POST POLIO MATTERS

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SEPTEMBER 2018
Issue 103

STOP PRESS

Post-Polio

RESCHEDULED WEBCAST
6.00 pm UK
1.00 pm ET

"Best of PPS"
with
Richard Bruno,
Pa Polio Survivors Network

See back page

Rotary club of Bangor light up Menai Straits PURPLE
see back page

Home of the Lincolnshire Post Polio Library

Enter 100+ articles

SEPTEMBER 4TH 2018
THE DAY OUR WEBSITE WAS HACKED

OCTOBER 12th 2018
OUR WEBSITE is RELAUNCHED
MAINTENANCE WORK CONTINUES TILL END MONTH

OCTOBER 27th 2018

OCTOBER 24th 2018
WORLD POLIO DAY

Therapeutic Cannabis and the Post Poliomyelitis Syndrome (PPS)

Dr. Peter Brauer MD

Pages 12 to 16

Photo: https;//pixabay.com.de

POLIO SURVIVORS SHARING INFORMATION

Polio Survivors have always been strong willed, determined folks who have done everything they can to prove to the world and themselves that they can achieve highly regardless of the level of disability polio left them with.

When you eventually admit to yourself that you cannot do as much of an activity at once as you did a few years ago and are more exhausted afterwards it is hard to deal with. Instead of that lovely sunny day person you notice black clouds forming that seem to get bigger the more difficult things become and you wonder what next.

It can be very difficult to talk to your family and friends about how you feel but what we don't often realise is that it is also difficult for them. My kids told me that they hated seeing the mum who did so much for years now struggling but I kept turning down their offer of help so they stopped offering and then I became annoyed with them because I could not understand when seeing me struggle that they did not offer to help. It was a no-win situation till we sat down and took a couple of minutes each to say how we felt about a long list of things…
What an eye opener that was. SEE PAGE 3 for more information...

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

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QUICK NOTES

1. Our Website was hacked 4th September.
2. Our Website now relaunched with many new services. Two more weeks work to upload all the information. Let us know what you think about the new format.
3. Thanks to Legacy from Ms A Brown and to ensure as many as possible can have access to our information we have decided that Membership of PSN is now FREE.
4. Donations towards the cost of our work, mainly the printing and publishing of our Newsletter, Post Polio Matters always welcome.
5. Share information to manage your post polio life easier. What do you need help with and what solutions - no matter how small - have you found that helped you.
6. Carers and Family members do you have questions?
7. We now have two part time employees - Philip who has taken over the PSN Admin and Michael who is already researching the latest Post-Polio information.
8. 24th October is World Polio Day, watch Rotary Celebrations in Philadelphia - information is on the back page.
9. Rotary Club of Bangor light up the Menai Straits Purple, the colour of End Polio Now.
10. Pennsylvania Polio Survivors Network with Richard L Bruno, HD, PhD rescheduled webcast "The Best of PPS" on 27th October 2018. More info back page..

Editorial by Hilary Boone

Apologies for the delay in your receiving this issue, next issue will be available before Christmas with a deadline for sending us information of December 4th 2018.

This year has not been easy, problem after problem, more and more paperwork for benefits and direct payments. Now six months after completing Richards Personal Health Budget we have to do it again next week because their rules have altered**.** From March 2019 you now have to tell Pension Credit of every increase and when it happens. Other Lincolnshire users/carers I am in touch with agree that the paperwork is increasing and taking huge amounts of the energy we have to live on out of our lives.

Then September 4th in the middle of a Lincolnshire Neurological Alliance meeting at my home I went online to look something up and my laptop seemed to have a mind of its own. Thankfully my PA Leah was here and quickly established that our **PSN Website had been hacked and loaded with loads of Trojan viruses.** Leah replaced the Website with a holding page and tracked the hackers IP address to Mumbai. She contacted our Website hosting company and explained what had happened. They insisted she go through a series of questions but ended up confirming that she was right and had taken appropriate action. They would now take this to a higher level and email us in two hours. Six hours later our Website was suspended due to terms of service violation, which was not true, and Leah could no longer access our client area where she had been talking with support. I made a Skype call at 10pm to Customer Services in the States and after a very frustrating hour long discussion they recommended we pay $50 a month to maintain the security. Leah advised 'No, they are not providing you with good service you need to move to another company'. So we set an account up with a different company and in the time when not working for us and looking after her family - she has been working very hard to relaunch our Website. She found a huge number of incorrectly loaded items on our old site framework - including a games app, duh! - and has had to start again from scratch writing all new code for the pages so they are accessible by all electronic formats. By the time you receive this you will find the updated format now live - with many new facilities. We hope most maintenance work will be complete by the end of the month.

It is 21 and a half years since we started Lincolnshire Post-Polio Network and up to now all the **work has undertaken by volunteers** mostly polio survivors themselves. We would like to thank them all. Thanks to the generous legacy from Ms. A Brown we have now recruited our first two part time staff through the University of Lincoln Job Shop. Philip will be taking on all the PSN admin work as psnadmin@poliosurvivorsnetwork.org.uk and Michael has taken the post as our Researcher, researcher@poliosurvivorsnetwork.org.uk. More about them in our Christmas Issue.

To ensure everyone seeking information about PPS from us can now afford it we have decided that **Membership is now FREE**. To join there is a new easy to use online facility or alternatively you can Email psnadmin@poliosurvivorsnetwork.org.uk or write to us. UK Members will be able to receive their newsletters and other information by post, by email as a pdf, or both. Donations towards the cost of printing and posting the newsletters will always be gratefully accepted online or by post. Overseas Members will receive information and newsletters as a PDF by email.

We look forward to receiving loads of 'this has helped me' items for our Xmas issue.

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 December 4th for publishing before Xmas.

MESSAGE FROM OUR CHAIR

Trustees.

I must first start by saying thank you to two of our Trustees, Dot Ives and Margaret Marris, who have been a tremendous help to us over the past few years and now have stepped down. Naturally this created a need for more trustees and committee members who can help us in the work we do to bring information and support to polio survivors and health professionals. Zsuzsanna Snarey has agreed to join us a Trustee and we have another candidate in process but would love to have more. Please get in touch to learn more.

An Exciting Future

I must say that this is potentially an exciting time to get involved, however little time you might have, as we are moving towards making our information and website more up to date and user friendly, both for members and health professionals. This is long overdue and as we now have some funds for this, we are moving forward on this vital project. We have also just engaged two part time staff who will be able to help us with day to day tasks but importantly keep in touch with you as members and others and get to know more of what you want as well as keeping us at the forefront of research and treatments for post-polio and polio people where that is being carried out.

Strength in Numbers

I am appealing to you, as part of this, to help us increase our membership by talking to other polio friends and contacts and make clear that we are now FREE to join, that we are here to improve information and do not compete but compliment the work of others such as the British Polio Fellowship. Unfortunately, we lost contact with a number of our members when we needed to update our contacts with GDPR and the more members we have, the more people and those such as health professionals take note of us. There are many polio survivors out there so please encourage anyone you know to sign up. Remember again it is FREE.

The hacking of our Website set us back a few weeks and caused an awful lot of extra work. I must thank Leah for all the hours that she has spent, sometimes late into the night, bringing the content up to date and accessible by all electric formats. The result however is that we have now relaunched our site with new and improved services. Just a couple more weeks and the Website work should all be complete.

We hope that by increasing the amount of information on our Website and making it all searchable [including the newsletters] that we will begin to have a bigger impact on how polio survivors are treated, assessed and advised as well as ensuring professionals, as well as polio survivors themselves have access to the latest research and information from around the globe to equip them in their day to day lives and bring to their health professionals attention. We believe we are unique in this in the UK and so it is important that we grow in influence and numbers.

Stop Press. Carol Ferg from the Pennsylvania Polio Survivors Network has contacted us to let us know that their Webcast with Dr. Richard L Bruno "The Best of PPS" has been rescheduled to the 27th October 2018. It will be available for 3 days. Information is on the back page.

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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.

We know that it is extremely hard to hear a health professional tell you for instance ‘you need to give up working; you need to use an electric scooter or electric wheelchair now; or employ someone to do the heavy housework’; etc., and know that many of you will have answered like we did at first ‘but I am not there yet’.

In late 1996 about ten months after I found PPS existed I replied ’Oh, I am not there yet’ to a Registrar in Lincoln who told me that I need to change the way I did things. He picked up our newsletter off his desk and asked me ‘Who wrote this article?’ I was proud to say ‘I wrote that’. He then said, ‘I am sorry but you cannot expect other people to take advice that you will not do yourself’. I had to admit he was right which was hard.

We are so very proud of all our achievements since polio and are renowned to be very determined, pig headed, ‘do not need any help thankyou’ folks. Thinking about making changes just flashes up the ’I am not there yet’ brick wall. However, PSN has found over the last 22 years that it is much easier to read an article by another Polio Survivor telling of a new problem and what they have done to overcome this and maybe try it when no-one else is looking.

If you have been the only person being assessed for equipment then you have probably experienced feeling somewhat awkward - many of us have shared this information - but definitely have more fun if we can be with others with similar issues. Have you ever been to Naidex/ Disability Exhibition/Motability Event/Large Disabled Equipment Store where other disabled folks are in the majority?

See the article on Cystitis, UTI’s and Issues with our Guts where we are asking for members and other polio survivor readers to share information with us. What issues do you have and if you have found something that makes life easier please share it with us.

The other headings to start with are:-

1. How our family and friends have and are coping with our changing ability.
2. How do/did you feel having to go back to wearing or for the first time start wearing Braces/Callipers, Ankle foot orthoses [AFO’s] or Knee Ankle Foot Orthoses [KAFO’s].
3. How do you cope with Health Professionals who it appears have very little knowledge of how Polio affected us in our earlier lives, how we recovered and how much we achieved during those stable years and Post Polio Syndrome. Did they admit to knowing or not being taught very much or were you like many of us told ‘It does not exist or you do not have it’ at the start of an appointment.

We recommend to members and those that enquire for information that you practice what you might say to a new health professional before an appointment. If you were that health professional who had not been taught or had experience of many polio survivors issues how would you feel if you turned up to see you? I would NOT have wanted to meet me in the my early days of trying to get my pps issues assessed. Certainly makes you think… I am more prepared now to ensure that I tell it like it really is and make sure that my answers give health professionals enough information to understand how I perform the action that they have asked me about. [Painting the same Picture in their mind that matches yours is very important and the title of my presentation at the 2nd European Polio Conference in Amsterdam in 2014. Information from this presentation was featured in our special double issue 100th Newsletter. This presentation is not available online at the moment but the EPU are looking into this for us.

https://www.informed-scientist.org/presentation/painting-the-same-picture-can-provide-better-clinical-outcomes?symfony=31fc6c1fcd6e8fdac4677ef3e5a7fd8f [Unavailable at time of printing]

Meet Zsuzsanna Snarey, Trustee and Secretary

Even though I had polio as a child, I had always been very healthy. With the help of my mother, I overcame my disability and coped with life as if I were able-bodied. I was not able to run and I always used a stick but that did not stop me from working. I married and had three trouble free pregnancies and easy births. I became a part time teacher, I kept our house clean and tidy, did the shopping, attended evening classes in pottery, learnt to play the violin and joined an orchestra, later I joined the Manwood Singers and stood for long hours in concerts. I could lift if not carry heavy shopping bags, school books and when I became a chiropodist I managed to lift and pull my chiropody case and visit people in their homes as well as seeing patients in my surgery.

I was quite used to tripping and falling over but that did not worry me, I could always get up and hardly ever did any real damage until one day in January 2001 my good knee gave way in the shower and I cut my right shin on the edge of the shower tray. There was a lot of blood and my first thought was to stop the bleeding. So I lifted my leg up and supported it on the wall while I called to Michael to get me some bandages from the surgery downstairs. I stopped the bleeding and bandaged it so well that when the ambulance people arrived they were quite satisfied with my efforts and I walked down the stairs to be taken to the hospital. I had a V-shaped wound which was stitched up with 27 stitches and I was sent home with antibiotics. Even though I was on antibiotics the wound became infected and had to be dressed in the hospital twice a week. I realised that I should have washed the wound with cold water before dressing it and in the hospital, they did not clean it either because they assumed it had already been done. After about four weeks the wound became gangrenous and I nearly had to have a skin transplant, but when I was allowed to dress it myself daily it began to clear up and eventually healed.

In 2005 I was diagnosed with breast cancer and had to stop taking HRT which I believe helped my muscles and my joints because soon afterwards I started a steady decline. I started having joint pain and my stamina decreased dramatically. Two operations and two anaesthetics did not help either. The following year we bought a folding wheelchair to take on holiday which was liberating for both Michael and I and the year after that I had a Pride GoGo electric buggy. In 2011 we flew to Budapest with my family and took a small folding buggy, called a Luggie on the plane.

The day before Christmas 2014 I had a surprise, I was diagnosed with Hepatitis C. I have no idea how long I have had the disease caught from infected blood which also has harmful effect on the body. It may have contributed to my failing muscle strength. I could have picked it up in the hospital in 2001 although one doctor suggested that it was caused by the blood transfusions sixty-five years previously! I was hoping to have treatment but after two years of fruitless waiting I decided to buy the drug privately from India and took the twelve week course. I was cured within four weeks. I have by now overcome three possible killer diseases: Polio, breast cancer and Hepatitis C not to mention falling headlong down the stairs three times. It is possible that any one of these had an effect on my mobility, but it is impossible to know which one had the most decisive influence. Another reason for declining strength is getting older. We lose precious neurons daily.

For quite some time I have been using a wooden stool to do the cooking. I now have a hairdressers' stool on which I can scoot about as well as lower and raise myself. I sit down to use the vacuum cleaner, sometimes on the computer chair and I use the mobility buggy for trips to the shops and to cover any distances outside the house. I expect the day will come when I will have to use a wheelchair even inside the house, but I try and keep going as long as I can without it. I have a UTX swing caliper for both legs. It took many years of persistence to get them from the NHS.

I spend my time now in doing mainly sedentary occupations, such as writing, reading, studying mostly on the computer, having spent 18 years looking after people's feet. But I am aware of the fact that too much sitting is not good for me, so to increase my strength I stand up from time to time and also try to do exercises.

Fifteen Year Old Wife by Margit Bozzay translated by Zsuzsanna Snarey nee Bozzay is available on Kindle.

Cystitis in women by Zsuzsanna Snarey.

Cystitis affects four out of five women at some time in their lives. There is much self-help information in a book ‘Understanding Cystitis’ by Angela Kilmartin excerpts from which are given in the following article. Angela Kilmartin has published several books on the subject and they are available on Amazon or other bookshops.

Cystitis is a general term for infection or unexplained bladder problems. It is a diagnosis but it does not explain the cause of the problem. A woman is susceptible to infections because the delicate openings of the urethra and the vagina are so close with secretions containing a variety of organisms while the rectal orifice which is further back has many more organisms which harmful when out of their natural environment and not checked by effective hygiene.

Cystitis can result from infection or bruising and can be either ascending from the perineum or it is already present in the kidneys and the bloodstream and descend from the bladder. Symptoms are pain, burning or stinging when urinating, increased frequency of urination, sometimes uncontrollable and urgent, feeling like you need to urinate again soon after going to the toilet, urine that is dark, cloudy or strong-smelling, pain low down in abdomen, feeling generally unwell, achy, sick and tired and also having blood in the urine. In adults, cystitis doesn't usually cause a high temperature (fever). If you have a temperature of 38C (100.4F) or above and pain in your lower back or sides, it may be a sign of a kidney infection.

Causes of cystitis can be found in sexual activity which may introduce the highly virulent E-coli normally harmless in the bowel. E-coli bacteria multiply very quickly and are responsible for a vast amount of cystitis. Another group of organisms implicated are Trichomonals and the fungal infection Thrush which becomes a problem after taking antibiotics which clears out not only the bad infection but also the good bacteria which live naturally in the vagina. Thrush provides a breeding ground for E-coli.

Another reason for cystitis is stress which can upset the hormonal balance of the body affecting the acid/alkaline balance of the vaginal lining and increasing the bacterial flora. This accounts for the major cause of unexplained, recurrent cases.

There are antibiotics for proven cases, but for many people self help management of good hygiene, avoiding internal bruising by the use of lubricants is effective. But recurrent attacks need to be further investigated by the GP in case there are other than simple causes, for example kidney disease.

At the first signs of an attack pass a specimen into a clean closed container for your GP. Make yourself two hot water bottles. Then drink a pint of cold water followed by a quarter of a glass of orange squash mixed with a teaspoon of bicarbonate. Repeat the bicarb drink twice more in the next three hours. Take two tablets of a mild painkiller. Have a strong black coffee once each hour. This is a diuretic and helps to pass water. Go back to bed or to your chair after drinking another half pint of water and place one hot water bottle behind your back and the other one wrapped in a towel between your legs. Every time you pass water wash the perineum gently, dab dry, but don’t rub! This method takes three hours and should prevent the infection reaching the ureters and the kidneys.

Polio Survivors Sharing Information on UTI’s and Slow Moving Guts!

By Hilary Boone

Sharing information builds your database of what might help.

Remember you must speak with your Doctor before trying anything new

Before I knew about PPS I ended up in Lincoln A&E one night feeling dreadful and was stunned when the nurse practitioner suggested that I give a urine sample for testing and she was right I had a UTI but none of the normal symptoms. I started on antibiotics, soon back to ‘my’ normal.

About ten years ago I ended up in A&E again – why is it always at the weekend when you cannot see your GP – feeling absolutely terrible. Nothing was found at first and then I had a flash back to my previous time there and mentioned this. I got that look down over the glasses that most of us already know from mentioning Post-Polio Syndrome. They humoured me and did a urine test and were stunned once again that it was UTI without normal symptoms.

Both Richard and I have had repeated UTI’s [ecoli based infection] in the last few months and are doing all we can to learn of anything to try and prevent them.

We have also had to take urine samples to the doctor a couple of days after taking antibiotics have finished to find that it still showed infection and we were told we needed more antibiotics. We are not happy to keep on taking antibiotics and our GP has agreed with us that if we have no symptoms then we do not have to take more antibiotics. Hospital doctor agreed with the antibiotics only if you have symptoms and contact GP as soon as you suspect this is why you are feeling ill. They have also scheduled more tests for Richard.

About two years ago I had constant terrible pain from about 8pm in my right groin. I rang 111 and had to wait for triage call, then the Nurse call but after two and a half hours of increasing pain - as Richards PA was now here - I went to A&E. I was surprised that they did not share information so had no idea that I had rung earlier. It was another hour before 111 contacted me again. The A&E doctor had urine test done which was ok so was going to send me home. Thankfully when she saw me she called me back in for a scan. Firstly she had never seen a lower spine like mine…. [congenitally fused vertebrae] The scan also showed I had a kidney stone so was admitted at 12.30 to a ward. The ward staff were not able to give me any more pain killers until I had been seen by a Doctor, yet 111 had told me to take them over the phone earlier that evening. I sat on the side of the bed leaning on a pillow on my walker sobbing because the pain was so bad till 5.30 am when the stone passed. You guessed! the doctor arrived ten minutes later to prescribe me some pain killers. Another scan revealed the stone had passed and I was discharged.

If you are also taking medication that has constipation as a side effect - have you checked how many of your medications have that as a side effect - then it can become even harder to excrete. My husband when asked by the Incontinence Nurse what were his stools like said ‘asteroids’.

We all know a varied diet including protein, fruit and vegetables with plenty of fibre, some carbohydrates and plenty of water helps. Jann Hartman, a member and Nutritionist in the States has told us that she finds ground flax seeds added to the above helpful. We take two good probiotics and vitamin C.

We look forward to hearing from anyone who has similar issues and has found ways that work for them. We are all different so just because something works for one person it will not necessarily work for others, but if it only helps one other person then its important information. The more information we have on a subject the more we can discuss with our health professionals what else we could be doing to manage our health to the best we can.

SLOW GUTS AND POLIO SURVIVORS

Dr. Richard L. Bruno Chairperson International Post-Polio Task Force and Director
The Post-Polio Institute International Centre for Polio Education
http://www.PostPolioInfo.com

N.B. The spelling of medical terms and medication names are American.

Question. I have trouble swallowing but no one believes me. Food doesn't get stuck in my throat, but seems to lodge somewhere behind my breastbone. I had a normal swallowing study and the doctor doesn't believe I have a problem. But, food sticks and it hurts when it does! Do other polio survivors complain about this?

Answer. They surely do. It's hard enough to "swallow" having PPS without doctors refusing to believe you're having trouble swallowing. It's true that most Post-Polio Institute patients report having only occasional, mild problems swallowing. The problem is usually high in the throat: not being able to get down pills, largish pieces of meat and, maybe even more often, difficulty clearing their own secretions. A barium swallow study (where you eat and drink food containing barium and "video" is taken with an X-ray camera) usually shows mild muscle weakness in the throat or sometimes, as in your case, no problem at all. This "negative" finding is just like a muscle test of an arm or leg not showing weakness in the doctor's office, even though you feel weaker or even stumble at the end of the day as you get more tired.

Polio survivors also have swallowing problems below the throat. What you describe -- food getting stuck behind your breastbone in the esophagus (the tube connecting the throat to the stomach) is not uncommon in polio survivors. The muscles of the throat and esophagus should contract in a coordinated sequence, like a snake, to move the food downward and into the stomach Food gets stuck when the esophagus doesn't contract and its muscles go into spasm, not unlike when back muscles go into spasm when your leg muscle are too weak to hold you up. Food usually gets stuck right behind the top of the breastbone. And, yes, stuck food is painful...and scary! Even if food does make it down to the bottom of the esophagus, in some polio survivors the "valve" at the bottom of the esophagus doesn't open and prevents food from entering the stomach, a condition called acalasia.

Why do polio survivors have trouble with muscles from their throats to their stomachs? Fifty years ago, Dr. David Bodian discovered that every polio survivor had some damage to neurons in the brain stem, the so-called "bulb" of the brain. When brain stem damage was severe and "breathing neurons" stopped working, "bulbar polio" was diagnosed. But the most common bulbar polio symptom was trouble swallowing not trouble breathing, because the poliovirus also damaged the bulbar neurons that control the vagus nerve, the nerve that activates and coordinates muscles from your throat down to your stomach.

Unfortunately, 99% of gut doctors have never seen food get stuck in the esophagus and don't know what to do about it. We've found that a low dose of the muscle relaxants Klonopin and Bentyl, taken 30 minutes before eating, can relax the esophagus and allow food to slide down to its intended destination.

But wait! There's more! Vagus damage likely explains our first Post-Polio Survey finding that diarrhea, colitis, ulcers and constipation are as much as six times more common in polio survivors than in the general population. Some polio survivors report that their stomachs don't empty, a condition called gastroparesis. Other have their intestines abruptly stop moving -- as a side effect of medication, after surgery, a gall bladder attack, or for no reason at all -- a condition called paralytic ileus. Often, the muscles of the stomach and intestines get moving again on their own. But, sometimes the drug Reglan is needed to jump-start the stomach and intestines. Reglan can have bad side effects, since it enters the brain. DOMPERIDONE, [Editors note - See addendum article over page for caution for Parkinsons patients) a drug that does not enter the brain (or the US, so you have to buy it from Canada) is the better choice if you can take it by mouth). Also, polio survivors need to try to prevent gut slowing by being careful when taking drugs that are anti-cholinergic (drugs that have dry mouth as a side effect) since they block the activity of the vagus nerve.

Finally, polio survivors who have a chronic sore throat, husky voice, or burning in the chest should be evaluated for reflux by an ENT doc, who'll look at the upper throat and vocal cords, and a GI doc, who may do a gastrosccopy to look down your esophagus and into your stomach. If you have a gastroscopy, make sure that the doctor goes light on the anesthesia and uses the anesthetic Propofol, since it's short-acting and allows polio survivors (usually) to wake quickly (see http://www.postpolioinfo.com/lib_surgical.php).

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ADDENDUM: CONSTIPATION NATION?

Polio survivors have slow guts, thanks to poliovirus-damage to the vagus nerve (see above) that should fire to move food from your mouth all the way through to the other end (see articles in The Post-Polio Library at http://www.postpolioinfo.com).

Here are some things about constipation you may not know:

1. Constipation isn't one thing. Sometimes poo gets stuck in the ascending colon on the right side of your belly, sometimes in the transverse colon across the top of your belly, sometimes in the descending colon on your left side or in the rectum. So, you have to focus treatment where constipation occurs.

2. Not all laxatives work in the same way or in the same place:

    A) Roughage and Senna irritate the whole colon to make it move;
    B) Miralax and Colace add water to your poo to "lubricate" the colon;
    C) Dulcolax stimulates the ASCENDING colon if you get plugged there;
    D) Psyllium absorbs water and expands to stop diarrhea but also combines with sludge to make one single poo (and not lots of little "rocks") that itself stimulates the colon naturally to make things move. (You should plan to sit on the throne after eating to take advantage of the natural stimulation caused by food in the colon);
    E) Magnesium supplement may help with moving things along
    F) Suppositories are for rocks in the lower colon and rectum.

3) If nothing is moving, your stomach isn't emptying or the colon won't respond to the above treatments, there is a great drug -- domperidone (sadly NOT Dom Perignon) -- that directly turns on the muscles that empty the stomach and move the colon. Domperidone has no side effects and doesn't enter the brain (as does Reglan, which can cause Parkinson's-like shaking and should not be used by polio survivors). Of course, the FDA hasn't approved domperidone even though it's been sold over the counter for 20+ years in Europe for nausea during pregnancy! (Apparently, not enough payola on it.

So, there's a short course on pushing poo. You may need a combination of treatments or different treatments at different times for different types of constipation. Keeping a poo diary (quantity, quality and time of day) that includes symptoms and what laxatives you've taken is vital so that you can identify your natural rhythm, where things get stuck and what you need to take to make things work.

Happy eating (and the other thing).

The SPINE

No - not the bones that hold us up.

Did you know that the NHS has one? And the NHS one often causes problems too. This one is there to store our data; it has the habit of losing this, or going spectacularly wrong - and when it goes wrong the NHS gutlessly tries to fob off its victims.

If you are waiting for an appointment, it could be because 'Spine' has lost your data.

About as reliable as a politician's promise, the NHS Spine is another of its 'IT initiatives which "allows information to be shared securely through national services such as the Electronic Prescription Service, Summary Care Record and the e-Referral Service". Or so they say.

NHS Digital develops and maintains Spine through the Digital Delivery Centre. Recent developments include enabling the sharing of child protection information via the Child Protection Information System, and developing ways to allow easier access to demographic data through the Spine Mini Service.

So what can possibly go wrong?

My brother appeared one day, with 30 envelopes in his hand. "I think these might be yours". All addressed to me, but sent to an entirely fictitious address which contained my brother's postcode. When the pile had grown high, an astute Postmaster looked at my surname, thought that someone else with that surname lived in his area, and contacted my brother. Spine had my brother down as next-of-kin, and had included his postcode at the end of the fictitious address.

The envelopes went back three months, starting off with appointment letters - some of those letters were urgent, and as no-one knew what had happened, I ended up going privately. Later letters were angry : "as you didn't turn up for your appointment we have informed your GP that you are discharged".

Of course my 'caring' NHS surgery hadn't even thought to contact me to find out what was going on. Typically, when I phoned to try and sort things out, they treated this as if it were my fault. And when I was told I couldn't correct the information on Spine myself, but would have to get my GP to send a confirming letter with my correct address, the surgery almost refused to do this. Then said I would have to pay £15 for the doctor to send this!   The telephone line must have melted!

And Again!

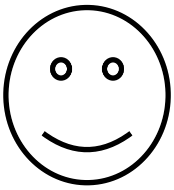
I moved from London to Oxfordshire. Made absolutely certain I informed EVERYBODY of my new, correct address. But never underestimate the NHS's ability to muck things up - the same pattern is repeating. But Spine has added another layer :

I actually receive a letter for a Rheumatology appointment with Dr. D for Oct. 22nd at 1400. Then I am booked in for a DEXA scan on Oct.22nd at 1400 (how my Consultant is to review the scan at the same time heaven only knows). Even though it is in same department. The next post brings a letter re-directed from my old address in London, saying I have a third Rheumatology appointment with Dr. (unknown to me) on Oct 22nd at 1400.

Boy, when Spine mucks things up, it produces some interesting ideas.

Meantime, everyone in the NHS is telling me it's nothing to do with them! So we start the cycle again - but this time I have approached the CCG and told them to deal with this**. Reminding them I made the London lot re-imburse me for the fees I had paid private consultants!**

Somehow that seems to have concentrated their minds!



A possible new P.A. was offered a few hours trial to see if she would like to work for us. We went into the City and were happily looking round the Central Precinct when Richard suddenly decided to go off on his electric wheelchair at top speed by himself….

She ran about five steps after him then turned and asked ‘Will a sports bra be part of my uniform because these babies will need more support if he is going to go off at that speed.”

Great sense of humour and yes we employed Helen and they are both out at an Antique Fair whilst I finish this newsletter.

Therapeutic cannabis and the Post Poliomyelitis Syndrome

© Dr. Peter Brauer MD

"In its natural form, Marijuana is one of the safest therapeutic substances that is known to mankind" ***Frances L. Young. Judge for administrative law at the Drug Enforcement Administration (DEA)***

Front Page Photo: https;//pixabay.com.de The history of cannabis goes back thousands of years. There are written records of its medical use e.g. in China and India (Wikipedia). In modern times, commercially competing outgrowths finally forced it out of the market for all applications. Under the pretence of illegal addiction the pharmacologically important substances and their medical use were unfortunately affected. Reference was made to the psychoactive THC component of the intoxication hemp. Other medically active ingredients have been deliberately overlooked. The beneficial hemp fell, in trusted togetherness with the THC drug hysteria victims, without differentiated consideration for a long time. Instead, far more dangerous drugs found their way into everyday practice.

Quote: "Every 19 minutes, a person dies of an overdose through prescribed medication. This cannot happen with cannabis. "(Sanjay Gupta, M.D., neurosurgeon, USA, 2013)

There are many ingredients of the existing hemp varieties that possess an individual specific pharmacological effect. They complement, reinforce or inhibit each other, depending on the type of hemp and cultivation conditions, growth phase, harvest time and extraction methods in different proportions to obtain, depending on individual illnesses, a matched medically usable spectrum of action. The relatively low concentration of the components in the natural extracts compared to synthetic cannabis medicines, together with their synergistic effect, offer the advantage of a low-side-effect to side-effect-free application in therapeutic dosage.

Half a million patients in Germany suffer severe drug-related side effects each year, especially the fight against chronic pain using conventional pain medicine. Other long-term medication is also often associated with significant side effects and even death. Estimates for Germany amount of up to 58,000 deaths per year due to adverse drug reactions. Patients with chronic analgesic treatment include, e.g. most dialysis patients, thousands of deaths from internal bleeding, and up to two thirds from acute liver failure.

Quote: "Despite the millions of people who have been using cannabis for millennia, there has never been a case of anyone who has died from an overdose." (Professor Lester Grinspoon M.D., psychiatrist at the Harvard Medical School)

Cannabis has more than 600 ingredients, including over 200 terpenes, over 100 cannabinoids, 50 hydrocarbons, and over 200 other biochemical compounds such as cannaflavins as cannabis-specific flavonoids. According to current knowledge, the cannabinoids and terpenes are of particular importance and interest for medical use. Cannaflavins are still awaiting further research. The medicinal properties of the already known ingredients of cannabis and the experience gained from and with patients, as well as from research, suggest that cannabis is more than just a painkiller.

The selection of cannabis ingredients with their medically significant spectrum of effect is consistent in the majority of known publications. In the following, the most important of them are presented:

Cannabinoids

CBD (Cannabidiol):	Non-psychoactive, anti-inflammatory, anti-bacterial, analgesic, anticonvulsant, anxiolytic, nausea-inhibiting, calming (high dose), stimulating (low dose),
THC (Tetrahydrocannabinol):	Psychoactive (intoxicating), pain relieving, muscle-relaxing, anticonvulsant, muscle -spasm inhibiting, anti-inflammatory, allergy-inhibiting, bronchial expanding, appetite-increasing, anti-cancer, neuroprotective, nerve growth promoting, anxiety
CBN (Cannabinol):	Weak psychoactive, soothing, sleep promoting, antibacterial, muscle-spasm inhibiting, nausea-inhibiting
THCA	Non-psychoactive, anti-inflammatory, neuroprotective, nausea-inhibiting, selected cancer retardant
CBDV (Cannabidivarin):	Not psychoactive, CBD-like
CBC (Cannabichrome):	Calming, painkilling with THC, antifungal, antibiotic, cancer cell destroying, anti-inflammatory
THCV (tetrahydrocannabivarin):	THC-like in a much weaker form
CBG (Cannabigerol):	Analgesic, anti-cancer, anti-depressant, anti-inflammatory

Terpenes

MYRCEN:	Antiinflammatory, sedative, soothing, muscle relaxant, antibiotic, antimutagenic, sleep promoting, potentiating THC, potent analgesic, anticarcinogenic (anti-cancer)
LIMONS:	Antifungal (fungicidal), antibacterial, anticancer, anti-inflammatory, thinking ability, attention and concentration improvement, mood-enhancing, analgesic, immune stimulating, anxiolytic, antioxidant
LINALOOL:	Psychoactive, slightly calming, anti-cancer, sleep-inducing, anti-inflammatory, anti-spasmodic, anti-seizure (anti-epileptic), promoting attention
CARYOPHYLENE:	Strong anti-inflammatory, anti-viral, anti-biotic, fungicidal, analgesic, antioxidant
PINEN:	Anti-inflammatory, anti-cancer, asthmatic, attention, improving concentration and memory, THC-inhibiting
TERPINEOL:	Antioxidant, soothing, relaxing
NEROLIDOL:	Soothing, relaxing, antifungal
BORNEOL:	Pain-relieving, sleep-inducing, antiseptic, soothing, antispasmodic
EUKALYPTOL:	Soothing pain
HUMULES:	Antibacterial, anti-inflammatory, appetite suppressant, anticancer (anticarcinogenic)
3-CAREN:	Anti-inflammatory
Alpha-BISABOLOL:	Antibacterial, anti-inflammatory

Flavonoids

CANNAFLAVIN A:	Anti-inflammatory (30 times stronger than aspirin and twice as strong as cortisone)

Synergism / Entourage effect

Mixtures of substances often have other medicinal effects by nature and / or strength than the individual substances contained in them.

Synergism is understood to mean the co-effective action of various active substances with and without mutual enhancement of action or only unilateral or mutual enhancement of action.

In addition, the so-called ***entourage effect*** (combination effect) is mentioned, which states that the overall effect of a drug mixture is more than the sum of the effect of their individual active ingredients. For example, isolated CBD is less effective than in a cannabis extract with all cannabis drugs.

Examples of synergism among the cannabis active ingredients are:

β-myrcene + THC mutually reinforce pain inhibition.
β-myrcene + THC-A lead to a mutual amplification in anti-inflammation.
THC + CBD-A + THC-A is said to be particularly effective in inhibiting muscle spasms.
Limonene is credited to have a synergistic effect with THC-A, CBD-A, CBC-A, CBC, CBG, caryophyllene and linalool.
A combination of THC-A, THC, CBD, CBD-A, CBG-A and myrcene is particularly suitable for the treatment of muscle and skeletal pain, as well as inflammation and muscle tension.

Post-polio syndrome (PPS)

The post-polio syndrome is characterized by wear- and tear-related degenerative failure leading to cell death of the previously damaged and / or numbers of diminished healthy nerve cells as a result of comparatively chronical as well as absolute overloading. The cell disintegration triggers an immunological reaction in conjunction with an inflammation, which is further enhanced with the release of any polio virus fragments that may still be present in the nerve cells. This process is associated with pain. In addition, in many cases, the central nervous pain processing system may have been directly damaged by polio and cause pain sensations of different localization to the whole body. Overloaded muscles tend to cramp with PPS. Similarly, the stress-control system may be polio damaged, causing high levels of exhaustion. PPS is a concurrent stressor and self-stressor. As PPS progresses, attention and concentration via the formatio-reticularis are also affected by polio and in later stages memory as well.

These functionally and structurally degrading processes can be effectually inhibited by many cannabis ingredients. Although the controlling of chronic pain with the PPS is of particular importance for the quality of life of those affected, the anti-inflammatory effect can significantly reduce the effects of cramps, the inhibition of stress, the improvement of attention, concentration and memory, the pacification, the lightening of mood, sleep promotion and above all the neuro plasticity as well as the nerve growth promotion within the framework of the neuro plasticity of the central nervous system – essentially the only limited symptomatic treatment possibility for PPS and thus the long-term preservation, or even the improvement of the quality of life, as well as a postponement of the need for care in relation to occurrence and progression.

The call for controlled trials of cannabis medication in the course of the disease PPS should be rejected as absurd. A control group is ethically unjustifiable. In view of the average age of the patients and the enormous diversity of the PPS manifestation in the associated inequality or inconsistency of the subject groups, this would mean a comparability obstacle and for those affected the withholding of an effective therapy with minimal to no side effects. The latter should be considered first, given the calculable, but undetectable subliminal (subclinical) however clinically effective and randomly complex the previously damaged CNS may be, as this may affect the entire regulatory system directly or indirectly. On the other hand, case studies and field research should receive their due importance in scientific evaluation. In addition, there are reputable experiences and findings regarding treatment options with cannabis to be taken into consideration. Numerous studies are to be found among them.

The current focus should be on the targeted characterization of hemp varieties in terms of their ingredients and their largely complex extraction and as far as possible standardization, which does not mean that the existing cannabis-based therapeutics should not be used and / or further developed. Due to the known entourage effect, preference should be given to natural extracts in complete form before the use of mono-isolates, synthetics and semi-synthetics.

Table: Selection of cannabis active substances and their post-polio syndrome significant medicinal effects

Medicinal effect	**Cannabis drug**
Pain inhibition	CBD, THC, CBC, THCV, CBG, myrcene, limonene, cariophylls, borneol, eucalyptol
Anti-inflammatory	CBD, THC, CBC, THCA, THCV, myrcene, linalool, cariophylls, pinene, humulene, 3 -carene, alpha- bisbolol, cannaflavin A
Stress inhibition	CBD, THC, CBDV, CBC, THCV, CBN, myrcene, limonene, linalool, terpineol, nerolidol, borneol
Muscle spasm inhibition	CBD, THC, CBN, CBDV, THCV, myrcene, linalool, borneol
Nerve protection and Nerve building	CBD, THC, THCA, CBDV
Attention and Concentration improvement	Limes, linalool, pinene
Sleep promotion	THC, THCV, CBN, myrcene, linalool

In essence so far:

The call for research has failed primarily due to the illegalisation of cannabis and commercial unattractiveness of the pharmaceutical market, especially regarding the late effects of polio due to a lack of knowledge or widespread medical disinterest of the same. The victims are the patients.

A highly individualized treatment is required due to the special characteristics of the medical condition of the PPS. As with other drugs, cannabis does not always provide the desired effect, although it is usually the case. Apart from cannabis, there is no drug on the market which would be more suitable for the symptomatic treatment of PPS, especially not for chronic use with the serious side effects not to be expected in a therapeutic dosage. In addition, a treatment covering all sensitive areas is more effective for the overall course of events, as every single disorder, including parallel diseases, have a negative impact on the incurably chronically progressive polio late effects PPS.

It goes without saying that a therapy with a cannabis preparation must be carried out under medical supervision in order to ensure its desired effect per targeted selection and dose control and not to overlook possible undesirable interactions with other simultaneously prescribed drugs. With regard to the usually almost negligible side effects of cannabis preparations, particular PPS symptoms such as muscle weakness and continuing pre-existing clinical pictures should be kept under observation.

Indispensable prerequisites for such a treatment are:

Comprehensive knowledge of the clinical picture post-polio syndrome and relevant knowledge in the cannabis application.

Conclusion: ***The medicinal effect of cannabis is not reduced purely to the effects of THC and / or as an application for pain relief. In view of its various ingredients, cannabis offers the reasonable possibility of a complex effective PPS therapy for anti-inflammatory, pain relief, nerve protection, muscle spasm inhibition, stress inhibition, attention and concentration promotion.***

Literature on request - Published in "Polio Europa aktuell 2017 No. 72, pp. 4-7." (Last edited: 04/2018)
https://www.polio-initiative-europa.de/literatur/polio-europa-aktuell - © Dr. Peter Brauer.

German and then English Literature

Inhaltsstoffe von Cannabis - Inhaltsstoffe - CannabisMedizin.org
cannabismedizin.org/cannabis/inhaltsstoffe/
Terpene im Cannabis und ihre Interaktion mit Cannabinoiden ...
1000seeds.info/.../terpene-im-cannabis-und-ihre-interaktion-mit-cannabinoiden/
Die Terpene im Cannabis und ihre Wirkung - 1000Seeds
1000seeds.info/wordpress/die-terpene-im-cannabis/
Der Entourage Effekt - Cannabinoide und Terpene im therapeutischen ...
www.hanf-magazin.com › Cannabis in der Medizin › CBD in der Medizin
Welche Terpene sind hauptsächlich im Cannabis enthalten? - Dinafem
https://www.dinafem.org › Dinafem Seeds › Dinafem Blog
Cibdol - Komplexes Cannabis - Terpene, Terpenoide, Flavonoide
https://www.cibdol.com/de/.../586-komplexes-cannabis-terpene-terpenoide-flavonoid...
Terpene: Wie Sie Arbeiten Und Ihre Auswirkungen - RQS Blog
https://www.royalqueenseeds.de/blog-terpene-wie-sie-arbeiten-und-ihre-auswirkunge...
Der „Kombinationseffekt": Isoliertes CBD weniger effektiv als die ...
https://www.dinafem.org › Dinafem Seeds › Dinafem Blog
Cannabinol (CBN) in der Medizin - 1000Seeds
1000seeds.info/wordpress/cannabinol-cbn-in-der-medizin
Chemiefabrik Cannabis | Cannabis.info
www.cannabis.info/de/abc/10003583-chemiefabrik-cannabis
58.000 Tote jährlich durch falsche Medikamente: Wie Ärzte ihre ...
www.rp-online.de › Mehr... › Gesundheit › Medizin & Vorsorge
Tod durch Medikamente - Zentrum der Gesundheit
https://www.zentrum-der-gesundheit.de › ... › Nebenwirkungen weiterer Medikamente
Medikamente und Nebenwirkungen - Bis zu 25.000 Todesfälle durch ...
www.sueddeutsche.de › Wissen
Tödliche Nebenwirkungen - 20.000 Opfer durch Medikamente | Das ...
daserste.ndr.de/panorama/archiv/1999/erste7222.html
CBD (Cannabidiol) - CANNABISINMEDIZIN | Cannabis in der ...
www.cannabisinmedicine.de/cbd-2/
Die medizinische Verwendung von Cannabis und THC
*www.**cannabis**-med.org/german/patients-use.htm*
Cannabis for Medical Use - A Scientific Review - Department of Health
health.gov.ie/wp-content/uploads/.../HPRA-Report-FINAL.pdf
Efficacy and adverse effects of medical marijuana for chronic ...
https://www.ncbi.nlm.nih.gov › ... › PubMed Central (PMC)

Translation of the original - German to English:
Thomas House-Arno (Tom House) April 2018
thomas.house@gmx.de

We would like to thank Dr. Peter Brauer for permission to reprint his article.

Dr. Brauer gave this presentation on the day of the European Polio Union Annual General Meeting on July 16th 2018 in Rheinsburg, Germany.

www.europeanpolio.eu

This event was featured in our last newsletter sadly Polio Survivors Network were not able to attend this year.

Permission must be sought from Dr. Brauer to reprint this article.

We have a copy of the English translation of Dr. Peter Brauer book Aspects of PPS.

PROBLEMS WITH SKIN CARE CREAMS THAT CONTAIN PARAFFIN.

London Fire Brigade have found a shocking amount of deaths they attribute to cheap skincare prescribed on the NHS. So I thought this article might be timely, as they are concerned about those with mobility problems.

Most of us use some sort of body moisturiser on our skin, but products that are often prescribed by doctors are concerning London Fire Brigade.

These are skin creams that contain paraffin. Apparently these creams are inexpensive, but sit on our skin rather than get absorbed. Eventually they rub off on bedding, are difficult to wash off, with the result that when a naked flame (cigarette, candle, etc) comes in contact, everything combusts,

Recently **London Fire Brigade** issued this warning:

"Many commonly used moisturising products, or emollient skin products, contain ingredients like paraffin or petroleum and are highly flammable. These products are widely used by elderly people and those with mobility problems, and help with conditions like eczema, or to prevent bed sores".

The Brigade's Group Manager **Mark Hazelton** said: “It’s a real issue that people simply don’t realise that these skin products are in fact highly flammable. You’ve got elderly people, or those with mobility problems, using them liberally on their skin, which is fine, until a flame is introduced into the mix. These (products) soak into dressings, clothing and bedding, which makes the fabric flammable. And the problem is, it’s really difficult to wash the product out, even on a hot wash.

“**We are really concerned about smokers, and those using candles.** If a flammable skin product is being used, a small spark can quickly lead to a serious blaze. This is a real concern for elderly people and those less able to escape if a fire takes hold.” Fire Brigades around the country are concerned, as far too many deaths are caused this way. See more on http://www.bbc.co.uk/news/uk-39308748 and http://metro.co.uk/2017/03/19/skin-creams-with-paraffin-in-them-linked-to-house-fire-deaths-6519276/

They may have been free, but I stopped using these creams when I found they didn't absorb well - how glad I am. If you find a body moisturiser just sits on top of you skin, and doesn't seem to sink in - beware!

So what do I use?

I used to be a beauty editor of an American magazine, so am picky - even more so now that I am getting ancient with all the skin problems that brings. So I blog about skincare products that I have come across in European hospitals - and believe me their dermatologists understand how important these are to us, and carry out clinical trials to approve them. More info on aftercancers.com/skincare.

Verité Reily Collins - verite@greenbee.net - aftercancers.com

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AFTERCANCERS.COM - https://aftercancers.com/why-write-this-site/ - Excerpts

LIVESTRONG **, the American cancer charity, says “We believe in information – not pity”**. This was exactly what I wanted when I got cancer. I did NOT want “poor you” comments. Neither did I want advice on eating miracle foods, nor Alternative treatments. What I ***did*** want was sensible, down-to-earth medically-approved advice based on clinical trials and scientific evidence – and understanding and help for what my body was going through, especially handling poisons contained in cancer drugs…..

...When I had polio I discussed my treatment with my Consultant and nurses, asking questions and evaluating possible courses of action. But that was then, when the NHS was ‘young’ and under Matron’s wise guidance. In the days before ‘outcomes’, MDTs, tick boxes and computers – when the Patient was at the heart of treatment; not made to feel we were on a production line, to be abandoned once this reached going-home time…..

POST POLIO NEWS [ppn] - www.post-polio.org.uk

An online news cutting service from Chris Salter that specialises in news relating to polio, post polio, disability and other health related issues.

Twitter, Newspaper, RSS feed, Facebook, LinkedIn, Daily digest emails.

Two of the news items from ppn

Many options to choose from to receive all the news items.

SEPTEMBER 8th 2018

Ireland: Local support group for polio survivors | Sligo Champion.

The National Polio Register is a new initiative by Polio Survivors Ireland aiming to find out how many polio survivors there are in Ireland. They are inviting people who had polio as a child to join the National Polio Register. The group estimates there is 7.000 polio survivors living in Ireland. Despite this, less than 1,000 are members of the organisation.

They have consulted with their members to see what the main concerns are for polio survivors as they continue to age. It is vital that they are not forgotten as a population, and that statuary planning for medical care and social welfare benefits take into account their needs relating to polio. They encourage all polio survivors to register to help them find out how many are still in Ireland.

Many will develop late effects of Polio or Post Polio Syndrome. The group is there to help if that happens. People who are already members of Polio Survivors Ireland do not need to sign the Polio Register, as they are automatically included in this campaign.

To register, fill in the Polio Register form online at www.polio.ie/national-polio-register or call 01 889 89 20. Printed forms, still available in some medical centres can be posted to Polio Survivors Ireland, 319 Capel Building, Mary's Abbey, Dublin 7 .

For more see www.polio.ie or call 018898920.

SEPTEMBER 15th 2018 | DAWN

Pakistan: Presence of polio virus feared in samples taken from Rawalpindi's Nala Lai

Tahir Naseer writes:

The polio virus may be rearing its head again in Rawalpindi's Nala Lai area, the provincial Health Department said on Saturday.

Chief Executive Officer (CEO) Health Dr Khalid Mehmood told *DawnNews* that the department has put Nala Lai on high alert after water samples from two areas — Safdarabad and Dhok Dalal — were taken and sent for testing.

"The World Health Organisation will confirm the presence of polio virus in the water," Dr Mehmood said. However, sources within the health department claimed that the presence of polio virus has already been confirmed in the area.

"The polio vaccine is the only way to save children from getting infected with the virus, which enters the body through the respiratory system," Dr Mehmood said.

The health department will carry out an anti-polio drive in the area from September 24 to September 27.

However, it has emerged that the department does not have any health workers and thus will be reaching out to non-governmental organisations (NGOs) to help in the anti-polio drive.

https://www.dawn.com/news/1433097/presence-of-polio-virus-feared-in-samples-taken-from-rawalpindis-nala-lai

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 Syndrome** and link to our website 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

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 December 2018

Editors Note:-
Articles from Polio Survivors and Health Professionals Welcome for future issues

Management Committee [Trustees] and Operations Team

Membership

Membership Fees

With grateful thanks to the generous legacy from Ms A Brown

Membership will now be FREE.

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 PayPal

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.

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

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

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.

Thankyou.

giftaid it

Post-Polio

The "Best of PPS"
With Richard L. Bruno, HD, PhD
and a Very Special Guest
October 27, 2018

Join us for a webcast, that is easily available internationally.
1:00 PM US Eastern Daylight Time*
(Please verify time in your own time zone)

Note: Because of the need to postpone from our original date, this webcast will be available for 3 days for all registrants.

Registration Details are available:
www.papolionetwork.org
Presented by:
Dr. Richard Bruno and
The Pa. Polio Survivor's Network

ROTARY CLUB OF BANGOR

Aim to floodlight 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 from Monday 22nd to Friday 26th October. We intent to cover the Strait with purple light, the signature colour of the "End Polio Now" campaign, which we believe will arouse the publics attention and interest. We hope that this will generate donations and perhaps even interest in becoming a Rotarian.

Rotary Great Britain & Ireland
Purple4Polio
End Polio Now & Forever

24th October 2018
WORLD POLIO DAY

How to Watch Rotary's Celebration from your Living Room.

https://www.endpolio.org/world-polio-day

You don't have to travel to Philadelphia to take part in Rotary's World Polio Day event on 24th October. You can watch a livestream of the proceedings from your computer or smartphone starting at 18:30 Philadelphia time (UTC-4). [UK time will be11.30pm] A recording will be available shortly after the event on endpolio.org.

Global health experts and Rotary's celebrity polio ambassadors will discuss our remarkable progress toward a polio-free world. Patience Asiimwe, the protagonist of Rotary's upcoming virtual reality film "Two Drops of Patience," will introduce the movie. A sneak peek from Rotary's documentary "Drop to Zero" will also be featured. Jeffrey Kluger, senior editor for Time magazine, will discuss his experience traveling to Nigeria with Rotary to report on polio eradication. And we'll celebrate the 30th anniversary of the founding of the Global Polio Eradication Initiative.

On your Computer on the day of the event

In Google Chrome, go to KUDO and complete the form, then click Submit.

On the next page, click Floor and select your language from the list.

On your Smartphone

Download the KUDO app at the Apple App Store (for iPhones)

or Google Play (for Android).

Go to KUDO and tap Open in Kudo App. Complete the form, then tap Join.

On the next screen, tap Floor and select your language from the list.

Need help? support@kudoway.com

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