversarial, it will make listening a lot easier. This definitely applies from the doctors perspective; docs need to listen to their patients, get to know them, and understand their perspective to be able to give good care. When I see a patient for the first time, I have to guess as to what certain things mean. The quality of the guess is dependent on my skill with listening and the patient's skill at explaining themselves. As time goes by, however, I can understand them much better through experience. It is key that I do this based on what I know about the patient. I have to have a relationship with them – a real relationship. I have to know them.

The same thing goes for patients. Going to the doctor is as much about building relationship as it is about receiving care. The jerky docs out there are not going to be willing to accept relationship, while the sensitive docs will listen and open up much better. But still, it is very important to figure out who it is that is sitting across the room. It is important to put down agendas as much as is possible (I do realize it's not always possible), and to build relationship. You need to know your doctor. July 23rd 2010

Editors Note:- I hope that this insight into the doctors perspective may help all of us. I went through seven years of appointments seeking help for my new pain, weakness, fatigue and functional decline. I then found PPS existed, 18 years ago, and at last my polio was in the equation but the hoped for help did not materialise as I had expected. It took two more years and a second hospital before my GP received a letter confirming my diagnosis, ten years and three appointments to get my swallowing issues confirmed and my 8 years of reporting respiratory and sleep position issues are still 'you have nothing to worry about yet see you next year'.

The following are a few of the statements made to our members. Have you had things like this said to you and if so how did it make you feel?

'Are you sure you had Polio?' 'You look fit and healthy to me'

'There is nothing wrong with you, all the tests are negative'

'Your pain down your left side is all in your mind'

'PPS - what is that? Or it does not exist, or I have just read something about this **new** condition [first medically recorded in 1875, 138 years ago]

Have you like me gone to appointments already expecting the health professional probably wont have much knowledge about polio and post polio? Am trying not to do this now.

How do you react when a medical fact about Polio or Post Polio Syndrome is made that you know or believe to be incorrect? In the early years I used to say and often got the 'its in a medical article you would not understand'. If I think the response is not going to be good and I don't have the energy at the time to deal with it I just leave it. E.g. Which leg did you get your polio in?

At PPS conferences medical professionals have said that we are pretty scary because we are so strong willed, determined and very likely to reply 'that we are not there yet, so don't need this or that equipment' that it is difficult to broach things that will help us. This is from health professionals that have knowledge and experience of polio and pps... what must it be like for

those that have not been taught anything or not enough facts by their Colleges of Medicine?

How would you feel if you were the health professional and a patient with far more knowledge and definitely considerable experience of a medical condition sat opposite you seeking help? I know I would feel uncomfortable. Health professionals don't just see us, they see a stream of people one after the other with their problems. I know it is not going to be easy [personal recent experience] but I think we need to think about this.

We developed My Polio Life to help you think about your condition and how it affects you and prepare for appointments. www.poliosurvivorsnetwork.org.uk/MyPolioLife%20110914.pdf
If you or a member of your family do not have access to the Internet to print off a copy then please write or phone for one.

We advise that you find out how long your appointment is for ahead of time, e.g. GP appointments are usually ten minutes. If a hospital appointment ask if they have scheduled any tests. Try writing a little scenario with you as the patient and doctor, what will you say, what do you expect them to say, how long do you think they will spend examining you or asking you more questions, and how long to tell you what the next step is? This will give you an idea of how many points you will have time to raise.

Ask who are you going to see, and if you have been before are you scheduled to see the same health professional or someone who works for him who you might not have seen before? What of your probably many issues are they likely to be able to help you with? Rate them in order of priority and start with the most important one. If you run out of time then ask if you can have another appointment.

Take someone with you who you agree ahead of time can remind you of anything you forget. Ask them to take notes. We have an appointment sheet that we use and update it for each appointment and offer a copy to the health professional. Some take it some don't. For hospital appointments, especially new ones we include:-

Date, time, place of appointment and who we are going to see.

Date of Birth, Age, Address, phone numbers, and email address.

Date and diagnosis at time of Polio. [non paralytic, paralytic, spinal, bulbar, spinal/bulbar]

Date of PPS diagnosis and name any other diagnoses we have been given.

Medical Prescriptions and then Vitamins etc that we take. [Timings of medications if they are important to another medical condition]

Allergies or Intolerances.

Ventilator name and current settings. If not a respiratory appointment then we add the name and contact details of our Respiratory Therapist.

Latest test results, if relevant, e.g. HbA1c, Cholesterol, Blood Pressure, etc.

MOST IMPORTANT BIT.

Why we are at the appointment, and the main symptoms or issues starting with the most important issue and/or the one that you can demonstrate most change.

[Remember the time limit of the appointment will dictate how many of these you can discuss, you may need to ask for a second appointment]

A couple of facts about English.

Only two English words in current use end in "-gry". They are "angry" and "hungry".

The word "bookkeeper" (along with its associate "bookkeeping") is the only unhyphenated English word with three consecutive double letters. Other such words, like "sweet-toothed", require a hyphen to be readily readable.

Tips and bits.

1. Member Jann Hartman recommends If you want a good book on nutrition and half of it is a cookbook. Power Nutrition for Your Chronic Illness: A Guide to Shopping, Cooking and Eating to Get the Nutrition Edge. Used paperback copies on www.amazon.co.uk are reasonable price, new its £64.55.

Nutrition is fast becoming a powerful tool in handling health issues of all kinds, and Kristine Napier is in the forefront of teaching people how to eat to achieve the maximum advantage. People with chronic illness have two nutrition needs. First they need to eat to get the edge on their illness, then they also must avoid the health problems common to everyone, such as heart disease and obesity. Moreover, people with a chronic illness are often energy -- and/or pain-challenged, making shopping for and cooking nutritious meals seem overwhelming. The genius of Power Nutrition for Your Chronic Illness is that it tells people how to shop and cook even when it's the most difficult, and provides 200 easy recipes that put nutrition theory into action.

2. Caramel filled apples. Cut apples in half and scoop out the core leaving a well to fill with caramel. Pour in some caramel and when set you can slice the apples.
3. How to clean a microwave with a lemon. Cut the lemon in half and squeeze the juice into 300ml of water. Microwave on full power for between 5 to 10 minutes, the lower the power of your microwave the longer you will need. The steam will loosen all the splashed bits. Take a soft cloth and wipe the inside easily. Smells fresh too.
4. Need to fill a dustbin or item that wont fit in the sink. Use a plastic dustpan with hole in the handle as a funnel.
5. Add a teaspoon of water when frying minced beef. It will help pull the grease away from the mince when cooking.
6. Store your opened chunks of cheese in aluminium foil. It will stay fresh much longer and not mould! (But you can scrape off any mould and still eat the cheese without changes in flavour,
7. Use a comb to hold a nail steady for hammering.
8. A post-it note folded in half will open slightly and when stuck to the wall just below where you want to drill will catch the dust.
9. Remember if you are buying any item between £100 and £30,000 cover yourself with extra insurance free by paying with your credit card. Even just paying the deposit so long as its over £100 covers you. The credit card company are then equally liable for any issues. For Debit cards read www.money.co.uk/article/1004510-is-debit-card-protection-the-same-as-for-credit-cards.htm
10. The higher the glycemic index of a food the higher your blood sugar peaks when you eat it....., then your blood sugar drops as deep as it went high and that's when your brain says.. "hey I would like to feel that high again so have some more". How many times do you say to yourself I will only eat one square of chocolate a day but after one piece you want another and another and then you say to yourself "Well I should not be eating chocolate if I want to lose weight so I might as well finish it all up" Try changing the high glycemic foods that you eat to low ones and see the difference. <http://www.mendosa.com/gilists.htm> Mendosa.com is a highly respected diabetes website in the States which I have used for over ten years now. This includes being in contact with Polio Survivor Derek Paice - featured in LincPIN - whose information started me researching further on controlling diabetes with diet after I was diagnosed two years ago. My diabetes is controlled by Low GL eating. Read Derek's article. www.mendosa.com/paice.htm
11. Want to keep informed of what is going on in the world on polio and post polio? Visit Chris Salters Post-Polio News [ppn] service, www.post-polio.org and subscribe to the daily email digest. Great reading. [See top of page 18]

Respiratory Muscle Weakness (RMW) with Bi-Pap and C-Pap use

Written and submitted to ALPS Newsletter by Linda Rowan, Arizona, USA.

Have you ever been told that you have **Respiratory Muscle Weakness** due to Polio? You can have this even if you didn't have a diagnosis of Bulbar Polio or were not in an iron lung. *This is what happened to me.* I use a Bi-Pap at night and have to sleep almost upright (O2 level drops if you lie flat). The Bi-Pap machine (Bi-level Positive Air Pressure) pushes room air into your lungs on the INhale [UK, IPAP] and then the pressure backs off (or lowers) on the EXhale [UK, EPAP] (Bi-level pressure) so we can get rid of CO2 by exhaling it, which is what people who are "normal" do naturally. Most polios who have Respiratory Muscle Weakness have trouble exhaling against the Continuous Positive Air Pressure (C-PAP) of a C-Pap. This happens because of atrophying (weakening) of the diaphragm and other respiratory muscles, (chest muscles and Intercostals which are between the ribs) due to Polio. A Bi-Pap lowers the pressure on the exhale so that we can rid our bodies of excess CO2.

If you have Respiratory Muscle Weakness and are given Oxygen without mechanical support (a Bi-Pap), the lungs "send a message" to the brain which signals the Respiratory Muscles: "we are getting enough oxygen, so you don't have to work so hard." Then if the respiratory muscles aren't working [* well enough] to push air in and out of the lungs, the CO2 can build up which is very dangerous, and can be life threatening. It would be helpful to read Dr. Oppenheimer's article on this subject, (Every Post Polio does not need a Bi-Pap instead of a C-Pap. For instance, if you have Sleep Apnea and Don't have Respiratory Muscle Weakness a C-Pap may work well for you) **

This is very complicated. Insurance companies have tried to put people with Polio Respiratory Muscle Weakness on C-Pap because I have been told they are much cheaper (by my Physiatrist). I tried to use one that my Respiratory Technician brought to me (just to see what it was like) and had a feeling like I was being smothered. I could not exhale against the continuous air pressure rushing in. We had to submit a lot of documentation to Medicare for them to approve a Bi-Pap for me: A Sleep Study (interpreted by a qualified Sleep Technician and/or your Physiatrist [UK, Physical Medicine and Rehabilitation] or Pulmonologist) A PFT (Pulmonary Function test), the FVC (Forced Vital Capacity) of your lungs, (mine was 31%) were required. And an ABG (Arterial Blood Gas, done in Respiratory at the hospital by a Respiratory Technician) to test if you are retaining CO2 was done, and a prior diagnosis of Post Polio Syndrome. If you have Respiratory Muscle Weakness and are not on Bi-Pap (yet), you may experience some or several of the following symptoms. Talk to your Pulmonologist or Physiatrist ASAP.

- morning headache
- confusion, or other cognitive deficiencies
- excessive daytime fatigue and sleepiness
- shortness of breath, and inability to have a productive cough
- problems speaking without taking breaths between words
- unexplained muscle pain in the chest and trunk muscles
- trouble sleeping lying flat

Some of these symptoms may also be caused by other problems, such as heart trouble, (shortness of breath).

The purpose of this article is primarily to explain what Respiratory Muscle Weakness is, and the difference between a Bi-Pap and a C-Pap. I hope that after reading this you have a better understanding of RMW.

[Editors Note:- Members are also reporting being started on a CPAP in the UK, definitely cheaper but also possibly because the staff are not aware of Polio Survivors with RMW needs. One member reporting now - feeling much better on bi-level. * added the words well enough for added clarification. ** See LincPIN, Volume V, Issue 9, June 2006. 28 pages full of Respiratory Info.]

EUROPEAN POLIO UNION MEETING & ANNUAL GENERAL MEETING

in Tullamore, County Offaly - IRELAND 18th – 21st October 2013

John R. McFarlane, President European Polio Union - jmcfarlane1@iolfree.ie

Tullamore (Irish: Tulach Mhór, meaning "great mound") is a town in County Offaly, in the midlands of Ireland. It is Offaly's county town and the centre of the county.

18th October 2013 - Latest arrival date in Dublin, EPU will arrange transport for delegates from a designated point (probably the airport, but yet to be confirmed) to Tullamore and your hotel. Ordinary delegates will have a free evening.

19th October 2013

08:00 – 10:00 hours	Breakfast
10:30 hours – 13:00 hours	European Polio Union Annual General Meeting
13:00 hours – 14:30 hours	Lunch
14:30 hours – 17:00 hours	European Polio Union Annual General Meeting (continued)
17:00 hours	Close of European Polio Union Annual General Meeting
19:30 hours	EPU Annual General Meeting Dinner – to be confirmed

20th October 2013

10:00 hours – 13:00 hours	Presentations from EPU Member Organisation – to be confirmed
13:00 hours – 14:30 hours	Lunch
15:30 hours – until late	Join in the Irish Post Polio Support Group 20th Anniversary Celebrations with music & fun

21st October 2013

Departure from Tullamore by EPU provided suitable transport to Dublin & airport.

[Editors Note: For Transport arrangements contact with John McFarlane was requested if at all possible by the end of June so they could co-ordinate transport with flights. If you did not do that and still want to attend then contact John to see if they can fit you in. Richard and I will be going by car and taking the Ferry. If anyone is thinking of going then please let us know.]



MAY 2014

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
25	26	27	28	29	30	31 PHI's

JUNE 2014

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
1 Promoting Healthy Ideas	2	3	4	5	6	7

**11th International PPS Conference
Promoting Healthy Ideas
St. Louis, Missouri, USA.**

www.post-polio.org/net/confs.html

PPS Conference

“Post-Polio Syndrome: A Condition Without Boundaries”

25th to 27th June 2014 in Amsterdam.

Initiated by:-

**European Polio Union,
Academic Medical Centre of Amsterdam in co-operation with the
Danish Society of Polio and Accident victims (PTU) Copenhagen
And Karolinska Institute, Stockholm.
www.poliocconference.com**

Following the successful conference in Copenhagen, the 2nd European Polio Conference will be held in Amsterdam from 25-27 June 2014.

The Conference aims to promote better care for the large number of 700.000 Europeans suffering from late effects of polio by exchanging knowledge between health care professionals, researchers, polio survivors and patient organisation representatives from Europe and world wide.

Although the majority of people in Europe affected by polio during the large epidemics of the previous century, is nowadays aging, there is also a considerable number of younger European immigrants with polio residuals who contracted polio more recently in their country of birth. World wide there are large numbers of young polio survivors who are facing a life ahead with polio residuals.

For the many aging polio survivors who suffer from declining muscle function and experience increasing disabilities due to post-polio syndrome, the challenge is to retain muscle function and to treat and prevent overuse damage of the locomotory system, with the aim to preserve independency and quality of life. The challenge for the younger polio survivors inside and outside Europe lays in the prevention of late deterioration. The conference theme refers to the aim to exchange knowledge about the treatment of polio residuals in different age groups across the world to best preserve functioning throughout life.

Main Conference Topics

- Polio Eradication Progress
- Pathophysiology of Post-Polio Syndrome, New Avenues for Treatment?
- Best Practices for Post-Polio Syndrome
- Innovations in Orthotic Devices
- Treatment of Young Polio Survivors Inside and Outside Europe
- Nutrition
- Coping & Exchange of Experiences
- Societal and Caregiver Issues

Call for Abstracts and Registration is October 1st 2013

[including online hotel reservation]

Besides thematic sessions for professionals and for polio survivors, there will be free paper and poster sessions.

Conference secretariat, Jeanine Mulders

P.O. Box 23213, 1100 DS Amsterdam, The Netherlands

Phone: +31 20 566 8585, Fax: +31 20 696 3228, Email: poliocconference@amc.nl

All You Need Is A Web Browser To Read POST POLIO NEWS [ppn]

Twitter and Newspaper can all be browsed
without requiring extra tools or subscriptions.

Go to www.post-polio.org.uk/ and check out the "Tips"

An online news cutting service from Chris Salter that specialises in news relating to polio and post polio issues - Subscribe to the Daily Digest.

7th June 2013

First ever National Clinical Director for Neurological Conditions announced



We are delighted to announce that Dr David Bateman has been appointed by NHS England as the first National Clinical Director (NCD) for Neurological Conditions.

Dr Bateman is currently consultant neurologist in Sunderland at City hospitals, having previously held posts in North Cumbria and Bath. He has had a career long interest in improving care of neurological conditions. He chaired the working party that produced the 2011 Royal College of Physicians and Association of British Neurologists report on local adult neurology services, which was endorsed by the Neurological Alliance.

A NCD for neurology to champion the needs of people with neurological conditions at national level and coordinate service improvements has been a long term aspiration of the Alliance. As such, it was the primary policy call of our 'Better Deal for Neurology' campaign, which we launched in January 2012 following a seminal report on neurological services by the National Audit Office. The Public Accounts Committee went on to make a neurology NCD a key recommendation of in its own report on neurological services last spring and NHS England's decision to act on this represents a major step forward for the entire neurological community.

Dr Bateman will provide vital leadership for neurology at a time of major reform in the health service and play a critical role in supporting the NHS to enhance the outcomes it delivers for people living with a neurological condition.

Dr Bateman is keen to work with neurological organisations and the Alliance use the present opportunities to improve neurology services to greatest effect.

Arlene Wilkie, Chief Executive of the Neurological Alliance, said:

'I am delighted that Dr Bateman has been appointed. He will be a great champion within NHS England for all neurological conditions. I look forward to working with him and making improvements to neurological services within England for the 10 million people in England with a neurological condition.'

Your Newsletter needs your stories, hints, tips and bits to make us laugh..

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 15th 2013.

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

Chair - Simon Parritt, simon.parritt@poliosurvivorsnetwork.org.uk
Secretary & Newsletter Editor - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk
Treasurer - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk
Trustee - Chris Salter - chris.salter@post-polio.org.uk
Trustee - Dot Ives - dot.ives@poliosurvivorsnetwork.org.uk

Operations Team

Membership Secretary - Gillian Bryan - membership@poliosurvivorsnetwork.org.uk
Phone and Email Enquiries - Hilary Boone - info@poliosurvivorsnetwork.org.uk -
Administrative Support - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk
Printing and Website - Elpeeko 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 to keep costs down.
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.
 - UK Taxpayers can Gift Aid their subscription and donated amounts.

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. [See page 15 and enclosed new Gift Aid form]

If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%).

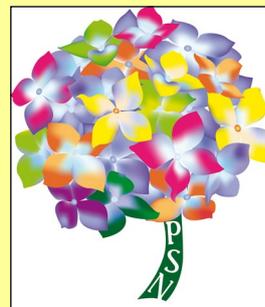
Polio Survivors Network

Registered Charity No. 1064177

Website - www.poliosurvivorsnetwork.org.uk

Email - info@poliosurvivorsnetwork.org.uk

P.O. Box 954, Lincoln, LN5 5ER, U.K.



☎ 01522 888601

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

NEW to the concept of PPS?

The best analogy I have ever heard to describe Post Polio.
A description without the medical jargon.

Imagine that your body is a house. Inside the walls of the house you have electrical wiring. That electrical wiring in the house is like the nervous system in a body.

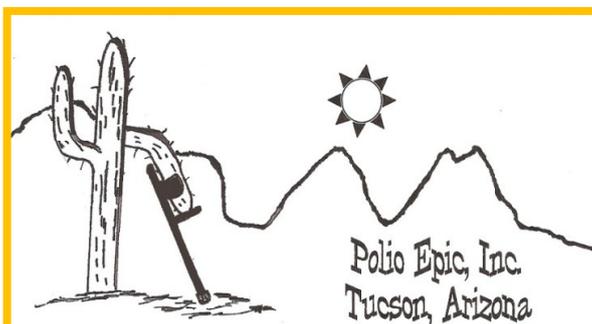
The polio virus damages some of the nerves that provide motor control, so when you repair (or recover) from the polio virus, your body has actually spliced into the wiring to run new wires to make the muscles work. Those "new" wires are smaller and work harder like running a normal 220v through a 110 voltage line!

So, you never know when/where/how the wire is going to short circuit! When it blows, you have a power outage and the outlets where the blown line was located don't work anymore!

What our marvellous bodies do, is try very hard to run extension cords to cover the loss and they just aren't powerful enough to do everything the main lines do. The more you push electricity through those extension cords, the more dangerous it is!

Micki Minner, Polio Epic, Inc, Tucson, Arizona.

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