

POST POLIO MATTERS

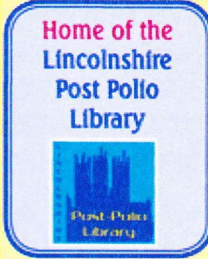
Polio Survivors Network Newsletter - Volume 9, Issue 3/12
 n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

JULY 2017

**British Polio
Fellowship
AGM**

**23rd
SEPTEMBER
2017**

**Ramada Resort
Toll Bar Road,
Marston
[Grantham]
Lincolnshire**



Enter 100+ articles

MY DIAGNOSTIC LABEL IS NOT WHO I AM

I AM A SURVIVOR OF POLIO...

but those photos in the medical books give you
NO IDEA of the jobs I have done and
 things I have achieved and
 even with Post-Polio Syndrome continue to achieve in my life.

**PLEASE ASK ME AND/OR MY FAMILY
ABOUT HOW I LIVE MY LIFE
YOU MIGHT BE SUPRISED**

Circulating Vaccine Derived Polio Virus. These cases look remarkably similar to regular polio. But laboratory tests show they're caused by remnants of the oral polio vaccine that have gotten loose in the environment, mutated and regained their ability to paralyze unvaccinated children.

"It's actually an interesting conundrum. The very tool you are using for [polio] eradication is causing the problem," says Raul Andino, a professor of microbiology at the University of California at San Francisco.

The oral vaccine used throughout most of the developing world contains a form of the virus that has been weakened in the laboratory. But it's still a live virus. [This is different vaccine than the injectable one used in the US and most developed countries. The injectable vaccine is far more expensive and does not contain live forms of the virus]. [See contents page for link]

POLIO CASES - BREAKDOWN PER COUNTRY - 12th JULY 2017

| COUNTRIES | 2017 TO DATE | | 2016 TO DATE | | TOTAL 2016 | |
|----------------------------------|---|-----------|--------------|----------|------------|----------|
| | WPV | cVDPV | WPV | cVDPV | WPV | cVDPV |
| Afghanistan | 5 | 0 | 6 | 0 | 13 | 0 |
| Democratic Republic of the Congo | 0 | 4 | 0 | 0 | 0 | 0 |
| Lao Peoples Democratic Republic | 0 | 0 | 0 | 3 | 0 | 3 |
| Nigeria | 0 | 0 | 0 | 0 | 4 | 1 |
| Pakistan | 2 | 0 | 13 | 0 | 20 | 1 |
| Syrian Arab Republic | 0 | 27 | 0 | 0 | 0 | 0 |
| TOTALS | 7 | 31 | 19 | 3 | 37 | 5 |
| WPV | Wild Polio Virus type 1 | | | | | |
| cVDPV | cVDPV - Circulating Vaccine Derived Polio Virus. | | | | | |

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New Members and Donations received from March 2017

We apologise for not including this time due to an unforeseen issue that cannot be published. All will be included in the next issue early October .

IMPORTANT INFORMATION ON RENEWALS

As we, and our carers, age with PPS everything seems to take longer to deal with. We decided to streamline our Renewals to just two six monthly dates, the 1st of July and the 1st January. We will be sending out reminders but if your membership is due now then it will not need renewing till January 1st. In the first half of next year then 1st July 2018.

You can pay by Cheque, or Standing Order through your Bank or through PayPal.

With great thanks to the generosity of our more affluent members who are able to add a donation with their membership renewals we will not be increasing the £12.50 a year fee.

OCTOBER ISSUE WILL HAVE MORE PAGES.

HOW MANY WILL DEPEND ON HOW MUCH YOU SEND US.

We would welcome more photographs showing your three ages of Polio. We will put them together as Tryptic pictures for you [like those on the front page of our Website]. Time with health professionals is short but that one Tryptic can say more about you in a few seconds than a 1000 words.

How about some short stories about your Polio Life, achievements, hobbies, funny times, maybe you have had some really odd statements made to you that whilst serious will make us laugh... Like the Polio Survivor who was told ...

“Following extensive tests the pain in your left leg is just down to age”

His reply, “Bit of a problem there Doc, my right leg has no pain and it is the same age”

Email, Post, Ring and Dictate if you need.

YOUR NEWSLETTER NEEDS YOU

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

July already... where is this year going? We are pleased to report that David Marris is doing well post his many surgeries although Margaret [Treasurer] reports caring for Polio Survivors is an exhausting task. We are not the best patients at taking the best advice for our every day lives and when recovering from hospital visits even worse. I have to admit she is right. Having fallen coming in from the garden onto my head on the carpet and knees on the metal strip of our level access [don't ask me what my arms and hands were doing..} I ended up with a black eye, bad sinus headaches for a week although daily they eased as I took my Echinacea drops. My right knee still hurts to kneel on it and OK I agree 'do not kneel' but the way I get into bed is on my right knee first! Advice to ME Use your Rollator in the garden and concentrate as you walk and say, 'left, right, left, right'. With age comes wisdom.. Leading me onto....

This newsletter contains a couple of articles from Post Polio BransonGoers Newsletter June 2017. Millie, author of **With Age Comes Wisdom** [page 8] I have met on a few occasions including the 2nd BransonGoers reunion in 2000 is a brilliant writer and we have featured some of her other articles in previous newsletters. As I read down her Newsletter I thought about the quite a few operations that have gone similarly wrong for our members have had since we founded in 1996. I decided we could all benefit from reading **A Cautionary Tale about Post-Polio Shoulder Surgery: One Story, Three Perspectives** by Sunny Roller, M.A. and Frederick M. Maynard, M.D. [both of whom I have met a few times at PPS Conferences] was too important not to share with our members. The points raised do not just relate to this shoulder surgery although Richard experienced this with this operation and two others. Other members have also had surgery where the surgeons professed knowledge of polio did not result in the promised outcomes. I added a couple of points to this from our own experience.

TEXT BOX ON FRONT COVER. MY DIAGNOSTIC LABEL IS NOT WHO I AM.

Following on from last newsletter where there was lots of advice about preparing for hospital visits and emergencies, I would now like to add another suggestion.

Recently I had the opportunity to view some polio survivors records where the patients were unable to answer questions at the time and their diagnoses were leading the assessing health professionals down the route of 'poor outcome'. Medical professionals, where polio has been eradicated, are taught very few facts about polio and often alongside pictures of iron lungs, atrophied limbs, scoliosis, callipers, wheelchairs, arm crutches. There is often little mention of how well the majority of people recovered and rarely any mention of Post Polio Syndrome.

Do not allow health professionals to label you as your diagnoses [and we usually have more than just Polio and PPS] Make sure your family and friends that will be with you or contacted tell the doctors a little about your life.

This is my suggestion and I have already done this for both Richard and I. Prepare an extra sheet for What You Need To Know about my Condition adding a few photos and info that will quickly tell any health professionals you come into contact with a little more about who you really are. Not only the educational, sports, hobby, employment qualifications but how many children you have brought up, voluntary work you do, places you have been, etc.

One side - Ten things you need to know about Me with the photos and the Other is Ten Things you need to know about how I manage my conditions. We cannot have a standard list because we are all different.

One not to be left out is. Assessment of my Ability will provide more accurate information if you ask me How Do I Do the Action, not can I do it.

If you had or have paralysis add this one. Paralysis in Polio is not the same as a spinal injury. I have full sensation in that leg but it can get cold through poor circulation.

I sleep best on my left side in the recovery position.

If you were the Doctor assessing you, what would You want to know about You?

MESSAGE FROM OUR CHAIR

Social Justice and Healthcare

This July I had the pleasure of being invited to give a short presentation on the theme of Social Justice and Counselling Psychology, along with several other Counselling Psychologists at The British Psychological Society, Counselling Psychology Annual Conference in Stratford Upon Avon.

Following the keynote speech from Dr Lawrence Gerstein of Ball State University, USA, it occurred to me that, despite the many shortcomings of its healthcare system, psychology in the USA has embraced some of the critical concepts that our health professionals still struggle with in the UK. For it would seem that we still adhere slavishly to the medical model which treats conditions and symptoms, championing cure and marginalising the individual's unique experience and the quality of life of those who do not fit the model, referral criteria or priority treatment group.

The Invisible Costs

Many of us have lived our lives successfully adapting to the day to day impact of our 'condition' whilst others struggle as the dramatic impact of PPS hit them 'out of the blue' after what appeared, erroneously, to have been a full, or virtually full, recovery. Whichever you identify with as a survivor of polio, the impact of living with this on our health and wellbeing was, and is, immense. We may try to minimise, or deny this fundamental truth in order to feel triumphant, strong, or often just be seen to pass as 'normal' but it remains self-evidently a fact of our lives.

It isn't All Medical

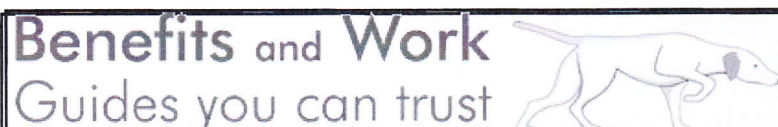
PSN exists to promote, educate and disseminate information and support polio survivors as well as educate professionals. However, we must be aware that explanations that are purely biomedical and locate 'The Problem' within us the individual and our 'disease' or 'condition' are bound to only partially and incompletely address our experience living with polio and PPS. Hence the boost we feel when we are listened to and the subsequent crash when the follow up fails to address and meet our real concerns or problems is not easy.

The huge impact of the social and economic context in which we live determines how we experience our lives and impairments. Healthcare is not a single 'one size fits all' discipline but should be addressing quality of life and well-being. Whilst we may struggle to get orthotics, wheelchairs, PPS diagnoses, assessments and support, the reason these are important is because it makes us more visible, autonomous and enables a sense social worth and inclusion. However too often this is ignored or more than any medic or service can achieve in isolation.

Social Inclusion and Health

This brings me back to the role of Social Justice and Health professionals ability and willingness to see it as part of their ethical and professional practice. It is important to acknowledge that certain services, appointments, treatments and support are not available for Polio Survivors and other disabled people because of economic and social policy, not an inevitable symptom of our health, diagnosis or condition. I feel strongly that all health professionals should to be aware of, and where possible involved in, promoting social justice in their work with us by acknowledging the role socio-political and economic issues has upon us, them and the system as we strive together to improve all our lives.

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.



www.benefitsandwork.co.uk/
140,000 fortnightly newsletter
subscribers about ESA DLA and PIP

TWO DELICIOUS SWEET POTATO & CHOCOLATE RECIPES

Flourless Sweet Potato Brownies - DB March 2017 - healthy-holistic-living.com

We're always looking for ways to indulge in our favourite pleasures without the guilt. Brownies. Now, with this amazing recipe, you can! Everything you need to know about flourless **100% gluten / dairy free** sweet potato brownies!

What makes these brownies so healthy?

Natural sweeteners: Consuming anything that contains natural sweeteners rather than artificial is tenfold better for your body.

Sweet Potato: Naturally sweet and improves blood sugar regulation.

Anti-Inflammatory Benefits: The agent responsible for giving sweet potatoes their color, Anthocyanin, is full of anti-inflammatory health benefits – namely benefiting the brain and nerve tissue.

Vitamins: Sweet potatoes are great for boosting your immune system as they're loaded with vitamins A and C, as well as B6, B1, B2, and B3.

Minerals: Sweet potatoes are full of manganese, copper, phosphorus, potassium, and fiber; all working together to keep your blood, digestion, and whole body healthy.

The Supplies

1 cup mashed sweet potato
½ cup smooth nut butter of choice
powder
2 tablespoons maple syrup
¼ cup cocoa powder
Handful of chocolate/carob chips

The Dirty Work

Grease a small cake/loaf pan and preheat oven to 350F/
Melt nut butter and maple syrup then mix with the mashed sweet potato
Add the cocoa powder and mix then fold in the carob/chocolate chips.
Pour mixture into greased pan and bake for 20 mins or until cooked through
Remove from oven, allow to cool completely before slicing and refrigerating.

If you found this delicious recipe worth passing on, please share with your friends and family.

FLUFFY VEGAN [& egg free] CHOCOLATE MOUSE [with AQUAFABA]

Ania @lazycatkitchen is part of an inspiring Facebook group solely dedicated to making things with aquafaba and everyone who tries to **whip chickpea water like egg whites** has the same reaction of amazement mixed with the excitement of opportunities of making other vegan food and also for people with an egg allergy.

INGREDIENTS and METHOD

1 cup mashed sweet potato [approx. 225g / 0.5lb sweet potato]
120ml / ½ cup smooth 100% hazelnut butter*
50g / ½ cup cocoa powder
6 tbsp. maple syrup
120ml / ½ cup aquafaba / chickpea brine**
1/s tsp apple cider vinegar [or lemon juice]

1. To cook our sweet potato, set up a bamboo or other steamer over a pot of gently simmering water. Slice your potato into 1.5cm / 0.5" slices and steam for about 20 minutes [until very tender]. Cool before proceeding.
2. Place cooked [peeled] sweet potato and hazelnut butter in a food processor. Process until very smooth and well combined, then add cacao powder and process until smooth. If you want to sweeten the mousse with dates, process the dates and sweet potato first, then add hazelnut butter and cacao. Please be aware that dates won't produce an end result quite as smooth as with maple syrup.
3. If using maple syrup, add to the sweet potato, cacao and nut butter mixture. Process until smooth.
4. Place aquafaba in a clean [that's very important as any grease residue will prevent aquafaba from foaming] glass or metal bowl. Add vinegar [or lemon juice]. Whip it until you achieve stiff peaks—you should be able to invert the bowl and the whipped aquafaba should not budge an inch, if it does it means that it has not been whipped enough.
5. Fold whipped aquafaba into the chocolate mixture until the two are well incorporated. The mixture will deflate a fair bit, don't worry, that's normal. Spoon the mixture between 4 small glasses [my ramekins hold 180 ml/ ¾ cup each] and place in the fridge for 8 hours [or overnight] for the mousse to set and then EAT.

Smooth almond or peanut butters would work well too. If using homemade nut butter, you may be able to detect tiny particles of ground nuts in the final product. For best results make sure your nut butter is super smooth.

Instead of maple syrup you could use softened dates [plunge into boiling water for 20 mins, squeeze the excess water out]. Process with the sweet potato. It will not be as smooth.

Aquafaba - The word *aquafaba* is the common name for the cooking liquid of beans and other legumes like chickpeas. You may know it as the typically discarded liquid found in retail cans and boxes of beans, or as the liquid left over from cooking your own.

www.lazycatkitchen.com/fluffy-vegan-chocolate-mousse/

Why are neurological conditions continually left out, in the Joint Strategic Needs Assessments [JSNA] for the next five years for some counties in England?

The Association of British Neurologists and the Royal College of Physicians - Local adult neurology services for the next decade. Report of a working party. JUNE 2011.

Executive summary.

Neurological disorders are very common,

accounting for about **one in ten general practitioners consultations**,
[BMA media brief April 2017 is 340,000,000 - 34 million neurological GP consultations?]
around **10% of emergency medical admissions** (excluding stroke)
and **disability for one in 50** of the UK population.

They include many different conditions of varying severity, some very common and others exceedingly rare, from migraine to motor neuron disease.

Patients require access to different parts of the neurological care pathway at different stages of their illness (acute admission, out patient care and long term care). However, these are currently poorly planned and organised. Good management requires better integrated primary, secondary and tertiary resources to achieve a neurology network that is easily accessible, provides local care when appropriate and, when necessary, involves the regional neurosciences centre.

DGH [District General Hospitals] services have suffered particularly due to a lack of local neurologists, with an unplanned increase in outpatient demand driven by waiting time targets, inadequate resources and poorly structured services networked across health providers.

Acute neurology services are of particular concern because they are rarely provided by neurologists, in contrast to those for stroke and other acute medical specialities, resulting in potential adverse outcomes.

Despite these concerns, the central recommendation of the 1996 RCP report, to appoint neurologists with appropriate infrastructure support in every DGH, has not been achieved and has been outpaced by **spiralling demand**. Neurology remains a shortage speciality, with appointments mainly to the regional neurosciences centres and an inequality of more than three to one in the numbers of neurologist in different part of the UK.

Mid 2000 - Lincolnshire Neuroscience Forum [now Lincolnshire Neurological Alliance] at one of our bi-monthly meetings were given sight of their Specification for Neurology that was used by Lincolnshire Health Authority to commission services. We were astounded when we turned to the page listing the top 16 neurological conditions in Lincolnshire. Number 16 was Myasthenia Gravis with 24 patients. The MG representative informed the meeting that they had 112 members and not everyone joins and I informed the meeting that there were 5 support groups in attendance with more than 24 members that were not included.

With help from NHS Performance we learned at a meeting with the Chief Executive and the Director of Public Health that their statistics had for decades come from extrapolating population figures from published national documents. How many other local health authorities were doing the same thing? We later learned that most national figures were obtained by adding up local Health Authority figures.

Lincolnshire had population of 634,300 and No Resident Neurologist. Lincoln County hospital had one visiting neurologist ONE DAY A MONTH. [I saw him twice, in 1989 and 1996 but had to request a second opinion at another hospital before I received an 'all tests negative diagnose the post polio syndrome'] Statistics for how many people were sent out of county for neurology was not available. [I have just attended a meeting with Public Health asking the University of Lincoln Research to find some statistics they can use. Why have Public Health not done this before?]

LNF requested, and LHA agreed, that a survey of GP's with only one question 'How many patients do you have with any of the listed 32 conditions. Only 10.4% of GP's responded with a figure of 6,633 patients which multiplied up for just 32 conditions could be in the region of 66,000.

Following this extra clinics were offered and within weeks GP's were referring back in county and it was soon obvious that Lincolnshire Health Authority needed to develop their neurology services. Lincolnshire got its first Resident Neurologist, Neurophysiologist and MS Nurse.

United Lincolnshire Hospital Trust Annual Reports. Excerpted phrases where the word neurology/neurologist is included.

2001/2002 - Agreement to develop an in-county **neurology** service with the appointment of a consultant **neurologist** based at Lincoln. As a consequence of this a **neurology** clinic will be provided at Grantham for the first time and waiting times will reduce •

2002/2003 - In **Neurology** – Dr John Bowen, Consultant **Neurologist** joined the Trust. Based at Lincoln County Hospital, Dr Bowen also has outpatient clinics at Grantham Hospital A Multiple Sclerosis Nurse Specialist was appointed to work in conjunction with the Consultant **Neurologists**, and a multiple sclerosis centre was established in Lincoln. These two posts are part of the Trust's strategy to develop a local **neurology** service with Nottingham and Sheffield

2014/2015 The Trust has had significant activity challenges in two particular specialities - breast surgery and **neurology**.... The **neurology** service relies on visiting consultants and therefore it is difficult to be flexible with capacity, creating capacity shortfalls. The Trust has addressed these two specific shortfalls as part of the negotiation process with 28 commissioners and confirmed a level of activity that can be provided by ULHT. We remain committed to providing these services in 2015/16 and through these actions we can be more confident in providing a service that meets the NHS constitutional standards.

2015/2016 We deliver services across: The word **neurology** is included in a chart.

Lincolnshire JSNA 2013 to 2018 -we have committed to including more on **neurological** conditions in the JSNA and to consider this within the priorities at a future date;

The **Midterm Review 2015** does **NOT** have the word neurology/neurological in it.

The **current JSNA under discussion** does **NOT** include the word neurology. We come under Physical Disability and Sensory Impairment with 60,000 people in the County. [JSNA page 26]

http://www.research-lincs.org.uk/UI/Documents/JSNA%20Summary%20Report_Final_v1.4_040517.pdf

ABN reports 2011 and 2014

<https://shop.rcplondon.ac.uk/products/local-adult-neurology-services-for-the-next-decade?variant=6595193733>

<http://www.theabn.org/media/Acute%20Neurology%20Survey%20-%20FINAL%20Dec14.pdf>

MEMBERS

We think we have a problem with so few health professionals being taught about Polio in its first instance let alone how we recover and what we achieve during our stable period of functioning. Then we come to Post Polio Syndrome where it is very hard to find any health professionals with knowledge and experience of seeing Polio Survivors. We are not the only neurological condition in this position. Counties have services for Stroke Patients. Other neurological conditions mentioned are Parkinsons, MS, MND, Epilepsy and Acquired Brain Injury but that is about it.

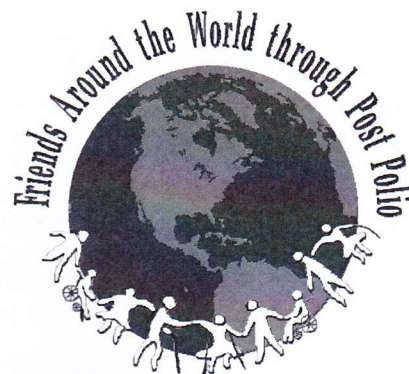
Do you know or can you find out if neurological conditions are mentioned in the Joint Strategic Needs Assessment for your area? If it is please email us a link so that we can compare those where neurology/neurological conditions are mentioned to those where it is not.

Thank you for your support.

Post Polio BransonGoers

Polio Perspectives – June, 2017

Millie Malone Lill, Editor Wilma Hood, Publisher



WITH AGE COMES WISDOM

by Millie Malone Lill

Sometimes. Not always, that's for sure. Sometimes age comes all by its little self. We are going to pretend it didn't in my case, OK? So today I will give you the benefit of my experience. You can't always learn from the mistakes of others...sometimes you ARE the others. Such has been my life.

First of all, remember the PPS Motto: Conserve to Preserve. As Dr. Bruno admonishes, if something hurts when you do it, either don't do it or do a lot less of it. That is great advice.

Rule 1: Do as I say, not as I do. I have been known to tell people to take it easy, don't sweat the small stuff and it's all small stuff. Stress is not good for us. I know you've read those words or words to that effect in many of my columns. However, I am still a typical Type A, with just a dash of Obsessive Compulsive behaviour. That trait has sometimes found me teetering on a ladder instead of waiting for someone to come help me. I don't recommend doing that.

Rule 2: Pace yourself. Do one major thing a day. If it is laundry day, just do the laundry. Don't try to do laundry, plus go to the grocery store, the library and the swimming pool all on one day. There will be another day, trust me. If there isn't, well, then it doesn't matter, does it?

Rule 3: Ask for help. That is without a doubt the hardest thing for most of us to do. We are used to being the go to people who help others, not one of those wimpy people who ask for help, right? It does make us feel good to help some out, so why not share that good feeling with others by letting them help us out?

Rule 4: Try to develop a positive attitude. I don't mean that you have to wear a smile all day, every day. It is a good thing to look at the bright side, though. And I most definitely do not recommend you have the "there is always someone worse off than me" philosophy. For one thing, how would you feel if someone saw you as the someone who was worse off than they are? Not very uplifting! Besides that, though, it diminishes your own value. You have a right to your own problems. If you are sitting in the ER with a broken leg, next to someone with terminal cancer, your leg is still broken. You have as much right to empathy as they do. Just try to think of something you are happy about. I write a list of five good things that happened to me every night. It's my gratitude list. It sent me to bed in a positive frame of mind. I heartily recommend it.

Rule 5: Your head bobs sideways as easily as it does up and down. You can say NO. If you are tired, but someone wants you to do just one more thing, form your mouth into an O, touch your tongue to your upper teeth, make that noise in the back of your throat followed by the O sound. Try it...NOOOO. See how easy it is? Practice it.

Rule 6: Give yourself permission to be joyful. Yes, I am well aware of what a mess the world is in, but I realize that my happiness doesn't make anything worse. At the very least, it makes things better for me and sometimes it also cheers other people up. Watch children play, listen to music, go outside and let the sun shine on your face and the soft breezes kiss your cheeks. Or enjoy the air conditioned comfort of your own home. Whatever puts a smile on your face. There now, don't you feel wiser already?

<http://postpoliobransongoers.org/>

Editors Note:- The story about Shoulder Surgery starting on page 10, I first read in Millie's newsletter. There is no time to read all the polio newsletters and websites so thank you Millie for the heads up on this one.

Post Polio BransonGoers 20th Anniversary Meeting June 1st to June 3rd 2018.

We gather once a year in Branson, MO. USA. We enjoy visiting with one another and learn from speakers and from other people who have had the same experiences as we have. Some are further along this path of Post-Polio... others not as far. Each has something to share; isolation, fatigue, concerns about the next step they should take, or experiences. Or, exchanging information, lending support, encouragement, and/or hope. All these lead to enhancing self-esteem. Along with the care and support polio survivors receive from their medical team, more and more of them are finding relief and comfort from participating in support groups.

We are here to promote independence and enhance the lives of all polio survivors. We do this by offering support, information and education, while raising national awareness of polio and Post-Polio syndrome.

Our guest speakers may address topics such as psychological adjustment, nutrition, exercise, durable medical equipment, braces and orthotics, power chairs, scooters, or home modifications. We welcome all polio survivors, their friends, family, and other supporters to join us, even though you may already be a member of a local support group in your area.

Editors Note: Richard, Hilary Boone and Tony Meladio attended the 2nd event in 2000 after the PHI Conference in St. Louis, MO. What fun we had as we hugged in real life, shared our stories and learned from others. Readers be assured that Polio Survivors family and friends are all welcome and will gain much from the event. Be warned though you are likely to end up with aching ribs from laughter from others odd medical experiences and the differences between English and American English. For instance Bum Bags are Fanny Packs, they do not call their cats pussies or feed them pussy biscuits, and in 2000 they had not heard of a Jacket Potato - you know the one where we turn back the lapels and make Tomato Ketchup ties.... Memories eh Millie...

If only you could 'Beam us up Millie'. www.postpoliobransongoers.org

Interesting Bits from PSN Member Barbara Taverner.

Polio Survivors can have swallowing, gut and eliminating problems. Recent items on polio lists have brought many out of the woodwork able now to discuss the other end issue. One medical term used is that we have Low Motility. It takes longer for food to get from one end to the other. The longer food remains in our large bowel the more water is extracted and normal movements can become [my husbands term] 'meteorites' and boy can these be hard to pass into their toilet 'space'.

Dr. Michael Mosley new book The Clever Guts Diet Book. £ 8.99. [Daily Mail 13.5.2017] - Excerpted. There has been an explosion of new and exciting research into the goings on in our gut that particularly focus on the 'microbiome' - the trillions of microbes that live in our intestines. Only recently have scientists begun to fully appreciate the hidden influence these microbes have on our lives, and it looks like this is something we have sorely underestimated. My book is based on scientific evidence, and which explains just what our gut bacteria is up to, and how it can best be nourished and cherished... At its heart is a simple message; eat the real unprocessed foods that have been shown to encourage the growth of the 'good' bacteria in your gut, and try to avoid or minimise the foods that feed the 'bad' ones.

Dr. Melanie's Health Advice in Woman's Weekly - Is your Gut in a Rut? Excerpted. If tests don't suggest a cure, simple changes to diet, or perhaps reviewing medications, may be the answer. .. We may notice any combination of indigestion symptoms, such as heartburn, acid reflux, poor appetite, trouble swallowing your food, excess burping or trapped wind, nausea, vomiting or tummy pain before or after meals, jaundice and/or unintended weight loss. [Editors note: have had some of these, found earlier this year had Helicobacter pylori bacteria and had a course of antibiotics and a PPI [omeprazole]. I also have a yeast/fermented foods issue so have cut yeast breads, cheese, anything that ferments, some fruits foods from my eating, added better probiotics - including Saccharomyces boulardii which have helped.

A Cautionary Tale about Post-Polio Shoulder Surgery: One Story, Three Perspectives

By Sunny Roller, M.A. and Frederick M. Maynard, M.D.

<http://www.sunnyrollerblog.com/cautionary-tale-post-polio-shoulder-surgery-one-story-three-perspectives/>

One must be very careful about choosing to have orthopedic shoulder surgery, especially if one is a polio survivor with a complicated disability. It's not because of the surgery itself. It's the complexity of the rehabilitation process and the uncertainty of functional outcomes that make it perilous.

A few months ago, we met with long-time friend, Liina Paasuke, over a lingering cup of coffee for a heart-to-heart conversation about her recent ordeal with shoulder surgery. Liina graciously told us her story that day. We asked her questions, listened, and took notes. Then the three of us shared ideas about how to proceed.

Since that empathetic and thoughtful exchange, we have individually continued to reflect upon Liina's difficult experience and have each come to evaluate the situation from our varied perspectives as the

Post-Polio: medical specialist surgical patient and friend/consumer

We first present biographical background information about Liina, followed by the account of her surgical experience. Dr. Frederick Maynard then reflects upon what happened from his perspective as a Post-Polio physician. He offers important medical information and insights. Liina then provides a personal update as she continues her rehabilitation process. Finally, Sunny Roller reflects upon the whole experience as a friend with a similar Post-Polio disability who, like others, may someday face the same decision—whether to have such surgery - or not.

Due to little previous discussion of, or experience with this matter, a decision about having shoulder replacement surgery can suddenly confront and confuse people who are growing older with polio or another neuromuscular disability. It is our hope that by presenting Liina's account and our individual perspectives of it, readers—both consumers and professionals – will more fully understand the issues and benefits of the choice to have, or to prescribe, shoulder replacement surgery (also known as Total Shoulder Arthroplasty or TSA).

Liina's Story

Liina was born in 1948 in a German displaced persons' camp. She developed paralytic polio at age 17 months as she and her Estonian parents were arriving in Michigan after an immigration journey to the US. She spent most of the next four years in a Grand Rapids, Michigan hospital and underwent several surgical procedures on her severely paralyzed legs. By age six, when she began mainstream schooling, she was able to walk only by using bilateral long leg braces, a corset and bilateral forearm crutches.

After high school graduation, she studied at the University of Michigan and earned a Master's degree in Guidance & Counselling. She had a 36 year career with the Michigan Department of Vocational Rehabilitation at the University of Michigan, mostly providing counselling for people with physical disabilities. During her college and early employment years, Liina was entirely independent in all personal and advanced activities of daily living (ADLs). She walked as far as she needed or wanted to go using her devices with minimal difficulty. She drove a regular car with hand controls. In 1979, she purchased a 3-bedroom home that she still lives in today.

Although Liina's general health remained excellent, by the early 1980s she found it increasingly difficult to walk long distances and experienced symptoms of Carpal Tunnel Syndrome. In 1984, she obtained her first motorized scooter, had a ramp built for entry into her home and purchased a van with a rear swing-arm lift for scooter transport.

Over the next 20 years until her retirement in 2006, she very slowly gained about 25 pounds and gradually decreased the amount of time and distance that she walked due to increased effort and greater fatigue. By 2006, she was essentially ambulatory inside her home only. She began dragging her right foot during swing and could not negotiate a single step. By 2010 due to slowly declining strength and endurance, she could no longer complete bathing and toileting in a regular bathroom. Voluntarily, her long-time church's congregation - The First Congregational Church of Ann Arbor - immediately raised money to partner with Liina and a home improvement contractor. Together, after Liina tapped into personal funds and the church garnered additional financial support, volunteers got to work to complete the necessary architectural modifications. Within a few months, they had fully redesigned and remodelled Liina's home bathroom, bedroom and kitchen for fulltime scooter use. This collaboration with an exemplary church enabled her to remain independent in self-care and homemaking, primarily from her seated position.

Beginning gradually in 2012, she developed increasing right shoulder pain, especially with overhead elevation and turning. After her physiatrist diagnosed her with rotator cuff tendonitis, she had some short-term benefit from several bouts of Physical Therapy (PT) over the next three years. Nevertheless, she lost Range of Motion (ROM) and strength in the right shoulder. Her pain levels rose and severe pain was more frequent

Her Choice to Have Surgery

By late 2015, Liina decided to investigate surgical options for her right shoulder problems because of concerns that further worsening would jeopardize her ability to continue to live independently. Her primary goals were to maintain the ability to walk a little in her home, to stand up after toileting and to reach higher objects in her home. Her secondary goals were to decrease pain and increase ROM in the right shoulder.

She was referred to an Orthopedic surgeon who specialized in upper limb joint replacements and who performed “Reverse Total Shoulder Arthroplasty” (rTSA). In this procedure, the head of the humerus is removed and replaced by a shallow cup that articulates with a rounded ball (head) which is implanted firmly into the glenoid fossa of the scapular bone. This newer procedure is thought to restore better motion and strength in people whose shoulder rotator cuff muscles or tendons are torn or completely frayed from degeneration and cannot be repaired.

The surgeon led her to believe that the use of her arm would be as good as before. However, she was unable to have him answer specific questions regarding the eventual post-operative function of the arm for routine weight bearing which was critical for standing up and for transfers. The doctor said that the right shoulder would need to remain immobilized and bound to her chest for 6 weeks and thereafter she could **gradually** do anything she wanted to do and was capable of doing with that shoulder.

Despite reservations, she decided to proceed with the surgery. To prepare, she arranged to stay in a ‘subacute rehabilitation bed’ at a rehabilitation center with a good reputation in her community. She also quickly purchased an adapted minivan with a side ramp that would allow seated entry using her scooter. The r-TSA was done on April 13, 2016 and three days later, she was discharged to the rehab center.

Rehabilitation after Surgery

She was dependent in all ADLs while her right arm was immobilized. She received therapy services and gained some modified independence in self-care using her non-dominant left upper arm and shoulder.

After four weeks, facility managers reported that they would very soon discharge her to go home alone because there were no further goals to meet *Medicare criteria* for her continued stay until she could use the right arm again. She knew she would be unable to function at home alone. Appealing this decision based on her pre-existing condition of Post-Polio paraplegia was unsuccessful, but the facility did eventually allow her to stay longer after a follow-up visit with her surgeon. He gave her permission to begin some controlled motion exercises with the shoulder and to use the right upper limb below the elbow for ADLs.

After a nine-week stay, the rehab facility discharged Liina to go home. She could now perform basic ADLs from her scooter with great difficulty— involving much time, effort and ingenuity. She received home therapy services for three months and increased the strength and ROM of the right shoulder. By five months post-surgery she was able to do all of her basic self-care independently with only mild to moderate additional effort and modifications than before surgery. She still could not stand up again after normal seated bathroom toileting, which limited her community re-entry.

Her right shoulder ROM was very good and she had no significant shoulder pain. When she began outpatient PT, her therapist noted surprising strength deficiencies in her shoulder’s scapular stabilizing muscles, which he determined had not been specifically targeted for strengthening during her home PT exercises. He began targeted strengthening exercises for the right scapular stabilizing muscles and advanced her generalized upper body-strengthening program in order to assist her reach the goals of standing independently after seated toileting and for reaching high objects from standing.

At seven months post-surgery, she felt ambivalent about whether the surgery had been “worth it”, but she was more hopeful about the chances of reaching her primary goals. She remained quite taken aback by how long her recovery was taking.

Looking back, she felt that her surgeon had misled, even betrayed her, with false expectations, conflicting messages and unresponsive communication. Before the surgery, he said that recovery would be easy. She soon recognized his lack of knowledge concerning the polio survivor’s potential challenges post-surgery. Since early on, he had ignored her questions. Her frustration grew when he would not return her emails and phone calls. He stated he had successfully operated on two other Post-Polio patients, but would not provide clearance for her to talk with them about their experiences. She continued to have some negative feelings about both his insensitivity and what seemed to be a disregard for her disability. At this point in her recovery, she worried more than ever about staying financially and physically independent.

Frederick M. Maynard, M.D.—The Post-Polio Physician’s Perspective

Identification of Surgical Goals

One important lesson from Liina’s story is how essential it is for people with chronic lower limb motor disabilities to identify their goals for having any shoulder surgery. This is particularly true for any functional goals that have been

lost and are hoped to be regained, or for functional goals critical for independence that are in jeopardy of being lost. While pain reduction and improved ROM may be desired, and are considered likely to be obtained from a successful surgical procedure, the achievement of any eventual post-operative goals dependent on higher levels of upper limb strength are harder to predict. Due to many unpredictable intervening variables, their achievement may require prolonged challenging effort by both professionals and patient. Honest and frank discussion about this reality pre-operatively between surgeon and patient can mediate any disappointing results.

Accepting the Lack of Medical Knowledge

A second lesson from Liina's story is greater awareness of how little the medical community knows or understands about the unique needs of people with chronic lower limb motor disabilities. This case in particular elucidates the current paucity of medical knowledge about successful post-operative restoration of weight-bearing function with the shoulders and upper limbs after a new reconstructive orthopedic procedure on the shoulder joint. Given the impressive results of TSAs for reducing pain and restoring functional ROM for otherwise able-bodied people, these procedures are likely to be offered to and considered by people with chronic lower limb motor disabilities more frequently in the next 10 years. This is a predictable result of first, the high frequency of shoulder pain problems observed among people with Spinal Cord Injury-related paraplegia (>80% incidence after 20 years post-injury). Second, it is inevitable that there will be greater need for TSA in the burgeoning older age cohort of people living with conditions such as Post-Polio, spina bifida, cerebral palsy, muscular dystrophy and other neuromuscular conditions who routinely use their upper limbs to bear full body weight. A medical literature review identified only two reports that addressed outcomes of TSA among a few people with paraplegia (including two patients with polio). [1] [2] Medical and surgical complications were numerous and functional outcomes beyond pain reduction and ROM were not well described. Just as hip and knee joint replacement surgery has become commonplace in the USA for treating older age-related "wearing out" dysfunction of these joints, shoulder joint replacement is becoming more widely and readily available. Many efforts at new and improved designs of utilized hardware and for surgical tactics are likely; but specific study, or even note, of the special needs, problems or complications of people with chronic lower limb disabilities having these procedures seems unlikely.

Current Recommendations

Not enough is known about post-surgical functional outcomes in people who regularly need to use both shoulders to support their full body weight. **Consequently, for the present, I recommend great caution when considering TSA or rTSA.** Clear goal identification for having any procedure, excellent communication between patient and surgeon about goals and special needs, and consideration of second opinions are also recommended. I am also promoting to my surgical and rehabilitation colleagues further investigation of strength and functional outcomes achieved after these procedures among people who rely on body weight bearing shoulder function.

Liina Paasuke—The Post-Polio Surgical Patient's Perspective

Post-Surgery Shockers

Now, **nine** months after her surgery, Liina reports that she is slowly regaining her strength and function, but is still not back to her pre-surgery capabilities. Astonished by the potent consequence of short-term muscle disuse for polio survivors, she has been dismayed by several post-surgery shockers. First, her total upper body strength is diminished, on both the right and the left sides. Second, crutch walking is now gruelling and, right after the operation, she could not even move her right leg to take a step, as she was used to doing before the surgery.

Third, Liina is functionally able to do a greater number of activities than she could right after her surgery, but she has also needed a greater number of environmental supports, which have been expensive. She purchased an adapted minivan and paid a contractor to construct a new door built into the sidewall of her one-car garage for entering and exiting her car, using the side ramp. She also bought an electric bed that raises, lowers, and has bedrails. She had more functional grab bars installed in her bathroom and bought a seat height extender for her scooter. She has newly hired a physical therapy assistant who helps her at home with exercises and some tasks around the house at \$15.00/hour, which is a reasonable rate. Liina discloses that all of these new adaptations at home have "eaten away at my confidence for any future travel that would involve staying overnight in hotels, condos and friends' homes."

Lessons Learned

Liina shares that she has learned first-hand how debilitated a polio survivor can become after just two months of inactivity. She was led to believe she would have a short recovery time. But even nine months after surgery, an all-encompassing sense of exhaustion when doing previously-normal activities has been overwhelming. As she now works to train her right shoulder muscles to compensate and operate in different ways than before, she cautions Post-Polio consumers to "carefully weigh any surgeon's expectation against reality".

She also recommends that the Post-Polio patient learn everything possible about Medicare payment guidelines. Scared that she would either be forced to go home alone before she could function, or have to pay out of pocket the daily cost of her nursing home rehab stay, she thanks Post-Polio Health International (PHI) for sending information

about Medicare's rehabilitation improvement standards. See article titled, "Judge Orders Medicare Agency to Comply with Settlement in 'Improvement Standard' Case, Provide More Education" at <http://www.medicareadvocacy.org/medicare-info/improvement-standard/>

After sharing this article with the Rehab Center, they got around it somehow, but she felt that at least it was self-empowering to wave it at them. She also warns not to trust the knowledge that an inexperienced social worker may have. Hers was not helpful at all. She also had a home physical therapist early on who was not helpful due to lack of Post-Polio knowledge. Often left to advocate for herself from her weakened position, Liina confides, "It's tough to fight when you're down". So, the advice is: **prepare**. Find a strong, enduring personal advocate before surgery and go into surgery armed with a list of resources such as senior centers, The Area Agency on Aging, Medicare, other insurance company numbers, PHI, local polio networks and support groups.

Liina has been home for seven months now and is doing regular physical therapy at home and at a special supervised physical therapy gym program. She has re-joined WeightWatchers to lose a little weight. She reports that the pain in her right shoulder is indeed gone and she moves it much more easily. She also reports that this experience has certainly been enlightening, but she would definitely think twice about having the same surgery in her left shoulder, which her surgeon recommended, if it further deteriorated. She is still not back to her desired level of functioning yet but is hopeful about making new gains. Liina says her story of surgery is definitely still a journey in progress. Maybe she'll know if it was worth it in two years...or so.

Sunny Roller—The Post-Polio Friend and Consumer's Perspective

As a polio survivor who grew up walking with crutches and braces and now at the age of 69 uses a scooter full time, I am very grateful to Liina for having the courage to reveal her private story to the rest of us. Even from the sidelines, hers has been a fear-provoking experience for me to witness and imagine. In the past, I had had first-hand experiences with broken legs that had taken nine months to heal and involved extensive rehab—and that was when I was much younger. What would happen with major surgery at this stage in life? At times, I was so worried for her. But I have also been impressed with her hutzpah. From my perspective, she took a huge medical risk. She chose to venture down the proverbial "road less travelled" not knowing what to expect; and it has indeed been a somewhat darkened and physically dangerous forest filled with ignorance and falsehoods to battle. But Liina is steadfast. She has been resolute about getting through this ordeal. She has been tapping in to her ingenuity and sense of hope all along the way, and is closer to her goal of continued independence with a shoulder that doesn't hurt.

My Take-Away Lessons

Liina has shared her arduous ordeal so we may better prepare for any future major surgery that might be prescribed for us. After being close enough to witness and empathize with Liina's experience, here are my take-away lessons:

1. We all have much more to learn about this type of surgery for polio survivors
2. If surgery is prescribed, always get a second or third opinion from a non-surgeon post-polio specialist
3. If you have a bad feeling about the surgeon and his office staff, trust it. Find someone else
4. Research all the alternatives to having this type of surgery. Consider thoroughly the future impact of any functional risks if you decide to opt out of this surgery
5. Know that muscle disuse in a polio survivor zaps previously accustomed strength and the ability to function and this is inevitable in any immobilized post-operative limb. Assume that the post-surgical rehabilitation will take much, much longer than anyone expects; then plan accordingly
6. Prepare thoroughly before the surgery. This includes:
 - Making sure the surgeon's team is informed about the proper cautions for anesthesia and recommended surgical recovery room procedures for polio survivors
 - Finding, even touring and interviewing at the best place for your rehabilitation based on location, skill, reputation, knowledge of polio survivor issues
 - Recruiting a loyal personal/professional patient advocate who will persevere and stand up for you through the whole process—from start to the point of fullest recovery
 - Tapping into your network of family and friends in advance for possible pledges of assistance; asking them to help mainly with what they are good at and like to do ("it takes a village!")
 - Gathering all information possible about resources that might be needed
 - Talking to occupational therapists in advance about home rehabilitation, care and recovery needs including possible home modifications
 - Talking with physical therapists about alternate ways to transfer and move about during post-surgery rehabilitation
 - Identifying post-polio specialists who will agree to consult with health care professionals about specific post-polio issues. PHI is a great resource for this information

- As if going away on a trip, preparing your home indoors and out for your potentially lengthy absence
7. After surgery and during the rehabilitation process, know that you and your advocate will need to teach most of your helping professionals about how best to care for you on a daily, even hourly basis
 8. Understand that recovery will not be easy, but it might be worth it. Weigh the pros and cons judiciously.

EDITORS NOTE I would add two more comments from personal experience to this very important article.

A. In 2001 Richard was to have Rotator Cuff Surgery and I was concerned at the surgeons 'no problems and recovery six months as normal' I wrote to Dr. Jaquelin Perry who recommended.. Firstly, you will need an electric wheelchair. Secondly see the power operative therapist prior to Surgery so they can see how you transfer and which muscles are working and ask her to put your arm in a sling and practice the post-operative exercises and all transfers that you will have to make so you can work out how you can do them without the post operative pain.

Brilliant advice. It took some practising to work out how to get up and down off the chair, bed, toilet and new electric wheelchair [previously had electric scooter] and in and out of the truck. It took a change of post operative therapist to one who knew more about PPS and her acceptance of 'I can do three repeats at a time then need to rest'. However, recovery took 15 months not six.

Sadly in 2006 his right shoulder received further damage following a fall out of his electric wheelchair [cataracts had lost him depth perception and he did not see the kerb] and less range of movement. Surgeons in the UK delayed making decisions knowing we were going back to the USA for the winter. However, the USA Shoulder Surgeon [yes in his facility there were shoulder surgeons, hand surgeons, hip surgeons, knee surgeons] decided that he would do this surgery on Richard and his arm would be out of action for three months.

I said, 'As you know he is wearing a full leg calliper on his left leg and uses a cane in his right hand to walk.' No problem', said the Surgeon, 'just use the cane in your left hand'. [Honest] We left with no more thoughts of surgery and he is still managing most tasks albeit with problems. The damage to his shoulders made putting a heavy calliper on and off and of course when walking it is the left shoulder that raises the left calliper leg off the ground and the reduced range of movement makes that impossible, so its electric wheelchair full time.

B. Manual Muscle Testing. Performed a single time it can give an erroneous result of the muscles power. If your muscles are over-graded then you have an added problem on top of health professionals lack of knowledge of polio and post polio.

In 1997 a neurologists medical report on me stated that the **power of my left leg, hip knee and ankle were normal.** I sat back in amazement. No medical professional writes something he does not believe to be true.. but how on earth did he get that result? I was paralysed waist down at age 5 and even after tendon transplants in both feet age 12/13 I still retained weakness in my legs, moreso on the left. If I bent my knees more than three inches my legs collapsed. I could not run.

Light dawned... there had to be something wrong with the form of testing as I had passed a medical for the Police in 1969 and I could NOT RUN. I nearly got thrown out of Training School the first day but for the fact that my Chief Constable responded that I had higher awards in Judo and Life-saving that were required for the Course and that the other three recruits from his Force had been accepted even knowing none of them could swim. [I taught them during Life-saving classes, I had higher awards than the PTI]. I did more research into this and found

Prof. W.J.W. Sharrard Muscle recovery in poliomyelitis. J. Bone Joint Surg (BR) 1955;37:63-9
muscle grades of 3 were given to individuals with 85% denervation of the muscles

Luiese Lynch. Manual Muscle Strength Testing of the Distal Muscles. Luiese Lynch
It does not measure the ability of the muscle to function as part of a movement pattern. "

Bohannon RW, Corrigan D. Percept Mot Skills 2000; 90:747-50
found that manual muscle tests of grade 5 had enormous variation in force, up to 86% of all quantitatively measured forces

I paid a private Physiotherapist for a full assessment and her report stated that my Quadriceps were 5, Normal. To use the Gym at the Sports Centre you had to be assessed and when I could not lift the exercise bar on the Quadriceps Exercise machine I was told 'you have something seriously wrong with your Quads', I then told him I had Polio,

Fred Maynard, M.D. - May 2002 - Marquette, Michigan, USA
President Board of Directors, Post-Polio Health International.

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

Lauro S. Halstead MD - May 2002 - Director of Post-Polio Program
National Rehabilitation Hospital, Washington DC, USA.

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

Letters over the last 16 years to Departments of Health, Colleges of Medicine all come back that Health Professionals are fully aware of this and take this into account. There is not enough time in the reduced time of NHS appointments to do more than the basic schedule. If you pass to normal on the first test they move on.

The Continuing Sagas of *Disastrous Dot!

You will continue to be pleased to know I remain free from injury and haven't attended an A&E department now for just over a year (fingers crossed, touching wood and anything else I can think of)!



This is indeed a record for me. We have now lived in Lichfield for four months (time seems to be flying by). I have not had any pavement skirmishes – it is obviously on 'his indoors' mind as he actually asked the neighbours which was the nearest A&E department as the local hospital only has a minor injuries unit.

It is Burton on Trent as we are in Staffordshire. We do not know where this is; we do know where the hospital is in nearby Sutton Coldfield as our granddaughter was hatched there. It is called Good Hope (although the locals call it something else Hope which I shall not repeat for fear of libel)!

SO....you must be wondering why Disastrous Dot as I haven't fallen? WELL.... See attached photo of my handbag of many pockets! I am very fond of said bag as the pockets are useful and I placed our passports and driving licences in said bag on the day we moved for safe keeping and thinking I would need ID to take to the Estate Agent when collecting the keys to our new kingdom! (said bag to be referred to as evidence bag number 1)!

Well..... a few weeks following our house move we decided to update the address details online for our above mentioned documents. The only problem was 'we' couldn't find them. 'We' as in me had decided I must have put them somewhere safe or thrown them out as they were not still in my handbag. 'Evidence bag number 1', including its many pockets, had been thoroughly searched frequently.

Thorough, frequent and repeated searches of 'EVERYWHERE' ensued. We stopped short of body strip-searches thank goodness! Unlikely places were turned over (garden shed, greenhouse, summer house) even the laundry basket (has a dodgy lining)! The mounting stress was now culminating in sleepless nights and nightmares of 'lost' documents on a par with Watergate or Hilary Clinton's lost emails. AND of course it was all my fault as I had them last! Unfortunately, I had no recollection of having removed them at all from the evidence bag M' lud – honest and swear on t'bible!! Passports and driving licences were eventually replaced at great expense.....

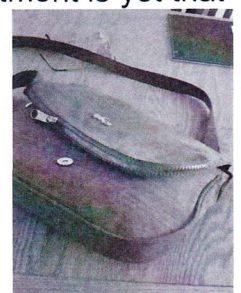
THEN, having lost our RSPB cards .. (there does seem to be a recurring theme developing here) that frantic search led to an amazing discovery of Darwinesque proportions.. the 'Evidence bag number 1's plentiful pockets includes the 'handy, 'safe' zipped pocket that of prior passport and licence guarding' zipped pocket was much bigger and deeper than I knew. Who knew? Who was to know? (not I M'lud)! Digging deep into the Tardis like depths produced not just the RSPB cards but..... I think you know! 'They' were there all the time, they had not been taken out and removed to a 'safe place'. They remained in a 'safe place' and I was carrying them around daily for 12 weeks!! Oops!.....

Suffice it to say that 'He indoors' has not murdered me (yet) and did vow **not** to mention it (apart from 10 times in the first 24 hours of the Great Discovery and after emailing everyone he knows..... Perhaps it is only because he hasn't discovered where the A&E department is yet that I remain undamaged!

I am blaming post polio brain fog – or just incompetence!

Dot lves

[Editors Note:- I wonder what D..... Dot will feature in our next issues...?]



Syria, Pakistan report new polio cases | CIDRAP.

July 5 2017

Stephanie Soucheray writes:

Another child in Raqqa, the ISIS-held city in Syria, is paralyzed after being infected with vaccine-derived polio virus, according to the World Health Organization (WHO). This is the second case in Raqqa reported in recent weeks. To date, there have been 24 cases of type 2 vaccine-derived polio in Syria this year.

In response to the latest case, the Syrian Ministry of Health is reported to be working with the WHO and UNICEF to consider adding Raqqa to the outbreak response, which would increase the targeted vaccine population by almost 120,000 children under 5 years of age. Syria said they have enough doses of monovalent type 2 vaccine (mOPV2) to meet this target.

According to the WHO, two immunization rounds are planned for July 8 and later in August targeting children under 5 years in Deir ez-Zor governorate and in the southern part of Shadadi district in Hasaka governorate.

However, a campaign in Raqqa is not yet planned because of ongoing conflict between ISIS fighters and the Syrian government.

AFP cases also climb in recent months [AFP Acute Flaccid Paralysis]

The majority of Syria's polio cases, 22, have been confirmed in the Deir ez-Zor governorate, with disease onset ranging from Mar 3 to May 28. Since January, there have also been 72 cases of non-polio acute flaccid paralysis (AFP) diagnosed in that same region. In Raqqa, there have been 10 cases of AFP not attributed to polio.

While oral polio vaccines are generally safe, they can cause problems in under-vaccinated populations. That's because the live-attenuated virus used in the vaccine can be excreted via the large intestine, allowing virus strains to circulate. That's the situation Syria is facing, where displacement caused by the terrorist group ISIS has led to uneven vaccination campaigns and children missing one or more vaccine doses.

Since 2000, the WHO said there have been 24 vaccine-derived polio virus outbreaks in 21 countries, resulting in fewer than 760 cases.

Fourth case of wild poliovirus detected in Pakistan

Meanwhile, media reports from Pakistan said the fourth wild polio case has been detected in an 18-month old from the city of Chaman in Balochistan province. This is the second case in that region this year.

Pakistan, along with Nigeria and Afghanistan, is one of three countries where wild poliovirus still circulates. According to reports, the 18-month-old's parents had refused oral polio vaccine.

Last year, Pakistan documented 20 cases of polio, a sharp decline from the 306 cases reported in 2014.

Source Article : <http://www.cidrap.umn.edu/news-perspective/2017/07/syria-pakistan-report-new-polio-cases>

5th July 2017 - Parity of esteem for people affected by neurological conditions - new report from the Neurological Alliance



The likelihood of having a comorbid mental health condition is higher for neurology patients than for the long-term conditions patient population overall. Yet the emotional, cognitive and mental health needs of neurology patients have tended to be invisible, even within policy on neurological conditions. The impact of this is reflected in the Alliance's 2016 patient experience survey, which revealed that just 19% of patients described services to meet their mental health needs as 'good' or 'excellent', against 45% describing services to meet their physical health needs as 'good' or 'excellent'.

<http://www.neural.org.uk/updates/281-parity%20of%20esteem%20mental%20health>

29th June 2017 - Going the Distance 2 - our new national calls to action to improve neurology services

In this report, we again examine neurology's representation within the health and social care quality improvement system, applying six tests to assess how well it is set up to drive neurological service improvement. We also put forward some practical calls to action for adoption by the relevant stakeholders, including NHS England, the National Institute for Clinical Excellence and the recently established National Neuro Advisory Group.

This report, alongside our patient experience survey report from earlier this year, provides a solid basis for our work throughout the rest of the year. We intend to work with key stakeholders and use this report by:

- sharing it with influencers and decision makers and discussing adoption and implementation of the calls to action;
- supporting the relevant organisations in implementing our calls;
- using the six key tests to assess the progress of England's neurological service improvement drive.

<http://www.neural.org.uk/updates/280-Going-the-distance-2017>

23rd May 2017 - Neurological Alliance Manifesto published

We set out five calls for improving neurology services, based on what thousands of patients with neurological conditions have told us about their current experiences of navigating through the health service.

We are asking all parliamentary candidates to help us address these key issues for the millions of neurology patients in England:

<http://www.neural.org.uk/updates/279-2017-Manifesto-published>

14th March 2017 - New report: how has neurology patient experience changed since 2014?

Today the Neurological Alliance releases its new report: **Falling Short – How has neurology patient experience changed since 2014?** This shares the findings of a survey carried out by the Alliance last year, with responses from thousands of neurology patients. The report reveals that services to diagnose, treat and provide on-going care are failing patients across the spectrum of neurological disorders.

The Neurological Alliance is now calling for neurology to be prioritised within the NHS and for new opportunities to improve the system to be implemented.

Analysis of the new survey data shows that patient experience in every area – the time taken to receive a diagnosis, access to specialists, on-going care and support – has significantly deteriorated in the last two years. With the number of neurological cases in England estimated to be 12.5 million and NHS expenditure on neurology amounting to £4.4 billion in 2012/13, this is a troubling finding, which potentially impacts millions of people.

http://www.neural.org.uk/store/assets/files/668/original/Neurological_Alliance_-_Falling_Short_-_How_has_neurology_patient_experience_changed_since_2014.pdf

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 15th September 2017

Editors Note:-

**Articles from Polio Survivors, family and friends 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, Membership & Email enquiries - Dorothy [Dot] Ives - dot.ives@poliosurvivorsnetwork.org.uk
Treasurer - Margaret Marris - margaret.marris@poliosurvivorsnetwork.org.uk
Newsletter Editor - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk

Operations Team

Phone Enquiries - 01522 888601 [Hilary Boone]
Email general enquiries - info@poliosurvivorsnetwork.org.uk [Dot Ives]
Printing and Website - Elpeeko Ltd, Lincoln.

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

Membership

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

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

Membership Fees

UK Individual - £ 12.50 per year [Renew on 1st July or 1st January after date joined.]

Associate Membership - £ 10.00 per year

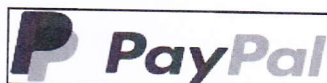
Yearly fees can be paid by Standing Order.

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

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

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

Email:- membership@poliosurvivorsnetwork.org.uk



All Forms are available on our Website,
by phoning our helpline or writing to us.
<http://www.poliosurvivorsnetwork.org.uk/>

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.

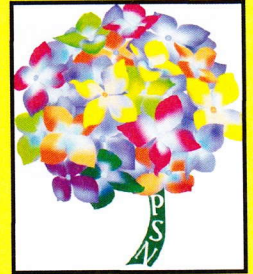
If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%).

Polio Survivors Network

Lincolnshire Post Polio Network - Registered Charity No. 1064177

Website - www.poliosurvivorsnetwork.org.uk

Email - info@poliosurvivorsnetwork.org.uk



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

www.post-polio.org

Triumph ON Baker Road

How the Walsh Family Defeated Polio



By Rose Walsh Landers and Mike Waller

With Sue Walsh Cocoma

The year was 1955, the month was September.

Keron and Anne Walsh and their 14 children were on their family farm preparing for the opening of the new school year in the small town of Durand Illinois, when 5 year old Rose complained about a terrible headache. An immediate trip to the family doctor identified the culprit - Rose had contracted polio, one of the most dreaded diseases of the era. And the new vaccine to prevent polio was in short supply.

Within less than a month, 11 of the children were diagnosed with polio, five of them with cases so serious they had to be hospitalized. Thus began the two-year siege that the Walsh family confronted with courage, prayers and their strong Irish Catholic faith.

They received never-ending support from both of their families, from their hometown and from across the nation. Hundreds of relatives, neighbours and friends, especially their family doctor and parish priest, flocked to their home to lend a hand and thousands more from across the nation and around the world sent money, cards and letters, all wishing for a speedy recovery for the children.

But it was the remarkable perseverance of Keron and Anne Walsh that led to the 'Triumph on Baker Road'.

Printed in the United States createspace.com \$16.95.

Please be aware it is much more expensive on amazon.co.uk

Editors note:

Bill Landers has kindly sent PSN a copy of this book for our Library of books by Polio Survivors. It is a very interesting read, specially for me as I remember nothing and I was 5.



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[Samples on every newsletter]

Order by writing to PSN

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