



POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 9, Issue 8/12
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

MERRY CHRISTMAS & HAPPY NEW YEAR 2019



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

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QUICK NOTES

1. The General Data Protection Regulation (EU) 2016/679 ("GDPR") is a regulation in EU law on data protection and privacy for all individuals within the European Union (EU) and the European Economic Area (EEA).
2. Even if you have been a member for years unless you complete our GDPR form letting us know by which methods we can contact you, e.g. by post, by email, by phone, by mobile, etc. then we will have to remove your name from our Database and this could be your last newsletter from us.
3. If we have not received a completed form back from you [one member posted but we did not receive it] you will find another form enclosed with this issue. Please complete it, sign it and return it to us so that we may remain in touch with you.
4. Please read the bit on the bottom of the next page and drop us a line/email/phone us and we will do all we can to help with your enquiry/add anything you send us for the newsletter, etc.

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Editorial by Hilary Boone

On the first paragraph of this Newsletter your Editor sends to you good wishes for a Very Merry Christmas and a Happy New Year 2019. ☺

Secondly, an update on our Website. I hope you like the new format. Leah has worked very hard in the time she has available between looking after us and her family to upload all the Lincolnshire Post-Polio Library articles and our Newsletters. The LincPIN and laterally called Post Polio Matters. Some of our older articles had been infected with viruses and each item has to be checked to make sure it is free of viruses before it is uploaded again. Please if you have any questions or comments we would love to hear from you. We now hope that by the end of January that all our plans for the new site will be up and running.

Thirdly, those members who have not **completed and returned their GDPR forms** will lose contact with us. Legally we cannot contact you if you do not sign to give us permission.

Fourthly, we hoped that members would share more information with us. Items that work for you, issues that have cropped up and what you are doing/have done about it. Remember you will not be the only one with the problem. Even if it helps just one Polio Survivor then it is worth it.

Fifthly, please help the Neurological Alliance increase the data they hold on Polio and Post-Polio Syndrome. Complete the survey by March 22nd 2019. This is their third survey and the last had 150 responses - so far this one only 9 - and it would be great if we could increase that number. Please ask all the polio survivors that you know to complete this. Anyone unable to get online then contact us and we will help you do this.

Sixthly the subject of being assessed and fitted with Orthoses in the UK compared with other countries. I started my journey in 96 and at the first appointment was given a ladies size 9 one off the shelf. I have a very wide foot and since then have had to wear men's trainers to get the AFO in as well. It was very painful underfoot. I went back and a foot shaped piece of rubber was cut to fit inside my shoe to make it more comfortable but there was now no room for my foot!! I had contacted other polio survivors on a polio email list and the responses came back that I must be properly cast for one that fits me. Well, without using expletives, I have had at least six made in the UK over the last 22 years that have not been comfortable to wear including one cast in the reception of the company and another at a larger hospital where the returned AFO went up behind my knee and the footplate again flat with no pressure relief for the ball of my foot. Took it unworn to the PPS Conference in the States a few weeks later comments unprintable.

I had one made in Canada in late 90's that was **so comfortable** I could now walk without pain and drive for hours instead of 45 minutes. That lasted seven years till I broke it in an Accident, and another in the USA by Richards Orthotist just before we came back to the UK in 2008. Both Orthotists assessed me similarly. They watched me walk with and without AFO on and also examined my feet. They said the same thing 'there is not enough pressure relief for the ball of your foot' and the American Orthotist opened his box of tricks and chose a shaped piece of rubber that he put under the ball of my foot then cast me. **Result comfortable AFO again.**

Can anyone give me some advice as to how and where I can be cast in the UK so that the AFO that is provided will fit and be comfortable?

PLEASE SHARE EXPERIENCES OF YOUR POLIO LIFE

Tell us about the solutions you have found that work for you.

Tell us about the issues you have managing your post-polio life.

Help us build a larger database of possible solutions to publish in our newsletter

NEXT ISSUE - Deadline March 4th for publishing late March 2019

MESSAGE FROM OUR CHAIR

I must start by welcoming Verité Reilly-Collins as our newest Trustee. Verité is not only a Polio Survivor but a Cancer Survivor as well and has contributed some items in the past. Read more about her on page 16

It has been a challenging year for us all in many ways. It was a very hot summer, which for some was not easy, though personally I would always opt for warmth rather than the cold of our winters. We also live in uncertain times with the dreaded BREXIT and the impact upon disabled has not gained much press or attention. For those of us who travel to and from the EU who rely on the IHIC card for peace of mind, its possible loss and impact even on the cost of special conditions health insurance has not been on the agenda so far. The problems that have afflicted the British Polio Fellowship also bring into sharp focus that we live in financially challenging times especially for small charities such as ours and we need to be aware of our core aims.

On the positive side, we had the bequest that meant that we could improve on the information we provide and make Polio Survivors Network much more responsive and accessible to members. The Trustees decided that Membership would now be FREE whilst we remained above a certain level of funds. Donations will always be gratefully received from anyone towards our work. We are especially grateful to those members who can afford to send us a donation for continuing to do so. Hopefully this will help us grow in numbers and influence.

Following the hacking of our website where viruses were added to some of the older documents our Website was updated with a new design. I hope that you like it and will soon get used to some of the new facilities. The Lincolnshire Post-Polio Library articles and our newsletters, firstly named the LincPIN and latterly Post Polio Matters will continue to be added once they have been fully checked to ensure virus free. This newsletter - email version - will have been sent out directly from the Website for you to download.

The new data protection rules under GDPR also put a major work load on us. I would love to say that all our members have returned the necessary GDPR form completed so that we have your permission to continue to contact you. Yes, even though you are a member of many years you need to return a completed form or this might be the last newsletter you receive.

Our new Admin Officer Philip and Researcher Michael have been making our lives much easier and we look forward to your seeing results from their work on the Website and in the next newsletter.

Despite our ageing polio cohort I think that this year has seen us move with the times and make considerable progress to becoming more relevant and a resource to you all as well as the health and social care professionals supporting and treating us. Please do take a look at the updated web site, bear in mind that there are still items to upload again. We welcome feedback at any time.

That leaves me with the hope that you all have a Merry Christmas and a good and Healthy New Year and that you will continue to keep in touch with us with any suggestions, problems or other issues.

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

Chartered Psychologist. HCPC Registered Counselling Psychologist, www.sp-psychology.com
Chair Polio Survivors Network.

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

POLIO SURVIVORS BENEFIT FROM SHARING EXPERIENCES

Managing our lives now with Post-Polio Syndrome is not easy

What works for one may not work for everyone but if it works for you it is worth sharing.

STOP PRESS. CNN 3rd December 2018. Elizabeth Cohen, Senior Medical Correspondent

**After a mysterious illness paralyzed her son,
this mom turned to polio survivors for answers.**

“Olivera was in her last semester of nursing school, and she was assigned to visit a support group that had meaning for her life. She chose a support group for polio survivors, since her son’s disease and polio are similar.

The members of that support group - elderly people who had suffered a disease long since eradicated in the United States - would change her life forever.”

Watch the video at <https://edition.cnn.com/2018/12/03/health/afm-polio-support-group/index.html>

1. Towels can be wieldy and tiring to use with long arm movements. Solutions offered are to try using a few flannels [wash rags for our USA readers] instead or if you have someone to help get them to wrap you up in a large towel, if not maybe a towelling dressing gown would work and then sit comfortably with a drink and drip dry.

2. Toilet raisers for seats so that we can get up off them more easily. If more than just you living in the home then others may not enjoy/want to use them and taking them off and on is not really an option. One solution would be to buy a toilet that fixes to a frame so that it can be built into the wall and then you can have it at the exact height that you need. Another was if your bathroom is large enough then a frame with a toilet seat on it at the height you need that can be placed over the toilet could work.

3. Difficulty moving around the kitchen and using your arms. There are some doing this from wheelchairs and others on our feet, with a variety of heights and scoliosis/lordosis of our spines and how much use we have of each arm, using arm crutches, rollators, walking sticks and believe me there are some amazing adapted movements that I have seen used to do what you need to do. Then there is how large is your kitchen, how much does it cost to have it altered etc.

A) You can have work surfaces that raise and lower electronically.

B) Have fitments inside wall cupboards that bring all the items down onto the work surface
If the work surface below is free from items you need on there.

C) Counter height cupboards with shelves make it difficult to see what is in them. Try having cupboards changed to drawer units. Our PA turned a plate rack on its side and screwed it into the drawer below the cutlery drawer,

D) If you cannot see what is on the back of the shelf of a counter height fridge then this might work. Open the fridge door and turn your back on it. Place one hand on one knee to balance you so that you can lean down and look back into the fridge. Pull forward what you need to the front of that shelf and turning back again you can reach it.

E) In a wheelchair and cannot reach items in the wall cupboards. Well one of our members, Jean Tapper, sadly no longer with us used to keep items like plastic jugs with handles in them. She would then use her walking stick hook it through the handle and down it would slide. No time to find it but she did write a piece for the newsletter about the ten things that she did with her walking stick and one was not walk because she could not.

NEUROLOGICAL ALLIANCE

Third Patient experience survey

About our patient experience survey 2018–2019

We are currently undertaking our third biennial patient experience survey. Our patient experience survey is unique in gathering the views of people with neurological conditions across England about their experience of health and care services across the country. It enables us to understand what's good, and what's poor, in people's experience of local services. As with our previous surveys, we will use the results to campaign for improvements to these services. We plan to publish a report of our findings and recommendations in summer 2019.

To access the survey, please [click here](#).

[Printed copy go to <http://www.myonlinesurvey.co.uk/NA18PAT/>]

The survey is live online from **17 October 2018 to 22 March 2019**. It may take around 20 minutes to complete. Survey responses are completely confidential, and information about this is provided at the start of the survey.

New methodology

Our previous two patient experience surveys 2014 and 2016 were run online in 2014 and 2016. For 2018/19 we're also adding a new clinic-based methodology, to enable us to achieve a more representative sample of people with neurological conditions, and increase our response rate. Clinical staff in hospitals across England will be hand out paper copies of the survey to their neurology outpatients. We are working with a survey company, [Quality Health](#), to develop and undertake this additional survey method.

Another addition is that we are working with the Stroke Association on a stroke version of the survey. Stroke is more of a priority area for the health service than the rest of neurology. So, by working jointly with the stroke community we hope to gain more traction for the whole of neurology.

Please promote the survey

Please help us promote the online survey – we're stronger together. The more people hear about the survey, the more they are likely to complete it, and the richer our data will be. This will enable us to use the survey results for a strong campaign for improved services for all people with neurological conditions. We will also provide our members with data for their individual condition, for use in your own campaigning work.

We offer a [communications toolkit](#) to aid with promotion. Accompanying social media graphics can be downloaded by right-clicking on the images below:

Editors Note:-

The Second Patient Experience Survey received 150 responses from Polio Survivors. Please pass this information to other Polio Survivors and let us see if we can see more than 150 Responses this time.

There is an option at the start of the Survey to say if you receive treatment in England or do NOT receive treatment in England. As many of us do NOT get much in the way of treatment I think we should respond at the start of the survey and tick either we live in England or do not.



Option in Survey

I receive treatment in England
I do NOT receive
treatment in England.

NEUROLOGICAL ALLIANCE

I don't want a lot for Christmas, there is just one thing I need, and I don't care about the presents underneath the Christmas tree...All I want for Christmas is you – to fill in @NeuroAlliance's #neurosurvey by Mar 22nd... www.tinyurl.com/neuro01

Rockin' around the Christmas tree, let the Christmas spirit ring, later we'll have some pumpkin pie, and we'll do some filling-in...of @NeuroAlliance's #neurosurvey. Do it today! www.tinyurl.com/neuro01

Oh, the weather outside is frightful, but the fire is so delightful. And since we've no place to go, tell us about your views of neur-o. @NeuroAlliance's #neurosurvey www.tinyurl.com/neuro01

Sleigh bells ring, are you listening? In the lane, snow is glistening. A beautiful sight, we're happy tonight, filling out the neuro survey. @NeuroAlliance #neurosurvey – do it tonight! www.tinyurl.com/neuro01

On the 12th day of Christmas my true love gave to me...

12 neuro nurses

11 new neurologists

10 technology appraisals

9 MRI scanners

8 outpatient appointments

7 care & support plans

6 Rightcare pathways

5 national indicators!

4 gov't white papers

3 service specs

2 neurointerventional radiologists

And a filled-in neurology survey

@NeuroAlliance #neurosurvey www.tinyurl.com/neuro01

Happy Christmas everybody

POINTS TO NOTE from my completing the survey.

1. I have completed both the previous two surveys.
2. This survey. Poliomyelitis and Post-Polio Syndrome both listed. Ticked both and numbered PPS as No 1 as the remainder of the survey is completed on what you mark as Number 1.
3. Some of the questions are not easy to answer. E.g. Do you get treatment from, names listed. We may get some treatment from one department but could list others that we would like appointment with but only if they are listed.
4. There are some questions ticked that I have received treatment from in the past but for me that treatment has often been incorrect through lack of knowledge and experience of our condition. There is no option to comment at this point of the survey.
5. There is an option at the end to comment but if it was there in the beginning I missed it. So make notes as you go along if you might like to add comment at the end. The best I could do at the end was say that I could be contacted to explain further.
6. You have to click Complete and then make sure you tick the SAVE RESPONSES.

The role of good bacteria in our digestive system by Zsuzsi Snarey.

Our bodies are covered inside and out with millions of bacteria which are mostly beneficial to our health. We have about 10 times as many microbial cells as human cells. By far the largest population of microbes, that is bacteria, viruses and fungi live inside our gut and it is called the microbiota or microbiome. If there is an imbalance between the good and bad bacteria in the microbiome our well being is affected and we may have problems with immunity, nutrition, brain function and even develop disease. There is increasing evidence that the nutritional value of food is influenced in part by each individual's gut microbial community, and that food in turn shapes the microbiota and the gut microbiome. The human gut microbial communities and immune systems co-evolve during the course of our lifespans, and parts of the microbiota can have an impact the immune system. Changes to the composition of the gut microbiome have been implicated in multiple human diseases, including inflammatory bowel disease and obesity. There is compelling evidence to support a link between the gut microbiota and brain function. According to the American Psychological Association, gut bacteria produce hundreds of neurochemicals that the brain uses to regulate basic physiological processes as well as mental processes such as learning, memory and mood.

Constipation is a frequent concern to many people. It is a tricky problem to define, largely because our digestive systems all function slightly differently. What might be normal for one might not be normal for others. Pain caused by constipation can range from a dull, constant ache to shorter, sharper cramps felt across the abdomen. If you're experiencing more severe, unmanageable pain, it could be a sign of something more serious than constipation. Seek advice from your GP. Likewise, if you notice any blood coming from your back passage – appearing on toilet paper or in the toilet – it is advisable that you contact your GP. Good bacteria in your gut help you absorb the appropriate amount of water. Constipation can become an unpleasant part of your life if the numbers of good bacteria in your gut start to fall, allowing less beneficial bacteria to take over. Bad bacteria can also damage the nerves in the muscles of the intestine, slowing them down even further. Underlying illnesses and medicines such as blood pressure drugs, iron tablets, anti-depressants, anti-convulsants and long-term use of laxatives can all affect your bowel movements.

Foods that cause constipation include: Red meat, Dairy products, refined sugars in products such as fizzy drinks and desserts Iron-rich foods such as liver and shellfish. A high fibre diet can increase stool bulk, which drives your digestive system into action. Adults should aim to eat about 30 grams of fibre a day by including the following foods in every meal: Fruit and vegetables, Wholemeal bread and pasta, Wholegrain cereals, Brown rice, Flaxseed. There are certain foods that encourage the diversity of the microbiome such as kefir, yoghurt and fermented vegetables such as sauerkraut. These can be all made at home. If you're not used to eating these types of food, introduce them to your body slowly. Some people find that the soluble fibre in fruit such as bananas and vegetables is easier for their bodies to process.

Irritable Bowel Syndrome or IBS affects about 10-15% of people in the developed world. It is more common in women than in men. The symptoms of IBS are abdominal pain or discomfort that is associated with diarrhoea or constipation and a change in bowel habits. These symptoms usually occur as acute attacks or episodes that subside over time, but they are likely to be recurrent. The symptoms may vary in individuals, and are often associated with the intake of food and typically, with bowel movements. The sensations of discomfort related to bloating and distension may be associated with urgency for bowel movements, which sometimes provides relief from the symptoms. People with IBS are also more prone to developing stomach reflux. If you are suffering from IBS you may also experience additional symptoms relating to disorders such as chronic fatigue syndrome, fibromyalgia, headache, backache, and psychiatric

symptoms such as depression and anxiety.

Alteration in the gut microbiota may play an important role in the development of IBS and there is growing evidence that shows that IBS is associated with an imbalance in the composition of the gut bacteria. Genetic, environmental, and psychological factors may also play roles in the development of IBS. Foods and drinks that can trigger the symptoms of IBS: alcohol and fizzy drinks, drinks containing caffeine, chocolate, processed snacks – such as crisps and biscuits, fatty or fried foods. Symptoms can often be managed by changing the diet and lifestyle, and through understanding the nature of the condition. Keeping a food diary may be helpful to identify the foods and drinks that trigger IBS.

Here are a few general eating tips: have regular meals and eat mindfully, try not to skip meals or go for long periods without eating, drink plenty of fluids during the day – particularly water, restrict the foods and drinks that trigger your IBS. Make a food diary to help monitor which foods flare your symptoms. <https://www.genome.gov/27549400/the-human-microbiome-project-extending-the-definition-of-what-constitutes-a-human/>

Recipes for gut health and more information can be found on www.loveyourgut.com

There was a special supplement in the Guardian about Digestive Wellness, 6th November 2018 <https://www.theguardian.com/lifeandstyle/2017/nov/06/microbiome-gut-health-digestive-system-genes-happiness>

Post Polio Matters Editors comment.

Richard has both Post-Polio Syndrome and Parkinsons and so do six others locally that we are aware of and others abroad. We find a lot of helpful information on this website as Parkinsons is now thought to start in the gut.

Michael J Fox Foundation for Parkinsons Research, michaeljfox.org/foundation

Gut Check on Parkinson's: New Findings on Bacteria Levels

Posted by Rachel Dolhun, MD. December 8th 2014

“Listen to your gut” is common advice when faced with an important decision. Researchers are now heeding these words to gain further insights into Parkinson's disease {PD}

The human digestive tract contains up to a thousand different types of bacteria, which help you digest food, make vitamins and maintain your immune system. The amount of bacteria is influenced by diet, age and other variables, and is thus unique to each individual.

Filip Scheperjans, MD, PhD, and colleagues from the University of Helsinki, Finland examined the intestinal contents of 72 people with Parkinson's and 72 without PD. Their research, funded by MJFF and published recently in *Movement Disorders*, revealed that people with Parkinson's had lower levels of a certain bacterium and that concentrations of another bacterium varied among subgroups of those with PD with differing motor symptoms.

Intestines as a Window to the Brain.

There is a clear effect of Parkinson's disease on the gastrointestinal system. Nearly 80 per cent of people with PD have constipation, and this condition often predates the motor symptoms of Parkinson's by several years.

Additionally, alpha-synuclein—a protein that clumps in the brains of all people with Parkinson's—has been found in several locations outside the brain, including the nerves controlling the intestines. Investigators question whether the abnormal protein could show up here first, causing non-motor symptoms, and later spread to the brain to cause motor symptoms.

Lastly, researchers believe the normal bacteria of the gut might affect the functioning of the gut

nerves which could in turn affect the nerves of the brain.

Specific Bacterial Levels Are Affected in Parkinson's Disease.

In Dr. Scheperjans' study, the bacteria *Prevotella* was present at lower levels in the guts of people with Parkinson's disease. This bacterium aids in the creation of the vitamins thiamine and folate and the maintenance of an intestinal barrier protecting against environmental toxins. This finding may therefore have implications not only diagnosis but also for dietary adjustments or vitamin supplementation for management of PD in the future.

In people with Parkinson's with more severe postural instability and gait difficulty, as opposed to tremor, the bacterium *Enterobacteria* was present at higher levels. The reasons for this association were not clear.

Studying Intestinal Bacteria Will Advance Understanding of Parkinson's.

Deciphering information from the gut would lead to earlier and more definitive diagnosis, a better understanding of how Parkinson's progresses, and ways to separate the populations of people with differing symptoms of PD.

If researchers determine that there are specific and consistent differences in the gut, bacteria may serve as biomarkers—objective measurements to diagnose or track PD. As the gut is much more accessible than the brain and can be analysed through stool samples, a bacterial biomarker is an attractive prospect.

Additionally we don't know why people with Parkinson's disease show such varied motor symptoms (gait problems versus tremor, for example) or who will get which. Bacterial differences may allow us to separate the subtypes of Parkinson's and, as a result, give individuals a better idea of the symptoms and disease progression they might expect.

More Research is Needed.

Further studies are called for to learn more about the relationship between these and other gut bacteria and Parkinson's. In the meantime, researchers are intensely studying alpha-synuclein to determine how and why this protein contributes to Parkinson's, and its connection between the gut and the brain.

Until a disease-modifying therapy is found, symptomatic treatments, including a drug for constipation, remain under development.

Watch a webinar on symptoms like constipation.

https://www.michaeljfox.org/foundation/news-detail.php?newsid=2767&smcid=ag-a1b3600005Ur4m&gclid=EAlaIqobChMI9vjbuv2k3wIV1eF3Ch1WhAcZEAAYASAAEgLYxPD_BwE

Third Thursdays Webinars on Parkinson's Research. On the third Thursday of every month, join our live webinars to learn about various aspects of living with Parkinson's disease and the Foundation's work to speed medical breakthroughs. Log on, listen to the expert discussion and submit your own questions to our panellists. Can't make it for the live event? Watch when you can through our archive library below.

Bill Vaughan

Youth is when you are allowed to stay up New Years Eve.

Middle Age is when you are forced to.

An optimist stays up till midnight to see the New Year in.

A pessimist stays up to make sure the Old Year ends.

Anonymous

“Many people look forward to the New Year for a new start on old habits.”

“ A New Year's resolution is something that goes in one year and out the other.”

Jingle Bells

Dashing thro' the snow,
In a one horse open sleigh,
O'er the hills we go,
Laughing all the way;
Bells on bob tail ring,
Making spirits bright,
Oh what sport to ride and sing
A sleighing song to night.

Chorus

Jingle bells, jingle bells,
Jingle all the way;
Oh! what joy it is to ride
In a one horse open sleigh.
Jingle bells, jingle bells,
Jingle all the way;
Oh! what joy it is to ride
In a one horse open sleigh.

A day or two ago
I tho't I'd take a ride
And soon Miss Fannie Bright
Was seated by my side,
The horse was lean and lank
Misfortune seem'd his lot
He got into a drifted bank
And we - we got up sot.

Chorus

A day or two ago,
The story I must tell
I went out on the snow
And on my back I fell;
A gent was riding by
In a one horse open sleigh,
He laughed as there I sprawling lie,
But quickly drove away.

Chorus

Now the ground is white,
Go it while you're young,
Take the girls to-night
And sing this sleighing song;
Just get a bob tailed bay
Two forty as his speed
Hitch him to an open sleigh
And crack, you'll take the lead.

Twelve Days Of Fast Food

On the first day of Christmas,
my drive through gave to me:
a Big Bacon Classic with cheese.

On the second day of Christmas,
my drive through gave to me:
Two Happy Meals,.....

On the third day of Christmas,
my drive through gave to me:
Three Biggie Fries....

On the fourth day of Christmas,
my drive through gave to me:
Four Egg McMuffins,....

On the fifth day of Christmas,
my drive through gave to me:
Five onion rings,....

On the sixth day of Christmas,
My drive through gave to me:
Six chocolate milkshakes,....

On the seventh day of Christmas,
My drive through gave to me:
Seven pints of cole slaw,....

On the eighth day of Christmas,
My drive through gave to me:
Eight bowls of chili,....

On the ninth day of Christmas,
My drive through gave to me:
Nine polish hot dogs,....

On the tenth day of Christmas,
My drive through gave to me:
Ten baked potatoes,.....

On the eleventh day of Christmas,
My drive through gave to me:
Eleven pounds of blubber,

On the twelfth day of Christmas,
My drive through gave to me:
Twelve bags of Pepto,
Eleven pounds of blubber,
Ten baked potatoes,
Nine polish hot dogs,
Eight bowls of chili,
Seven pints of cole slaw,
Six chocolate milkshakes,
Five onion rings,
Four Egg McMuffins,

Sharing with other PPS Groups around the World.

**Pa. [Pennsylvania] Polio Survivors Network
Information and Inspiration for All Polio Survivors and Their Families.
Serving the Keystone State and Beyond.
www.papolionetwork.org**

Excerpt with permission from December 2018 Newsletter.

Self Care—its especially important at this time of year.

Dr. William DeMayo has some suggestions to help with the overwhelming fatigue that comes to so many of us. Let's not forget to laugh, love, find something to be grateful for and strive to keep our cups full.

Here's a "Self Care" holiday reminder from Dr. William DeMayo, MD.

"The holidays are a particularly difficult time when it comes to these activity decisions. In order to avoid chronic overuse activities, some helpful questions to consider this holiday season may include:

Do I want to continue to push myself to prepare the big family dinner (and risk creating pain and exhaustion) or do I **Want** to put my relationship with family first and preserve my energy by asking for help?

Do I **need** to climb that ladder to put up decorations despite the obvious risk?

Do I **have** to bake 12 dozen cookies or do I **Want** to avoid overdoing it and dial it back a bit and ask for help?

Should I "shop till I drop" or do I **Want** to be a better example to my kids and grandkids by purchasing or even making one special gift."

All these questions center around individual values, desires, and goals. It is my hope, especially during this holiday season, that we can all focus on our real Wants and be less driven by passing desires/wants, "have to", "need to", and a "should" mentality."

(From his article—"Conserve to Preserve, What does it Mean?")

<https://www.papolionetwork.org/demayo-articles.html>

William DeMayo, MD.

Dr. DeMayo has nearly 30 years of clinical experience in the field of Physical Medicine & Rehabilitation. He has served as Medical Director for several comprehensive inpatient rehabilitation units and has also maintained an active outpatient practice.

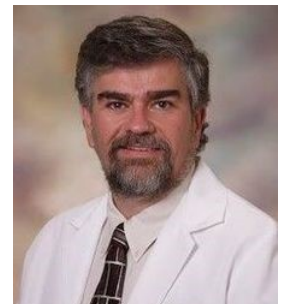
We met Dr. DeMayo in St. Louis, MI at the PHI International Conference.

(He has taken a temporary position in Abu Dhabi and has been working with us from there).

Dr. DeMayo writes for us on a regular basis and is happy to address articles to the questions submitted by Polio Survivors and their Caregivers. His regular articles are easily available for downloading and sharing:

DeMayo's Q&A Clinic - papolionetwork.org/demayos-q--a-clinic.html

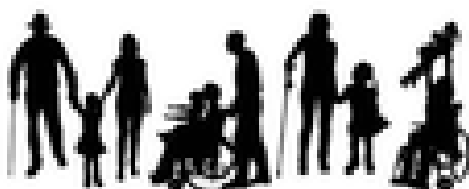
Dr. Demayo full biography.



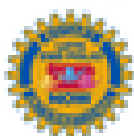
Polio

It's only a plane ride away.

Please Have Your Children Vaccinated.



**The Pain and Disability from
Polio Lasts a Lifetime.**



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POLIO THIS WEEK as of December 11th 2018

<http://polioeradication.org/polio-today/polio-now/this-week/>

POLIO TODAY. To eradicate polio, the Global Polio Eradication Initiative brings together the latest scientific knowledge on the virus and tracks the status of the virus every week. We look back on the history of the poliovirus to make the most of lessons learned and plan ahead for a world without polio.

Wild poliovirus Type 1 [WPV] and Circulating vaccine-derived poliovirus cases [cVDPV]						
COUNTRY	To date 2018		To date 2017		Total 2017	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	21	0	11	0	14	0
Democratic Republic of the Congo	0	20	0	10	0	22
Niger	0	8	0	0	0	0
Nigeria	0	31	0	0	0	0
Pakistan	8	0	6	0	8	0
Papua New Guinea	0	26	0	0	0	0
Somalia	0	13	0	0	0	0
Syrian Arab Republic	0	0	0	74	0	74
TOTALS	29	98	17	84	22	96

GREAT TRUTHS THAT LITTLE CHILDREN HAVE LEARNED:



1. No matter how hard you try, you can't baptize cats..
2. When your Mom is mad at your Dad, don't let her brush your hair.
3. If your sister hits you, don't hit her back. They always catch the second person.
4. Never ask your 3-year old brother to hold a tomato.
5. You can't trust dogs to watch your food..
6. Don't sneeze when someone is cutting your hair..
7. Never hold a Dust-Buster and a cat at the same time.
8. You can't hide a piece of broccoli in a glass of milk.
9. Don't wear polka-dot underwear under white shorts.
10. The best place to be when you're sad is Grandma's lap.

GREAT TRUTHS THAT ADULTS HAVE LEARNED:

1. Raising teenagers is like nailing Jello to a tree.
2. Wrinkles don't hurt.
3. Families are like fudge...mostly sweet, with a few nuts.
4. Today's mighty oak is just yesterday's nut that held its ground.
5. Laughing is good exercise. It's like jogging on the inside.
6. Middle age is when you choose your cereal for the fiber, not the toy.

GREAT TRUTHS ABOUT GROWING OLD

1. Growing old is mandatory; growing up is optional.
2. Forget the health food. I need all the preservatives I can get.
3. When you fall down, you wonder what else you can do while you're down there.
4. You're getting old when you get the same sensation from a rocking chair that you once got from a roller coaster.
5. It's frustrating when you know all the answers but nobody bothers to ask you the questions.
6. Time may be a great healer, but it's a lousy beautician.
7. Wisdom comes with age, but sometimes age comes alone.

SOME OF THE BEST CHRISTMAS CRACKER JOKES.

What does Santa suffer from if he gets stuck in a chimney?

Claustrophobia!

What do they sing at a snowman's birthday party?

Freeze a jolly good fellow.

Why does Santa have three gardens?

So he can Ho, Ho, Ho.

What kind of motor bike does Santa ride?

A Holly Davidson.

Why does Santa go down the chimney on Christmas Eve?

Because it 'soots' him.

Grandson age 7 offers the following

What do you call a pig that does Karate. A Pork Chop.

Two snowmen standing in a field and one says to the other, "Can you smell carrots?"

Why is it always cold in Decemberrrrrrr

What happened to the thief that stole the Christmas Calendar? He got 12 months.

What is the best thing to put in your Christmas Dinner? Your teeth.

Sent by Member Jann Hartman

Law of Mechanical Repair. After your hands become coated with grease our nose will begin to itch and you will have to pee.

Law of Gravity. Any tool, nut, bolt, screw, when dropped will roll to the least accessible place in the universe.

Law of Probability. The probability of being watched is directly proportional to the stupidity of your act.

Law of Random Numbers. If you dial a wrong number, you never get a busy signal, someone always answers.

Variation Law. If you change lines (or traffic lanes) the one you were in will always move faster than the one you are in now.

Law of the Bath. When the body is fully immersed in water, the telephone will ring.

Law of Close Encounters. The probability of meeting someone you know INCREASES dramatically when you are with someone you don't want to be seen with.

Law of the Result. When you try to prove to someone that a machine won't work. IT WILL.

Law of Biomechanics. The severity of the itch is inversely proportional to the reach

Law of the Theatre and Sports Arenas. At any event, the people whose seats are furthest from the aisle will arrive last. They are the ones who will leave their seats several times to go for food, beer, or the toilet and who leave early before the end of the performance or the game is over. The folks in the aisle seats come early, never move once, have long gangly legs or big bellies and stay to the bitter end of the performance. The aisle people also are very surly folk.

The Coffee Law. As soon as you sit down to a cup of coffee, your boss will ask you to do something which will last until the coffee is cold.

Murphy's Law of Lockers. If there are only two people in a locker room, they will have adjacent lockers.

Law of Physical Surfaces. The chances of an open-faced jelly sandwich face down on a floor are directly correlated to the newness and cost of the carpet or rug.

Law of Logical Argument. Anything is possible if you don't know what you are talking about.

Law of Physical Appearance. If the clothes fit, they are ugly.

Law of Public Speaking. A closed mouth gathers no feet!

Law of Commercial Marketing Strategy. As soon as you find a product that you really like, they will stop making it OR the store will stop selling it.

Doctors Law. If you don't feel well, make an appointment to go to the doctor, by the time you get there you'll feel better. But don't make an appointment and you'll stay sick.

Plus one more. Law of Moving. The number of things you lose when moving is directly

Why was the snowman looking through the carrots. He was picking his nose.

What does the Queen call her Christmas Broadcast. The One Show.

How did Mary and Joseph know Jesus weight when he was born.

They had a weigh in the manger.

What do you call a bunch of chess players bragging about their games in the hotel lobby.

Chess nuts boasting in an open foyer.

What do you get when you eat Christmas Decorations. Tinsillitis.

How many letters are there in the Christmas Alphabet. 25. There is no L.



Verite Reilly Collins. Polio and Cancer Survivor

Long time member and now new Trustee.

Probably the naughtiest girl in school, I avoided being expelled by the skin of my teeth, although a wonderful teacher at the English Girls High School in Istanbul, Miss Locke, inspired my love of travel and history. I had ended up there when Daddy was 'lent' to the Turkish Navy by the Royal Navy, to help teach naval matters. Much to the relief of teachers I left when I was 15.

Not having a vocation, I picked up jobs through friends of friends, so started out helping run fund-raising events for charities like the Red Cross, Lifeboats, etc. Eventually I realised I wouldn't have any friends left if I continued; they would run a mile if they saw me coming as they thought I would be selling tickets for something, so I drifted into working on Exhibition stands – originally selling Optimist dinghies (that was a lovely start). Exhibitions took place from Baltimore to Birmingham, and I got used to meeting people like Chancellor Kohl, The Queen Mum and others.

I ended up helping organise international conferences for up to 4,000 people. One achievement was moving thousands of delegates by coach from London to Hever Castle in Kent. The Chief Constable looked at me and said. "I suppose you would like me to make north Kent a one-way system for the morning?" I nodded, and he did.

Waking up in yet another hotel I had to phone Reception to ask where I was. That was a wake-up call; I had worked all over Europe, touched North American and even the Middle East, and had enough of living out of a suitcase. So I settled in London, and ran a group of multi-lingual exhibition staff called Union Jills. Our brief from the Government was to promote British exports in Britain and abroad, from fork lift trucks to containers. I had just enough travelling to keep me on my toes, and we had a whale of a time. Working 12 hour days took its toll, so I thought it would be easier to set up my own company, Dundas International Conferences and Promotions, with the help of my brother.

Needing trained staff, we set up training courses. These were bought by the United Nations and eventually Oxford came hunting for an exam in 'Tourism' English, as spoken by hotel staff, airline pilots etc. The first exam was so successful they asked for my CV to promote it abroad. I sent them one, they phoned to say "you've left out your Degrees". 'But I left school when I was 15'. Stunned silence – until they decided not to mention this.

Since then I have enjoyed taking courses, but purely those that interest me. Sold my company, and became a journalist writing about everything from Antiques to Dogs.

Learning how to cope when trains and planes were delayed, floods swept away roads and how to sort out problems with officials at Borders gave me the training to 'handle' the NHS, and my languages enabled me to get cancer care in the best country where it could be found. So it was easy to set up my website, and help others hopefully through the minefield that is our treatment.

AFTERCANCERS.COM - <https://aftercancers.com> - Last 3 items from her Blog.

Revised 'deaths'

An enquiry has found Jeremy Hunt's statement to the House of Commons in May that nearly 500,000 had not been invited for breast cancer scanning and that 270....

Why your 'Five a Day' is good for you

Winter Eating - don't forget your Fruit and Veg Health Benefits. They come in many colours, all offer healthy benefits but often we neglect to eat enough in Winter.....

C(r)apita boobs again

An additional 3,591 women have not received information about NHS cervical cancer screening, Capita (or as Private Eye rightly calls them Crapita).....

**Viewpoint: How physicians are fighting the polio-like illness sickening kids
Becker's Hospital Review.****[November 28, 2018]****Megan Knowles writes:**

After the CDC reported 286 cases of possible and confirmed acute flaccid myelitis, the polio-like illness affecting children, physicians want the public to know they are working to find the best treatments, three physicians with Washington, D.C.-based Children's National Health System write in a *STAT* op-ed.

Five insights from the op-ed, written by Roberta DeBiasi MD, chief of the division of pediatric infectious diseases, Elizabeth Wells, MD, medical director of the neurosciences unit, and Jessica Carpenter, MD, associate professor of pediatrics and neurology:

1. "Parents have a right to be concerned about this illness. But they should also know that AFM is rare, a one-in-a-million event," the physicians wrote. "It does not spread within families, hospitals or towns.

A virus called enterovirus D68, along with other viruses that cause respiratory and diarrheal illness, has been connected to AFM, but a definitive cause has not been found, the authors said.

"This isn't because we aren't looking: Physicians, scientists, and public health officials are working tirelessly to find answers and the best treatments," said the authors.

2. Since AFM first appeared in news headlines in 2014, progress has been made in epidemiologic and research data, which is shared across centers to standardize how children with the illness are treated.

3. Children's National Health System has long had specialized programs to fight emerging infections and neuroinflammatory disorders, which includes AFM.

"Thanks to our program and similar programs in place at other pediatric medical centers, evidence-based, standardized clinical pathways now guide the evaluation and treatment of every child suspected to have acute flaccid myelitis," the physicians wrote.

4. Additionally, the CDC recently standardized and publicized case definitions to help identify children with AFM and announced a new task force on the disease. The task force aims to publicize its first report in early December.

5. "Clinicians in our program and similar ones at other pediatric centers across the country apply continually updated information to guide a standardized approach to evaluate and treat children with acute flaccid myelitis and help them achieve the best possible chance of full recovery," the physicians concluded.

Original source article - <https://www.beckershospitalreview.com/quality/viewpoint-how-physicians-are-fighting-the-polio-like-illness-sickening-kids.html>

Go to post-polio.org.uk and choose the method you would like to receive the information.

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. There is a massive overlap of symptoms with other neuromuscular conditions. Tell them about **Post Polio** and link to our website **Syndrome** and give them links to where they can find more information.

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 headed paper with permission

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 4th March 2019

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

Secretary, Zsuzsanna Snarey - zsuzsanna.snarey@poliosurvivorsnetwork.org.uk

Treasurer, Newsletter Editor - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk

Trustee - Veritée Reilly-Collins - veritee.reillycollins@poliosurvivorsnetwork.org.uk

Trustee Vacancies - [please contact us if you are interested.](#)

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Researcher - Michael - researcher@poliosurvivorsnetwork.org.uk

Webmistress - Leah Rice - admin@poliosurvivorsnetwork.org.uk

Membership

Membership Fees

With grateful thanks to the generous legacy from Ms A Brown

Membership will be FREE whilst our funds remain above an agreed level.

UK Members can choose to get their newsletter by post or email or both.

Overseas Members will get their newsletter by email

Use our new online membership service

Write to us at PO Box 954, Lincoln, LN5 5ER

Email - psnadmin@poliosurvivorsnetwork.org.uk

Phone - 01522 888601, please be prepared to leave a message, your name and phone number and we will ring you back as soon as we access our messages.

Donate by cheque or



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

Towards our GENERAL FUNDS, inc. printing and posting Newsletter.

Or specifically for the CONFERENCE AND MEETING FUND

To support attendance at National Meetings and PPS Conferences.

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

- Postage Stamps, 1st and 2nd Class both normal and large size.

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%).

If you have not filled in a current Gift aid form please contact us and we will post you one.

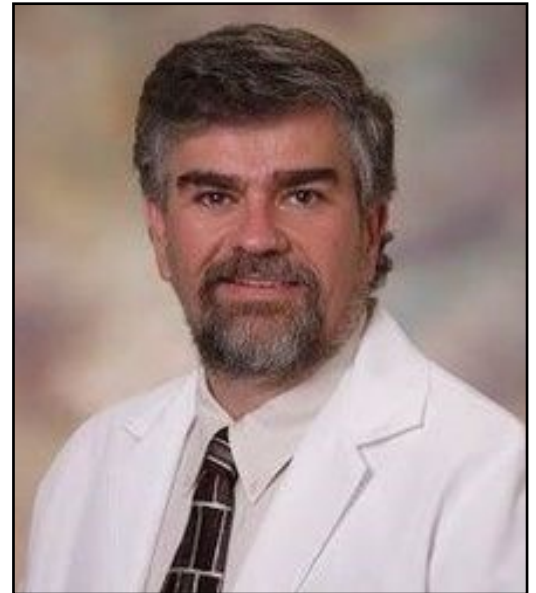
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**DECEMBER
2018
Issue 104**



Long Time Member and
now New Trustee
Verité Reilly-Collins
Polio and Cancer Survivor
Page 16

Dr. William DeMayo MD
Self Care Holiday Reminder
Pa.Polio Survivors Network



Page13
Read the latest
Wild Poliovirus Type 1
and
Circulating vaccine-
derived Poliovirus
figures for
2017 and 2018

24 October 2018

**One Day, One Focus,
Ending Polio.**

Did you watch our 6th annual
World Polio Day event at the
College of Physicians in
Philadelphia, Pennsylvania?

If not then you can watch
the livestream program featuring
global health experts and
celebrities sharing our progress on
the road to polio eradication at

www.endpolio.org/world-polio-day

ROTARY CLUB OF BANGOR

Floodlit various iconic buildings along the Menai Strait including Caernarfon and Beaumaris Castles at each end of the Straits, Bangor Cathedral and the Pontio Arts Centre at Bangor University during Monday 22nd to Friday 26th October 2018.

For pictures Google Images
North Wales Purple for Polio



© PHOTO CARDS by MEMBER VAL SCRIVENER

Sold in aid of **POLIO SURVIVORS NETWORK**

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Or ring Val Direct on 01234 346 397

