POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 9, Issue 1/12
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DECEMBER 2016
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NAIDEX
28th to 30th MARCH 2017
At the NEC Birmingham
naidex.co.uk

Home of the Lincolnshire Post Polio Library
Post-Polio Library

Enter 100+ articles

Polio Survivors Network

Wish All our Members,
Family and Friends
A Very Happy Christmas and
Prosperous New Year

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PSN
Sends
Special Hugs
To
Lynn Hobday
and
David Marris

Naidex 2017
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Donation
sent to
Crippen Cartoons
probably the
best disabled
cartoonist
in the world
for Cartoon
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There are some
great cartoons
in the Gallery
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What do you get if you eat Christmas Decorations?
Tinselitis

What is the most popular Christmas Wine
I don't like Brussel Sprouts

Why don't Penguins Fly
There are not tall enough to become Pilots

Contents

New Members and Donations received.

Polio Survivors Network welcomes New Member

James Underhay

Donations

Always so gratefully received towards our work.

Sincere Apologies
therefore for not including names and amounts
due to my [Hilary] forgetting to get the information in time
from Margaret our Treasurer who is now spending a few days in Nottingham whilst husband David is in hospital,
This has to be with the Printers first thing Monday 19th December.

A full list for 2016 will be published in our next newsletter.

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

Where has this year gone? I have been told that the older you get, the more experience of time, the faster the months go, so I must be very very old.

For Richard and I, this year has been an overload of NHS in and out patient times and appointments with months and months of delays for assessments with pretty poor local services. Added to that visits from Social Services for our Personal Budgets, the NHS for Richards newly agreed Personal Health Budget all of which come with a plethora of ongoing paperwork. Plus a new Social Services computer system [Mosaic] has gone live this week in Lincolnshire [over two years later than planned] which has meant all new formats to get to grips with. Then came the email telling me we were being allocated a new Social Worker increasing my stress levels.

However, I have great delight in reporting that my fears were unfounded. His knowledge and experience having worked in Mental Health were just what I needed to “tell it like it really has been”. The relief of someone ’official’ genuinely listening was cathartic. I had not realised, till after he left, how near rock bottom I had got to. Now maybe I could move up that ladder, albeit slowly, again. I tell you this to explain the delays in producing this newsletter and because I have already had two ‘thankyous for sharing Me Too’ from polio survivors going through similar issues. I have been sharing for over twenty years now across the world and when online there is always someone awake to respond - remember I heard from nine different countries during Richards operation last December. Peer support can make a huge difference to coping. However, make sure any groups you join online are ‘closed’ groups or have expert admin that can weed out men and women who get turned on by disability called devotees. A great example is Linda who I have met a few times and correspond with regularly. Read Lindaonwheels blog on page 13.

Margaret Marris, our Treasurer, and polio hubby David have also been going through some pretty poor Lincoln NHS services. They are now going out of County to Nottinghamshire. Margaret rang me today to say that David is out of surgery and doing well. This operation was delayed a week through someone failing to provide them with medication needed to be taken ahead of admission. Margaret is adding this to the points you need to check before having an operation so that it does not happen to you. She is going to stay in Nottingham for a few days to be near David and we forgot to ensure I had the full list of names of people who have kindly donated funds to PSN to add to this newsletter. We apologise and will include a full list for 2016 with the next newsletter. Many of our members give up valuable time and energy to other organisations and we often overdo [don’t we, when we should not] but there comes a time when family must come first.

ENDURANCE is the buzz word you need to remember. Most members find actions of daily living becoming more difficult and painful. It can take weeks and months, sometimes longer, before we accept that we really should be seeking a health professionals advice. If we then attend and are not 100% honest and ’tell the whole truth about our new issues’ we can be doing ourselves a disservice. All the Trustees, and nearly all other support group organisers around the world, understand how difficult it is to change the habits of a lifetime. We have all pushed ourselves to the limits and beyond to achieve all our lives. We have delighted in answering ‘yes we can’ when asked things like ‘Can you get yourself a meal, get up a flight of stairs, etc?’

Now PPS is in the equation we have to ensure that when questions are asked and answered that the picture of ‘HOW the action is performed’ is the same in both our mind and the health professionals. Picture a few of the polio survivors you know and someone asking them ‘Can you get up a flight of stairs and they all say ‘YES’. How many different ways do you think they are actually using stairs? Normally, One step at a time, One leg first on each step just holding onto the bannister rail or using a cane/arm crutches as well, stopping part way to rest and sometimes twice, no longer being able to carry items with you and moving items up stair by stair [and throwing the laundry down from the top], coming down facing the stairs, right through to sitting on your bottom and pushing yourself up/down with your arms one step at a time. I am sure there are even more comments you can add to this list. Page 10 added after writing this.

I have reached the bottom of the page so Richard and I would like to send you our sincere good wishes for Christmas and the New Year.

MESSAGE FROM OUR CHAIR

CHRISTMAS GREETINGS

Whatever our beliefs, Christmas offers us a chance to celebrate and enjoy the company of friends and family, and also reach out in whatever way we can, to our fellow human beings however different, alone or less fortunate than us and hopefully remind us that this is a way of being that should be not be just at, or for, Christmas alone.

NEW YEAR 2017

Looking back 2016 has been a challenging year in so many ways but the New Year is about looking forward to the future and what we can do to improve our lives and the lives of others despite the problems both personal and societal. To reflect upon what we have done and how we might change for the better in the coming year. As polio survivors and disabled people, we face increasing challenges as we negotiate the ongoing changes and problems that having had polio in our youth and the massive loss of knowledge and interest in our condition, especially in the UK.

PROMOTING BEST PRACTICE

Polio Survivors Network has existed to help and disseminate information in order that we can educate and support each other but also the medical and social care providers that we need in order to live life to its full, as is our right as human beings and disabled people. We hope in the coming year to increase our attention on, challenge, and promote best practice within an NHS which is in both an economic and existential crisis. I hope we will be able to examine and call to account the marginalisation of polio survivors and our needs, questioning the lack of active research into post polio at all levels in the UK and ensuring as much as possible that as we go through the BREXIT process we don't lose cooperation and support from the rest of the EU polio population.

LET US KNOW

We will, of course, continue to offer any support and information we can as one of the only UK charities whose prime concern is the medical and health aspects of post polio and polio survivors. I hope that you continue to support us and where possible please let us know of your experiences, positive and negative. We need to increase our database of examples as we are regularly asked to back up our statements. If you do not wish to be identified please send the information on a separate sheet from your letter or email. We would be happy to take down the information over the phone if writing/typing is difficult for you.

In closing, I wish you all a very good and positive 2017

Simon Parritt, ***C.Psychol, AFBPsS, MSc, BSc(Hon), BA, CPsSC, MBACP***
Chartered Psychologist. HCPC Registered Counselling Psychologist,
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Chair Polio Survivors Network.

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

Neurological Alliance Annual General Meeting and members meeting on 23 November 2016

SUMMARY OF PRESENTATIONS AND DISCUSSIONS

Last week, the Alliance hosted its annual members' meeting and AGM. The event saw a great turn out with over 50 delegates. The meeting brought together chief executives, regional representatives, service users, policy and communication leads and corporate representatives from across our membership to hear the latest news on the current work of the Neurological Alliance and its strategies for 2017. The morning plenary session was presented by Professor Philip Smith, President of the Association of British Neurologists. The afternoon session was focused on the topic of mental health among people living with neurological conditions, with a range of speakers and workshops addressing different aspects of the topic.

Morning plenary session

Professor Philip Smith, President, Association of British Neurologists

Professor Smith introduced his remarks with the theme of 'working together' and discussed the benefits of the ABN's close working with the Neurological Alliance over the past year. He went on to discuss the discrepancy between the diversity and complexity of neurological conditions and the level of priority given to neurology within the NHS. He noted that there are only c.800 neurology consultants, which remains too low despite an increase from c.100 consultants in 1990. However, he argued that neurologists remained crucial to the pathway of care and may have an increased role as new treatments become available requiring specialist expertise to administer.

Professor Smith also discussed the need for effective guidance and training to support other health professionals to improve their understanding of neurology. He discussed approaches to prevention in neurological conditions, and called for a stronger focus on managing conditions effectively and preventing critical episodes. He also discussed the need to draw on the expertise of the voluntary sector more effectively. The group discussed the possibility of developing standard paragraphs providing information on different conditions for inclusion within clinical letters copied to patients, and agreed to take this action forward.

Afternoon mental health theme

Professor Adam Zeman, Professor of Cognitive and Behavioural Neurology, University of Exeter

Professor Zeman gave a presentation which called into question the traditional distinction between neurology and psychiatry. After reviewing changing attitudes over time to the relationship between the mind and the brain, he noted that CNS disorders typically have neurological, cognitive and behavioural aspects, giving a number of examples showing how these different aspects manifest in different ways. Professor Zeman went on to argue that neurologists must be equipped with psychological skills and should aim to take a bio-psycho-social view of illness and treatment. Observing that around one third of neurologists' appointments relate to functional disorders, he questioned the lack of training for neurologists in psychiatry and psychology. He went on to suggest a number of recommendations, including that a bio-psycho-social approach should be taken in both neurology and psychiatry. He called for close working across the two disciplines, supported by initiatives such as joint clinics, improved training, and freer integration of psychology into medical services.

Chris Naylor, Senior Fellow, King's Fund

Chris Naylor gave a presentation setting out the importance of well-integrated mental and physical health services within the NHS. He drew primarily on two recent King's Fund reports examining integrated mental health care for long-term neurological conditions (these are *Long term conditions and mental health: the cost of co-morbidities* and *Bringing together mental and physical health: A new frontier for integrated care*). Chris presented research findings showing extensive mental health comorbidities among people with long-term conditions, and showing that poor mental health care increases the costs of physical care. This has a significant impact on patient outcomes, as well as a significant financial impact across the health system. He set out a number of areas where better integration is needed, including: prevention/public health, primary care, chronic disease management, hospital care and community care. Chris also set out a number of recommended areas for improvement, including: empowering people through self-management training and support; improving access to low-intensity interventions; investment in workforce development; and normalising mental health within routine care.

Ben Walters

Ben Walters gave a presentation discussing his personal experience as a carer for his late wife, Megan, who suffered from Huntingdon’s Disease. Ben described how he looked after Megan at home with the help of carers until the last twelve months of her life. Mental health issues, untreated for 18 months leading up to her sectioning in August 2014, forced her to leave home at this time. Megan then endured 7 months in a mental health unit where her wider health needs were neglected and she was unable to access services such as rehabilitation or be visited by her neurologist. Her general health then declined rapidly, and discharge planning was ineffective. Megan was moved to the Royal Hospital for Neuro-Disability in February 2015, which Ben described as the ‘gold standard’ of care. Sadly, Megan’s health continued to decline and she passed away from a post-operative infection following a PEG insertion in June 2015.

Ben went on to describe the complex range of mental and physical health needs and necessary services for a person living with Huntingdon’s disease, including speech and language therapy, dietician, occupational therapy and physiotherapy, neurologist, care and nursing, general medicine and mental health. He explained that the interaction of symptoms is unique for each sufferer and called for practitioners to listen to the carer and accept advice from experts in the condition. Ben explained that only a multi-disciplinary team approach is capable of addressing the full range of needs. This requires clinical specialists, combined with quality care in the right setting, with relevant experience and expertise in the disease. This approach improves and prolongs quality of life, and ultimately saves resources within the system.

Dr Jason Price, Consultant Clinical Neuropsychologist, South Tees Hospitals NHS Foundation Trust

Dr Price gave a presentation explaining the added value of clinical neuropsychology in supporting the emotional wellbeing of individuals with neurological conditions. He argued that mental health services are not well attuned to the needs of people with neurological conditions, and that patients with neurological conditions should be provided with specialist, person centred, emotional support and evidence within their medical pathway. Neuropsychology services are essential to providing comprehensive cognitive and emotional support.

Dr Price went on to describe the South Tees Stroke Neuropsychology Service, which was commissioned in 2011 to provide neuropsychological services (cognitive & mental health) for 55 stroke survivors. It covers a local population of 280,000. The service covers hyper-acute, acute, rehabilitation, and community settings. Referrals are taken from any involved professional, and outpatient referrals are screened within 4 weeks. The service provides effective screening & triage, and clear pathways based upon clinical formulation. The service works closely with local Stroke Association branches and provides effective signposting to personal development services, mental health, support groups/organisations, and neurorehabilitation. The service also provides consultancy and training, acceptance and commitment therapy, and mindfulness training. Jason concluded with a call for patient groups to contact and engage with their local neuropsychology departments.

Anna Mouser, Division of Neuropsychology, British Psychological Association

Anna introduced the afternoon’s workshops by discussing the Neurological Alliance project around delivering effective mental health services for people living with neurological conditions. She discussed the complex interaction between neurological and mental health conditions, and set out data showing that neurological patients have a high level of need in this area. For example, NHS England's GP survey data shows that those with neurological conditions have the highest level of need. 40% stated that they were either moderately, severely or extremely anxious or depressed. Anna discussed the need for effective assessment and diagnosis, including full neuropsychological assessment for differential diagnosis and complex or rare cases. She called for improved access to care and a stronger focus on prevention and self-management. Anna then thanked all the staff members who have contributed to the mental health project so far.

Tees Valley, Durham & North Yorkshire Neurological Alliance HIDDEN IN PLAIN VIEW - 5th Conference

Middlesbrough Riverside Stadium Friday 25th November 2016

Reported by PSN Trustee and Secretary Dot Ives.

The title of this conference was very apt as we all know, neurological conditions and especially PPS may not be obvious to an observer or indeed to our friends and family.

The Conference began as it meant to go on. The Introduction by the Chair, David Mudd highlighted the need for social care and patient care to be to be viewed and funded together not funded differently and separately as is the case now. He pointed out that the NHS's STPs (Sustainability and Transformation Plans) appear to not mention Neurological conditions and there is a real fear that the services and resources available will be further squeezed. It was felt that it may be left to charities to fill the gaps.

The day had notable speakers and signposted the services and innovative work going on across the region:

- a Clinical pharmacist talked about her role as part of a multi disciplinary team working within a 'movement disorder clinic' and as part of a 'Parkinson's Advanced Symptoms Unit' (PASU) based at James Cook Hospital.

- Later in the day the work of the PASU was further explained and explored by the unit's lead Consultant Neurological Specialist who provided statistics regarding numbers of patients with a diagnosis of PDD – Parkinson's Disease Dementia and the work the unit was doing working directly with patients with a primary focus on the complications of hallucinations and dementia in patients with Parkinson's Disease. Older patients also have a mixed pathology linked to the ageing process.

Interestingly and perhaps a little controversial the unit have had some remarkable results in treating patients with 'Clozapine' (a drug that is rarely used but is effective) as part of a closely monitored planned intervention. Whilst it has proven to be very successful in treating hallucinations in patients it may also lead to exaggerated tremors. The PASU acts as a rapid response service and aims to prevent patients from needing to be hospitalized and thus Dr Price gave a presentation explaining the added value of clinical neuropsychology in supporting the emotional wellbeing of individuals with neurological conditions. He argued that mental health services are not well attuned to the needs of people with neurological conditions, and that patients with neurological conditions should be provided with specialist, person centred, emotional support and evidence within their medical pathway. Neuropsychology services are essential to providing comprehensive cognitive and emotional support.

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Other speakers talked about:

- the services and care pathways for patients with rare conditions (less than 1 in 2,000 in Europe) available in Newcastle. There are more than 6,000 rare diseases, 80% of which are genetic and some conditions become more severe with each new generation.

- an excellent insight to Tourette's and it's effects on mental health and wellbeing was provided by a Trustee of TVDNY who talked with heartfelt sincerity and thanks to the support received from the Tourette's Service based in Newcastle. His Psychiatric Consultant clearly outlined what patients need and want. Depression and mental health problems display differently with neurological disorders. Tourette's presents in different ways in different people and the process and 'toolbox' needs to be adjusted and individualised. A collaborative approach working with the patient and within a team in developing a pathway is central. It is a complex, sparse speciality and patients need a 'voice' to access services.

The keynote speaker, a Consultant Neurosurgeon specialising in neuro-oncological conditions presented an amusing portrayal of a highly complex profession; 'It's not Rocket Science'…… the progress and technological inroads being made in the last 10 years was highlighted as was the fact that James Cook Hospital now has 5 MRI scanners within the Trust whilst in 1997 there were only 2 available in the whole country. There are now 55,000 people living with a diagnosis of a brain tumour and 25 people are diagnosed daily. Survivor-ship has improved. Importantly the medical profession need to also look at the quality of life and mental well being and not just survival – surgery is only part of a bigger picture. The Sustainability and Transformation Plan (STP) for the Tees Valley does not mention neurological services as a specific entity. This reinforced the view that charities such as the Neurological Alliance are vital in moving things forward.

Attendees had an opportunity to attend workshops, a 'marketplace' promoted by local charities, view a promotional film, titled 'It's No Joke' and the chance to vote to choose a new name for the charity. The afternoon session was further enlivened by not one but two fire alarms each proclaiming a fire in the West Stand! Whilst a fire was not detected the more able attendees were able to get some unexpected exercise climbing the stairs twice whilst less able attendees and wheelchair users were dispatched to a lift at the far end of the building – not an 'e-vac' chair in sight! The Conference was informative and varied. Jo Cole, Head of Operations and her team of Trustees are to be commended for their time and efforts. A great day!

Dot Ives

How many times do we still hear statements like this? 11 years ago we published

LincPIN **Volume 5, Issue 5 - August 2005**

Dr. Albert Esquenazi stated "patients tend to overestimate the strength of their muscles and often present with pain in, say, one area. However, it is not a focal disease **but a systemic disease and affects the whole body**. It had a larger effect in the areas where clinical paralysis and weakness were seen. He described polio as 'throwing a large bucket of black paint at a white wall, ending up with one large blob and lots of little blotches everywhere else. That's POLIO."

See Page 10 for more excerpts from our Newsletter

Santa went to the Doctors with a problem.
Doctor: What seems to be the problem?
Santa: I seem to have a mince pie stuck up my bottom!
Doctor: Well your in luck because I've got just the cream for that!

The Continuing Sagas of *Dilapidated Dot!

You may recall that I needed a new ‘monicker’ as ‘Deleted Dot’ was no longer appropriate 17 months after I was made redundant and hence deleted from usefulness to any paid workforce!

Having asked for suggestions and so far not receiving any as to what adjective should prefix my name I have decided to have a ‘guest’ prefix each time – one that may or may not be topical. The difficulty may be in finding one that fits alliteratively! Dilapidated kind of fits for now!

You may also recall that I had fractured my wrist (hence dilapidated being a synonym for broken)! I duly attended the Outpatients Department in July to have the ‘wires’ removed. WIRES!….they were more like Allen keys!! Three L-shaped appendages were protruding ominously through my wrist expecting (I hoped) a painless release! The look at this point on Mr Dot’s face was a joy to behold – the furrowed brow was superseded by his queasy pallor as the colour drained from his face! Nurse Nightingale went into Nurse Ratched mode and threatened to throw him out if he thought he was going to faint!

The nice Ortho man on duty assured me that the removal of said wires would be an anti-climax and not painful. He was correct – however the pressure he applied to stem the spurting blood following their removal was not! Ouch! Also ‘ouch’ was his advice that ‘washing up’ was good therapy! This has now been engraved into a tablet of stone befitting Moses by Mr Dot who was delighted!

My wrist is mending nicely and he commented that the bones had healed remarkably well (I wonder if taking extra extra strength Vitamin D capsules has helped)? Unlike the tendons in my hand that have left me looking like an arthritic witch or the Hooded Claw from Penelope Pitstop!

Other evidence of being dilapidated and in decline was brought embarrassingly home to me on two occasions recently. One was when I could not put my ‘weight’ upon my raised foot on a step on a bus and needed to be pushed unceremoniously in the derriere! The other was a similar action when I tried to step up and on to a boat and needed to be pulled by the arm. Who says my muscle strength is fine Mrs Benefits courtesy of www.gov.uk? As I am banned by Mr Dot from explaining why I couldn’t perform these simple actions I just smiled wanly and hoped the surprised faces of the onlookers would blame my broken wrist or lack of functioning brain cells or too much gin! Yes, before you cry, I know I should be using my crutches!!

I will leave you with the wise words of the medical profession. I am now attending physiotherapy with my withered claw-like hand and weak wrist. In response to the physiotherapist’s voiced concern that my muscles appeared weaker than she had expected. I explained about PPS. She asked if the polio was in my hand. I said, “No, it was in my leg”. “Oh well, it hasn’t affected your arm then”……

When being escorted through outpatients department by my Ortho Consultant last week, he smiled and sent me off with these prosaic words: “ Well. Good luck and I hope your hand and wrist continue to recover – I will see you next time”!

Looking shocked, I said that I tried ***not*** to trip up deliberately and break things! His response was to smile and look at my ever increasing file notes!

Hence I am feeling truly dilapidated, depleted and disconsolate…..until next time!……

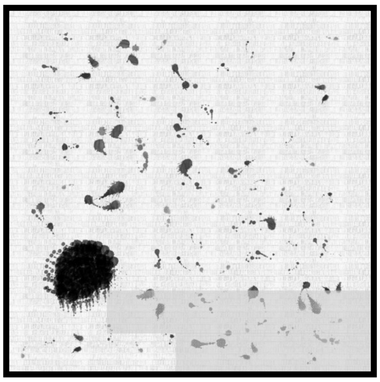
…….and the new name? ……..to be revealed at a later date! Suggestions welcome.

Dot Ives

Dilapidated - Adjective

reduced to or fallen into partial ruin or decay, as from age, wear, or neglect

Should we apply for PPS to be added to the dictionary definition?



Art Work by Chris Salter

LincPIN
Volume 5 - Issue 5 — August 2005
Front Page

"Throwing a large bucket of black paint at a white wall, ending up with one large blob and lots of little blotches everywhere else. That's POLIO."

Dr. Alberto Esquenazi at
Post-Polio Health International's 9th International Conference on
Post-Polio Health and Ventilator Assisted Living:
Strategies for Living Well, St Louis, MO, June 2 - 4, 2005.

Excerpts from the above PSN Newsletter then called the LincPIN.

"Specifically I would like to draw your attention to the following points that Dr. Esquenazi and Dr. Mary Ann Keenan made during their talks at this Conference.

Doctor's Esquenazi and Keenan.

- have learned now that Manual Muscle Testing is NOT a good way to assess muscle strength because a Grade 5 muscle - NORMAL - could have as much as 30% weakness before Manual Muscle Testing could detect it.
- have found out that it is really difficult to truly improve muscle strength. That they do see, and can measure, some improvement in muscle strength after adjustments with bracing, lifestyle, weight etc., but they think that once people have stopped abusing their muscles they just recover their base line strength. It is very important to continue to exercise to maintain that strength and flexibility and prevent disuse weakness
- have learned that if we have weakness in our legs then we will end up with problems in our shoulders and wrists

Patients tend to

- overestimate the strength of their muscles
- underestimate the demands they place on their muscles every day

Health Professionals need to

- **understand that each patient is different**
- **understand the pattern of strength and weakness and the compensations that have been developed over time.**
- **look at the whole person, not just the leg, or both legs, and how patients do actions of daily living.**

According to Dr. Esquenazi, the meat of the matter is calf weakness and everyone needs to appreciate what this means. He explained that our calf muscles have to hold our whole body weight when we are in the stance phase to prevent us falling. That we have to lose a huge amount of calf weakness before it is detected by strength testing. When we walk we take many steps which is what needs to be assessed, not just one step.

He explained how we also underestimate the demands that we place on our muscles every day; just sitting, keeping our head and back straight plus demands on our legs to cross them and move them around. Then add walking! Also as we get older we tend to get a little bigger and that adds to problems producing fatigue.

Commented then and slightly modified now… when we really look at how we are actually doing actions of daily living now and compare this with how we used to do the same action some months/years ago 'It is amazing how much we pretended we were still doing it the same way.'

We need to be our own medical detective, be honest with ourselves, tell the health professional we are seeing what has changed and ask them to assess us and tell us what has changed.

Lindaonwheels blog

"I have no medical degree……. you could think of this site as a sort of "users manual"…."

In order to have Post Polio Syndrome, first of all you need to have had Polio. I contracted Polio in 1952 when I was 2 1/2 years old. The actual sickness phase of the disease only lasted a couple of weeks. I had a very serious case of Polio. Part of that time I was in a coma. When I came out of the coma, I was virtually a quadriplegic, unable to move anything but my head but able to breathe and swallow. The Doctors gave my parents zero hope of any improvement. My Mother and Father did not take that for a final answer and began to take me from Doctor to Doctor….carrying me on a board because I was like a rag doll. An Orthopedic Physician in Charleston suggested that they could try something new called Physical Therapy. In fact, there was a German lady right in Charleston who had just opened a clinic. So my parents made an appointment with her. She started me out with simple exercises. My parents would take me to Charleston every week and she would add new exercises, which my parents did at home with me 3 times a day. This went on for several years. Gradually I was able to hold my head up, sit up, crawl and stand. I didn't walk again until I was nearly 5 years old.

I regained strength slowly and was able to "pass" as a normal healthy child, although my ability to keep up with other kids my age was apparent. I excelled academically. I only wore a back brace to correct a scoliosis for a few years. I was not using leg braces, crutches or a wheelchair, nor did I ever have the need of an Iron Lung as some Polio victims did. I lived a pretty normal life, going to school and dating and eventually marrying when I was 19. It was then that I was told that I should not get pregnant because my body was not strong enough to carry a child to term.

Flash forward to about 1976. I had finished school and working for my husband who was an Optometrist. I had become an Optometric Assistant while he was in school and was working part-time in his office. I began to fall again, mostly at dances, when my "Polio leg", which was weaker and under developed, would "give out" on me. This started happening more and more. I became tired from doing the simplest of things…I couldn't clean my house or lift my newly adopted baby boy who was 10 1/2 months old.

As time went by, the list of things that I could not do got longer and longer….I was living in San Bernardino in 1986 (new husband) and I complained to my Allergist that I was short of breath and so tired from just walking from my car into his office. He did tests and found out that my Diaphragm was atrophying. He knew of my history of Polio and suggested that I get evaluated immediately by a neurologist. The Neurologist did a through examination, including EMG, ruling out such things as ALS, MS, and other horrible diseases. He explained Post Polio Syndrome to me. I had Post Polio Muscle Atrophy in every muscle group that he tested! It was not just my breathing muscles, but also both legs (I thought my "non-Polio" leg was healthy), my arms and all muscles that hold me upright in a sitting position…even my hands were affected! There is no way to re-generate nerves that die from over-use.

He told me that after original Polio that PT was necessary to get me walking again…BUT over the years, my nerves that control ALL of my skeletal muscles and diaphragm were slowly loosing their ability to innervate the muscles. This was from over-use. Doctors and Physical Therapists had it all wrong when they encouraged us to exercise, exercise, exercise to get and stay stronger. What was actually happening was that we were "wearing out" our nerves with so much exercise (with me it was golf, dancing and running after a toddler) and now with Post Polio Syndrome we had to conserve what we had left…. Conserve to Preserve… that this PPS was a degenerative disease process but we could slow it down if we slowed our lives down and stopped doing the very things that we had been told were good for us…. I was relieved that what I had been experiencing… the horrible pain and fatigue… had a real cause… and a NAME! ….. Then the reality of living with Post Polio Syndrome began to became clear to me and my husband. The PPS nightmare had begun……

https://lindaonwheels.wordpress.com/category/about-linda/ lindaonwheels@sccoast.net

From Pennsylvania Post Polio Network.

De Mayo's Q & A Clinic. Monthly Articles from Dr. William De Mayo.

Restless Leg Syndrome (RLS) & Periodic Leg Movement Disorder [PLMD]

Article #3 in the series about Sleep

Question: Do many other post polio patients have restless leg syndrome? How is it usually treated?

This recent question from a reader ties perfectly into our multi-part series on sleep. As you will recall Part I discussed insomnia and problems caused by lack of restful sleep. Part II discussed Sleep Hygiene and outlined habits that can improve quality and quantity of sleep. This month we will talk about one of several underlying sleep disorders. When discussing sleep disorders, is important to understand that most individuals do not have either a problem with Sleep Hygiene or an underlying sleep disorder. Is usually an "and/both" situation - most individuals with underlying sleep disorder also have problems with Sleep Hygiene. So before specifically talking about specific treatment of Restless Leg Syndrome (RLS) & Periodic Leg Movement Disorder (PLMD), I want to emphasize that good Sleep Hygiene is imperative for an optimal outcome. Given the fact that old habits die slowly, it may be helpful to review Part II of our series multiple times.

So what does RLS have to do with sleep? The answer is "A Lot!".

Since part of the definition of deep sleep is lack of muscle movement, anything that prevents muscle relaxation can prevent deep sleep. PLMD is a variant of RLS in which there is a neurologic drive for movement which battles the bodies drive for complete muscle relaxation/ deep sleep. If the PLMD wins then an individual may have multiple awakenings or simply a very poor quality sleep, leading to all the consequences we discussed in Part I* of our series. Interestingly, lack of sleep can make RLS/PLMD even worse, leading to a "snowball effect". This also highlights the importance of Sleep Hygiene and some individuals with a tendency towards RLS/PLMD may need no further treatment than to improve their Sleep Hygiene. Similarly, there is a significant overlap with Sleep Apnea and PLMD such that treating the sleep apnea may lead to resolution of the PLMD.

Since Sleep Apnea and suboptimal Sleep Hygiene are quite prevalent in the post polio population, it is no wonder that RLS/PLMD is quite prevalent. Additionally, there have been theories that fatigue plays a role in creating neurologic changes in the brain that facilitate RLS/ PLMD. Excessive fatigue and Post-Polio Syndrome could, therefore, be another factor increasing prevalence of this problem. The exact prevalence is hard to determine and experts can argue different figures. A very brief review of literature showed studies have been small but some have noted a prevalence of RLS/PLMD as high as 63.6% in the polio population (7.5% in "healthy controls") . Another uncontrolled study showed a prevalence of 40.4% in polio survivors .

It is widely accepted that RLS/PLMD is likely underdiagnosed in the general population. My personal opinion is that most of us have an underlying tendency towards this condition, which can be "uncovered" at different times in our life in different stressful circumstances.

So what exactly are RLS and PLMD? Both are neurologic conditions. PLMD, in simplistic terms, can be thought of as a night-time cousin of RLS. Up to 80% of individuals with RLS also have PLMD but the reverse is not true and many individuals with PLMD do not have RLS. PLMD can be objectively measured in a sleep laboratory using electrodes over the muscle. Diagnosis of RLS on the other hand, is based on history and symptoms. A strong family history can also aid in the diagnosis. RLS is often unrecognized or misdiagnosed, especially when symptoms are mild or intermittent yet, other cases of RLS are quite obvious. The hallmark symptom of RLS is an irresistible urge to move which worsens at rest or when laying down. It is important to stress that the urge comes first and is followed by voluntary movement. This is in contrast to movement which is involuntary such as muscle twitching or spasm. Some individuals also complain of “itchy”, “pins and needles” or “creepy crawly” feeling in their legs. I have also had patients complain of intense aching in their legs, although this is much less common.

Restless leg syndrome is more common with other, more common, chronic diseases and medical conditions including Parkinson’s disease, kidney failure, diabetes, and peripheral neuropathy. Iron deficiency can also cause RLS and iron levels should be checked for this reversible problem. Some medications can also aggravate symptoms (check with your pharmacist) as can alcohol or caffeine.

Treatment of RLS/PLMD depends upon the severity. It is always important to address the above underlying causes first and to address Sleep Hygiene (see Part II article*). For more significant cases medications are indicated. Many primary care physicians use “dopaminergic” medications such as Mirapex or Requip and these can be quite effective. I personally favor medications such as Lyrica, Neurontin, or Horizant. The latter is newer (and more difficult to obtain) but very effective. In the past, physicians used narcotics or Valium type medications. I avoid the use of these medications unless we determine them to be absolutely necessary. Given the intermittent nature of these neurologic conditions, I always encourage periodic “drug holidays” to see if the medication is still needed and close monitoring to see if dosages need to be restarted or increased. Seasonal changes and personal stress issues that affect fatigue and sleep can profoundly impact these conditions and a holistic approach might include initial medical management to control the problem with a long term goal of transitioning to nonpharmacological methods of avoiding stress and sleep deprivation.

1 Eur J Neurol. 2015 Mar:22(3):472-8
2 Kumru H, PortelE, Barrio M, Santamaria J. Restless legs syndrome in patients with sequelae of poliomyelitis. Parkinsonism Rela Disord)2014)20(10):1056-8

Dr. William DeMayo November, 2016

*Parts 1 and 2 of Dr. DeMayo’s “Sleep” Articles were in our September and October, 2016 Newsletters.

http://www.papolionetwork.org/uploads/2/7/7/2/27726699/insomnia__part_1__by_william_demayo.pdf

http://www.papolionetwork.org/uploads/2/7/7/2/27726699/

NAIDEX AT THE NEC, BIRMINGHAM dates are 28th - 30th March 2017. www.naidex.co.uk

PRYSM Group, the UK’s fastest growing independent exhibition organiser, are “absolutely ecstatic” to have completed their acquisition of Naidex.

The country’s most established event for the independent living industry, Naidex is held at NEC Birmingham and attracts over 9,000 trade visitors, consumers, and health professionals across three days.

And following July’s acquisition, the event will now be celebrating its 43rd birthday under the guidance of the Bristol-based company, home to such shows as Farm Business Innovation, winner of the Best Trade Show award at this year’s Exhibition News Awards.

What do you call a man with a pole through his leg?	**Rodney.**
Who was England's first Chiropodist?	**Willian the Corncurer.**
What is Santa’s favourite Pizza?	**One that is deep pan, crisp and even.**
How will Christmas Dinner be different after Brexit.	**No Brussels.**
On which side do chickens have the most feathers?	**The outside.**

Australasia-Pacific Post-Polio Conference

By Mary-ann Liethof, National Program Manager, Polio Australia

The **Australasia-Pacific Post-Polio Conference: Polio —Life Stage Matters**, has provided much food for thought, and even some life-changing strategies for the post-polio delegates. This was all made possible thanks to the huge pool of Australian and International expertise provided by the 23 Keynote Presenters, 38 additional Oral Presenters, and 8 Poster Presenters, which provided a total 85 stimulating Presentations across a broad spectrum of post-polio issues. All abstracts can be viewed and downloaded in PDF format from the *Journal of Rehabilitation* website here: www.medicaljournals.se/jrm/content/abstract/10.2340/16501977-2137

There was a total of 229 delegates from 14 countries, and many important connections, as well as new friendships, were made in the 3 days of the Conference. In my mind, this is the true mark of a successful Conference.

Post-Polio Health International recorded 11 Presentations at the Conference and has generously given Polio Australia permission to embed the videos on our Polio Health website here: www.poliohealth.org.au/phi-videos-sydney-2016/

Over the Christmas break whilst most of us are enjoying a bit of ‘down time’, our web-guru, Gillian Thomas, will be uploading all the available presentations, photos, articles and feedback on the Conference website, so keep checking: www.postpolioconference.org.au

My Thoughts on the 2016 Australasia Pacific Post-Polio Conference: Polio - Life Stage Matters

By Gary Newton, Volunteer National Communications Coordinator and Board Member, Polio Australia

Prior to the event, I was asked by Mary-ann Liethof from Polio Australia if I would provide my written thoughts on the 2016 Australasia-Pacific Post-Polio Conference. I was very happy to do so and would like to share them with you now.

It was billed as ‘life changing for many’ in so far as self-management of the late effects of polio. An opportunity to set a new benchmark for best practice techniques in health clinics, both in Australia and other parts of the world for polio survivors. And it was.

But for me the 2016 Australasia Pacific Post-Polio Conference delivered so much more.

You could literally feel it from the moment you entered the main conference area of the hotel. The goodwill from staff and event crew putting the last minute touches on the preparations was obvious. (You see I arrived two hours early having completely misjudged Sydney traffic and the time it would take from my lodgings in Canterbury). Then, as the delegates and presenters began arriving, there was a wonderful sense of ‘comfort together’, of being as one with other polio survivors and a shared excitement of what the next 3 days might uncover for us all.

How many times have you entered a room and felt accepted, completely at ease with the people around you? It was like these people knew you, were part of your ‘family’ yet most of us had never even met. As strange as it may seem, I felt like the people at this event really had a tremendous bond, a shared understanding of the unique struggle that polio and its late effects provides. As one said: *"So many people in one space understanding how I cope with life with PPS”.* (Jenny Jones)

And so to 'the learning', the sharing of information and **My Top 5 List** of what I got from the Conference (in no particular order of importance).

No. 1 - Day 1, first up on stage (and what a wonderful opening) semi-retired MD and polio survivor herself, Dr. Marny Eulberg, spoke about *“What polio causes, does not cause and might cause”.* BANG! Right there in the first 5 minutes! My first light bulb moment when Marny said: *“Polio can cause emotional issues”.* Suddenly (knowing that I had 32 days in isolation when I contracted polio at 15 months. I knew why I am so regularly moved to tears, and why, as I often joke ‘my bladder seems attached to my tear ducts’. By the way, *knowing* and *controlling* those emotions are two different things, as many found out at the end of the conference when I did my wrap up as MC and seemed to once again experience some ‘bladder problems’.

No. 2 - My heart jumped for joy when Queensland Nurse, the superb Jenny Horton, on the frontline in Nigeria with Rotary International’s PolioPlus Program gave us a marvelous insight into the Global Polio Eradication Initiative. Jenny explained how 2.5 BILLION children have been immunised since the program began in 1988. That equates to 15 million people who have received an ‘invisible gift’. 15 million kids who would otherwise be paralysed but can now walk, run, jump and dance thanks to vaccines, the work of Rotary and its amazing partners.

Also as part of Jenny’s presentation, it was wonderful seeing Sir Clem Renouf’s video talking about Rotary’s original joint commitment to not only eradicating polio but to **alleviating the symptoms of polio for polio survivors**, which is so very important to us who are ‘still here’ (and there are plenty!).

No. 3 - Conference Chair and well respected medico, Dr. Steve de Graaff, taught me about the challenges of managing pain, something so many ‘old polios’ suffer from on a daily basis. Another excellent presentation.

No. 4 - Did you know there are, or were, actually 3 types of polio? Professor Robert Booy, Head of Clinical Research at Sydney Institute for Emerging Infections and Biosecurity, explained polio types (now just 2) and said how many of us in the room were very unlucky kids given the low incidence of paralytic polio at the time, which was <1%.

And No. 5 - Brilliant Dr. Kerry Highley, Medical Researcher and Author of *“Dancing In My Dreams: confronting the spectre of polio”*, gave us a marvelous ending to the three days with her closing address and a potted history of polio in Australia. If you can get your hands on her book, I recommend you do so.

So many outstanding talks and presentations, it’s really hard to restrict it to just my ‘Top 5’ but I do want to give special thanks to Gayle Kennedy for her amazing polio story and indigenous insight.

What Gayle endured through the 50’s and 60’s was truly heartbreaking. She is an incredible Australian.

Also special thanks to General Physician, Dr. Peter Nolan; Orthotist, Darren Pereira; and Occupational Therapist, Dr. Natasha Layton; for their excellent contributions, which made a real impact on me.

Everyone will undoubtedly take their own ‘Top 5’ from the Post-Polio Conference, which was over in a flash, it seemed, but such a significant three days that the memory of that experience with fellow polio survivors will live on for me for a very long time.

Remarkably, it was all made possible through much good will and a mutual desire by so many to recognise that polio survivors are ‘still here’ and that we still need support to maintain health and independence.

FACEBOOK GROUPS YOU MIGHT LIKE

POLIO SURVIVORS AT WORK. This group has been organized so that folks having battled Polio are able to sell their handmade items. While you do not necessarily have to sell to become a member you do have had to have had Polio. Please limit discussions to items being sold. No discussions of a personal nature. https://www.facebook.com/groups/poliosurvivorsatwork/

EZ AND DELISH FOODS. Looking to share recipes that are first of all easy to make with a minimum of ingredients. Also, need to have some nutritional value, except in extreme cases where something is just delish, and we need to just enjoy a little at a time. Please share your EZ recipes with us all. Managed by Life Member Jann Hartman. Try **Peanut butter cup Crack Brownies** - No Baking. Suggest make them bite size. **Stroganof Soup**. **Sprinkle some nutmeg** in your coffee, hot chocolate, oatmeal or eggnog. It is the perfect antidote to holiday stress! That’s because nutmeg is loaded with anxiety relievers and like calcium and vitamin C. Plus it contains a compound called ‘myristicin’ which mimics the effects of antidepressants. https://www.facebook.com/groups/418017771690039/

New Research finds achieving healthy vitamin D levels helps relieve symptoms of chronic widespread pain.

Posted on: December 14, 2016 by Amber Tovey

A recent study published in the *International Journal of Rheumatic Diseases* discovered that vitamin D replacement therapy improved musculoskeletal symptoms, depression and quality of life among patients with chronic widespread pain.

Chronic widespread pain (CWP) is defined as pain persisting for at least three months. It differs from localized pain by both its distribution throughout the body and by the heightened pain intensity. CWP affects physical and psychological health; patients with CWP are more likely to experience depression, anxiety and a lower quality of life.

CWP is very common, affecting approximately one in five people. However, its severity and symptoms greatly vary. The most severe form of CWP is formally known as fibromyalgia. Fibromyalgia has different qualifications for diagnosis, one of which is the possession of at least 11 tender points. Tender points are areas that are much more sensitive than others, causing pain when touched.

Vitamin D helps maintain muscle strength, while reducing inflammation. This combination led researchers to conduct a randomized controlled trial in which they discovered vitamin D supplementation significantly reduced musculoskeletal pain. Furthermore, several randomized controlled trials have concluded that vitamin D is an effective antidepressant.

Due to evidence from past studies, researchers conducted a study to investigate the effects of vitamin D supplementation on patients with CWP.

The clinical trial included 58 CWP patients who were considered vitamin D deficient as defined by levels less than 25 ng/ml. All patients received 50,000 IU of vitamin D3 weekly for three months.

Researchers assessed the pain, physical weakness, energy, depression, quality of life and patient satisfaction before and after the vitamin D treatment.

Here is what the researchers found:

- Average vitamin D levels significantly increased from before vitamin D treatment to after with levels of 10.6 ng/ml and 46.5 ng/ml, respectively ($p < 0.001$).
- Pain, physical weakness, depression and energy significantly improved after the treatment ($p < 0.001$).
- Before treatment, 30 patients met the qualifications for fibromyalgia. After treatment, this number significantly reduced to 20 ($p = 0.013$).
- A total of 85% of patients stated that they were satisfied with the vitamin D treatment.

The researchers concluded,

> "A 3-month replacement treatment has provided reductions in musculoskeletal symptoms, level of depression and an increase in quality of life of patients with nonspecific CWP and vitamin D deficiency. Patients with FM or CWP should be investigated in regard to deficiency of vitamin D."

They went on to state,

> "Patients with FM or CWP should be investigated in regard to deficiency of vitamin D. Oral vitamin D3 of 50,000 IU/ week for 3 months is substantially efficacious and safe r replacement treatment in vitamin D deficiency."

The lack of a control group limited the strength of the study's findings, potentially allowing a placebo effect to occur. Nonetheless, vitamin D is not often accompanied by any side effects and can be purchased at very affordable rates. Thus, patients with CWP will find that taking vitamin D is worth a shot. As always, the Vitamin D Council recommends supplementing with 5000 IU daily of vitamin D3, and after two months, testing 25(OH)D levels.

Source Yilmaz, R. et al. Efficacy of vitamin D replacement therapy on patients with chronic nonspecific widespread musculoskeletal pain with vitamin D deficiency. International Journal of Rheumatic Diseases, 2016.

Woman to beat post-polio blues with Himalayan dream | The Times of India. Dec 14, 2016, MT Saju..
CHENNAI: It was raining heavily when Subha Ganapathi decided to drive down to Kodaikanal from her hometown Nagercoil. Her mother didn't allow her to travel alone so Subha told her that some friends would be joining her on the way. With her one-year-old dog Bonzo, Subha, who suffers from a post-polio paralytic attack on her limbs, completed the distance in six hours on her customized Santro car. Today, she wants to participate in the Raid de Himalaya, one of the toughest rallies in the world.

It was her unplanned trips to various places with Bonzo that helped her dream big for a rally like the Raid de Himalaya. When Subha first drove down from Nagercoil to Kodaikanal, she never thought she could cover the distance in six hours. "It was the most adventurous trip. I had to stop in front of many tea stalls to get Bonzo milk and snacks. Otherwise, I could have covered the distance earlier," said Subha, who works as a lecturer in English at a college in Nagercoil.

Driving long distances with Bonzo later became part of her week-end outing. "I remember a trip to Bengaluru which is equally memorable. I don't tell my mother or relatives where I am going. They don't allow me to drive long distances alone. Each time I take a chance and every drive I made with Bonzo has been very entertaining," she said. Even though Subha wants to drive fast, she confessed that she could not go beyond 120kmph. "I don't mind crossing even 120kmph on highways, but I don't get grip as my limbs are weak. So I prefer a speed between 80 and 100kmph," she said. Unfortunately, Bonzo is not with her now. He died a month ago due to age-related illness.

"He was a great companion for me in all my adventure drives. He would watch out sitting on the front seat while I drive. If he wanted to sleep, he would move to the backseat. Now, I have to drive alone. It's a bit disappointing. But I am confident," said Subha, who suffered a post-polio paralytic attack on her limbs when she was four-year-old. However, Subha always remained a fighter and it's this attitude that made her think big. "I don't know whether I am eligible for participating in a rally like Raid de Himalaya (organized by the Maruti Suzuki). I love the Himalayan terrain and I am confident that I could do well if I get a chance," said the 47-year-old.

http://timesofindia.indiatimes.com/city/chennai/Woman-to-beat-post-polio-blues-with-Himalayan-dream/articleshow/55971022.cms

Nigeria: Rotary Club USA, Canada Donates Wheel Chairs To 50 Polio Survivors In Kaduna | Leadership Newspapers. [Dec 7, 2016 9:01 pm] - Isaiah Benjamin writes:

Rotary club of United States of America (USA) and Canada on Tuesday donated wheel chairs to fifty (50) polio survivors selected from the 23 local government areas across Kaduna State. The Rotarians who were led by Ann Hussey Lee who is also a polio survivor said, it was part of their efforts to help in the movement of the survivors from one place to another rather than crawling on the ground. According to her, ” whenever we have an opportunity to touch the lives of the less privilege people in the society particularly People Living With Disability (PLWD) we should count it all joy.

“We are in Kaduna state, Nigeria to participate in the polio immunization program in the state and we feel we should also touch the lives of this people as part of our contribution towards ensuring that they have a better means of moving from one place to another”.

Speaking on behalf of the Commissioner for health in the state, the Permanent Secretary in the Ministry Ibrahim Jere commended the Rotarians for their magnanimity prayed God to reward them for their continuous efforts at touching the lives of the less privilege people and PLWD in the state.

Also speaking, the Executive Secretary of the Primary Health Care Development Agency (PHCDA) in the state, Dr Hadiza Balarabe also commended the Rotarians and further urged the beneficiaries not to see their disability as the end of their lives. She urged them to use the wheel chairs to better their mobility from one place to another. Responding, one of the beneficiaries, Mary Johnson commended the donors and prayed God to bless the works of their hands now and always.

https://leadership.ng/news/563002/rotary-club-usa-canada-donates-wheel-chairs-to-50-polio-survivors-in-kaduna

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

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

REMINDER FOR MEMBERS

Have you changed your home, email address or phone number recently?

Did you let us know?

Your Newsletter needs your stories, hints, tips and bits

A way of doing something, or aid, that helps you might help someone else. Tell us.

How about a recipe that tastes great on the lips but not on the hips.

CARERS - Are you a Carer and would like to write and tell us how we might help Carers understand what you go through helping us manage our lives.

Articles and items for Post Polio Matters
are always welcome, by post, by email and by phone if writing is not easy for you.

Deadline date for next issue is 1st February 2017

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

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]
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Please contact us if you would like to help with our work

Membership

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

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

Membership Fees

UK Individual - £ 12.50 per year

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

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

We welcome members living in other countries and details will be sent upon request.
Please note the majority of information will be sent via the Internet.
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/

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.

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To support attendance at National Meetings and PPS Conferences

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Australasia-Pacific Post-Polio Conference

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