

# POST POLIO MATTERS POLIO SURVIVORS NETWORK 100th Newsletter

**APRIL 12TH 1955 - 10.20 E.S.T. 62.5 years ago**

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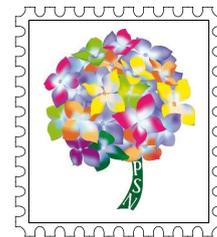
The University of Michigan Information and News Service - ANN ARBOR

From Our First Newsletter the LincPIN September 1996 - **21 years ago**

**OH! How we would love to post polio....  
If only we knew where to send it ?**



**OCTOBER 24th 2017  
ROTARY WORLD POLIO DAY**



To:- All Colleges of Medicine and Medical Schools

# POST POLIO MATTERS

because **WE'RE STILL HERE!**

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Lincolnshire Post-Polio Network - Registered Charity 1064177

Known as **Polio Survivors Network** since 2010

present our **100th Newsletter Post Polio Matters**

**Volume 9, Issue 4/12**

n.b. Volumes 1 to 6 published under the name LincPIN.

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

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## **New Members, Andrew Smith, Richard Dines, Norma Head rejoins**

### **Donations received with grateful thanks**

**Member Jennifer McGowan in memory of her mother member Iris Dawson**

**Kay and Lou in memory of their father Reginald Allison**

**Olivia Branson, Paul Stanton, C Darlington, Steve Clynych, R Liggins, S Freeman, S Tanfield**

**D Rose, Robert Bass, Michael Whitley, Pauline Dunham, Jennifer Paulger, I Downing, K. Norman**

**from March 2017 £683.55**

**Val Scrivener Photo Cards donated this year - £70.00**

**Conference and Meeting Fund donations this year - £430.00**

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 - Polio Survivor age 5, 1952

**November 24th 1995** - It only seems like yesterday when I found that my seven years of new pain, fatigue and functional decline were not 'Lloyd George Syndrome [when your GP records overflow the brown envelope 'it is all in her mind'] but could be related to the fact that I had waist down paralytic polio at the age of 5.

The Hospital Library sent me to the Health Information Service and I was given copies of two media articles. **Polio Returns to Haunt GP's in GP November 1992**  
[[www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/gp/haughtps.html](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/gp/haughtps.html)]

And **Patricia Rock story by Thomas More in the INDEPENDENT 12th January 1993**  
[[www.independent.co.uk/life-style/health-and-families/health-news/health-fighting-and-surviving-all-over-again-patricia-rocks-childhood-polio-returned-in-an-1478061.html](http://www.independent.co.uk/life-style/health-and-families/health-news/health-fighting-and-surviving-all-over-again-patricia-rocks-childhood-polio-returned-in-an-1478061.html)]

The following year I joined the British Polio Fellowship [I did not know they existed] and in late July having met Leicestershire Polio Network's Helena Edwards, Lincolnshire Post-Polio Network was founded. **We became a registered charity on the last day of August 1997**. We changed our name to Polio Survivors Network in 2010 to better reflect our membership.

**October 12th 2017** the 100th issue of our Newsletter goes to the printers. First issue the LinkPIN changed to LincPIN March 1998 and named by member Dinah Foweraker in 2010 as POST POLIO MATTERS. This issue has been compiled to provide a wealth of information on Polio and Post Polio Syndrome and some ideas on how we might better manage our lives. We will be posting copies to Colleges of Medicine and Medical Schools in the UK.

The most important point is that we must tell the Health Professionals we see '**How It Really Is**' and ask "Why have we had to change the way we are doing these actions?" Tell our Family and Friends too and ask for their support to help us manage our new symptoms of functional decline so that we get the most out of life. Remember it is as hard for our family to see the way our lives are changing as it is for us. Try talking about each issue by taking turns in having a short say about something worrying you. You might be surprised how much difference this makes.

When we were recovering from Polio, it was '**USE IT or LOSE IT**' and we showed how resourceful we could be achieving way beyond what was expected of us. After years of stable functioning we are now having some new issues and Health Professionals that know about Post-Polio now want me to '**PACE and REST**' and '**CONSERVE to PRESERVE**' Do they really understand how hard it is to change the habits of a lifetime?

However as you read through this issue you will see that if we **Pace and Rest** our actions of daily living and we start to use any aid or assistive device including human help so that we do not waste energy, that overall we can do **240% MORE** with less pain and less fatigue. The phrase most often heard by PPS Support Groups after you have been attending a few years is.... I wish I had listened to the advice earlier"... "No, I did not want to start using electric wheels for the first time or again but boy have I now gone miles and to places impossible without.it"

I have included items and excerpted bits from many different sources. Sharing information world wide is how all PPS groups have moved forward. So thank you to all the polio survivors in all groups, e.g. British Polio Fellowship, Scottish Post-Polio Network, Post-Polio Support Group of Ireland, European Polio Union, Post-Polio Health International, Polio Canada, Post-Polio Litaff AC Association, Polio Australia, Polio NZ Inc, Post Polio Network RSA, etc. Plus all on a variety of Facebook Polio Lists. Members of Rotary, The Neurological Alliance, Lincolnshire Neurological Alliance, TVDNY Alliance and more who have shared information with us over the years.

**See Post-Polio Health International Directory - <http://www.post-polio.org/net/PDIR.pdf>**

21 years and so many to thank. All who have given us years as Committee Members. Your Membership fees and added donations. All the articles. A special Thank You to member Chris Salter who built the Lincolnshire Post-Polio Library and who started Post-Polio News [ppn] that we feature each newsletter and link on our Website. Member Val Singleton for her wonderful Photo Cards. To all, please keep in touch and let us know how you are doing, hints, tips and bits that help and if there are questions you would like information on please let us know.

## **MESSAGE FROM OUR CHAIR**

### **Striving for the best not settling for the least**

First, forget, just for a moment, all you have been told about "pacing" "learning to accept decline" And no I am not going mad or trying to kill you all off early or rubbishing the long hard fought work to get the medical world to eat humble pie around PPS.

I want to suggest that the reality of having been a polio survivor is that we have had to have all the qualities of an athlete. Our remaining muscles have learned to operate at peak performance, using every last fibre to its maximal capacity in order to compete in a non-disabled world. Even though our peak performance may result in getting dressed, walking down the road, making a meal or just breathing, we are nevertheless working at the same efficiency as a top flight athlete!

And the 'so called' polio personality is an essential part of this requirement to maximise everything, to not give in, to function at our very best. Those who didn't manage or couldn't achieve this fell by the wayside long ago. We are left, we are the survivors and the medal winners.

I want to suggest that you take this on board. Not just nod and agree, but understand it, be proud of it, wear the medal and use it now at this stage in our lives. We have been so successful we have perhaps forgotten what it is that we do and have done. We are all top flight medal winning athletes, dare I say it yesteryears forgotten aristocracy of disability.

We should ensure this is understood and demand that we are treated as such. Just because we are no longer at that youthful peak and now have to work with a declining reserve of muscle and physiological resources we must not settle for less.

I suggest that you start by posing this question:

**If I were a top flight athlete, world leader or talented sports person what could you offer me to achieve the absolute best with what I have?**

Pose this first to yourself, think about it and understand what it means to you now. Then maybe directly pose it to the next professional who has the privilege of working with you. You are one of medical sciences true winners and athletes, think of them as your team trainer and coach, ensure they understand that.

Of course this doesn't mean they can always supply it or do it given the constraints on the NHS, their often limited knowledge and or ability. But you should demand to know what is possible and how that differs from what is available or probable.

I suggest it is time to wake up and smell the coffee guys. Reach back and claim your heritage. Ignore the rhetoric of politicians, establishment medics and NHS management - the current system is broken beyond repair. Speak, as I do to almost all of those who know, your old style NHS has gone. Forever. What you have is an emerging mix of charities, private health insurance and self-funding. Sorry but this is a fact and never more so when applied to chronic long term conditions and disability.

The best athletes win when the odds are against them, at worst they stay in the race until things change or they get new management. In order to get what we need and deserve we need to know what is possible for someone who is prepared to work at it, using all their personality and knowledge to maximise their life and abilities. No one gets out alive but you can go down fighting.

Just think of a few examples. Orthotics, there are amazing up to the minute and state of the art prosthetics. You should know about them, where to get them and how much they cost, not just what your local service offers. Same with wheelchairs, same with physiotherapy, same with respiratory care and dare I say it, the same with medical professionals.



**So in the 100<sup>th</sup> issue** I want to look back and forward at the same time. I invite you to reclaim your aristocratic heritage as polio survivors. You know more about you than any health professional, you know how to do your very best to make things work, all you need is the best advice, the best coach, the best facilities and the best training and health regime.

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## From Issue One LincPIN August 1996.

### Tom Walter in California -

In recent studies in the US and Europe about 70% of those who had paralytic polio now have symptoms of Post-Polio. And probably 50% of the anterior horn cells have to be 'gone' before strength/function is affected.

According to the observations of Rds. Perry and Bruno, those who had the worst affects at the onset of polio AND who made the most recovery appear to lost the most later on with PPS.

Dr. Halstead theorizes that in each decade of this century - 1910's, 1920's etc..... the polio virus became more virulent, with more limbs affected, more bulbar polio in the 1940's and 1950's than earlier.

That could explain why we see some more mature folks in their sixties and seventies (who had polio much earlier than most of us) do not seem to be affected by PPS.

Dr. Bruno has observed that those who had the Sister Kennedy treatments seem to have more PPS - but is this because they lived and recovered more with this treatment? or because the virus was, indeed, more virulent by the time this treatment came into vogue? or?

In my own case, I was completely paralyzed and in a coma at onset of Polio at age 12 in 1954. After 10 years of surgeries and therapies, I walked for 30 years with no aids - and only a slight limp and residual paresis in the left leg. Then starting about four years ago, I went 'over the cliff' with a very rapid decline from PPS - with all muscles and joints from head to toe (including breathing and digestion) affected by pain and weakness. Within a year, arthritis set in all the joints too - probably from lack of proper muscle support. Another secondary affect we may have from lack of muscle support and exercise is osteoporosis, which was already apparent two years ago in my 'bad' (now worse) leg.

I can still 'walk' (drag myself around) short distances inside, but use an electric power wheelchair for going out. I usually have the strength and energy to get cleaned up and dressed and leave the house twice a week - and the days in between I sleep and rest and nap and rest and sleep some more.

Curiouser and Curiouser. [See more from Tom Walter in the Lincolnshire Post-Polio Library.

[www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/cs\\_w.html#Walter](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/cs_w.html#Walter)

When your pet bird sees you reading the Newspaper does he wonder why you are sitting there staring at carpeting?

Some days you are the pigeon and some days the statue.

Isn't it a bit unnerving that doctors call what they do 'practice'?

Mixing bowl set designed to please a cook with round bottom for efficient beating.

At a Sante Fe gas station: 'We sell gasoline to anyone in a glass container'

On a long established New Mexico dry cleaners: '38 years on the same spot'

She slipped on the ice and apparently her legs went in separate directions in early December.

The patient was in his usual state of good health until his airplane ran out of gas and crashed

Accordionated adj. - Being able to drive and refold a map at the same time.

Aquadextrous adj. - Possessing the ability to turn the bathtub faucet (tap) on and off with your toes.

## The Continuing Sagas of Disbelieving Dot !



It is now September and still no falls to report folks! This is indeed a record for me. I cannot remember the last time that it has been over a year since a fall – not just a fall requiring surgical intervention, medical attention; not even a fall requiring my stock of Mr Bump plasters. Not even a bruise! It is unbelievable and my disbelieving friends cannot believe that I remain unscathed since decamping from 'up North'! I was greeted in Stratford for a get together with a "Wot, no broken bits"!!

However, to make up for the calamitous Ives's "he indoors" slipped and fell, whilst outdoors, a few weeks ago. Thankfully he was uninjured (apart from his pride) and keeps commenting that he could have broken his hip. "I could have broken my hip, you know" (Yes, I do know but you didn't)! He also shows me the 'spot' the exact sloping seemingly innocuous paving that dared to jump up and hit him in the jacksy..... every time we pass the incriminating and guilty lump of concrete!

Apart from feeling 'badly done to' and bemoaning my lack of sympathetic TLC I think he is realising just how 'mortal' and vulnerable he is or is becoming. He isn't used to falling or being accident prone or being in pain. He is also 'taking badly' to ever increasing creakiness and arthritic joints that befalls us all.

It got me thinking though as to how un-resilient and emotionally unprepared for 'old age', associated aches and pains and vulnerable to accidental damage we all are no matter how inevitable it all is. Even those of us who suffer from chronic pain and constant minor injuries through falls 'take badly' to yet more things happening.

This takes me to my first visit to our GP Surgery since we moved house and counties six months ago. (Repeat repeat prescriptions don't count)! I have been having niggling pain – sometimes stabbing, sometimes like an aching tooth around my right hip and outer thigh. As I explained to the GP it is different to my bad back, bulging discs, sciatic pains. I just thought I would get it checked out although I suspected it was arthritis. Apart from anything else I thought it would be useful to show my face to a GP! She asked how long I had had the said pain (I plucked at 3 months) as this didn't sound too bad although I know it has been niggling for longer. She looked at me as if I had two heads and stigmata and declared "3 months"!! Her examination led to x-rays the following day and yes, both hips are arthritic. I must say that I was impressed that I was able to get x-rayed so quickly... a 'drop in' system the local minor injuries hospital. Well done to South Staffs NHS! (and readers of previous sagas will be pleased to know that I have found where to go)!! So, one more thing to add to my list of ailments!! Watch this space!

Added note!

Further to my present good fortune. It must be noted that (apart from new hip pain) I am generally 'better' than normal – my back and sciatica is not as troublesome. Hilary commented at the AGM that I was quite sprightly (more so than usual). I think I am! I certainly seem to be able to walk quicker than my dearly beloved! Our son enquired "Since when have you been able to walk faster than my dad"?!

I 'think' it is due to downsizing to a bungalow (no stairs) and to supplements (Vitamin D and turmeric). More about this next time!

**Dot Ives**, Trustee and Secretary. [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk) Polio age 1 in 1956.

**Steve Ives writes** ..... You know how wives bully you? Well I got my own back! A while ago I became concerned that Dot was becoming more and more clumsy. I knew she had had polio as a child, long before I met her and I had asked her to go to the doctors to see if something was wrong but it was always a case of 'stop fussing'. At the time it seemed that I was a semi-permanent visitor to my doctor's surgery with blood pressure or cholesterol or whatever. Dot had tripped up again on the door step or a leaf or a worm or fresh air and as usual refused to see her doc.

So when I next saw my doctor, who was the husband of Dot's doctor and after I had my medication changed again I asked if he would have a word with his wife to maybe look into the causes of Dot's clumsiness. I told him that accidents were a regular event and that she only went to see his wife or A&E for the more major injuries. I assured him I didn't want to know anything confidential and he protested that it was highly irregular. With that I returned home.

A week later Dot visited her doctor, I was catching up on my favourite TV, probably Star Trek and when she got home the first thing she said as she walked through the door was 'Where's your father?' Always a bad sign.

But it worked! She got a referral to the hospital and got some attention which consisted of shoe insoles to make her walk properly. She was in the system and the rest is history. I know there is no cure but she isn't as clumsy any more.

## **Margaret Marris, Treasurer, Wife, Mother, MIL., Grandma & Carer Polio Husband 5 in 1948**

From as far back as I can remember I wanted to become a nurse /carer. My Mother's two sisters were in the nursing profession. One sister and my mother were stay at home mums during World War II. The other sister was a Queens Nurse working on the district and riding an auto cycle!

At the age of sixteen I left school to become a cadet nurse at the Maternity Home in Hull. There were 4 cadets in all. We did full time day work within the nurseries looking after the babies. Under supervision of the Midwives (in those days babies were taken to their mothers every 3 to 4hrs) my Carers life had begun and my aim was as always to be a midwife.

In 1964 I qualified as a midwife, working on the district on a large council housing estate. No mobile phones or computers just a list in my flat window saying where my visits were on that day in case a lady needed me. I was on call 24 hours a day for 10 days then 4 days off.

Midwifery changed in the late 60's which meant babies were mostly born in hospitals. I decided to continue being a midwife within that system until 2004. I then retired having spent the whole of my working life in midwifery, except for 1year when our daughter was born.

My husband David and I married in the 70's and we've always cared for each other. Suddenly four years ago CARE had an R added on to the word resulting in CARER, two different meanings!

As mentioned in a previous article David had Polio at the age of 5 years. He led a very active life, working here and abroad, climbing, shooting and caravanning. Things changed dramatically two years ago when he started complaining about pain in both of his legs. I found out about PPS on Google after searching "pains in legs". I found Polio Survivors Network and was stunned to find that it was a mile and a half away. His GP was unaware of PPS [PSN disappointed that after twenty-one years of providing information to Lincolnshire doctors obviously the message is not getting to all doctors.] I explained to him what I'd found on Google. Eventually got it confirmed by Dr. Prasad, Rehab Consultant in Lincoln. [now moved to Leicestershire Royal Infirmary]

David had been under surveillance for an aortic aneurysm for three years. We had a call from Nottingham Hospital after he had had a scan to say we should go to our local hospital as a pulmonary embolism (blood clot in the lung) had been diagnosed and needed treatment. Lincoln arranged another scan and this one showed a bowel issue that also needed dealing with. They had to put the aortic aneurysm operation on hold whilst they dealt with the bowel issue - a 5 hour operation over Christmas in Nottingham, this was successful.

A fall down stairs in February resulted in another hospital admission for fractured ribs! So the aneurysm operation postponed again till April. This was quite complicated but successful. For each appointment I would have as much information prepared explaining about PPS, it was never refused and many times gratefully received.

When he came home after the first operation I felt totally isolated. Community Nurses attended daily. I never had any idea as to what time they would arrive. I would leave David in bed to take the dog for a walk early so that I would be home for the rest of the day to be in when the nurses visited. I got this transferred to Nurses from our GP practice and was given an appointment time each day. This was good as it gave more time for me. David had no appetite for food, that was a real problem, so I bought him 'build up' powder. Lincoln Tesco pharmacist was and still is a good source of support. The local hospital stoma support nurses have been excellent seeing him at the drop of a hat. The phone is a good way to keep up with friends and family. David spends a lot of time in bed, TV was his saviour, [and mine phew!]

When the second operation was planned I was desperate for help. Having not had any information about equipment or care I contacted Adult Social Care [ASC]. This was one of the best things I did. They told me to ask for a physiotherapist to assess David now while he was in hospital as they would contact ASC who arranged equipment and care for a few weeks. David is doing well now with a lot less pain in his legs and he uses a scooter for longer distances.

Never struggle, there is help out there, but more times then not you have to ask.

## **NEW MEMBER ANDREW SMITH tells the story of his POLIO LIFE**

My experience began in 1956 when I was 4 years old. I lived in a small village in Leicestershire when myself and two other children, one from each of two adjacent villages were diagnosed with polio. Unfortunately one child died, the other was paralysed from the chest down their life was restricted to being in, what was called at the time a 'bath-chair'. Then there was me.

I was paralysed from the waist down with both legs affected but my right leg more severely. I initially was put into Derby Children's hospital later transferred to the then Bretby Children's Hospital for rehabilitation. With lots of physiotherapy, electro-therapy, and time, I regained feeling in my legs and was eventually able to walk again, albeit with callipers and with difficulty.

Over that period my feet however had become very misshapen. To such an extent that it was virtually impossible to wear shoes. I remember having to wear special insoles in over-sized shoes. The idea being that, in time, my feet would straighten out. This did not happen so when I was about 9 years old I was back in Derby Children's Hospital for operations on both feet - 5 operations on the left and 6 on the right. They were all completed at the same time and, as I understand, tendons were cut and re-routed in order to pull my feet straight. After I was allowed home I had special reinforced plaster casts made that I had to wear every night. They were bandaged on to both feet and held them at right angles to my legs. If I recall correctly it was necessary for this to continue for about a year. I was able to recover and go through secondary school with no physical problems competing in all the usual school sports in the mid 60's.

I wanted to join the Royal Air Force (RAF) straight from school but settled into working as an apprentice electrician at our local colliery. In 1970 though, I decided to join the RAF. I was 18 years old. The procedure was, at the time, to have a Test, a Medical and finally an Interview where you would then be told if you were successful in your application or not.

My problem started at the Medical stage. It was a case of strip off to your underwear and have a full examination by an RAF doctor. When he saw all the scars on my feet and I explained what they were he said that I would not be eligible to join as I would not be able to cope with the physical side of being in the RAF. When I challenged this with my school report, specifically the PE section he said I would have to be referred to a specialist. At the appointment the 'specialist' had me jumping, walking backwards, squatting and doing all manner of, what i can only describe as, dance steps!

I was eventually contacted by the Royal Air Force to say I had passed my medical and was to attend a formal interview. I did and joined the Royal Air Force in June 1970. I went on to serve for 22 years, leaving in 1992 at the rank of Flight Sergeant. In all those 22 years, the polio I had all those years before did not affect any part of my career.

It was not until around the millennium that I began to be aware that I was finding it more and more difficult to carry weights. I was a funeral director by now. I put it down to just getting older but as the years went by I began to notice that my right leg was becoming thinner than the left.

I went to the doctors in 2011 because I was having trouble breathing, especially when in bed and also because I was starting to be breathless, sometimes at the slightest exertion. I had loads of blood tests and all came back normal and by now my right leg was randomly 'giving way' at my knee. It was in 2012, on another visit to the doctors and seeing a locum doctor that I was told, after she asked many questions and looked into my medical history, that I had PPS. To be honest, I had never heard of it before but both my wife and I were almost in tears knowing what was apparently wrong with me. Not because of the diagnosis but because we now know what is wrong and we can adjust our lives accordingly. As a funeral director, carrying was part and parcel of the job but my confidence had gone due to the randomness of my knee giving way so I retired early and stopped working.

Now, because of the weakness in my right leg, I am apparently compensating and now my left hip and lower back are causing problems.

I am 65 now and have no regrets only gratitude, especially to the doctor at Derby Children's Hospital, Dr Lunt, who after straitening out my feet, gave me the ability to have a really good career and life.

## How to look after your feet.

Most of us who have had polio and now are battling with the effects of new mobility problems are unlikely to go on long walks and so will probably not suffer from hard skin, or calluses on the soles or heel areas. But it is still very important to care for the health of our feet. There are several ways to do this.

Good hygiene means daily washing and careful drying of feet especially between the toes. Use a good moisturising cream if the skin is dry. Most people wash their hands with soap several times a day and brush their teeth morning and evening but neglect to wash their feet. The feet are covered with a large population of bacteria responsible for the bad smell of sweaty feet.

Shoes, socks, or hosiery should be changed daily. Properly fitted shoes are essential. An astonishing number of people wear shoes that don't fit well, and cause serious foot problems. A shoe with a firm sole and soft upper is best for daily activities. Shower shoes or flip flops should be worn in public swimming pool areas when possible. It is here that verruca's are easily picked up. Often these are misdiagnosed as corns and are only apparent when the overlying hard skin is removed by the chiropodist. The longer they are allowed to grow the more difficult they are to eradicate.

It is surprising how many people are unable to cut their toenails. Toenails should be clipped straight across so that the nail does not extend beyond the tip of the toe. If you are unable to do this you need to find a chiropodist of good repute preferably one that has been registered with the Health and Care Professions Council which regulates the profession and protects the public from unscrupulous practitioners. Fingernails grow about twice as fast as toenails. There is a big variation between individuals. Growth rate depends on heredity, gender, age, levels of exercise. Nails grow faster in summer. If the nails are allowed to grow too long, dirt and dead skin can accumulate underneath causing problems such as fungal nail infection which first causes discoloration of the nail, then thickening, making it more difficult to cut. It can cause serious complications especially for diabetics and those with impaired circulation and it will not go away without proper treatment.

Another common problem is an ingrowing toenail which can develop due to inexpert cutting. If a person accidentally kicks a hard object, the nail can pierce the skin and bacteria will enter causing much pain, swelling and redness. In most cases the chiropodist can remove the offending piece of nail which caused the problem but often an antibiotic is needed from the patient's GP to get rid of the infection.

'Man's foot is all his own. It is unlike any other foot and feet are as individual as faces. It is the most distinctly human part of his whole anatomical make-up. It is a human specialisation and, whether he is proud of it or not, it is his hall-mark. As long as Man has been Man and as long as he remains Man, it is by his feet that he will be known from all other members of the animal kingdom'.

Now that chimpanzees have been shown to have language, it is really the only thing that can be shown to separate us from other animals! You only ever get one pair of feet!

Although I have heard there are second hand shops!

Zsuzsanna Snarey [nee Bozzay]  
HCPC registered Chiropodist/Podiatrist  
[www.eastry-chiropody.co.uk](http://www.eastry-chiropody.co.uk)

### Author of *Escape from Communist Hungary*

At the end of the Second World War Hungary became a Russian 'protectorate' without the consent of the population. Communism was established by stealth and the borders were closed. It was not possible to get a passport and leave the country. The only way to escape was crossing the border on foot which was both illegal and very dangerous.

In the late autumn of 1949 after our failed attempt I lay paralysed by polio in an isolation ward .....

Available on Amazon as a book and also on Kindle Unlimited.



# Iceland for Everyone

By Marcia Falconer, Ph.D. (cell biology) Life Member

A trip to Iceland has been on my bucket list for a long time. In August 2017, my husband and I 'filled the bucket' with a 5 day, 4 night, trip to Iceland.

Iceland is one of the most geologically interesting places on the planet! 80 million years ago, there was no Atlantic Ocean. Europe was nestled against North America. A major fault line developed between the tectonic plates that carry the continents of Europe and North America. As the plates began to separate, sea water flooded in creating the Atlantic Ocean. There is an area in the fault line where the earth's crust is thinner and where magma (lava) from the molten core can more easily reach the surface in volcanic action. This is Iceland.

The fault line is still active and widening at a rate of about 1" per year. The whole island is volcanic. Iceland is the size of Ireland and it has more than 130 volcanoes, of which about 72 are considered active. Currently 4 volcanoes (named on the map below) are considered at risk of a major eruption!



Map of Iceland showing four volcanoes ready to erupt. Source: [www.dailymail.co.uk/sciencetech/article-4203036/FOUR-Iceland-s-volcanos-brink-erupting.html](http://www.dailymail.co.uk/sciencetech/article-4203036/FOUR-Iceland-s-volcanos-brink-erupting.html)

**Thingviller** - This is the rift where two tectonic plates are slowly moving apart. On the right is the North American plate and on the left is the European plate. Photo: M. Falconer

It's no wonder then, that almost all the major tourist attractions in Iceland are related to volcanic activity. There are the volcanoes themselves - some of which are safe to visit. There are geysers and hot springs and lava flows, boiling mud pots, rift valleys, and magnificent waterfalls. Ancient lava flows and extinct volcanoes provide lots of hiking trails.

There is history too, of course. Iceland was permanently settled in 874 A.D. by Vikings from Norway. Land was free and a man could claim as much property as he could light fires around in one day and a woman could claim as much as she could lead a heifer around in one day. Within 50 years, the population grew to 60,000 and by 930 A.D. was governed by an assembly. This assembly, sometimes called the first Parliament, met once a year *in the rift valley* at a place called Thingvellir. Since the population gathered here for the assembly, a market was held in the same place. Amid merriment and food, goods were bartered, deals were made, and marriages arranged.

It is now possible to visit Thingvellir and to walk where history took place. A few foundations of market stands can still be seen. And of course, geology is always important. As you walk along the path in this narrow valley, the cliffs on one side are part of the North American plate while the cliffs on the opposite are part of the European plate and the area between is widening each year!

Another sight not to miss is the huge and impressive waterfall called Gullfoss - which is also the result of tectonic action. The waterfall has two steps, but unlike virtually all other waterfalls, the 'steps' are not directly in line, but rather arranged at right angles. Thus the river goes over the first waterfall and then makes a sharp bend to the right and drops over a second fall into a narrow gorge. This is because the waterfalls are the result of two fault lines which make an " X " at exactly this place. The power and beauty of this waterfall is not to be missed.



**The Blue Lagoon** - a very large, completely accessible, hot spring. Photo: M. Falconer.

**Gullfoss.** The upper falls run diagonally to the upper right. The lower waterfall is in the foreground where it drops off into a narrow gorge. The path at left leads to the peninsula that juts out into the river. The three small 'bumps' on the peninsula are people! Photo: Marcia Falconer.

One question - how accessible is Iceland? From my limited experience, I would say that the major sights are reasonably accessible. Gullfoss waterfall for instance has two parking lots, one at the top of the waterfall, another at the base. The top lot has a wheelchair accessible path to the falls as well as an accessible restaurant and gift shop. However at the bottom parking lot there is only a very slippery path that is difficult even for an able-bodied, older adult. I believe there is an intent to make this part more accessible in the future.

What about Thingvellir? Once again there are two parking lots. The top one will soon have a new museum and visitors center, which is now under construction. From the top parking lot there is a steep, but accessible, wheelchair path. Fair warning, if you don't have a motorized wheelchair, you will need a strong 'pusher'. Still you can enjoy riding between two continents. The lower parking lot will lead you to a lovely, accessible path and to accessible bridges that will take you to the old church.

Finally, do not miss the Blue Lagoon! Because of all the volcanic activity, geothermal plants are widespread in Iceland. They pump superheated water from the ground and use it to generate electricity. They also pump this hot water into towns and cities where it is used to heat houses. The Blue Lagoon is formed from the run-off water used to make electricity. This is not 'waste' water, but simply water that has cooled off as heat is extracted for other uses. The company started releasing this water onto the adjacent lava field. It formed ponds and Icelanders began coming to bath in the perfect temperature hot ponds. The blue colour is the result of silica, a natural salt, in the water and makes bathing particular good for the skin as well as attractive. The Blue Lagoon is totally wheelchair accessible and even has a Hoyer lift to ease you into the water!

Iceland may be far north, and next door to Greenland, but the Gulf Stream means that the winters are not overly severe. Summers are cool and can be wet. Still the northern lights are seen quite often and English is spoken everywhere. With all these positives, there must be a down side. There is. Being a tourist in Iceland is expensive. And it can be very expensive.

In 2008 Iceland suffered a complete economic collapse. The banks failed. People could only take out minimal amounts of money from the bank. Jobs were lost. The fishing industry collapsed. Then someone thought about making Iceland a tourist destination. This seemed

ludicrous at first. Who would want to go to an island located between Greenland and Norway and with active volcanoes? It turns out - lots of people do.

The population of Iceland is about 330,000 but nearly 1 million people visit each year. Most material things must be imported - as is much of Iceland's food. There is very little arable land but there are greenhouses where vegetables grow and the sheep and cattle industry is doing well. Fishing has revived and fresh, delicious cod is available everywhere. But the price for all of this: recovering from total economic collapse and the need to import 90% of what is consumed, means that the prices will be high.

If you're a cautious consumer, and you purchase food in supermarkets, carry picnics and avoid most restaurants for dinner, you can manage. Still hotels and some activities carry prices higher than you're used to. The best thing to do is to save your money and then - when you get to Iceland - simply enjoy the visit. Eat where and what you want. Drink coffee even if it is expensive. Don't convert to Pounds or dollars. Simply enjoy the holiday, the incredible scenery, the friendly people and the amazing things Iceland offers.

*Marcia had polio at age 6 and sometimes wears a leg brace. She uses a cane and/or forearm crutches, but not as often as she should. She enjoys traveling and writing.*

*There are several websites that are useful to explore handicap access and tours of Iceland:*

<https://icelandunlimited.is/category/tours/accessible-travel/>

<http://www.wheelchairtraveling.com/accessible-tour-in-iceland-for-wheelchairs-access-seniors-handicap/>

M. Falconer. [www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/falconer/biography](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/falconer/biography).

## Room 101 and all that! By Dot

We booked a well known 'lodge accommodation' room with access for people with disabilities. We arrived to discover we were in **Room number 101**. With echoes of 1984 and the TV show ringing in my ears we opened the door with some trepidation!

We were pleasantly surprised. The bathroom / wet room was a very good size and ticked all the boxes. The bedroom layout provided ample space – the wardrobe was at an accessible height for wheelchair users.

Initial thoughts were well done! But... whilst the wet room was accessible, there wasn't anywhere to place a toiletry bag except on the floor or in the bedroom. The bed is the standard king sized bed found in every room. This surely is too low for most users with disabilities. So, all in all, nearly there 'well known lodge accommodation' but not quite! So following the protocol on the TV show, here you are Frank Skinner 'a candidate for the Room 101 box.

This got me to thinking generally about facilities for the disabled that may be piecemeal at best and laughable at the worst or would be if it wasn't so annoying, frustrating or downright insulting. From clothing shops that provide an entrance ramp but then have the clothes rails so closely packed that wheelchair users face an obstacle course and are in danger of textile suffocation. Or the pub that provides a disabled toilet to comply with legislation but does it 'on the cheap' as one pub I visited had done.....it was upstairs! When a complaint was made they said they had another one 'out the back' through a corridor that you would struggle to swing a cat. Non wheelchair users could manage as long as they were not desperate as it was a trek!

### **Polio Survivors with Cancer as Well.**

**See Member Verite Reilly-Collins Website - [www.aftercancers.com](http://www.aftercancers.com)**

**Many cancer patients find once hospital treatment is over, they feel 'abandoned' and have to work things out for themselves. If this happens to you, this website is here to give you ideas and information about where to find help, and examples of what others have discovered, so you don't feel so alone.**

## IF YOU KNEW POLIO LIKE WE KNOW POLIO.....

Pages of Information on Polio and Post-Polio Syndrome [PPS] to:

- Help us discuss issues that we are having with our family and friends and then health professionals in a way that allows us to **tell it like it really is**
- Ensure that everyone understands that Post Polio Syndrome does exist [WHO International Classifications of Diseases, ICD-10-CM G14] and that this could be a reason for our new problems
- That we can have any condition **instead of or as well as** post polio. Plus because we had nerve damage from a polio virus in our earlier lives this may cause issues with how we react to other conditions/medications/anaesthetics/treatments/respirator masks/returning to equipment thought long gone/etc.
- Accept that sharing and learning from our peers can help us take on board any changes that health professionals and/or we want to make to manage our lives with greater ease, less pain and less fatigue.

It is not easy for Polio Survivors, who have no idea that there is a later stage to polio following stable years, to hear or read about what might happen to them in the future. Similar happens in many other conditions.

Most people diagnosed in the early years were children hence the early name 'Infantile Paralysis'. Our members go from catching polio at just a few weeks old to adults and therefore have different levels of understanding and language of what happened. The younger we were the lower our language level to put into words our experiences. All of us have sights, smells, and sounds of medical establishments hidden in our memories. These memories can come to the fore again and when we least expect them and can cause considerable stress and anxiety, sometimes with us not knowing why.

Whilst reading **Healing the Blues**, A success story by a Patient and her Therapist by Polio Survivor Dorothea Nudelman and David Willingham. [1.8.1999 available at book stores and online] I suddenly burst into tears for what seemed no reason. I emailed Dorothea who explained that it was most probably a forgotten memory of similar happening to me that had been triggered. I was five, remember nothing but my mother confirmed this had happened to me. I know of others who cannot go into a launderette because of the smell of washing and remembering the hot wet wool blankets that were placed on muscles. Those hospital times as an in-patient, being fitted for braces & body casts, physiotherapy maybe with 'put your feet in this bowl of water that has cotton covered metal plates in it now pull this lever to give your feet electric shocks to make your toes move!,' etc mean that we can take months if not years to seek medical help.

Maureen Allison whose story we told in an earlier newsletter had been in an iron lung at age 15. A few years ago in ICU she really struggled to wear a respiratory mask. Not only the memory of being in an iron lung but having one arm that did not work well she feared that if she choked she would not be able to take the mask off. Her daughters Lou and Kay persuaded Doctors that she would manage to wear it if they sat with her, in shifts, and held her hand so she could squeeze it if she needed anything. A couple of days later she was much better. Thankyou so much to you both for sharing this information so we could pass it on to others.

## **POLIOMYELITIS, POLIO, INFANTILE PARALYSIS - Information and Timeline.**

Poliomyelitis, [Polio, Infantile Paralysis] is formed from the Greek words meaning "inflammation of the gray matter," It is an acute viral infectious disease caused by one of three enteroviruses.

**Enteroviruses** are a genus of the family picornaviridae. Over 70 serotypes of enterovirus have been isolated from man. Their normal site of replication is the GI [gastro intestinal] tract, where the infection can be subclinical or result in a mild GI disorder. However, in a proportion of cases, the virus spreads to other organs, causing severe disease which are typical of individual enterovirus types. The human enteroviruses include the polioviruses [Polio type I Brunhilde - Named after a female chimpanzee from which it was first isolated, Polio type II Lansing - Named after the city in Michigan where the first patient lived who was found to have this virus and Polio type III Leon - Named after the patient in California from whom this virus was first isolated] coxsackieviruses, enterocytopathic human orphan (ECHO) viruses and enteroviruses 68 - 71. It is important to note that other enteroviruses are occasionally associated with a polio-like illness, in particular Coxsackievirus A7 and enterovirus 71. [virology-online.com/viruses/Enteroviruses.htm ]

Excreted in faeces, the virus passes from person to person by infected water in swimming pools, lakes, and the like. It can also be transmitted if those affected with the virus fail to wash their hands after changing diapers or using the bathroom and then handle other people's food, water, or dishware. The poliovirus can survive up to two months outside the body.[www.pbs.org/wgbh/rxforsurvival/series/diseases/polio.html]



This Egyptian stele (an upright stone carving) dating from **1403-1365 BC** [18th Dynasty] shows a priest with a walking stick and foot, deformities characteristic of polio. [www.bbc.co.uk/news/health-17045202]

The disease was given its first clinical description in **1789** by the British physician Michael Underwood (1736? To 1820) -Underwood describes "...the debility of the lower extremities which gradually become more infirm, and after a few weeks are unable to support the body." [https://en.wikipedia.org/wiki/Michael\\_Underwood\\_\(physician\)](https://en.wikipedia.org/wiki/Michael_Underwood_(physician))

Jakob Heine (1800 to 1879) a German Orthopaedist who is most famous for his **1840** study into poliomyelitis, which was the first medical report on the disease, and the first time the illness was recognised as a clinical entity. [[https://en.wikipedia.org/wiki/Jakob\\_Heine](https://en.wikipedia.org/wiki/Jakob_Heine)]

The first modern epidemics were fuelled by the growth of cities after the industrial revolution. caused by Polio type I. [www.bbc.com/news/health-17045202]

Before a vaccine was introduced in the **1950s**, epidemics of polio would result in up to 7760 cases of paralytic polio in the UK each year, with up to 750 deaths. [vk.ovg.ox.ac.uk/polio ]

### **The Scotsman - Friday 23 August 1946.**

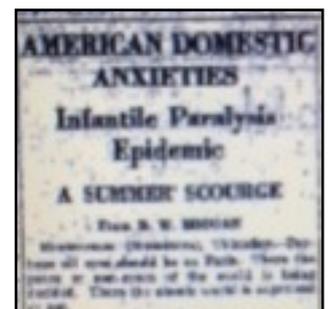
#### **AMERICAN DOMESTIC ANXIETIES**

#### **Infantile Paralysis Epidemic**

#### **A SUMMER' SCOURGE. From D. W. BROGAN**

Minneapolis (Minnesota), Thursday.-- Perhaps all eyes should be on Paris. There the peace or non-peace of the world is being decided. There the atomic world is organised or not.

But in Minneapolis, and in more places than Minneapolis, the main theme in the minds if not always on the lips of the people, above all of parents, is not the post-war world but "polio." Poliomyelitis, or infantile paralysis, is a yearly summer scourge of American life. It strikes in Michigan and Connecticut as well as in Minnesota. It was in Maine that, a quarter of a century ago, it struck at its most famous victim, Franklin Roosevelt.



The regular medical profession is baffled and admits it. Polio spreads by contact. It is inadvisable to have teeth or tonsils out when an epidemic is on. It is advisable to fight flies with D.D.T. It is safer not to eat raw fruit. It is safer not to eat in restaurants. Eating at home diminishes risk of infection from dirty and strange contacts.

#### **ENTERTAINMENTS DISLOCATED**

Children should be kept at home – no easy job in high summer. Gallant efforts are made to entertain them. Local radio stations run incessant children's shows, to the boredom of adults. The Mayor reads out comic stories to the interned youngsters. The medical expert of the local paper advises the "teen-agers" to forgo the adolescent pleasures of petting because that way polio may spread. And the advice is taken.

The schools have postponed reopening. Round the twin cities of St Paul and Minneapolis lie the lovely lakes that are the pride of the community. The beaches, normally crowded with bathers and canoers, are as empty as in mid-winter. Cinemas and dance halls see ever-dwindling audiences. The first release of "Caesar and Cleopatra" is here. This film has got a far better Press in the United States than it did in Britain, but here it suffers from the pressure of polio panic.

Fear has even got to the point that the Governor has postponed the State Fair, the greatest event of the year and a source of great profit to the local business community.

#### **THE SISTER KENNY TREATMENT**

Naturally, rumour magnifies the dangers. There is a widespread impression that the number of cases and deaths is concealed. This is untrue, but it is believed in typical American fashion. There is resentment at the use of local hospital facilities for out-of-town patients. The credulous believe that this has increased the risk of infection. And there is wonder and anger that modern science, in an age of medical miracles, can do so little.

Popular faith is pinned on the Sister Kenny treatment. Sister Elizabeth Kenny is a combative Irish-Australian nurse with original ideas on the origin and treatment of polio. Doctors are far more sympathetic to her treatment than to her theories.

She holds that, like Pasteur and other pioneers, she is being snubbed by orthodox medicine. Yet many doctors work with her. In 1940, during the previous epidemic, she was given her great opportunity by Minneapolis, and she is in charge again.

Her treatment does seem to diminish the risk of permanent crippling, but it is at least doubtful whether it cures. Yet she is now such a great national figure that Hollywood has paid her the compliment paid to Pasteur and Ehrlich. A film has been made around her story, with Rosalind Russell impersonating the pioneer nurse in whose skill and wisdom so many parents in this community of near a million put such hope.

But there is little hope that the plague will go till the summer goes, and the parents of Minneapolis watch for every dangerous symptom and continue their exhausting efforts to keep their children at home.

Image © Johnston Press plc Published: Friday 23 August 1946

Newspaper: The Scotsman County: Midlothian, Scotland

<http://www.britishnewspaperarchive.co.uk/viewer/bl/0000540/19460823/147/0007>

OCR'd and Proofchecked by Chris Salter, editor, Post-Polio News.

Since **1984**, there have been no cases of polio contracted naturally in the UK, and vaccination has eradicated the disease from Europe, and almost all other countries in the world as well.

Until **2004**, the routine vaccine against polio was a live, oral polio vaccine (OPV). In a small number of cases this vaccine actually caused polio itself (**30 cases in UK between 1985 and 2002**). Although the disease had been eradicated in the UK, it remained endemic in many countries, so there was a risk it could be reintroduced to the UK through travel and immigration.

By **2004**, vaccination had eradicated polio from all but a few countries worldwide, and the UK was able to switch over to the inactivated polio vaccine, which cannot cause the disease itself. [vk.ovg.ox.ac.uk/polio ]

Sadly too late for our youngest member Hamish who in late 1997 at six weeks old was given the live vaccine - "The nurse cautioned us 'to wash our hands after nappy changing as polio can be caught from the excreted virus'". when he had an abscess on his bottom. This was lanced under anaesthetic a few days later but very difficult to dress the wound so that every time he had a bowel movement the wound was infected. LincPIN [www.poliosurvivorsnetwork.org.uk/lincpin5-11.pdf](http://www.poliosurvivorsnetwork.org.uk/lincpin5-11.pdf)

Polio cases have decreased by over 99% since the launch of the Global Polio Eradication Initiative (GPEI) in 1988, from 350,000 to 1,352 by 2010, 650 cases in 2011, and 223 in 2012 and 54 by June this year. The UK has contributed significantly to this progress, has been a consistent supporter of this global effort since its launch, and is the second largest public sector donor to the initiative (behind the US). [www.who.int/mediacentre/factsheets/fs114/en ]

**2017 to date**, 10 people diagnosed with Wild Polio Virus [WPV] and 47 people with cVDPV polio, 18 in the Democratic Republic of Congo and 39 in the Syrian Arab Republic. [Polio Global Eradication Initiative - <http://polioeradication.org/polio-today/polio-now/this-week/>]

**2013 to 2018 World Health Organisation. Replacing trivalent OPV with bivalent OPV** - Objective 2 of the Polio Eradication and Endgame Strategic Plan 2013-2018 calls for an important transition in the vaccines used to eradicate polio and requires the removal of all oral polio vaccines (OPVs) in the long term. This will eliminate the rare risks of vaccine-associated paralytic polio (VAPP) and circulating vaccine-derived poliovirus (cVDPV). [www.who.int/immunization/.../poliomyelitis/endgame\_objective2/oral\_polio\_vaccine/]

**DIAGNOSIS of Polio.** [[http://www.poliosurvivorsnetwork.org.uk/polio\\_postpolio.html#POLIO](http://www.poliosurvivorsnetwork.org.uk/polio_postpolio.html#POLIO)]

At the time of viral infection, depending on the level of damage to each area of the body, the diagnostic name was given to the highest level of clinically evident nerve damage and classified:-

**Abortive Polio:** Symptoms do not include neurologic symptoms. Mainly gastrointestinal upset and sore throat. Polio virus can be isolated from throat washings and stool. Interpretation: Polio virus growing in gut and throat lymphatic tissue and has not migrated to the spinal cord or brain. Post-Polio Syndrome would be unlikely in these cases because of the lack of neurological involvement to any appreciable extent.

**Non-paralytic Polio:** Symptoms include neurological symptoms: Headache, stiff neck, muscle stiffness and spasms along with other muscular symptoms. Muscle strength testing at this time and after fever breaks does not show weakness, however, there is probably undetectable permanent nerve damage to some extent.

**Paralytic Polio:** All of the above symptoms but in addition residual weakness and lingering paralysis of some muscles.

Which is further classified depending on the area of the body where the most damage was clinically evident.

**Spinal polio:** where the paralysis involves the skeletal muscles supplied by the spinal nerves

**Bulbar polio:** where there is involvement of the muscles supplied by the cranial nerves. This type was seen in about 5 to 35% of cases (depending on the epidemic) and led to problems of breathing, swallowing and speech.

**Spinal/Bulbar polio:** where both areas of the body were seen to be affected.

## The following two facts are important to take into consideration:-

1. The first descriptions in medical literature appeared in 1875 when 4 case histories were reported in the French literature by Carriere, Raymond, and Cornhill & Lepine. Their patients, all young men, had paralytic polio in infancy and developed new weakness not only in previously affected muscles **but also in muscles believed to be uninvolved**. They all had physically demanding jobs and performed repetitive activities. [[www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/gawne/ppspandcm.html](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/gawne/ppspandcm.html)]

2. Professor WJW Sharrard in 1955 reported in *The Distribution of the Permanent Paralysis in the Lower Limb in Poliomyelitis* that ' Motor cell destruction was always much more severe than would have been expected. One case in which there had never been any demonstrable weakness in any muscle in the lower limbs had suffered losses of up to 40 per cent of the normal number of cells in some cell columns .[[www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/sharrard/dpplp.html](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/sharrard/dpplp.html)]

These demonstrate that there were considerable levels of damage below which weakness was not clinically evident at the time of the diagnostic examination and that it is possible for polio survivors to now have new issues in that area of their bodies.

## NON-PARALYTIC POLIO

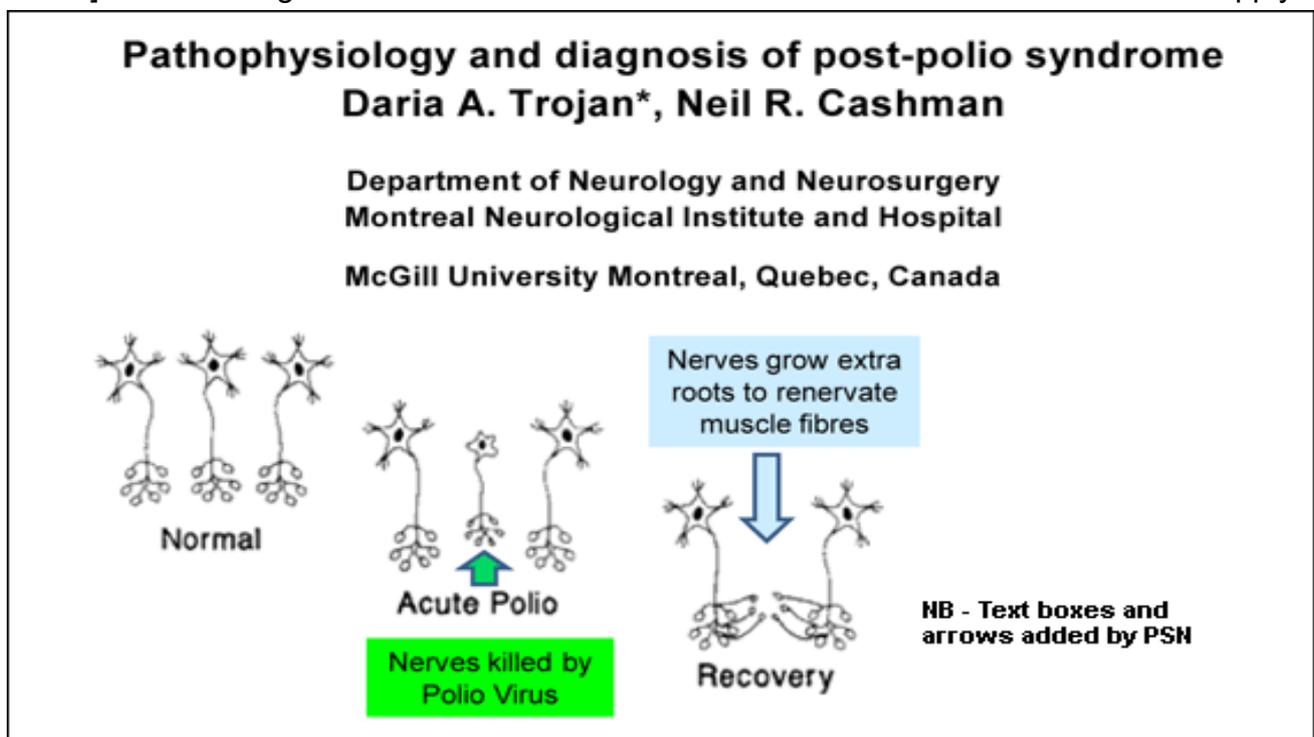
For several decades there has been a tendency to require a history of paralytic polio before any diagnosis of PPS will be considered. Such a pre-requisite is not supported by medical papers written in the 1950's and earlier that report evidence of a level of neuronal damage by the polio virus that does not present any clinical signs of paralysis at the time of infection.

Hence, a history of non-paralytic polio does not preclude new PPS symptoms or a diagnosis of PPS when all other possible conditions have been excluded.

For a detailed explanation read *Non-Paralytic Polio and PPS* by Marcia Falconer, Ph.D. cell biology and Eddie Bollenbach, M.A. biology. A Lincolnshire Post-Polio Library publication. [<http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/falconer/nonparalytic.html>]

## RECOVERY [Polio Survivors Network Presentation Slide]

Simply, a muscle has a number of nerves supplying it to work. The polio virus kills and damages nerves. Recovery was possible because nerves that were not affected grew extra [axonally sprouted] nerve endings that reinnervated some muscle fibres that had lost their nerve supply.



## **POST POLIO TERMINOLOGY**

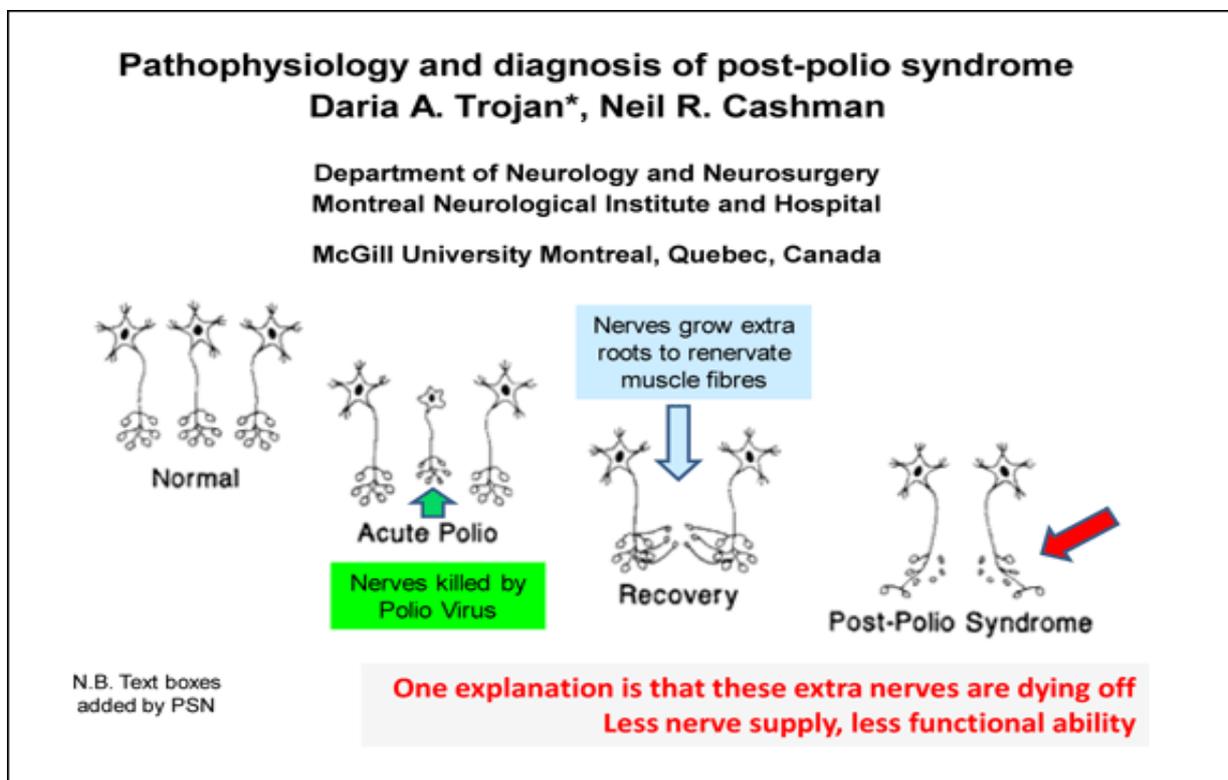
There are a variety of terms that have been used in medical articles over the last three decades. Unstable polio, late effects of polio, post polio muscular atrophy, post polio sequelae and post polio syndrome.

Read Tom Walter article on Terminology in Lincolnshire Post-Polio Library added in 1997. [www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/usa/terms.html]

The most commonly accepted terms now are the Late Effects of Polio [LEOP] and Post-Polio Syndrome [PPS]

**THE LATE EFFECTS OF POLIO** - which encompasses anything happening **after having polio** that is affecting how the polio survivor is managing. [Post Polio Newsletter, Dec 2010 Vol. 21 No. 4, Post Polio Network of Western Australia. [www.upnaway.com/poliowa]

**POST POLIO SYNDROME** (PPS) is the onset of new deterioration in function that may occur many years after partial or complete recovery from acute poliomyelitis. [1] PPS comprises various possible symptoms such as fatigue, weakness, joint and muscle pain, reduced respiratory function or dysphagia. PPS does not necessarily imply progressive deterioration and can be helped by treatment. Management requires careful assessment and a multidisciplinary approach. [https://patient.info/doctor/post-polio-syndrome.] N.B. Polio Survivors Network recommend this UK article written by Doctors for Doctors, widely accepted in the NHS, from Patient.co.uk Some of the references are our Charity work and we can provide printed copies of this to our members and we reference this in every newsletter. See Page 32.



### **What causes Post Polio Syndrome? [Polio Survivors Network Presentation Slide]**

The cause is unknown. However, the new weakness of post-polio syndrome appears to be related to the degeneration of individual nerve terminals in the motor units that remain after the initial illness. A motor unit is a nerve cell (or neuron) and the muscle fibers it activates. The poliovirus attacks specific neurons in the brainstem and the anterior horn cells of the spinal cord. In an effort to compensate for the loss of these neurons, ones that survive sprout new nerve terminals to the orphaned muscle fibers. The result is some recovery of movement and enlarged motor units.

Years of high use of these enlarged motor units adds stress to the neuronal cell body, which then may not be able to maintain the metabolic demands of all the new sprouts, resulting in the slow deterioration of motor units. Restoration of nerve function may occur in some fibers a second time, but eventually nerve terminals malfunction and permanent weakness occurs. This hypothesis is consistent with post-polio syndrome's slow, stepwise, unpredictable course. [[https://www.ninds.nih.gov/Disorders/Patient.](https://www.ninds.nih.gov/Disorders/Patient)]

## POST- POLIO SYNDROME

**Criteria for a Diagnosis** [Halstead L, MD - Silver J, MD Am.J.Phys. Med. & Rehab. Jan/Feb 2000]

1. A history of remote paralytic polio or findings on history, physical examination results, and laboratory studies compatible with polio virus damage of the central nervous system in earlier life.
2. A period where we recovered.
3. A stable period of functioning, from 10 to 50+ years.
4. **New symptoms for which there is no other explanation of :-**
  - fatigue often overwhelming, both physical and mental,
  - loss of muscle strength and/or use also in muscles below the line of clinically evident weakness at the time of the original infection.
  - pain in muscles and joints.
  - trouble breathing and/or swallowing
  - problems sleeping
  - intolerance of cold, causing muscle weakness and sometimes burning pain and/or discolouration in limbs

"Post-Polio Syndrome, what is that?"

"You say you had Polio, you look all right to me"

"You had polio but you are over it now. So forget it."

"There is nothing wrong with you, All the tests are negative"

"Your pain down your left side is all in your mind"

**The first description appeared in 1875** when 4 case histories were reported in the French literature by Carriere, [3] Raymond [4], and Cornil & Lepine. [5]

"Post-Polio Syndrome, I have just heard something about this new disease"

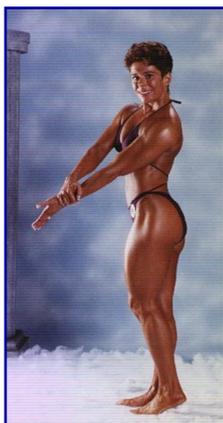
These patients, all young men, had paralytic polio in infancy and **developed new weakness not only in previously affected muscles but also in muscles believed to be uninvolved.**

All had physical demanding jobs and performed repetitive activities.

Post-Polio Syndrome : Pathophysiology and Clinical Management, Anne Carrington Gawne and Lauro S. Halstead.

Critical Reviews in Physical and Rehabilitation Medicine, 7(2): 147-188 (1995)

[[www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/gawne/ppspandcm.html](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/gawne/ppspandcm.html)]



### Which lady is the Polio Survivor? [PSN Slide]

The picture on the left was taken in 1995

The picture on the right was taken in 2003

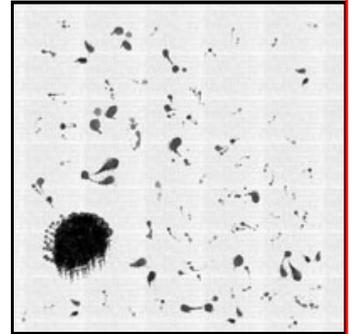
Gwen had paralytic polio as a child. She recovered well and took part in Body Building competitions and was Head Nurse for a 50 bed ward.

Gwen started to have new and unexpected symptoms of pain, fatigue and functional decline and in 2003 had to start using a wheelchair.



## Difficulties for Health Professionals. [taken from PSN presentation slides]

1. There are **NO TESTS** than can diagnose PPS. It is a diagnosis of exclusion.
2. **No set pattern of nerve damage.** Dr. Marinos Dalakas likened it to standing polio survivors in front of a white sheet, throwing a bucket of black paint at them and at the same time hitting a wind machine with millions of settings, a different one for each person. This means there is no set pattern to the damage caused to the body by a polio virus making health professionals lives much more difficult.  
[Artwork by Chris Salter - Life Member, Provider of Lincolnshire Post-Polio Library and Editor of ppn [Post Polio News - .www.post-polio.org.uk]
3. A very **high number of Polio Survivors** - including those with considerable paralysis and/or being in an iron lung - recovered that well externally that we **do not look like the photographs in the medical text books..**
4. **Polio facts** given to health professionals by Colleges of Medicine reduced after the success of the 1955 Polio Vaccine. By 1996 PSN was told it was a half an hour lecture with leprosy for doctors and nothing for some others. Post-Polio Syndrome rarely mentioned.
5. **Polio Survivors are stubborn**, strong willed and determined to continue as before....
6. **Assessment Difficulties Reported by Polio Survivors in the UK\*\*** The top four relate to:-
  - A) **Time allowed for medical appointments.** First, take down your history, then examine you, then arrange for you to have and/or read reports of tests, and then to explain what is going to happen next and at a huge number of our NHS appointments can be scheduled for as little as TEN MINUTES.

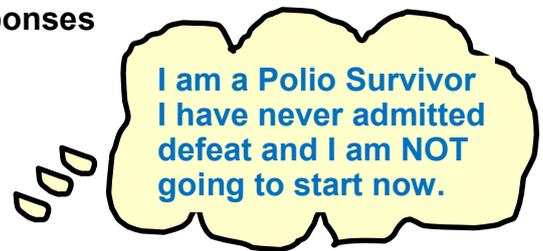


### B) Closed questioning & Polio Survivors Responses

Can you get up a flight of stairs? "YES"

Can you walk? "YES"

Can you get yourself a meal? "YES"



**Open Questioning** allows Polio Survivors to Tell It **Like It Really Is.**

How do you 1) get up a flight of stairs, 2) walk, 3) get yourself a meal.

1. **Well, I have to go up one step at a time right foot first using the bannister rail to pull myself up with my right arm. Oh!, I forgot and I have to stop halfway up for a rest.**

2. **I have walked since recovery from polio age 5 but walking for me is using two arm crutches and swinging my arms through.**

3. **Because I can no longer chop or peel items I usually buy ready prepared frozen food, Pop in in the microwave and wait for the "Ding"**



## \*\* PAINTING THE SAME PICTURE CAN PROVIDE BETTER CLINICAL OUTCOMES

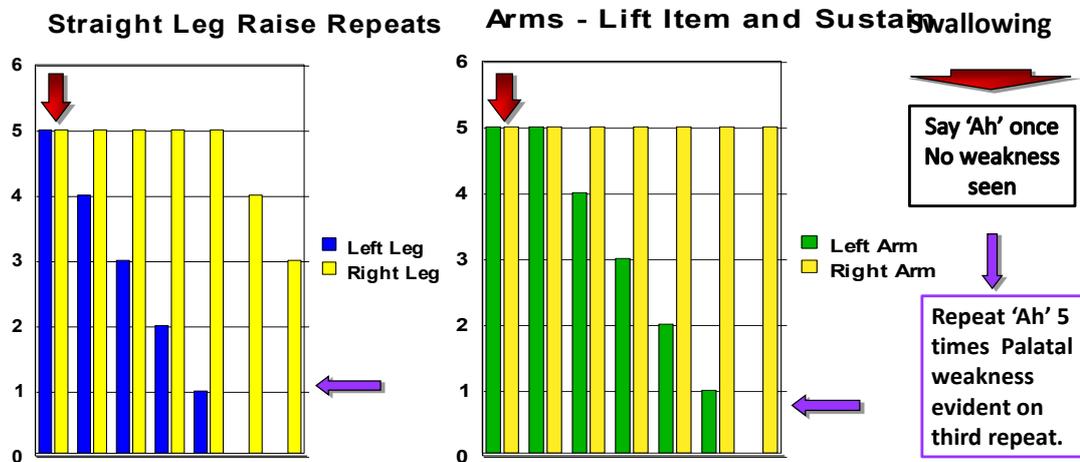
Presentation at the 2nd European Polio Conference June 25th to 27th 2014 in Amsterdam.

<http://www.informed-scientist.org/presentation/painting-the-same-picture-can-provide-better-clinical-outcomes>

- C) **Single action manual testing of muscles.** Manual muscle testing is a procedure for the evaluation of the function and strength of individual muscles and muscle groups based on the effective performance of a movement in relation to the forces of gravity and manual resistance.[2] - [http://highered.mheducation.com/sites/0071474013/student\\_view0/chapter8/manuual\\_muscle\\_testing.html](http://highered.mheducation.com/sites/0071474013/student_view0/chapter8/manuual_muscle_testing.html)

Manual Muscle Testing of Polio Survivors who are having new symptoms of functional decline, when done a single time, can and has over-graded polio survivors muscles on many occasions. Polio Survivors are able to do many actions once, twice or a few times but repeating and sustaining some actions is restricted. [See page 27]

**Assessments of Muscle Ability - Time constraints can mean single action.**



- 1) if the first action tests gets a good result the tester moves on to the next muscle to be tested.
- 2) Repeating or extending the length of time could give a different result.
- 3) Single action muscle testing of a limb with a good result does not necessarily mean together they can work as a pattern of movement. Basic arm test is 'Grip my hand', 'Link fingers and pull then push against me'.
- 4) Swallowing - if you have issues ask your GP and/or other health professionals to please use a tongue depressor and ask you to say 'Ah' and repeat this a few times. Members have reported being told no issues till saying 'Ah' is repeated instigating further testing that confirms that they do have issues.

**D. Issues with the forms of Respiratory Testing of Polio Survivors**

Members are reporting sleep and breathing issues to health professionals but after testing many told 'You are fine', yet their symptoms continue and increase.

Many Polio Survivors, including those originally not believed to have nerve damage in their upper body, can have nerve damage to either or both of the two domes of the diaphragm and/or new weaknesses in the Secondary Accessory Muscles of Respiration.

Most report they are asked 'To repeat each test three times and to the same level and as you fatigue easily you can rest all the time you need between each repeat.' Also that only the best of 3 repeats was included in the result sheet sent to the Consultant. For some no supine testing was included.

We ask that included are supine testing lying on both sides and that tests are repeated at shorter and regular intervals to see if reduction in ability is present. Plus overseas PPS Clinics report that Maximum Inspiratory Testing [MIP or PiMAX] as this is an indicator of weakness of secondary accessory muscles of respiration.

## A DIAGNOSIS of PPS IS NOT ALL DOOM AND GLOOM.

There is a huge amount of things that we can do to manage our lives to a greater degree.

"I wish I had taken the advice of 'please don't just dismiss making changes but try and then decide what works for you' at lot earlier."

Polio Survivors are renowned to be strong willed, determined, do not need any help thankyou, and dare I say 'pig-headed'. [Me included]. We had to be like this when we were recovering from Polio to achieve best recovery and we showed them didn't we. We had polio, past tense. Most of us had no idea that there was a later stage after best recovery. Even when we learn Post-Polio exists we will say 'We are not there yet' [I so remember in my first year of researching PPS being asked who wrote this article in your newsletter. I proudly said "I did". The Rehab Registrar replied "Then its time you started taking your own advice" and I said "But I am not there yet" and he said "Yes you are and you have been for some years now".]

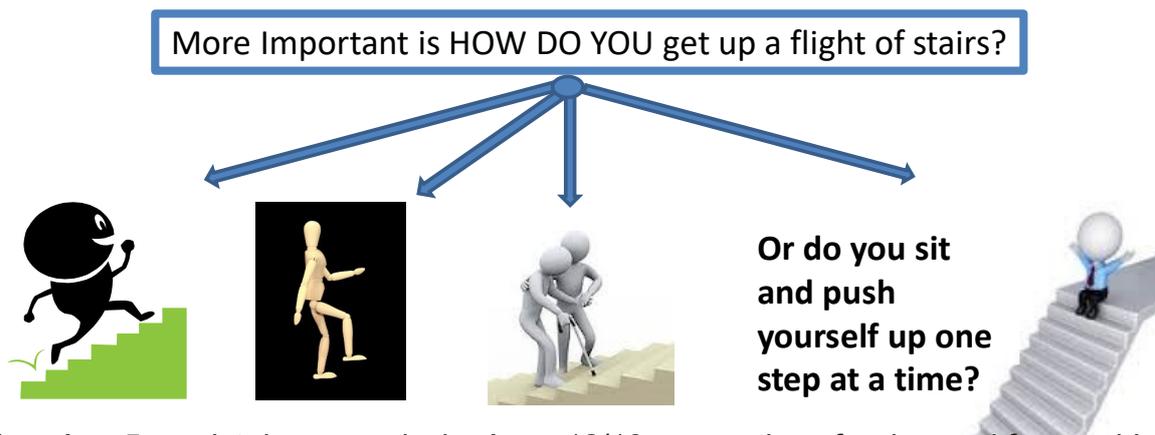
We start having new issues often after a fall/operation, where we are not continuing our normal level of activity for a time and our body thinks it does not have to keep the previous level up. We continue to push ourselves. This gives us more pain and fatigue and it can take months, sometimes years, before we approach our GP asking why this is happening. Many have later admitted I knew something was happening but I did not want to think about it and lets face it the last place most of us want to be is visiting a health professional. Health Professionals please note that if we are in your offices reporting issues it might help if you did not assume this was something new but ask us how long we have been experiencing this.

The first thing Polio Survivors need to do is not easy - but it is essential - is to think about how you are doing actions of daily living. My Polio Life - a self assessment tool - was devised as an aide to help you work through this. We know, as we have all experienced this, that we do not want to think about having new difficulties and doing this can cause a few tears.

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

Page 10 of My Polio Life lists actions of daily living, add any activities that you do that we have not added. The page only has columns for short comments as an aide memoire so you will need to start with a notebook/tablet/laptop and write in full how you did/now do the actions.

In addition to page 20 [B] and Can you get up a flight of stairs? Have you just answered "YES",



**Example.** Age 5 - waist down paralysis. Ages 12/13 - operations for dropped feet and I started to do sports that did not involve running. I became a Police Woman, Lifeguard, Swimming Teacher and mum of two.. I never stopped till 10.10.1988 when I slipped on a wet patch on a school corridor. I got up, as before, but this time I started with pain, then fatigue. My GP <sup>7</sup> prescribed pain killers, physiotherapy, then 3 weeks on neck traction, EMG, Nerve conduction studies, MRI but no definite diagnostic name. My Consultant suggested I returned to life-saving but I could not swim as fast, could not pull myself out of the water at the deep end of the pool and 9 months later failed the basic Life Saving Award and my career as a Lifeguard and Swimming Teacher ended. That was tough!! Why were health professionals finding nothing wrong when they assessed me when I knew there was? Come to think of it, How did I pass a medical for the Police when I could not run? [See page 21]

## **ASK “WHY HAVE I HAD TO CHANGE THE WAY I DO THESE ACTIONS?”**

Take each action of daily living and write down ‘How you did this at Best Recovery’ Then think about How you do that action now? Was this one level of change or more, like my ‘going up stairs’? Write each change up and pick a couple of words to remind you for the column on our chart. If you have had to change the way you do actions then there must be something different in the way your muscles are working. Politely ask why? Even if you are asked ‘Can you do this action?’ you MUST answer ‘HOW you do the action so you PAINT THE SAME PICTURE IN THEIR MINDS. Just answering ‘Yes’ does not help either you or the health professional.

Our experience is that until you think about how you do the actions you might not be aware or want to be aware that you have changed the way you do them and just blank it out. Ask people who know you well if they have noticed anything.

I met John Foyster from Australia on an email list in 1996 and then in real life when he flew to the UK. He could walk fairly well but not carry items so he used a rucksack on his back. A few years later he told me “I started to fall to the right about 2pm on a clock face. Our PPS physiotherapist examined my right side and could find no changes. As she had time she also did my left side and found that my left hip muscles were weaker and now unable to support my right leg.”

Millie Lill from America who I first met in 1997 tells of asking her granddaughter “why are you walking like that?” She answered “It is the way you walk Grandma”. Millie did not think she walked like that but after seeing the film her family made she realised how accurate her granddaughter had been and how she had no idea that she walked that way.

I am asking you now “How do you roll over in bed?” I bet most of you will have to go into the bedroom and do the action before you can tell me because it is something you do without thinking. I used to hold onto the mattress handle but my new mattress had no handle so had to change to holding onto the side of the wardrobe next to the bed meaning I have to leave the door open. Stay somewhere where there is no wardrobe and I really struggle to turn. [Snoozle page 27]

Working in the Kitchen. If you are standing do you hold on with one or the other hand and if you need to use both do you then lean against the work surface? I cannot work sitting on a perching stool as my arms work best down at 45 degrees. I used to do everything in the sink but when I moved I had one side of the kitchen worksurface lowered for cooking. There is no room in our small kitchen for a stool but I can perch on this lowered surface for a few seconds break.

2003 I met Dr. Raj Prasad [now at Leicester Royal Infirmary] who had read my file before my first appointment and wanted answers on a few questions... even one on my eye clinic appointment. After listening to my history and difficulty obtaining corroboration of the symptoms and issues I was reporting he agreed that a base line assessment would be useful. He told me it would be about nine months wait for an appointment. [Dr Prasad is co-author of a Survey of the Late Effects of Polio in Lothian January 1999. <http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/uk/lothiansurvey.html>]

In 2004 I met Gill Weir, a Senior Physiotherapist at Grantham Hospital who started by telling me about a useful website that might help. I explained this was our Charity website. She started my assessment and was happy for me to respond to what she found. “Arm strength good” I responded “why was I now scrambling eggs with elbow rotation and why can I now lift a jug of water but not pour it out?” She examined the muscles I would use for these actions and found considerable weakness in other muscles which had not been evident on the base line arm assessment looking for weakness. “Can you get up from the floor?” I answered “Yes but let me show you”. I got down onto my hands and knees then up onto my toes, walked my hands back to feet and stood up. “I would have had no idea... you are using hamstrings and back extensors.” She watched me walk back to my car - to see how I walked over some distance and noted how my gait altered the further I walked. She then watched as I got in and out of the car again in totally unexpected ways. Now we have a Kia Sedona so the seats are bottom height where I can put my left leg in under the steering wheel, then sit and lift my right leg in.

**TO COMMUNICATE EFFECTIVELY YOU MUST TELL IT LIKE IT REALLY IS.**

## THE WAY WE PERFORM ACTIONS OF DAILY LIVING [ADL's]

All our lives we have pushed ourselves to complete tasks and we have achieved way more than was ever expected of us after our diagnosis. The way we do these tasks is OUR NORM and often not the same way as a non polio. Note, **OUR NORM, not the norm**, which is why it is imperative that you 'paint the same picture of how you do it' in the health professionals mind.

As we recovered from polio we devised many different ways of using the muscles we had that worked to achieve tasks. If one muscle did not work we asked another/others for help. A couple of members have told us of getting down from their wheelchair and using a mat on the floor to change their babies for safety even though getting down and up again was not easy.

I remember visiting a Polio Survivor in Alabama, in 2000. who started to make us a meal and was moving about his kitchen seemingly with no problems. I asked how because he only had one arm that moved. "Let me show you how I manage". He had developed ways of holding jars between his body and work surface to take lids off, stops put on the worksurface so pans would stay still whilst he stirred them. What I remember most of all was him taking a bag of salad out of the fridge with a knife in his hand and with a quick movement he had slit the bag open and flipped the contents into a bowl.

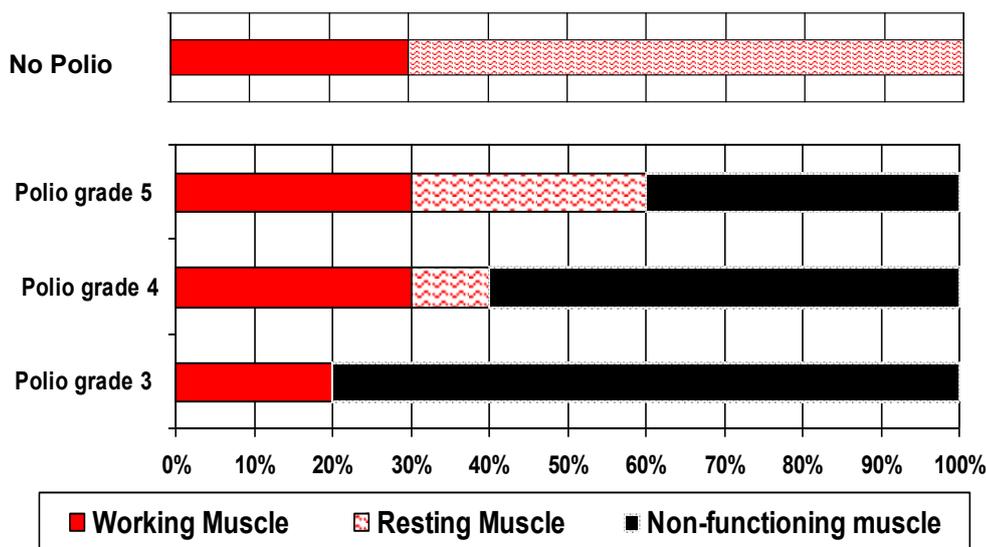
Think about how you did actions differently from the 'expected norm' and now think about how you are doing actions now? Has your creativity to modify come into play again?

### PACING AND RESTING AND ENERGY TOKENS.

Now actions of daily living are getting more difficult many of us continue to 'not give in' and push ourselves till we are exhausted and are in lots more pain. We start to learn about Post Polio and that pacing and resting actions and using aids and assistive devices helps. Plus horror of horrors going against what we have done all our lives we are told to 'ask others for help for chores'

#### WE KNOW THAT PACING AND RESTING ALLOWS US TO DO MORE

**WC Beasley [1961] and Jaquelin Perry [1995]  
Found on research that Polio Muscles functioned at a lower rate.  
Grade 5 at 60% - 4 at 40% - 3 at 20% - 2 at 10% - 1 at 1%**



Looking at the chart above and taking an average 30% of a muscle needed to perform a task you can see that a non-polio muscle has 70% resting to take over when that first 30% needs a rest. Muscles graded 4 and below just do not have enough resting muscle to take over. Watch an Olympic race on tv and see the exhaustion at the end of a race. As Simon says on page 4 we are polio athletes. Do **you** need to push yourself to be an Olympian for every task?

Try starting an action and go till you experience pain and fatigue, say 20 minutes. Rest and then do the same action again but stop after 12/15 minutes before fatigue sets in and take a rest. Your muscles will recover and they can do it again and after another rest again. The doing time can get shorter and the resting time can get longer. From PPS Questions and Answers 1995 Dr's Richard Bruno and Nancy Frick suggest under Exercise and Activity. "Listen to your body! If you are doing things that cause fatigue, weakness or pain STOP DOING THEM!!! Polio Survivors need to pace their activities, that is work and then rest about 2 times the amount they worked. Jim Agre showed that Polio Survivors can do 240% more work if they PACE. You don't drive your car until it's out of gas; you shouldn't drive yourself to exhaustion, weakness or pain; Agre JC and Rodriguez AA. *Neuromuscular function in polio survivors*. ORTHOPEDICS, 1991, 14(12): 1343. [www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/kessler/ppsq.html](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/kessler/ppsq.html)

We have **10 energy tokens a day and 70 a week**. They are personal to each of us. It is easier to think of them as money, £10 or \$10. Write down tasks you do on an average day from getting up to going to bed. How much money do you spend on each activity out of that £10 or \$10. Now think about all the other activities that you might have to add in, going for a medical appointment, driving some distance rather than the local area, shopping, etc. Think about each activity and how much of the average days activities [£ or \$] would you have to give up to do each task?

Now you can plan the week ahead. At the top of each day put in the actions you have to do and how much each takes. When you add in a visit to the hospital for a medical appointment you are likely to see that you need way more than 10 tokens, for me its about 17 tokens so only 3 left for that day. So where can you save energy. We suggest that you think about

- Getting someone to drive you there and back and if you use wheels load and unload them.
- Have a bath/shower the day before. On the day only wash the bit they are going to look at.
- Meals for the day could be prepared and left ready in the fridge.
- Wear clothes that are easily taken off and arrange with the person who is with you where you want help, we know you can do this yourself but.....
- Get some help and save the energy for something more exciting!

The following slide shows how you can save time resting, do more and have less pain and fatigue. The times are just suggested and not specific. Remember we are all different.

### PACING AND RESTING & USING AIDS AND ASSISTIVE DEVICES WORKS

ACTIVITY BEFORE AND AFTER CHANGE	Time of Day	Time Doing	Time Resting	Pain Level	Fatigue Level
Getting up, showering and dressing	8.00 10.00	30 mins	90 mins	3	5
Changed to showering Underwear and calipers Top Clothes <b>LESS PAIN AND LESS FATIGUE</b> <b>SAVED TIME RESTING</b>	8.00 9.00	15 10 5 30 mins	10 10 10 30 <b>60 MINS</b>	<b>2</b>	<b>3</b>
Walking round one shop pushing trolley	11.00 2.15	15 mins	180 mins	4	7
Doing the Town Centre using electric scooter, walking in shop where necessary, no bag carrying. <b>GAINED TIME DOING</b> <b>SAVED TIME RESTING</b> <b>LESS PAIN AND LESS FATIGUE</b>	11.00 4.00	180 <b>165 mins</b>	120  <b>60 mins</b>	<b>2</b>	<b>4</b>

PSN  
Presentation  
Slide

## AIDS AND EQUIPMENT

Polio Survivors recovered to different levels. Some of us having to use wheelchairs, others callipers or both. Many had operations and some recovered that well we did not use aids. Attend a PPS Conference or Meeting and see a huge variety of disability levels. The thought of returning to using aids again or for some of us for the first time can be daunting. No wonder we say 'I am not there yet'.

If you are having new difficulty performing an action of daily living think about/ research/ask other polio survivors what is out there that might help me do this action with less pain and fatigue.

Did you ever go with friends into BHS, M&S or shops like that and try on the hats? Was that fun? Have you met up with other Polio Survivors socially yet? Once you start sharing experiences have you had some laughs? I can tell you there have been times where we have laughed so much our ribs have ached. At an AGM Tony Meladio brought his Edward III re-enacting gear and we tried the helmet and other items on. I forget who but someone then picked up a cotton item and put it on his head... We nearly wet ourselves when Tony said 'They are the Royal Underpants!'

Looking at new disability equipment you really do not want to think about is hard. It is so much easier at large exhibitions like Naidex and Motability Roadshows where the disabled are in the majority. If you can't travel far then meet up with other Polio Survivors to look round local Disability Equipment shops so you are not alone. This will give you an idea of what equipment is out there.

You can be assessed by Social Services and the NHS for equipment and/or alterations to be made to your home. Be aware though that many social care and health professionals will have no idea how you, a survivor of Polio, do actions of daily living. Having worked for Social Services where money is tight you can be offered the cheapest item/alteration. If you can demonstrate how you do the action and where and how you need help that will make both your lives easier and most probably save money, time and energy on your having to go back and ask for re-assessment. E.g. Kitchen. My back is bent forward and I can only see the first few inches of the bottom shelf of wall cupboards. The OT's initial response was to have pull down shelf unit fitted. However, as my kitchen is small I needed every bit of work surface for electrical items and to work on. I can also not bend my knees without my legs collapsing so had great difficulty seeing what was on the shelves of the under the counter cupboards. I suggested that changing the two under counter units to drawer units and adding a carousel to the corner cupboard would enable me to see and get at items more safely. I demonstrated this and it was agreed. [Richards PA has screwed my plate rack on its side in one of the drawers and the remainder of items in this drawer are items I need to use at mealtimes.]

Do not wait till you have to use an item. It is much better to get it whilst you can decide each day if you have enough energy or need to use it to save energy to do something else. E.g. I have an AFO [ankle foot orthosis] folding cane, arm crutches with feet [[www.icanwalk.com](http://www.icanwalk.com)], folding walking frame, rollator, an electric scooter. Some items can be rented/borrowed from organisations which can help you try before you decide what might help you. Why waste energy if equipment and somebody doing part of the task will free you up to do something more?



**Do's and Don'ts to keep in mind when going for physical therapy.**

DO	trust yourself and the knowledge you have gained over the years about your body.
DO	be willing to alter your lifestyle
DO	avoid fatigue.
DO	get enough rest.
DO	pace your activities rather than discontinuing them
DO	conserve energy. It may make more sense to spread your activities out, allowing for rest periods, rather than eliminating interests and activities
DO	recognise that your body is aging and some physical changes will occur which are not related to post-polio. There IS a normal aging process even though post-polio may be a part of it.
DO	respect your feelings. This may be a difficult adjustment time for you; seeking emotional as well as physical guidance may be a wise thing to consider.
DON'T	follow advice regarding physical exercise if you become fatigued while doing it.
DON'T	become short of breath with exercise
DON'T	do more than your body feels comfortable doing
DON'T	cause pain with activity or exercise.
DON'T	gain weight.
DON'T	reject using aids and assisting devices without giving them serious thought. (They are meant to conserve energy and preserve anatomical structures, i.e. joints, muscles, tendons, cartilage and ligaments.) Most are delighted and surprised by the increased endurance and energy they have with the use of canes, wheelchairs, motorised scooters or the many other easily found assisting devices.

**LincPIN v5 issue 5 - August 2005.**

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.

**Analyzing Your Gait: The Roles of Exercise, Bracing or Surgery?**

**Read a review of Dr. Esquenazi and Dr. Keenan's presentation Pages 10 to 18**

**Question 6** – I am from the UK and we rarely get a chance to be referred to a gait laboratory. We get manually muscle tested done a single time and our repetitive and sustaining problems come later than the time we are tested. Could you make a video to help solve this situation?

**Answer** – Dr. Esquenazi explained that gait analysis is a relatively new technology. That there are probably 20 gait labs in the UK but half are devoted to research. Dr. Keenan said she had just been to an excellent lab in the UK whose focus was on Cerebral Palsy.

Dr. Esquenazi said he was in the U.K. two weeks ago at a two and a half days conference just learning about the basics of normal walking not pathology. He said "More than once I have had my Fellows and Residents look at a patient and tell me 'normal strength' and I say, 'Nix, come on lets go over and look at this patient together'. This patient, not meaningfully, not in a wilful manner, has done you a nice trick and showed that the strength of the hip is 5 when the strength of the hip is really 2. So you need to be able to pick that up, and that's experience. There is no way to learn that in a quick way. Making a video sounds lovely, but in reality you need more than that." [Go back to Page 21]

## Snippets of Items from Volume 1 of the LincPIN [1996 - 1998]

[www.poliosurvivorsnetwork.org.uk/lincpin\\_vol1.html](http://www.poliosurvivorsnetwork.org.uk/lincpin_vol1.html)

**Issue 4.** - What would I do without my walking stick? I don't use it for the purpose intended but living as I do in a wheelchair I find it invaluable.... Getting things from the top shelf of cupboards can be interesting, making sure they are not too heavy because they mostly land on your head, and also getting jugs and beakers from on high, you put the stick through the handle and catch them on the way down...Its handy in the bedroom for pulling the duvet straight, getting anything from under the bed, especially mice the cats brought in, one end of stick pulls the mouse out from under the bed and the other end clobbers the cat... **Jean Tapper.**

**Issue 5.** - Excerpts from Changing Your Life By Conserving Energy by **Mavis J. Matheson MD.** A fellow Polio Survivor “ ‘Using our energy well can allow us to do more and do it better.....

### **THE POST-POLIO HOKEY KOKEY - from Ron Amundsen in Hawaii**

jockey shorts left leg, jockey shorts right leg, long underwear left leg, long underwear right leg,  
left sock, right sock, left knit dancer's legging, right knit dancer's legging,  
left pantleg, right pantleg, left shoe, right shoe, STAND,  
up shorts, up long underwear, up leggings [this could be done sitting, but it would require another stand]  
up pants, tuck, button, zip, SIT, buckle, pant pant pant pant

**Issue 8. - Hilary.** Every time we speak to a Polio Survivor, and see the look of relief on their faces, see their frowns disappear and hear the words, 'You mean I am not the only one, other Polio Survivors are having the same problems, there is a possible explanation for my symptoms, I am not going barmy, its not all in my mind. You have information that I can give to my doctor, that might explain all this.... We know how they feel, 50% better immediately, How do we know? Because that's how we found out as well.

**Ginger Hastings writes...** Adjustment to a disability occurs in stages, and these stages are much like the process involved in grief and bereavement. Hanoch Livneh, Ph.D.. is a Rehabilitation Therapist and researcher/scholar, and has defined these phases as: shock, anxiety, denial, bargaining, anger, accommodation and adjustment. I won't go into the emotional content of each phase, but each one raises some very different emotions and is vital to the total adjustment process

Polio Survivors are people who are in various stages of their adjustment process. Some in the early stages can no more "just get over it" than they can "just get over" having PPS; it is something they will have to work through and come to terms with. What may be seen by some as whining and complaining, may be a very necessary part of the initial healing process. Those who have already been through this and have reached accommodation or adjustment often don't remember what it was like for them in the beginning. At any rate, I see Post Polio Support Groups as places for all PPS-ers to process whatever stage they are currently in, and to receive support and feedback from both those who share their current situation, and those who have successfully adjusted to it.

**El Panadero [The Baker] writes...** Let's talk about falling down, and getting up again.... and how we deal with it. Maybe those who have never hit the floor and looked up in embarrassment can get a glimpse at what it feels. When it happens to me, I immediately yell out, expletives included: "Who the '&^%\$... dropped the '^%\$@&\*' banana peel on the floor." While everyone around me unsuccessfully searches for a banana peel, taking their attention off me temporarily, I get up off the floor as my dignity and self-esteem struggle to return to normalcy. This line is somewhat more difficult to use when falling in the snow, but I use it anyway knowing that there will always be somebody who'll take your word for it!. Often down but never out....

**Tom Walter** adds some other symptoms to the definition of Post Polio Syndrome...

And don't forget about all these POSSIBLE symptoms

- digestive tract involvement, including constipation and/or diarrhoea;
- genito-urinary involvement;
- weight gain;
- slowing of memory, concentration and attention;
- diminished eyesight and/or hearing when "over" tired;
- falling down more than usual or customary;
- a chronic "itch" in the ear canal;
- muscle twitching and tingling, sharp shooting pains; and
- intolerance for cold (especially) and/or heat. Other diseases that may mimic the above have to be "ruled out" for a diagnosis of PPS.

Other diseases that may mimic the above have to be “ruled out” for a diagnosis of PPS. [Diagnosis of Exclusion]

**Issue 9. - Priscilla [Cilla] Webster [Post-Polio Network RSA - South Africa]**

**'I went to count, on my hand, the doctors who accept PPS and then discovered I only had a thumb'**

**Issue 9. - Grace Young, MA, OTR, Polio Survivor writes about scooters..**

I am on my third electric scooter and have some suggestions about features to look for.

1. A sturdy base which can't be tipped over.
2. The brakes should lock automatically as soon as you stop (no hand brakes).
3. Make sure the tiller is not stationary and can easily be pushed forward out of your way.
4. Armrests which can be pushed up or down (no fixed armrests).
5. Enough power to go up steep inclines.
6. Large enough tires (tyres) to go over rough terrain. Test various models outdoors on many different surfaces in addition to testing inside your house.
7. Can your hand operate the tiller while your elbow is supported on the armrest - if not, your shoulder muscles will become fatigued.
8. Practice getting on and off different types of seats. Although most brands have swivel seats, I found that bucket seats were difficult for me.

**Issue 11. - Grace R. Young, MA, OTR Fatigue and pain must be respected. Overuse to muscles is not always apparent while it is occurring. Muscle pain is a warning signal that the muscles have been overused. The damage accumulates over a period of time and may not become obvious until you lose the ability to do an activity which was previously possible.**

© Copyright Brooke E. Tuft 1998 - POLIO CHILD. Dear PPS Family, You are the only people that I know who might understand this poem and why I wrote it.

A child is softly crying, she's maybe five or six.....  
The Doctor says no problem, your hurt we're going to fix.  
Her eyes plead to her mother, but her mother does not see.  
She is talking to the Doctor, of the things that are to be.

[plus 12 more very thought provoking verses]

**Richard in Florida.** A family story I love: Great Great Grandmother from Georgia saddled a horse and rode 12 miles to see a Doctor. She'd never seen one. She rode back disappointed and reported "it was only a man."

**Seppo Utriainen from Finland Polio Association** wrote.. This is the best time of my life, when I have the opportunity to communicate with all you polio's and PPS's in the Western Hemisphere.

**Patrick Ross from Canada** replied.... Seppo you are so right...This is a communications revolution that we are in the midst, and it comes at a time when our ability to get around physically is being restricted by P.P.S. So, it makes it all the sweeter for us, and for me too, and I'm sure for most of us hit with P.P.S. This is the best of times to have this ability to communicate with an almost telepathic capability here on the NET. There you are in Finland, many thousands of miles away, and yet we can know each other's feelings and thoughts. It is somewhat ironic, that at a time when our body's communications systems is rapidly breaking down, we are compensated by a rapidly growing global communications network. Let us together, celebrate this blessing of new technology, and embrace it, for it will make our world closer, and allow us to share so much.

**Issue 12. - Elizabeth Lounsbury, Chair of the PPS Committee Ontario March of Dimes, [Editor, now Chair of Polio Canada] writes.....** One of the most important things that we do for people contending with Post-Polio problems is hold bi-yearly Post-Polio Conferences. The latest, "Solutions for the Future," was held last month in Toronto. There I met so many wonderful people from all over the world. I became reacquainted with Hilary Hallam, and met Lynn Singleton from Sussex. Both these ladies I had previously known as Cyberfriends on the Internet. The most important thing we all did at the conference was meet new people, wonderful people all fighting the same battle. No one that attended need ever feel alone again. Many people that had been in complete denial felt so comfortable being with so many others in the same boat that they were finally able to realize that they are in trouble and have to start looking after themselves. Registrants had the opportunity to try out assistive devices such as scooters and realized 'hey this isn't so bad.'

Many of the following suggestions are a compilation of the insights shared at the **Family and Post Polio Syndrome Workshop** sponsored by the **Post Polio Clinic at West Park Hospital in June 1994.**

**Permission to do What.** 1. Make Changes: Give yourself permission to make changes. Acknowledge your new limitations and adjust your expectations of self. Consider how altering your lifestyle can help you maintain your independence. Conserve your energy by pacing, prioritizing and changing how things are done. Work on receiving new information into your thinking. This may be difficult, as many of you have developed coping approaches which have worked until recently. Experiment with strategies that work for you and take control. Accept that change is a process that takes time and effort. In your time, allow yourself to feel the loss associated with these changes and explore new interests and roles.

**Ageing with Post Polio. Mavis Matheson, M.D.** 5. Appropriate Exercise Get enough exercise to prevent disuse atrophy, but not enough to produce overuse damage. Many survivors are prescribed or actually ask for the kind of physical therapy they had right after polio: exercising to the point of exhaustion. Several studies show that pumping iron will not increase the strength of muscles that are becoming weaker, and can actually cause an irreversible loss of strength.

Welcome  
to PHI



HANDBOOK ON  
The Late Effects  
of Poliomyelitis  
FOR PHYSICIANS

POST-POLIO  
HEALTH

Post-Polio Health International  
Doubles Research Fund Grant to \$50,000

William Stothers, Post-Polio Health International's 2014 Board Chair announced that PHI will increase the greatly amount given from The Research Fund to \$100,000. Photo: Board of Directors

**Joan L. Headley**, Executive Director of Post-Polio Health International for 28 years retired on 1st September 2017. "Joan Headley has been in a real way the heart of PHI for nearly three decades," PHI's Board of Directors said "She will be greatly missed."

Joan, a polio survivor, graduated from Huntington College, Huntington, Indiana, in 1969 with a degree in biology. In 1974, she received her MS in Education from Indiana University, Bloomington. Before joining GINI in 1987, she taught junior high science and high school biology in LaGrange County, Indiana.

Hilary Boone first met Joan Headley in 2000 when she attended and presented [one of 89 speakers] at the Eighth International Post-Polio & Independent Living Conference in St. Louis, Missouri USA. Hilary also presented at PHI's 2005 and 2014 Conferences and met Joan at many others.



Polio Survivors Network are members of PHI and our Charity has benefited enormously from this and would like to express our thanks for all her hard work and swift answers to our emails.

The Board of Directors of Post-Polio Health International (PHI) is pleased to announce the appointment of Brian M. Tiburzi as Executive Director of PHI, including International Ventilators Users Network (IVUN), effective September 1, 2017.

Board President William Stothers said that Brian Tiburzi has been assistant to PHI's retiring Executive Director Joan L. Headley for more than nine years. "He has been a critical link between PHI and its Members, providing them with information and services."

"I want to thank everyone on the board for placing their trust in me," Brian said. "I think we all realize just how dedicated, intelligent and hard-working Joan was in her 30 years of tireless advocacy on behalf of polio survivors and users of home mechanical ventilation. I'm somewhat in awe of her and what she accomplished here."

Brian has also represented PHI at past conferences in Toronto, Copenhagen, and, most recently, Sydney. He helped coordinate two of PHI's conferences, when he was able to meet many of our members face-to-face. In addition, he met leaders of national organizations and local support groups, and many health professionals with expertise in managing the late effects of polio.

"During the past nine years," Brian said, "I've communicated with many of them on the phone and through email and that has given me a sense of what our members are looking for from PHI as an organization. I believe this familiarity will aid in the transition by providing a sense of continuity for our membership."

Brian has been very involved in the design and management of Polio Place [www.polioplace.org](http://www.polioplace.org)), as well as the new IVUN site, [www.ventnews.org](http://www.ventnews.org).

"With so much incorrect or misleading information floating around on the web," he said, "the role of PHI as a source of trusted, accurate information cannot be overstated. PHI plays a vital role in helping polio survivors and ventilator users maintain their health and independence, and I am excited to carry on that legacy."

## GREETINGS FROM PHI

PHI would like to hear from you. What concerns or questions have your members voiced at support group meetings? Do you have ideas for articles? Do your members have items to contribute to Polio Place? Are there opportunities for us to collaborate? How can PHI better support your group? Let's truly strengthen our partnership and maximize our power!

Brian Tiburzi, Executive Director Post-Polio Health International.

[director@post-polio.org](mailto:director@post-polio.org) [www.post-polio.org](http://www.post-polio.org) [www.polioplace.org](http://www.polioplace.org)

### POLIO PLACE — A service of PHI.

#### CONSTIPATION By William M. DeMayo, MD.

From my standpoint as a specialist in Physical Medicine and Rehabilitation, the connection between constipation and post-polio syndrome is academic. i.e., it is an interesting discussion and may be important, but I am not sure it changes treatment. *William M. DeMayo, MD*

Here are some practical thoughts. I would address the issue the same as a partial neurogenic bowel, i.e., in a stepwise fashion. It's hard to give a cookbook one size fits all answer, but some points would include the following:

- High fiber diet can be key.
- Keep up fluid intake, because in the absence of water, fiber turns to "concrete." Due to mobility and bathroom access issues, some people need to limit fluid intake. If so, then avoid fiber.
- Keep stool soft. If it is hard despite fluids and fiber, then add Colace® 50 or 100 mg two or three times a day.
- If there are still problems, add regular use of Senna® (2 tablets up to 4 tablets) about 6 hours prior to planned bowel movement (BM).
- Set a regular schedule to be on the toilet every 24 or 48 hours, so the bowels can develop a rhythm. Social issues sometimes necessitate M, W, F, but I encourage avoiding this since it makes it hard to "train" the bowels when the rhythm gets interrupted. For some it is best, after a large meal and some hot fluid, and, for many, that means in the evening.
- If at all possible, be up (out of bed) on a commode to take advantage of gravity.
- Do not give up on a routine due to a bad day or a few bad days. Bowel response to changes in routine can take a couple of weeks. Patience is key prior to making thoughtful changes.
- Avoid saying "this" or "that" doesn't work for me since a combination of approaches often works when each individual approach did not. As an example, fiber and Colace® may be needed to prevent a hard stool but Senna® maybe needed to initiate the bowel movement yet none of these worked alone).
- Avoid letting the interval of BM's exceed 3 days. At this point feces get dry and hard and they have generated gas internally, leading to colon distention. A distended colon loses even more of its contractile ability.
- Additionally, peristalsis occurs by sequential reduction in the cross sectional area of the bowel. The cross sectional area of the bowel varies exponentially with the radius ( $\text{Pi} \times \text{Radius squared}$ ), but the circumference varies directly ( $2 \times \text{Pi} \times \text{Radius}$ ), so a 50% reduction in the cross-sectional area occurs much more easily at a small diameter than a large distended bowel. The major point is: DON'T let the bowels get distended.
- Use a Dulcolax® suppository or even a Fleet® enema to be sure bowels move "on schedule." Once routine is established then try to taper to a glycerine (glycerin) suppository then digital stimulation, then nothing. If constipation reoccurs, go back and restart the next level up the chain, and continue to try to wean over time. [[www.polioplace.org/category/blog-tags/constipation](http://www.polioplace.org/category/blog-tags/constipation)]

[**Editors Note**:- Mention to Health Professionals that we can have Low Motility - slow moving]

## **POST POLIO SYNDROME EXISTS**

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

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

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

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

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

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

### **POLIO PATIENTS AND SURGERY. Information for health staff.**

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

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

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

## **REMINDER FOR MEMBERS**

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

**Did you let us know?**

Your Newsletter needs your stories, hints, tips and bits

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

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

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

Articles and items for Post Polio Matters

are always welcome, by post, by email and by phone if writing is not easy for you.

**Deadline date for next issue is 15th December 2017**

## **Editors Note:-**

**Articles from Polio Survivors, family and friends  
and Health Professionals very welcome for future issues**

## Snippets to wet your appetite from previous newsletters

### LincPIN Volume 4, Issue 11.

#### Polio in Lincolnshire. Excerpts from the Sleaford Gazette

**CITY HOSPITAL** Today's report on patients in Fever Wards; Ill, (relatives may inquire by telephone); 349, 262, 9, Making satisfactory progress: 268, 61, 86, 97, 132, 137, 143, 146. All others convalescent.

**July 1950** Paralysis cases in Digby Area      **August 1950** 51 Paralysis Cases – Two in Sleaford.  
Schools to stay closed: Precaution. Fewer New Cases – But No Relaxation Yet

**May 26th 1952** - The Lincolnshire Echo. I.P. VICTIMS FORM FELLOWSHIP Two years ago the people of Lincolnshire were made unpleasantly aware of the existence of Infantile paralysis. On Saturday Lincoln's first Infantile Paralysis Fellowship Group was formed at a meeting in Hannah Memoria I schoolroom.

[**Editors Note. 1996.** Lincolnshire Polio Survivors reform the Lincolnshire Branch of the British Polio Fellowship after 20 years. Contact Caroline Gordon-Wilson, Branch Secretary, [carolinegordonwilson@gmail.com](mailto:carolinegordonwilson@gmail.com)]

#### Polio Survivor researches his diabetes

Article about Derek Paice written by Rick Mendosa. <http://www.mendosa.com/index.html> All people with diabetes stand to gain from the Derek Paice's LOSS. A 71-year-old research engineer who was diagnosed with diabetes 11 years ago, Derek applied engineering principles to determine how inputs--food --related to outputs--his blood glucose levels. The result was his Low Sugar Score (LOSS) Diet. This way of eating, neither low nor high carb, leads not only to lower blood glucose levels but also helps to reduce weight, he says.

### LincPIN Volume 5, Issue 9 - Special 24 page Respiratory Issue.

<http://www.poliosurvivorsnetwork.org.uk/lincpin5-9.pdf>

### Post Polio Matters Volume 7, Issue 6 - Report from 2nd European Polio Conference

<http://www.poliosurvivorsnetwork.org.uk/ppmv76.pdf>

**Save our Shoulders: A Guide for Polio Survivors** by Jennifer Kuehl, MPT, Roberta Costello, MSN, RN, Janet Weschler, PT. Investigators, Mary Klein, PhD, Mary Ann Keenan, MD, Albert Esquenazi MD.

[http://www.einstein.edu/rx\\_files/yourhealth/mrri\\_sos9510.pdf](http://www.einstein.edu/rx_files/yourhealth/mrri_sos9510.pdf)

#### A couple of things that are working for Hilary and Richard

[Remember we are all different but if we share items maybe someone else would benefit]

#### Turning over in Bed and how the Snoozle helps me. [thesnoozle.com]

I have had difficulty for years turning over in bed and as said earlier in this newsletter you will probably have to go back to bed to do this to explain how you do it. It is a normal daily activity that we do but not think about. 10 years ago when I got a new mattress it did not have a handle and I then had to leave the wardrobe door open to use the wardrobe side to hold onto to shift myself. Then I heard about the Snoozle. It is a tube and the inside shiny and one surface rolls against the other and turning is much much easier for me.



#### Swimming, Hydrotherapy and Hot Tubs.

Exercise is good for our health but Polio Survivors need to work with a Physiotherapist to find out what level of exercise is possible for them. I ask for a demonstration of each exercise and then try it. I have found that three repeats is good for me. Depending on how much spare energy I have from the days chores and helping Richard I will repeat them later in the day. As an Advanced Swimming Teacher who has worked with many disabilities during 1980 - 1994 I know the benefits of being able to move our bits easily in water. Hydrotherapy has been suggested for me but the benefits that I would get were far outweighed by the effort to do all the necessary steps to get from home to the pool and back again.



Two months ago we found a Hot Tub [Zen Sanctuary] online that we thought would give the room to do the sort of exercise we could manage, stretching and gentle repeats of exercises, some swimming movements. We had it fitted and the benefits are great. A daily dip of 20 to 30 minutes at 38 degrees. The biggest benefit is from Richard's first statement on sinking down into the warm water "Ah.....I cant remember the last DECADE I was up to my neck in warm water, so good for tight muscles'. We have a bath-lift on a base to help getting in and out if needed.

**20 September 2017 Update:  
DLA To PIP Award Rates Fall Close To Almost Record Low  
Plus WCA Repeat Assessments At Record High**

**NEWSLETTER**

Even by our standards this is a pretty gloomy newsletter.

We have the disappointing news that the success rate for disability living allowance (DLA) to personal independence payment (PIP) transfers is almost at the lowest level it's ever been.

Then there's the unsurprising news that a survey has found that PIP assessments are harmful to your health.

There's the revelation that repeat testing of ESA claimants is back with a vengeance. There are now more repeat assessments than fresh claims, in spite of a DWP promise to stop unnecessary testing.

And the number of warnings that speeding up the universal credit rollout from next month will lead to a catastrophe for claimants is growing.

There is, though, the slightly more positive news that whilst the backlog of social security appeals has almost doubled in the last year, claimants continue to win in the majority of cases – except in connection with one benefit.

Finally, we'd like your feedback on whether you have used our PIP GP Notes, before we decide whether to create a similar resource for ESA.

**DLA TO PIP AWARD RATES FALL TO ALMOST RECORD LOW [Editors Note see bottom page 37]**

The latest figures from the DWP show that award rates for DLA to PIP have fallen to their lowest level almost since the transfer of DLA claimants began.

In January 2017, 72% of DLA to PIP claimants received an award, rising to a high of 75% in March 2017.

However, the award rates have now been falling for the last four months for which figures are available.

In July 2017, the award rate for DLA to PIP reassessments had fallen to 68%.

Only in January and February 2014, when reassessments first began on very small numbers of claimants, were success rates lower.

**WCA REPEAT ASSESSMENTS AT HIGHEST EVER LEVEL**

Back in 2014, Benefits and Work broke the news that all repeat WCA medical referrals to Atos were to be stopped until further notice, due to a massive backlog of cases.

We can now reveal that the number of repeat assessments has risen to a record high since they were reintroduced in December 2015.

In the quarter to March 2017, the most recent for which figures exist, there were 154,200 repeat WCAs. This is more than double the number carried out in the same period last year, which stood at 72,000.

It means that, in the most recent quarter, 54% of all WCAs were repeat assessments as opposed to 42% which were initial claims.

Yet in October 2016 the secretary of state for work and pensions, Damian Green, told MPs "*we will stop reassessing people with the most severe health conditions and disabilities.*"

**[STOP PRESS - 4th October 2017. REPEAT WCAS END FOR SOME CLAIMANTS]**

*Last month we revealed that repeat WCAs – the assessment system that decides eligibility for employment and support allowance (ESA) - were at their highest ever level and now outnumber WCAs for new claims.*

*However, the DWP have now announced that from 29 September some claimants who have to undergo a WCA may be told that they will be exempt from any further repeat assessments.*

*This only applies to claimants who are in the support group of ESA or who have limited capability for work-related activity for UC.*

*You will also have to have a severe, lifelong disability, illness or health condition. And you must be unlikely to ever be able to move into work.]*

Green went on to say that the IT changes needed for the new system would be completed by the end of 2017, but:

*"In the meantime, we will be working to ensure these people are not reassessed unnecessarily."*

The latest figures suggest that the exact opposite is happening.

### **PIP ASSESSMENTS HARMFUL TO HEALTH AND INCOME**

It will come as no surprise that a survey by the Disability Benefits Consortium has found that 79% of claimants reported that the stress and anxiety of the PIP assessment process had made their health worse. In some cases people said that the experience of claiming PIP was so distressing that it had caused new conditions to emerge.

The survey also found that almost three quarters (71%) of respondents found the PIP application form 'hard' or 'very hard' and 11% of respondents were unable to complete it at all.

Over half (58%) of people said that assessors did not understand their condition.

Half (50%) they were receiving less money under PIP than they were previously entitled to under DLA, or they had lost their award completely.

### **UC A 'DISASTER' AND 'CATASTROPHE'**

Citizens Advice has warned the government that its plans to massively speed up the rollout of UC from next month will cause a 'disaster'.

The chair of the work and pensions select committee, Frank Field, meanwhile has warned that it will be a 'catastrophe'.

Both are particularly concerned about the massive hardship caused by the 6 week wait for a first payment, which is often made even longer by processing problems.

Citizens Advice say that the expansion of UC is 'a disaster waiting to happen', as new findings show it is pushing people further into debt.

Frank Field was even more outspoken, warning of *"a human and political catastrophe"*. He said that his committee was:

*"... hearing evidence of people being plunged into all sorts of vulnerability as a result of the debt, risk of hunger and homelessness, and resulting stress of being migrated onto Universal Credit, with its in-built 6 week delay in receiving a first payment and much longer waits for many people.*

*"People already on low incomes simply cannot cope without any income for such a long period of time."*

An announcement from the secretary of state about whether the rollout will be delayed is expected next month.

### **CLAIMANTS WIN MAJORITY OF GROWING APPEALS BACKLOG**

The number of social security claimants waiting to have their appeal heard has increased by 88% in a year, according to the latest tribunals service statistics.

The vast majority of these cases are PIP at 46% and ESA at 38%.

And, whilst around 80% of claimants continue to lose at mandatory reconsideration stage, those who go on to appeal have a very good chance of success.

68% of ESA claimants won their appeals, as did 65% of PIP claimants.

The success rate was lower for the small number of DLA appeals, at 55%.

But only for JSA, where the success rate was 49%, is the DWP able to say they won in the majority of cases.

The message remains clear: you won't get a fair result from a mandatory reconsideration, but you might well do from an appeal tribunal.

Continues page 36

## Continued. **HAVE YOU USED OUR PIP GP NOTES?**

A few months ago we published a set of **PIP GP Notes in the members area**. These are a copy of the PIP descriptors that you can take your GP to ask them to select which ones they think apply to you, add any comments and sign and date as evidence for your claim or appeal.

We'd be grateful for any feedback about whether you've used them, how helpful you found them and any changes you would suggest before we decide whether to create a similar resource for ESA.

Many thanks to Gordon for taking the time out of his demanding moderation schedule to create the notes for us.

Good luck, Steve Donnison. [Membership is £19.95 a year]. [[www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk)]

Membership includes... Information on DLA, PIP, ESA, WCA, Carers Allowance, Attendance Allowance. Surviving Life on Benefits with sub-sections on Shopping, Cooking, Managing your money, Paid and Voluntary work, Dealing with the Department of Work and Pensions, Getting expert advice and help, Emotional issues and also some miscellaneous tips.

## **ACTIONS OF DAILY LIVING - ARE YOU PAINTING THE SAME PICTURE?**

The PIP GP NOTES [24 pages] mentioned above and available to Benefitsandwork members, has some really useful information that Polio Survivors could use to think about how you are now doing actions of daily living prior to seeing any health professionals. The accompanying letter to the notes to the GP contains the baseline information and explanations of the terms.

We know that realising you are doing actions differently and being asked to think about it is definitely not easy. We have been there and are still going there. To communicate effectively with health professionals - especially those who do not have the level of knowledge you do about polio and how we recovered. You need to tell it like it really is and you must start with being honest with yourself. [2nd European Polio Conference in Amsterdam - <http://www.informed-scientist.org/presentation/painting-the-same-picture-can-provide-better-clinical-outcomes>]

**[Editors note:-** PSN suggestion completing these pages as if you were your own GP could help you think about how you are managing daily living activities. Please contact us if you need more info on this - Benefits and Work Members can download the letter to GP - text follows - and 23 pages which are broken down into Preparing food, Eating and Drinking, Managing Treatments, Washing and Bathing, Managing Toilet Needs, Dressing and Undressing, Communicating, Reading, Mixing with Other People, Making decisions about money, Going out and Moving Around.

**Dear GP,**

I would be grateful if you could have a look at the following and make any comments that you believe are relevant. Please tick each item that you think is applicable to me, if you don't know then it is OK for you to say so.

I need to be able to complete each activity reliably, this means;

- **Safely** – in a fashion that is unlikely to cause harm to me or another person.
- **To a necessary and appropriate standard** – given the nature of the activity.
- **Repeatedly** – as often as is reasonably required.
- **In a timely manner** – in a reasonable time period.

I also need to be able to do these activities on the majority of days, so I would ask you to take these points into consideration when commenting.

Some definitions that might help you understand what I am being asked to do.

**Prompting** means reminding, encouraging or explaining by another person.

**Supervision** means the continuous presence of another person for the purpose of ensuring your safety

**Assistance** means physical intervention by another person and does not include speech.

**Aid or Appliance** - (a) means any device which improves, provides or replaces your impaired physical or mental function; and (b) includes a prosthesis.

**Aided means with** – (a) the use of an aid or appliance; or (b) supervision, prompting or assistance.

## Independent Age - advice and support for older age

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

About Independent Age, 18 Avonmore Rd London W14 8RR ☎ Helpline 0800 319 6789

Whatever happens as we get older, we all want to remain independent and live life on our own terms. That's why, as well as offering regular friendly contact and a strong campaigning voice, Independent Age can provide you and your family with clear, free and impartial advice on the issues that matter: care and support, money and benefits, health and mobility. A charity founded over 150 years ago, we're independent so you can be.

### Our 8 care home quality indicators

Deciding to make the move into a care home is a big decision. There are a lot of things to think about all at once, and it can be difficult to know what questions to ask or how to quickly judge a really good care home.

#### A good care home should...

1. **Have strong, visible management.** The manager should be visible within the care home, provide good leadership to staff and have the right experience for the job.
2. **Have staff with time and skills to do their jobs.** Staff should be well-trained, motivated and feel they have the resources to do their job properly.
3. **Have good knowledge of each individual resident and how their needs may be changing.** Staff should be familiar with residents' histories and preferences and have processes in place for how to monitor any changes in health and wellbeing.
4. **Offer a varied programme of activities.** Care homes should provide a wide range of activities (and ensure residents can access these) in the home and support residents to take part in activities outside the home.
5. **Offer quality, choice and flexibility around food and mealtimes.** Homes should offer a good range of meal choices and adequate support to help residents who may struggle to eat and drink, including between mealtimes. The social nature of eating should be reflected in how homes organise their dining rooms, and accommodate different preferences around mealtimes.
6. **Ensure residents can regularly see health professionals such as GPs, dentists, opticians or chiropodists.** Residents should have the same expectation to be able to promptly see a health professional as they would have when living in their own home.
7. **Accommodate residents' personal, cultural and lifestyle needs.** Care homes should be set up to meet residents' cultural, religious and lifestyle needs as well as their care needs, and shouldn't make people feel uncomfortable if they are different or do things differently to other residents.
8. **Be an open environment where feedback is actively sought and used.** There should be mechanisms in place for residents and relatives to influence what happens in the home, such as a Residents and Relatives Committee. The process for making comments or complaints should be clear and feedback should be welcomed and acted on.

[[www.independentage.org/policy-and-research/our-8-care-home-quality-indicators](http://www.independentage.org/policy-and-research/our-8-care-home-quality-indicators)]

**Disability Living Allowance (DLA)** is ending for people aged 16 to 64.

You can keep getting DLA if you're under 16 or you were **born on or before 8 April 1948** and have an existing claim.

You'll continue getting DLA until the Department for Work and Pensions (DWP) invites you to apply for PIP. You don't need to do anything until DWP writes to you about your DLA unless your circumstances change. <https://www.gov.uk/pip>

**'Breathe's Claire Foy On Inspirational True-Life Story - Contenders | Deadline** [October 8, 2017 9:00am]

Matt Grobar writes:

Breaking out with a Golden Globe win and an accompanying Emmy nomination for her portrayal of Queen Elizabeth II in critically acclaimed Netflix drama series *The Crown*, Claire Foy has quickly risen through the ranks to become one of the most well known and busiest actresses not only in the UK, but in the entertainment community at large. Recently announced to be taking over the role of Lisbeth Salander from Rooney Mara for the upcoming *Girl in the Spider's Web*, Foy will vie for a chance at an Oscar this year with her turn in Andy Serkis' directorial debut, *Breathe*. Based on a true story brought to Serkis by producing partner Jonathan Cavendish—the story of the producer's own parents—the romantic drama centers on Robin Cavendish, who contracts polio while abroad in Africa, attached to a respirator for the rest of his life and supported throughout by his adoring wife, Diana.

Having just completed production on the first season of *The Crown* when *Breathe* came around, and with a new baby in tow, Foy initially was looking for a way to say no to the project, hoping to take time away to be with her family. Running into Serkis, her *Little Dorrit* co-star, in a café and catching up briefly, Foy soon found herself with an offer for the role of Diana—set to star opposite Andrew Garfield—and reading William Nicholson's script for the film, the opportunity proved too great to turn down.

"I was like, 'Maybe I just won't read the script, because I know I'm not going to do it, because I haven't got the time. I want to go on holiday.' And the worst thing [my team] ever did was read the script. Bill Nicholson's script was the most beautiful script I had ever had in my life," Foy said, sitting down on Friday morning opposite Deadline's Nancy Tartaglione at the inaugural Contenders London event. "I just read it, beginning to end, and cried—and then I found out it was a true story, and the producer was the child in the story. Then, I met Andrew and I was just like, 'Oh, god. I walked into this,' and I just couldn't not. It was just the most beautiful experience I've ever had, really."

In preparing for the role of Diana, Foy found it crucial to understand the illness of polio and what is required to care for individuals who contract it, speaking first with her own family about the illness, and ultimately meeting with Diana Cavendish herself. "I talked a lot with my family because obviously it's within living memory, and it's still around today. I didn't feel like it was massively important for me to go and meet people who were on a respirator," the actress shared. "It was important for me to meet Diana, who pretty much is the expert in caring for someone who is on a respirator. It was very important for me to get the technical aspects of caring for someone like that right, but from her perspective, as opposed to polio as a whole."

Meeting Diana, Foy quickly recognized the verisimilitude with which Nicholson had drawn her in his script. "Bill has just drawn her absolutely as she is. She is the most incredible woman, but thinks she's completely ordinary, run-of-the-mill, didn't do anything special—that her and Robin were just doing what the right thing to do was," she said. "I read the script, and I just understood that love was the motivation for every single thing she did, and making [Robin] happy was her life's work. Meeting her, she just was incredibly generous, and through her, I got to know Robin. He lives on, and I feel very lucky to know them."

Reflecting on the production process, Foy mentioned that the film was, ambitiously, shot in a six-week period. "I don't know how they did it—not for a period film, not for a film that required aging of the actors, so much medical equipment and things to get right. It was meant to happen, I feel like," Foy said. The actress attributed most of the heavy lifting to Serkis and to Garfield, whose role required him to perfect the art of remaining perfectly still, given Robin's paralysis. "Within those six weeks, Andrew did so much work," she said. "He prepared for it more than you could possibly imagine, and in a weird way, that helped me, because he would often email me with things, conversations that he had."

Initially, the actress didn't know how to evaluate Garfield's seemingly method approach to his role, though she took away from the project a deep respect for the actor and his craft. "I just have nothing but admiration for him. There was no way he could have done that [role] and not entirely surrender his body to it," she opined.

Of her takeaways from *Breathe*, Foy said the experience impressed upon her the importance of taking risks and making whatever moves necessary to live one's life to the fullest. "You can't underestimate that [Robin] lived three minutes from death for the rest of his life, for 35 years. If you're faced with that, with never being able to take someone for granted because they may go at any moment... They had an amazing gift, in a way, in that they couldn't take this amazing thing for granted," she said. "I think I learned so much from them about decision-making, and just going, Why not do it? Why not take the risk? Why not move to that country? What's stopping you, for heaven's sake?"

Original source article

<http://deadline.com/2017/10/claire-foy-breathe-contenders-london-oscars-news-1202183186/>

# 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 [Renew on 1st July or 1st January after date joined.]

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

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

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

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

Email:- [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk)



All Forms are available on our Website,  
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## 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
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  - UK Taxpayers can Gift Aid their subscription and donated amounts.

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To support attendance at National Meetings and PPS Conferences

**The Gift Aid scheme.** Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year.

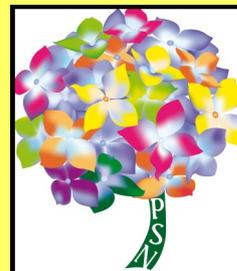
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# Polio Survivors Network

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## POST POLIO MATTERS

because **WE'RE STILL HERE!**

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## Life skills for polios – a light hearted handbook

The exchange of ideas on management for polio survivors in their “second round” of the fight with the poliovirus, has proved vital.

To make that trade easier, Mornington Peninsula Post Polio Support group has published ‘Life Skills for Polios – a light-hearted handbook’ to bring together the most recent as well as tried and true information and advice from medical experts plus those living with PPS.

The book has been compiled and illustrated by retired journalist, author and polio survivor Fran Henke, in themes of Home, Body and Mind – covering downsizing, tips for the kitchen and laundry, plus the big topics of pain, fatigue, exercise and coping with past treatment in the face of the new symptoms.

Printing has been funded by generous donations from Mornington Peninsula service clubs, other support groups and individuals, with the aim of all sales proceeds going to benefit Polio Day 2017, being held in Bendigo, Victoria, Australia on October 21.

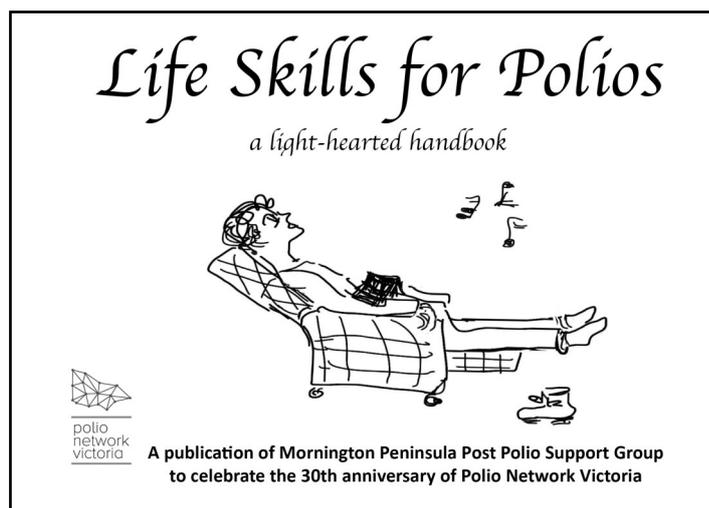
The book will be available for \$Aus15 at Polio Day, through Polio Network Victoria and the MPPPSG (email: [flyingponypress@gmail.com](mailto:flyingponypress@gmail.com)). Online soon through the International Centre for Polio Education (thanks to Dr. Richard Bruno) for \$US5 and £3. {[www.postpolioinfo.com/randomharvestabout.php](http://www.postpolioinfo.com/randomharvestabout.php)}

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