

# POST POLIO MATTERS

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**JUNE 2018**  
**Issue 102**  
**Vol 9 Issue 6/12**

**European Polio Union**  
**Annual General Meeting**  
**June 16th 2018**  
**in Rensburg, Germany**

**Polio Survivors Network receive legacy of £ 54,708.57**  
See page 4



**STOP PRESS**  
**Two Photos from member and Polio Survivor, Klaus Kunert**

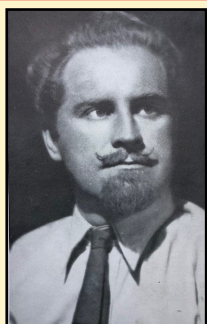
**Stefan Grajcar, Slovakia**  
**Daniel Pelzer, Belgium**  
**President**  
**Gurli Nielson, Denmark**  
**David Mitchell, UK**  
**Margret Embry, France,**  
**Paul Neuhaus, Germany,**  
**Erika Gehring, Switzerland**

**31 Groups**  
**from**  
**20 Countries**



**PoPSyCLE**  
POST POLIO SYNDROME CENTRE FOR LEARNING EXCELLENCE

**President John R McFarlane - Pages 10 to 12**



**Page 5**

**“MY CANDLE AT BOTH ENDS”**  
BY  
**JOHN CARVETH WELLS**

Page 133... I developed a low fever and was often slightly light-headed; I continued my work, but towards the end of August I used to walk around like a drunken man. Then my temperature suddenly shot up, and I went to bed; a local GP told me that I had a return of my old malaria, and ascribed a painful stiff neck to muscular rheumatism.

My GP was a busy man, I had a past history of malaria, and there was no reason to suspect infantile paralysis! As a result, through one of those quite unavoidable oversights, the germs entrenched themselves

Then, on a Thursday night, the disease swept down on me with a rush; by the Sunday everything had stopped save my heart and bowels, and, strapped into a breathing apparatus rather like an iron lung, I was gasping for breath and fighting for my life.

I have never walked since. © Jarrolds 1944.



Enter 100+ articles

## THE TEN COMMANDMENTS OF PPS

**Dr. Richard L. Bruno, HD., PhD.**  
**Director, International Centre For Polio Education**

Read on pages 14 to 15

INTERNATIONAL CENTRE



POLIO EDUCATION

**Polio Survivors Network is the working name of**  
**Registered Charity 1064177, The Lincolnshire Post-Polio Network**

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Page 19	Contact Information.
Page 20	Back Page. Jokes from Crippen, the Disabled Cartoonist. Donation sent.

## STOP PRESS

### THOUSANDS OF THANKS FOR DONATIONS RECEIVED

**Legacy from member Ms A Brown received of £ 54,708.57**

**Donations from other members added another £1,182.00**

**I apologise for not adding individual names due to unexpected increased personal paperwork but I needed to get this to the Printers.  
I will ensure that all names for 2018 are included in the next issue.**

## WATCH THIS SPACE

**MEMBERSHIP IS NOW FREE - See Page 4**

**WEBSITE IN THE PROCESS OF BEING UPDATED**

**TRUSTEES ASK - Can you spare us a few hours a month to help with our projects?**

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

Firstly, some great news about our funds that you can read about in Simon's Chairs piece overleaf.

Secondly since May 25th 2018 we have the dreaded GDPR [General Data Protection Registration] to deal with and guess what? A few of our members have NOT returned their forms. We know we can think 'oh I must do x' and later think about it again and assume you have done it but sadly sometimes we only thought about it again. Read Dot's piece on page 13.

Thirdly, we have a new regular contributor to the Newsletter Verite Reily Collins, a Polio survivor, cancer survivor and health journalist with a wicked sense of humour. Many of the issues she raises on her blog are experienced across many other conditions so we hope you will enjoy reading her contribution. She would love to hear from members. Page 6 to 8.

Fourthly now we have more funds to improve on the information we provide we need a few more folks to join our committee. We meet once a month online and by email in between to ensure we keep things running well and legally. If you have a few hours a month that you could spare us then please drop Dot, [our Secretary] a line and discuss how you might help PSN.

Read about John R McFarlane and his life and how it has progressed through to now being President of PoPSyCLE on pages 10 to 12.

I had a lovely letter from Linda Hartnell [North west England] asking if we had information about John Carveth Wells, a member of the Royal Geographic Society and author of 'My Candle at Both Ends' On page 5 Linda tells us about how her mother knew him. I have only had time to read a few of the chapters and it is a fascinating read. First book I am reading as a book and not in my iPad for a few years.

Pages 14 and 15 Thankyou to Carol Ferg [Pennsylvania] Pa.Polio Survivors Network [www.papolionetwork.org/contact-info-and-donation-information.html](http://www.papolionetwork.org/contact-info-and-donation-information.html) Links to many resources. From their latest newsletter we reprint Dr. Richard Bruno's updated Ten Commandments for PPS

How else could you help us? Ask us questions and you can be sure you will not be the only one who has asked that question. Now we are all getting that bit older, and everything seems to take so much longer to do, any hints or tips that have worked for you would be great to share. Headings below taken from subjects that come up across the many contacts PSN has:-

- Therapy for any of your symptoms that has helped you,
- Issues with personal care including incontinence and slow moving guts, etc.
- Easy nutritional less fattening meals and kitchen equipment that makes your life easier,
- Mobility vehicles, and how you travel by bus, train or taxi, oh and boat on a cruise maybe.
- How about the equipment you use now that a few years back you would have said 'Oh I don't need one of them', but now accept its benefits,
- Completing those dreaded benefit and social service assessment etc., forms.
- Family relationships that are just not there as you would hope.... Many report, including me, that no matter what you try you still don't have a relationship with your 'xx' Does anyone have any ideas how we might get on again or should we just leave it?
- Employing Personal Assistants, the joys and the pitfalls.
- The future and how and where you think you might or do now live.

**Stop Press from Front Page**, The European Polio Union Annual General Meeting was held in Rensburg, Germany on Saturday 16th June 2018. I had hoped to attend but then found the Ferry from Harwich to Hamburg was no longer operational. Choices were travel on the Ferry from Hull to Rotterdam and then have Richards Personal Assistant drive us but too much for us in one day even just sitting as passengers or travel by air and be without our wheels when we got there restricting getting out and about. Those 10 energy tokens a day don't go as far these days.

Klaus and I met on the SJU Polio Email list 20 years ago. He has visited us in the UK but now we keep in touch by Skype. It would have been lovely to have met up with him and his wife Renate. Margret and Erika are both PSN members and we will have more information from them all in the September issue.

## MESSAGE FROM OUR CHAIR

### Summer is here

The summer is upon us and hopefully a bit more sun gives us some respite from the added burden many of us have with cold and the restrictions of just moving around in our often cold and damp conditions.

Along with summer comes the good news that we have received a substantial legacy from long time member Ms A Brown. This came in two parts to a total of £54,708.57. PSN are now able to do more in terms of making sure we can offer you the most up to date information and getting across to health professionals the particular and unique aspects of their patients who may have had polio in the past. Watch this space to see what we will be doing as the year progresses.

In addition to this following on from the legacy members at the last AGM accepted the proposal that we move to free membership from now onwards. Of course, those who wish to remain contributing as a donation to our work will be more than welcome to do so as a donation.

It is timely and fortunate as this legacy comes as the impacts of the new data protection laws come into force. This has had the effect of us having to confirm and ensure all our members know what we information we hold and what we do with it. Of course, we are a small charity and basically only use your details to send you the newsletter and information about our work. However, if you don't respond we can no longer keep in touch with you or list you as members. It has meant however that we are now slowly building a more accurate picture of those of you out there and hopefully can get feedback as to what you want and need from us. So if you haven't responded please do so or we will lose you forever, and we don't want that!

Finally, I am aware that none of us are getting younger and the pressures on social care and the NHS are getting greater. It is therefore even more important to arm yourself with knowledge and become your own, or your partners, advocates and experts on polio and PPS to help yourself, and avoid medicals professionals blundering around in the dark.

In the last few months we have heard from some of our members that they are having issues with Direct Payments, DLA to PIP applications, medical appointments where it appears that Polio and Post Polio Syndrome [Post-Poliomyelitic Syndrome, see page 10] are not fully understood, orthotics, and issues with slow moving bowels have appeared eventually three times this month. If we can't answer your question we can usually suggest other organisations that might have answers.

We, at PSN are here to do all we can to help you achieve that effective expert patient status. Please keep sharing your issues and good results so that it adds more to our information database.

Do you have a spare few hours a month to help or know anyone who would like to help us achieve our aims? If you do then email Dot Ives [contact information on page 19] or ring our charity line.

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

Chartered Psychologist. HCPC Registered Counselling Psychologist, [www.sp-psychology.com](http://www.sp-psychology.com)  
Chair Polio Survivors Network. Simon Parritt <[simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)>

It was lovely watching **Britain's Got Talent** to see more **Comedians with a Disability**.



The first place went to Lost Voice Guy, Lee Ridley, who has cerebral palsy and communicates using a text to speech app on an iPad. He wore T shirts with slogans on, "I was disabled before it was popular" and "I'm a friend with benefits" and "I'm only in it for the Parking"

The second place to Robert White, 41, who has Asperger's Syndrome. "In answer to all the people who want to know where I get my tank tops ..... some I get from the rail by my window and some I get from the draw under the mirror. Hope this helps :-)" @robertwhitejoke

About 35 years ago I watched a Jasper Carrot half hour full of disability jokes. Media reports the next day said how awful but the day after had to report disabled people loved the program. Laugh with us.

## John Carveth Wells. July 1911 - May 1946

**Linda Hartnell** wrote to us asking if we had any information about John Carveth Wells. I googled him and found his book on Amazon and bought a second hand copy which is full of his fascinating travels, definitely worth a read. Front page excerpt from when he caught polio in August 1935.

Linda writes... 'The name John Carveth Wells is not so familiar now, but John had a connection with the early days of the Polio Society in the early years of the Second World War. He had also been a famous person in his own right at the very youthful age of 21 years, as he had been elected as a member of the Royal Geographic Society for his adventures travelling around the world.

The Royal Geographic Society Library collection holds his travel accounts and a copy of his autobiographical work 'My Candle at Both Ends' published by Jarrolds in 1944. This is an appropriate title as Johns adventures read like something from Boys Own newspaper, colourful, daring, and not without a few brushes with authority or with some very mysterious characters, and all at a tremendous pace.

Unfortunately John burned some of his own energy away after his travels, trying to run several small newsheets concerning the film industry, and generally involved with different projects and publications. Symptoms thought that were maybe a flare up of malaria from his travels proved to be polio, and by his thirties John was wheelchair bound.

My mother met John during the Second World War and she offered to assist him at the wars' end, in a general secretarial role. My mothers eldest brother had been disabled by polio as a baby and had undergone many hospitalisations and operations to be able to stand up and to walk.

John was also helped by his cousin Lita who enabled John to live more independently following his early acute stages of polio. Initially he had been so ill that he was placed in the very institutional setting of an old work house hospital, and he dreaded this existence.

His few remaining finances were stolen from him when he was ill by one of his business partners. It is uncertain that John knew Lita before she is mentioned in the book. Her husband was serving in the Forces but she came very warmly to Johns aid and John was able therefore to have an almost 'independent' existence again. However, this was not before a prolonged period where he struggled to maintain some financial means of existence, selling matches from his wheelchair, then flowers, then handmade jewellery, then small volumes of his popular style poems.

My mothers time with John was only quite short - just under a year. The chronic effects from the polio had caused kidney problems and John suffered severe bouts of pain which would eventually contribute to renal failure. My mother remembers going out in a dark and foggy London night to try and locate his doctor.

John was placed at the Free French Hospital in London for his final days. He spoke French and this assisted in assuring his place. The setting was calm and peaceful - the nursing sisters were nuns and were very kind. My mother remembered the peaceful chapel and the atmosphere of calm.

Nevertheless the loss of John in May 1945 devastated her life and she was very grieved by his death. She was only in her early 20's herself and the trauma of the wartime years had only just reached some kind of ending. The world was still in a very shattered state. The devastation everywhere was terrible. John's legacy is a bright spirit, his dreams and determination, the little house in London was always busy with the coming and going of people, often people connected to theatre or the film world or from his travels or given some lecture tours.

In my mothers copy of his autobiography she has placed the telegram she sent to her parents on the morning of Johns death in London. She has also written a poem at the end of the book concerning the peaceful chapel at the Free French Hospital.

I am glad John received care and kindness in his final days and that he had a peaceful place in the hospital. He had experienced some very bleak times and circumstances and it is of comfort to know that in his final hours he was loved and cared for.

For this was still an untimely end, for a young man who still had so much to give - and so much yet still to become. He would be glad to inspire others and give comfort and courage.

**Editors note:-** His book Published in 1944 ends with the words..

**Dear Reader, let me give you a tip, for the next fifty years, keep your eyes and ears open. You'll be hearing from me! The End.** [That was 74 years ago before I was born.] © Jarrolds 1944.

## VERITÉ REILY COLLINS OUR NEW REGULAR CONTRIBUTOR

### HAVING FUN AFTER CANCER! [Aftercancers.com](http://Aftercancers.com)

**My CV** - I am a Polio survivor who was told I would never walk again, but caused so much trouble at the Royal National Orthopaedic Hospital that they all worked hard to get me out the door. I was in tourism for years, then became a writer. When I got cancer I was so shocked at the difference between the 50s when polio patients had superb care under a Matron, and today's NHS where everything is targets, performance, budgets etc. that I started a blog [aftercancers.com](http://aftercancers.com), where I try to tell readers how to 'work the system', whatever condition you have. Otherwise, I have to behave myself as I have just moved from London to live in a manicured Oxfordshire village featuring in Midsomer Murders.

**"Here we go again"** I thought, as the doctor confirmed I had cancer. As a teenager, I'd spent a year as an NHS patient with polio. This had been an 'experience', but once I'd got wheelchair racing organised, and a midnight feast rota sorted, life on the ward was easy. Patients were king, there was a very competent sister who spent her time on the ward, not hidden in her office dealing with emails, and sufficient nurses to really care for us. I foolishly thought treating cancer would be the same; concerned, helpful staff with treatment centred on me, ensuring I had superb care.

**How wrong could I be!** First, today there is a MDT (multiple disciplinary team) approach. Instead of gathering round your bed during the weekly ward round, when you could hear what was planned, today 'they' discuss your case without you and sometimes notes get mixed up. The 'one-step-fits-all' system does not take into account our needs as polio survivors; one day it might occur to the NHS to ask what are **our** needs.

Having survived a year in hospital with polio, I had learnt a trick or two. I hope no reader gets cancer, but as we get older we can all suffer other conditions with similar problems. Experience will have taught us to suss out staff who are experts, and know those who haven't a clue. So I set up a website ([aftercancers.com](http://aftercancers.com)) to tell others what I learnt, with tricks I discovered when dealing with today's NHS.

Faced with the bumptious doctor/nurse who lectured "why didn't you have the polio vaccination?" I now burst into tears; this tends to make them up their game. I did answer one "because Salk hadn't invented his vaccine", and he hadn't a clue who Salk was. Ignorant idiot. Juniors don't like dealing with unexplained emotional outbursts, and with any luck will pass you up the chain to a senior colleague, who should be more knowledgeable. Yes, I know we all have to help doctors learn, but I did my helping - now I think it's payback time and I want to ensure I live longer.

Some treatments today seem more about egos (of medical staff) than patient care, so I began to sort out what I needed, and made sure I got it. I'd worked as an investigative journalist for Sunday Times, Telegraph etc. and three days after starting on the drug Tamoxifen, I needed to use these skills. Skin lesions burst out all over my body. and the pompous consultant tried to tell me "it's your age". Stupid man. I had been Beauty Editor of an American Magazine, and when I questioned his diagnosis he swept out of the room, looking a fool in front of his giggling trainees. I asked around and found a French centre, **La Roche Posay**, had developed special creams just to help patients with these problems, and treating over 10,000 a year, many presenting with horrid itchy, scratchy skin that comes from many of today's drugs. As the NHS is still prescribing unsuitable creams, I sell the French ones on my website, as well as some clinically-trialled in New Zealand, Japan, Spain and other forward-thinking countries. And, if I get any profit from sales it will go back to helping where it's needed, be it an adapted wheelchair or whatever.

I like to think my website can give NON-medical help in 'handling' today's NHS, and one of most popular articles is Karol Sikora's advice about getting an earlier appointment - oh! and some naughty explanations of NHS jargon!

[aftercancers.com](http://aftercancers.com)

## LETTER TO THE MINISTER

Dear Jeremy

Let's make it clear - normally I would address you formally as befits a Minister, but heigh-ho - your NHS seems to like informality when we become patients (even though it makes me cringe), so "when in Rome ....."

I have lots of bones to pick with you, but have decided to call a truce as I don't believe it's fair to hit someone when they are down, and you have been looking very peaky recently. Hugh Fearnley-Whittingstall pursuing you with one of those fluffy things on the end of a pole obviously terrified you, so don't want to add to your misery. You stop bugging me, and I 'll leave you alone.

Although you have been Minister for some time, you are still going around with a surprised expression, so this aide memoire might help you to understand what the officials obviously left out when briefing you::

### **Rule 1. Patients generally know what's best for them.**

Most of us hate taking pills, but realising some are helpful, we are careful not to upset the apple-cart. Please stop GPs that interfere by following your instructions to save money e.g. one tried to swop Clopidogrel for Aspirin (cheaper), so I told the eminent Consultant who first prescribed Clopidogrel that my GP wanted to swop; he got rather shirty and a broadside was despatched to the surgery. Afterwards I didn't hear a peep out of the shell-shocked GP, but he didn't interfere again.

### **Rule 2 , Junior Doctors don't deserve to take the can when your bright (or not-so-bright) ideas go wrong.**

A & E had been told no more pillows to save money. I gave the doctor attending me a succinct break-down on how much **InjuryLawyers4U** would be suing for on my behalf, as I had Kyphoscoliosis. He had to go up to a ward and returned with an armful of pillows to support my head, and saved you money because I don't take kindly to medical consequences when my head isn't supported.

### **Rule 3, Know what's going on - or don't open your mouth and put proverbial foot inside.**

I know you mean well when you stand up in Parliament and promise there is no post-code lottery, but having just moved from London I find there is one thriving in Oxfordshire. With a dozen or so co-morbidities (ugh - what a word) I need to make sure things work for me. (I know it would be easier for the NHS if I just kicked the bucket but I rather enjoy living). I don't enjoy having to work out what rules and regs. to bring in to play to ensure I get the correct care, so if only you would give up and realise I do know more about treatment than you (not hard, I must admit) I wouldn't have to waste the time of those few secretaries left (was it your clever idea to make so many redundant?). It takes up their time having to write letters couched in beautiful language but basically telling the recipient to stop mucking about as I need X and Y treatment. .

### **Rule 4. You must protect your future.**

I know you must be thinking of retiring in a similar platinum-plated fashion to your predecessor, but do realise that although you obviously are scared of the great British public, always ensuring there are lots of Dept. Health staff surrounding you so you don't have to talk to us, we are rather important - not least because our taxes pay your salary. So it might be an idea to start being nicer to us before the next election - or aren't you planning to stay on as an MP? I think we should be told.

### **Rule 5. Advice from expensive American management consultants might not always work when transferred to UK**

I have served on several NHS working groups; I know they are going to make policy decisions because we are paid to attend. Those run by McKinsey are excellent - hence you never seem to take their advice, but some are rubbish. We spent a year discussing care for the elderly under

the guidance of an American firm who ran text-book meetings on "how NOT to conduct a meeting", and upshot was that when rolled out for a pilot the sensible (English) lass in charge, changed everything to what we had suggested should be done, and it now works like a dream. So get rid of those expensive consultants and forego the 'all-expenses paid' trips to the States, Virgin Isles, etc. Sorry if your staff will miss out on their tan.

And finally - I could start up a chemists shop with the boxes of pain-killers I am handed after every visit to A & E. It's no use telling staff I don't need them, they don't listen. I am storing the boxes so if ever I decide I've had enough they will be a cheaper alternative to Dignitas.

Verite Reily Collins - [verite@greenbee.net](mailto:verite@greenbee.net)

I would love to hear from members. If you would like to talk on the phone then contact Hilary and she will get in touch with me.

## The Continuing Sagas of \*Deluged Dot

I was perusing last year's saga entry for February 2017. I was then Decamping Dot as we were busily sorting and packing for our imminent departure to the 'middle' of the country. We have been here in South Staffs albeit with a Walsall postcode for almost a year and whilst I do miss 'living on the edge'; I do not miss those biting North East winds battering our front door across the North Sea straight from the North Pole!



Although in fairness to my erstwhile geographical location we do appear to have moved to a more soggy, damp, grey and dreek area of the country that is also prone to more snow and ice than I am used to. I have never known it to rain so much and I am originally from Lancashire memorable for it's dark satanic mills, cotton and bucket-loads of the damp stuff!

Readers who are familiar with my meanderings (or have a good memory) may be surprised to learn that I am in rude health (for me) and have not had any serious injuries or breakages for over a year now. (Apart from a couple of mugs that missed the kitchen cupboard shelf I chucked them on.....oh, and a few scrapes and bumps on the car..... How boring is that?)

Being where I live now also means that I am nearer to my 'big' sister who we visited in Shropshire fairly recently. We had a curious conversation as she has no recollection of me ever having had poliomyelitis when I was a baby and still denies that I did. When I asked her how was it that I was hospitalised, didn't walk until I was over two years old and had one leg shorter than the other' she said that she hadn't really thought about it! Also..... my limping, frequent falls and weekly trips to the community clinic for therapy and physio was because I was a prem baby! (To be fair, she was a new bride with a baby on the way when this all happened). Now I know that my polio was not severe and 'not obvious' as I was a baby who was hospitalised with suspected meningitis and sent home as this was not the case. The retrospective diagnosis of mild poliomyelitis only forthcoming a few years later. My 'bad leg' and right tendon was operated on when I was 8 years old – by this time, even the family goldfish knew what caused it! Families eh!

On another but related note, the striking thing about moving house has been moving GP practices as well. My GP or should I say GPs have not been on my roller coaster medical journey and it is not easy starting again. Which of my ailments from my list do I take for my 10 minute consultation with an unknown doctor who has not read my medical notes on the screen? Will they think I am time wasting? A hypochondriac? A wimp who cannot manage pain? A junkie hooked on prescription drugs? Whilst the latter is probably true how enthusiastic should I look when asked if I have considered swimming.... or attending the pain clinic to manage pain better ..... or what I have sounds like fibromyalgia.... (they haven't heard of PPS of course nor read the newsletter that I left previously for them). Maybe I do have fibromyalgia to add to my list but WE know "Fibromyalgia is often seen in a Post Polio Clinic", article by Dr. Daria Trojan in our Lincolnshire Post-Polio Library <http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/trojan/fibromyalgia.html>. To be fair the Practice has recently amalgamated with the one in the same building and now has over 25 GPs and over 25,000 patients. Wonder if I can re-



register with my previous Practice.. it is only a 322 mile round trip... It all adds to a feeling of being 'mis-placed' or out of sync.... Maybe I am deluged in more ways than one or maybe they can't understand my northern accent and flat vowels!

Having read Verité's issues with moving from London to Oxford, and knowing how few services there are in Lincolnshire where Hilary lives, it really does seem to be a Post Code lottery as to what services you get. I wonder which is the best place to live?

Dot Ives, [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)

### **Hilary adds....**

Today I got a call from a Polio Survivor near Hull who is having similar issues and very little support as to what to do to help manage life more easily. We had a long chat on the phone and the comment was that it is good to talk to someone who understands where I am coming from.

We are all different. We had different levels of damage from polio at different ages, different treatments and equipment, different lifestyles and employments and physical abilities, all sorts of other medical conditions, where you live, etc. There is no set pattern and there are no diagnostic tests which does not make health professionals lives easy.

Maybe folks wonder what we say to new contacts? We can only speak from our own personal knowledge and experience because we are not medical professionals. We can suggest medical articles to read or pass on to your medical professionals. We can tell you about the problems we or other polio survivors have had and different things that have helped. We explain energy tokens. We have 10 per day and 70 per week and changing it into money £ or \$ helps. Sadly there is no list we have to write down an average day for ourselves and spread the £10 out. Then there are days when we need £15 to add in going for medical appointment or social event, etc. If you need to spend more on one day then remember there are less tokens for the day before and after. If you Pace and Rest activities you can do more overall. Using aids and assistive devices saves energy tokens for something more enjoyable. The best two articles we have found that are accepted by the NHS listed every newsletter on page 18.

Think about all the knowledge you have on polio, pps and how you have managed all your life. Think about all the problems you now have and the questions you want to ask.

### **Now put yourself behind the desk of the next health professional you are going to see.**

You look up to meet your next patient and there is a Polio Survivor coming through your door and your College of Medicine has taught you little about Polio and how it can affect the body, and little or nothing about Post Polio. You think 'oh, they will know more about all their issues because they are living it' .....

### **How would you feel meeting you?**

We believe being put in this position might explain why some health professionals quickly say things like 'PPS does not exist', and 'PPS does not exist and if it did you do not have it', and 'the pain in your right leg is due to your age... you reply "but my left leg has no pain and it is the same age....' yet another 'Oh, I just heard about this new medical condition'. Problem is that it was first medically recorded in 1875. That is 143 years ago!

### **From one of my slides.**

**4 case histories were reported in the French literature by Carriere, Raymond, & Cornil and Lepine. These patients, all young men, had paralytic polio in infancy and developed new weakness, not only in previously affected muscles but also in muscles believed to be uninvolved. All had physically demanding jobs and performed repetitive activities.**

**Post-Polio Syndrome : Pathophysiology and Clinical Management, Anne Carrington Gawne and Lauro S. Halstead. Critical Reviews in Physical and Rehabilitation Medicine, 7(2): 147-188 (1995) Full text in Online Lincolnshire Post-Polio Library <http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/gawne/ppspandcm.html>**



**John R McFarlane**  
**President**



The first thing I hear you ask is what is PoPSyCLE – and it's not an ice lollipop or popsicle as our friends across the Atlantic call them. Rather its a new charitable foundation and the name stands for **Post-polio Syndrome Centre for Learning Excellence**. But first let me introduce myself and it will help you understand why I have decided to go ahead with this that is intended to improve the care, management and treatment of the 25 million or more polio Survivors around the world – well eventually as a starter the target is Europe where there are about 1 million.

My name is John McFarlane, who arrived in this world in 1948 and within 18 months contracted chronic paralytic polio. This left me in a hospital outside London for the next 3 years. When I was discharged I had and have total paralysis of both legs, lower torso and partially the right arm. And that's how I started my adventure through life that brought me to the conclusion that although polio is nearly, hopefully nearly, eradicated something has to be done for the forgotten millions of polio Survivors whose life the virus has blighted.

Out of hospital, vaccinated against about every disease known to man, and onto a ship bound for the Far East. My father who had been born in China was working in Hong Kong at the time, so my mother, brought up in India, and I were off to join him and become a family once again. Straight out of virtual isolation in a UK hospital and suddenly thrust into the hurly burly of exotic lifestyles. First stop Alexandria, then through the Suez Canal with the Pyramids alongside and the local magicians – I can still remember those first sights and smells. Onwards via other ports to Singapore and then to Hong Kong where I spent the next few years. During that period we had a holiday in Japan. It was still not that long after WWII and I wondered why we got mobbed in Kobe, transpired I was the first western child, with blonde hair to boot, that the vast majority of the local population had seen. Almost a miracle we made it as the ship got caught in a Category 4 Typhoon, all 4,500 tons of her, and had to spend 6 months in dry dock being repaired.

Back to UK and school. Despite the fact that I used full length callipers and under arm crutches I went to ordinary schools, so no concessions to disability – just get on with it. The others found I had a good reach with the crutches – so there's the goalie. In the more senior years at school I became responsible for organising rugby, hockey and cricket matches against many schools over the south of England. Then the scary bit – out into the big bad world and here the fun really started. I decided, wrongly, not to enter University as I wanted to become an Air Traffic Controller. In those days it meant you had to learn to fly – so I did with hand controls in the cockpit but the powers that be decided there was nothing to say they could give me a licence and nothing to say they couldn't, so they didn't. Flying has and still is my passion. So I went to work for Unilever in their shipping company, Palm Line that traded between UK and Africa. Trained as a marine architect and surveyor, meant had to do day release at City of London University and had many trip up the West African rivers. Most notable event was a ship catching fire in the London port and only way we could get it put out fast was to sink it in the dock – gave the London Fire Brigade good practise though, took them 5 days to pump it out and re-float it.

I had taken and passed my driving test just after my 17th birthday and my first car was a Standard Pennant, 0-60 in a week but reliable and it got me around London fine. Being young and having a car was an attraction and it was through this combination I met my wife to be who was training as nurse. I left Unilever and went to Cunard where I was appointed as one of the staff surveyors on QE II . Perhaps most of the escapades we had on that famous liner should stay right there. We were married in 1971 and to honeymoon on the cruise ships – staff perk. Company was bought up – staff perk gone and my job so I went on to work for what would become British Steel Corporation (BSC) eventually rising to Board level before what we now know as Post-polio Syndrome (PPS) caught up with me and halted my international travels or so I thought, as I was medically retired from my job.

But other opportunities arose, one being to act as an Advisor to the EU Commission on many issues relating to disability from the design of hotel rooms, to adaptive technology. Gave me the opportunity for lots more. At the same time I had taken on the Chair of a Council for People with Disabilities in London and the Midlands that specialised in employment, a Trustee of the Cheshire International Foundation and founder CEO and Director of Computability in partnership with IBM and the University of Birmingham and in so doing created the largest IT resource for people with disabilities in UK and Ireland. It has since grown further into AbilityNet with centres all over the UK. So to say PPS slowed me down is rather untrue, rather it spurred me on to do more and more. I moved on from sporty and company cars to vehicles a little more suited to my needs. This was helped by an approach from a disability magazine who knew of my European work and invited me to become their “motoring” correspondent – I jumped at the chance – who wouldn’t, you get to keep the latest cars on the market for about 3 weeks while trying them out. Some like the original CRV Fiestas were absolute lemons – belt drive they couldn’t back up a small slope, belt slipped. The limited edition Peugeot 206 Special Auto went like the proverbial bat out of hell – great fun to drive or rather aim! The range I had went from the most luxurious to the mundane, quite a difference the greeting you got at a hotel when you turn up in an Escort to that a couple of weeks later driving a Bentley Continental.

So at this time I was still in UK but we had bought land in Ireland and we built our house here, that we designed with the knowledge I would be fully wheelchair dependent in a few years, came about quicker than either I, my wife and friends anticipated. I thought that was that and I slip quietly into retirement and obscurity – not to be! I got bored and became involved with the Post Polio Support Group (now Polio Survivors Ireland) and served as their magazine editor, board Member, Treasurer eventually becoming Chair in 2006. Before I stood down from that position it had joined the European Polio Union and my travels started again.

I had a wheelchair top-box fitted to the Volvo estate, went off to the mobility Trade Shows and once again discovered the lack of truly accessible hotel rooms – believe it or not the budget ones like Travel Lodge and Premier with their associated European brands have some of the best. The answer in 2006 I ordered a camper-van built to take a wheelchair with lift and all adaptations fitted as original equipment, not adapted but built to fit purpose. Delivery was July 2008 so we flew out to collect it, a 8 metre long by 2.7 metre wide vehicle. My wife asked what happens if you can’t drive it – my reply I’ve paid for it I’ll \*\*\* drive it.

Another development in the period was I had to give up the manual wheelchair and go to a power chair. So the Volvo went and I bought a Fiat Qubo 1.3 Turbo Switch, in other words a drive from wheelchair car. Found it’s a perfect companion for the camper-van, also a Fiat, so we take both when we take the very long breaks. Park up the camper and explore in the Qubo. We’ve had some travels as I was involved in the organising the 1st PPS Conference for medical personnel and polio Survivors in Copenhagen in 2011, Amsterdam 2014 and another in northern Spain perhaps next year. I also became President of the European Polio Union in 2011 and vowed to visit all its 23 member organisations in 18 countries from North of Norway to the Southern most tip of Italy and from Georgia in the east, to Spain in the west. I stood down as President in 2017.

So what now? One thing learnt over the years is very few medical personnel, and especially the local doctor don’t know how to treat PPS. It’s an incurable condition that affects up to 60% of paralytic polio Survivors and hits anything up to 40 years after the initial paralysis. There are 7,000 polio Survivors in Ireland, just over 1.2 million in the whole of Europe and 25 million plus around the globe.

So I have founded PoPSyCLE (Post-polio Syndrome Centre for Learning Excellence) to rectify the situation. Training centres and facilities, both hands on and distance learning, will be established at Beaumont Hospital, Dublin in association with Trinity College Bio-Medical Sciences Institute, Dublin, St Thomas’ Hospital Lane Fox Unit, London and the University of Amsterdam Medical School. All are leaders in care, treatment and management of PPS. After that and with World Health Organisation assistance other centres will be opened in sub-Saharan

Africa and the Indian sub-continent – but that is a decade or more away. More travelling, more places, more adventures more friends to make. PPS may have caused me to stand down from BSC [British Steel Corporation], I never thought then it would give me such opportunities and a fulfilled and fulfilling life.

So now you know a bit about what drives me look out for the next blog that will tell the story of how PoPSyCLE is being formed, what it will do to help polio Survivors and how they, families and carers can help in making PoPSyCLE a force to help Survivors all over the world.

So until then..... John R McFarlane, Director PoPSyCLE Limited (UK) & PoPSyCLE Foundation Ltd (Ireland) Registered Charity Number :- 20158989 - johnmcf@popsycle.eu

### **One Disease – 3 Names!**

Last week, we replied to a comment from one of the Polio Support Groups on Facebook. Virtually by return another comment was made by the coordinator of a support group in the UK [Hilary] asking whether I was using predictive text software as surely I could not be referring to something called Post Polio Myelitic Syndrome – surely I meant Post Poliomyelitis? I am afraid my response may have been a little short when I replied that “I only use World Health Organisation definitions”. This led to an interesting interchange of emails which brought to my attention and I think of others some of the terms used may not be well known even to those who work in the polio support groups or primary care medical community.

Professor Frans Nollet, a leading authority on all aspects of medical intervention and support for polio Survivors at the Amsterdam Medical Centre, in his conference speeches makes the point that polio under its various names is the only disease in the International Classification of Diseases (ICD) that has 3 separate and entirely independent entries and it is here that things start to get complicated.

1. ICD-10, A80-A80.9 – **Acute Poliomyelitis**. This is the active phase of infection and the initial consequences of developing polio with all the possibilities of paralysis and other known effects.
2. ICD-10, B91 – **Sequelae of Poliomyelitis**. This is what was commonly referred to as the Late Effects of Polio (LEOPs). Simply defined this is the plateau phase following the acute. This phase may last for the rest of the polio Survivors life or as we now know may turn into.....
3. ICD-10, G14 – **Postpolio Myelitic Syndrome**. More commonly known these days as PPS and which can affect up to 60% of those who previously could have been counted in the polio sequelae cohort. Itself a distinct and incurable condition.

To the vast majority the differentials may seem either inconsequential or as “clear as mud”. However, they are important because in some countries the ICD classification are used as the access point for benefit and medical billing procedures. This is certainly the case in the United States of America. (A revision of ICD-10 was due to be released in 2017 but has now being pushed back to sometime later in 2018, it will be known as ICD-11).

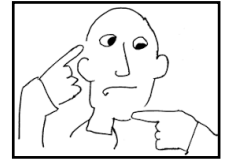
Just to add to confusion for both the polio Survivor, Doctors and allied medical staff together with those who have within their power the right to grant or deny benefit payments it now appears that a new set of categories which have been in use inside health services around the world for some years are now reaching out into non medical usage in the public domain. For example there is SNOMED International SNOMED CT Browser both in international and various national guises and languages. Open up this browser and in the search facility, type in Post Polio Syndrome and you get the following result classifying as SCTID:31097004 [See opposite chart download — <http://tiny.cc/7e2cuy>, NB text box on left retyped to right for easier reading]

Now if you understand all the above you will be in a better place to argue your case with anyone on the subject of Polio and its consequences. Well if you think that perhaps you can explain it all to me in terms of one syllable – or as Rudyard Kipling would have said in his famous poem “If” – “you are a better man than me”.

**Its simple isn't it? John R McFarlane, President PoPSyCLE Foundation.**



# Polio Survivors Network NEEDS YOU!



As you must be aware by now there are new regulations regarding privacy and data protection that we must comply to. The General Data Protection Regulation (GDPR) came in force in May this year (25<sup>th</sup> May 2018).

Technically, if we have not received your Consent Communication Form sent to you in March then you will not be reading this as you will not have received your newsletter from us!

Importantly, this form needed to be completed and you needed to 'opt in' to continue to receive our regular newsletter, Post Polio Matters, any other information we may need to send you as well as giving us your permission to store your details.

So, a BIG THANK YOU to all members who completed and sent the form back to us. At the AGM and in the Trustees Report sent to members we noted that we had 185 members. To date, we now have only 75 members! We are now a very select few!

If you have returned this form to us please be assured that your details are kept safe and secure and will not be shared with anyone else. A copy of our Privacy and Data Policy is now available and will soon be on our website or we can send you a copy upon request. It would take up too much room to print our Privacy Statement in this newsletter. We have included a separate copy with your newsletter.

Further information concerning the GDPR is available online: <https://ico.org.uk/for-organisations/charity/charities-faqs/>

Thank you for being a valuable member of Polio Survivors Network (PSN). As a small charity we rely upon your support and this is appreciated. We would not be able to continue to promote the care and needs of polio survivors without you.

Thanks to the substantial legacy received it was decided at our Annual General Meeting that Membership will now be FREE but donations still gratefully received. See page 4.

Secretary Dot Ives - [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)

**<http://tiny.cc/7e2cuy>**

The screenshot shows a web interface for 'Concept Details' of 'Post poliomyelitis syndrome (disorder)'. The page has tabs for Summary, Details, Diagram, Expression, Refsets, Members, and References. Under 'Parents', it lists 'Post-viral disorder (disorder)' and 'Progressive muscular atrophy (disorder)'. The main content area shows the concept name, SCTID: 31097004, and a list of associated terms: 'Post poliomyelitis syndrome', 'Postpolio syndrome', 'Postpolio muscular atrophy', 'Post poliomyelitis syndrome (disorder)', 'Post-polio progressive muscular atrophy', and 'Progressive muscular atrophy following poliomyelitis'. A blue box highlights the concept name and SCTID. A light blue box shows relationships: 'After → Acute poliomyelitis', 'Associated morphology → Atrophy', and 'Finding site → Structure of nervous system'. A larger light blue box on the right lists the same associated terms as the main content area. Below the main content, it says 'Children (0) No children'.



## THE TEN COMMANDMENTS OF PPS

Dr. Richard L. Bruno, HD., PhD.

Director, International Centre For Polio Education

**After 35 years of searching, archaeologists from The Post-Polio Institute have unearthed the “Commandments“ for treating Post-Polio Sequelae (PPS) . . .**

### 1. Listen to Yourself!

Polio survivors often turned themselves off from the neck down after having polio. The first step in treating PPS is to listen to yourself, to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms. However, polio survivors sometimes listen too much, to vitamin salesmen saying some herb or spice will "cure" PPS, to other polio survivors who warn that you will eventually have every possible PPS symptom and to friends and family members (and the voices in their own heads) saying you're lazy and that you must "use it or lose it." Polio survivors need to listen to their own bodies, not to busybodies.

### 2. Activity is Not Exercise!

Polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs that their muscle weakness will go away. The opposite is true: the more you overuse your muscles the more strength you lose. Muscles affected by the poliovirus lost at least 60% of their motor neurons; even limbs you thought were not affected by polio lost about 40%. Most disturbing is that untreated polio survivors with new muscle weakness lose on average 7% of their remaining, poliovirus-damaged motor neurons per year, while survivors with severe weakness can lose up to 50% per year! You need to substitute a "conserve it to preserve it" lifestyle for the "use it or lose it" philosophy. Polio survivors need to work smarter, not harder.

### 3. Brake, Don't Break.

The follow-up study of our patients showed that taking two 15 minutes rest breaks per day - that's doing absolutely nothing for 15 minutes - was the single most effective treatment for PPS symptoms. Another study showed that polio survivors who paced activity -- that is worked and then rested for an equal amount of time -- could do 240% more work than if they pushed straight through. Our patients who took rest breaks, paced activities and conserved energy had up to 22% less pain, weakness and fatigue. But polio survivors who quit or refused therapy had 21% more fatigue and 76% more weakness. For polio survivors, slow and steady wins the race.

### 4. A Crutch is Not a Crutch . . .

. . . and a brace is not a sign of failure or of "giving up." You use three times less energy (and look better walking) using a short leg brace on a weakened leg. Overworked muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches (dare I say a wheelchair or a scooter) if they decrease your symptoms and make it possible to finally take that trip to Disney World? I know, you'll slow down and take care of yourself "when you're ready" and use a wheelchair "when there's no other choice." You don't drive your car until it stops because it's out of gas. Why drive your body until it's out of neurons?

### 5. Just Say "No" to drugs, unless...

More than a half dozen studies have failed to find any drug that treats PPS. And there have been no studies showing that herbal remedies, electric stimulation or magnets reduce symptoms. Polio survivors shouldn't think that they can run themselves ragged, apply a magnet or pop a pill and their PPS will disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done! Masking symptoms -- with magnets or morphine -- will not cure PPS. However, two of our studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury (see 10 below).

### 6. Sleep Right All Night.

A significant majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders, such as sleep apnea (not breathing), hypopneas (shallow breathing) or muscles twitching and jumping all over your body during the night. However, polio survivors are usually not aware that they stop breathing or twitch. You need a sleep study at a sleep disorders center if you awaken at night with your heart pounding, anxiety, shortness of breath, choking, twitching or awaken in the morning with a headache or

not feeling rested. "Postpolio fatigue" may be due to a treatable sleep disorder.

### **7. Some Polio Survivors Like it Hot.**

Polio survivors have cold and purple "polio feet" because the nerves that control the size of blood vessels were killed by the poliovirus. Polio survivors' nerves and muscles function as if it's 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of the silk-like plastic fiber polypropylene that holds in your body heat.

**8. Breakfast Is the Most Important Meal of the Day.** For once Mom was right. Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. Our dietary study showed that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When our patients follow a hypoglycemia diet (have 16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your mid-day yawning.

### **9. Do Unto Yourself as You Have Been Doing For Others.**

Many polio survivors were verbally abused, slapped and even beaten by therapists or family members when they had polio to "motivate" them to get up and walk. So polio survivors took control, becoming Type A super achievers, "the best and the brightest," doing everything for everyone...except themselves. Many polio survivors do for others and don't ask for help because they are afraid of being abused again if they even look "disabled." Isn't it time that you got something back for all you've done for others? Accepting assistance is not the same as being dependent. Accepting assistance can actually keep you independent. But appearing disabled by not doing for others, asking for help or using a scooter, will be frightening. So please remember: If you don't feel guilty or anxious you are not taking care of yourself and managing your PPS.

### **10. Make Doctors Cooperate Before They Operate.**

Polio survivors are easily anesthetized because the part of the brain that keeps them awake was damaged by the poliovirus. Polio survivors also stay anesthetized longer and can have breathing trouble with anesthesia. Even nerve blocks using local anesthetics can cause problems. All polio survivors should have lung function tests before having a general anesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist - and especially your anesthesiologist - long before you go under the knife. Polio survivors should NEVER agree to having same-day surgery or outpatient tests (even an endoscopy) that require an anesthetic without their doctor 1) Reading the information on polio survivors increased sensitivity to anesthesia and 2) Being prepared to admit them overnight if too much anesthesia is given and the polio survivor is unsafe to leave the hospital.

#### **The Golden Rule for Polio Survivors.**

If anything causes fatigue, weakness, or pain,  
DON'T DO IT (or do a lot less of it)! .  
. . and ...

#### **The Golden Rule for Polio Survivors' Friends & Family.**

See no evil, hear no evil . . . and help only when asked.

Polio survivors have spent their lives trying to look and act "normal." Using a brace they discarded 30 years ago and reducing their super-active lifestyle is both frightening and difficult to do. So, friends and family need to be supportive of life-style changes and accept survivors' physical limitations and new assistive devices. Most important, friends and family need to be willing to do the physical tasks a polio survivor should not do...but only when the polio survivor asks. Friends and family need to know everything about PPS but say nothing: neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of themselves and ask for help when they need it.

The PPS Library and all of our papers describing our research and treatment of PPS can be found at [www.postpolioinfo.com](http://www.postpolioinfo.com)

The 10 Commandments of PPS Video ; produced by the Polio Network of Australia is available

<https://www.papolionetwork.org/information-for-pps-caregivers-and-providers.html>

JUNE 1st 2018

**DAWN.COM - Pakistan: Polio eradication still seems far from reality**

Ikram Junaidi writes:

**ISLAMABAD: Despite expectations that the poliovirus would be eradicated in 2018, the emergence of two cases in Pakistan and nine cases in Afghanistan has panicked authorities in the health sectors as the two countries have been declared one block.**

"Recently, an 18-month-old girl was diagnosed with poliovirus in Dukki district of Balochistan, taking the count for the first five months of the year in Pakistan to two. As poliovirus remains in a recessive mode during winters and becomes active with the increase in temperatures the coming days can be more worrying for us," said an official of the Ministry of National Health Services, requesting anonymity.

"Though the health authorities in Pakistan and Afghanistan have stopped levelling allegations against each other, it is a fact that due to security issues polio campaigns cannot be held in many parts of Afghanistan. Even if Pakistan eradicates the virus it cannot be declared a polio-free country unless the virus is eradicated in Afghanistan too," he said.

*Two cases from Balochistan and seven from Afghanistan worry health authorities as the two countries have been declared one block*

"We showed improvement during the last few years but it seems we may fail to give the final push to the virus as so far two cases have been reported from Balochistan. There is less than 30pc routine immunisation in Balochistan. In Punjab, the situation is a bit better but it is bad in interior Sindh and southern Khyber Pakhtunkhwa. In Islamabad, routine immunisation is ignored during polio campaigns."

The official said that in May experts from different countries were called for 'focus group discussions'. The experts spent almost two weeks visiting different provinces but came up with findings that were already in the knowledge of everyone, he said.

At a function arranged for Minister for National Health Services Saira Afzal Tarar on the last day of her tenure on Thursday, government officials claimed that there was a huge improvement and the virus of the crippling disease would be eradicated this year.

Prime Minister's Focal Person on Polio Eradication Senator Ayesha Raza Farooq said Pakistan's historic progress towards polio eradication would not have been achieved without the dedicated leadership of Ms Tarar.

She said since 2014 there had been an overall 97pc reduction in polio cases in Pakistan: from 306 cases in 2014 to eight in 2017. This year two polio cases have been reported.

Earlier, National Emergency Operation Centre Coordinator Dr Rana Mohammad Safdar spoke on the current polio epidemiology and the plans to interrupt the virus.

"Maintaining highest quality supplementary immunisation activity campaigns in alignment with Afghanistan with focus on hotspots will do the job along with convergence of efforts for strengthening routine immunisation, water and sanitation as well as nutrition especially in areas of remaining polio concerns," he said.

Speaking on the occasion, Ms Tarar said: "Polio eradication enjoyed broad political and popular support in our country and this commitment has made a difference when our people come together to work above political lines towards a national cause."

**Post-Courier - Papua New Guinea: Morobe on alert as boy, 6, is diagnosed with polio**

Natalie Cholohei writes:

THE Morobe provincial disease control officer and a team made up of the Department of Health and World Health Organisation (WHO) are investigating a suspected polio or poliomyelitis case at Four-Mile outside Lae city.

Provincial Health adviser Micah Yawing said yesterday that a six-year-old boy from Eastern Highlands Province, who cannot be named, had been diagnosed with polio at the Angau Memorial Hospital early this



week.

“The case has been confirmed from Angau and polio is identified at the Four Mile area,” Mr Yawing said. He said one case is very serious and the team of health practitioners is addressing this situation with high importance.

As a strategy by the DoH and WHO, they aim to eradicate polio in the world, and their role in public health is to protect the lives of the people. “One case is very serious and our aim is to fully immunise all children from under one to 12 years old,” Mr Yawing said.

Children under the ages of one and five years, who are not fully immunised have a high chance of contracting the disease.

According to the working team, they are still investigating the child’s health record to see if he is fully immunised or the cause of the disease.

The health team is calling on mothers to make sure their children under the ages of one and five years are fully immunised to avoid the contraction of such disease.

“Prevention is better than cure and one case is very serious for the children who are not fully immunised because the disease can spread,” Mr Yawing said.

The team will be giving vaccination to the children in the area today and over the weekend, and monitor the symptoms of the disease.

Signs and symptoms of polio can be identified through fever, sore throat, vomiting, back and neck pain or stiffness in the arms or legs which can last up to 10 days.

**13.6.2018 - Updated on 15.6.2018 below.**

### **Acute flaccid paralysis case under investigation in Venezuela | GPEI.**

In response to media reports about a polio case in Venezuela which emerged last week, the Global Polio Eradication Initiative (GPEI) wishes to clarify that these reports cannot be confirmed at this time.

### **Update on suspected polio case in Venezuela | GPEI.**

Following unconfirmed reports on 8 June of suspected polio re-emergence in Venezuela, final laboratory testing has confirmed **the cause of the paralysis is not wild poliovirus or vaccine-derived poliovirus.**

**Kate Oliver Webb from Tennessee, USA** posted the following in the Facebook Group ‘The Post-Polio “Coffee House” and has given permission for me to add this to our Newsletter. How many of our member can relate to these words? Richard and I can.

**Warning. Rant Coming.** People who don’t get it: Just the other day, when I commented to someone that I’d been awfully busy the last few days, she said “Good, that will get your system up and active again!” Now, I’ve told this person many times about the danger of overdoing, what exhaustion can lead to (being over-tired and not being able to recoup, etc.) and that this continuing high pain level is dangerous that my body cannot heal from overuse.

I’m 73 years old. At this point, my fond hope is that I can ENJOY the rest of my life by carefully conserving my strength and trying not to ‘work through pain’ (I can’t count the number of times I’ve heard that phrase as advice). I try to use my energy on things I enjoy doing. I realise that that may mean people close to me may need to pick up on the things for me that I would otherwise do for myself - and I don’t like the idea any more than they do. But I’ve had to come to grips with the fact that I’ll never again be energetic and able to do chores, welcome guests to my home, enjoy noise and hubbub, etc. If I have to spent my energies on “the dailies” as I like to call the everyday jobs of living (cleaning up after a meal, folding my underwear, even showering!), then I can’t enjoy the family visits, the outings, the artistic things I like to do. I just don’t have the energy to add those fun things. My outings have been reduced to doctor visits and getting medical tests etc.

I also have trouble with unexpected things, like visits, even telephone calls, all of which tire me, and if I’ve already used up my energy, the frustration of these unexpected things can reduce me to tears. Can you tell I’ve had a super draining week? And NOBODY really “gets it”. Not that I can blame them - how could anyone who has not walked this path understand these feelings?

Comment or not - I just appreciate so much being able to vent to a group who understands.

## **POST POLIO SYNDROME EXISTS**

**Colleges of Medicine** please add more facts to your lectures on the Polio Virus and the effects that it could have had on our bodies. Ensure health professionals understand how varied our nerve damage, our recovery and stable years have been. The majority of us recovered that well that externally we do not look like those photos in the old medical books. That there is a massive overlap of symptoms with other neuromuscular conditions. Tell them about **Post Polio Syndrome** and give them links to where they can find more information. Thankyou.

**The most accepted articles we have found by NHS professionals are:-**

### **PatientPlus article POST-POLIO SYNDROME**

**Written by U.K. Doctors for Doctors**

<http://patient.info/doctor/post-polio-syndrome>

**And in case you need an anaesthetic  
an excellent leaflet translated into English  
now used by many PPS Groups around the world.**

### **POLIO PATIENTS AND SURGERY.**

**Information for health staff.**

**Lise Kay, MD, Surgeon PTU – Danish Society of Polio and Accident Victims**

[http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU\\_PDF/BROCHURER/  
Polio\\_operation\\_ENG.pdf](http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU_PDF/BROCHURER/Polio_operation_ENG.pdf)

Text copies of both have been sent to members and are available on our Website link on front page

### **REMINDER FOR MEMBERS**

**Have you changed your home, email address or phone number recently?  
Did you let us know?**

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 1st October 2016**

**Editors Note:-**

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

# Management Committee [Trustees] and Operations Team

## Management Committee [Trustees]

Chair - **Simon Parritt** - [simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)

Secretary, Membership & Email enquiries - **Dorothy [Dot] Ives** - [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)

Treasurer - Margaret Marris - [margaret.marris@poliosurvivorsnetwork.org.uk](mailto:margaret.marris@poliosurvivorsnetwork.org.uk)

Newsletter Editor - **Hilary Boone** - [hilary.boone@poliosurvivorsnetwork.org.uk](mailto:hilary.boone@poliosurvivorsnetwork.org.uk)

Trustee - [Want to see your name here?]

## Operations Team

Phone Enquiries - Hilary Boone - [info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk)

Printing - [imprintcolourprinters.com](http://imprintcolourprinters.com) Lincoln.

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

## Membership

**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.

### Membership Fees

**Annual General Meeting Decision - APRIL 28th 2018**

**Membership is now FREE**

We welcome members and groups living in other countries.  
Please note the majority of information will be sent via the Internet.  
Email:- [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk)

Our Website is in the process of being updated...



Donations and Help towards our Work always welcome

[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

*giftaid it*

## Donations

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

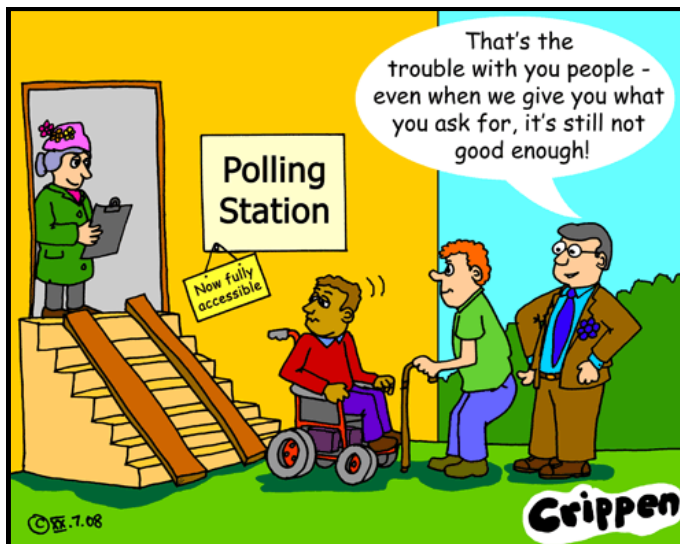
To support attendance at National Meetings and PPS Conferences

**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.

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%).

[www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk)

## Benefits and Work Guides you can trust



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