

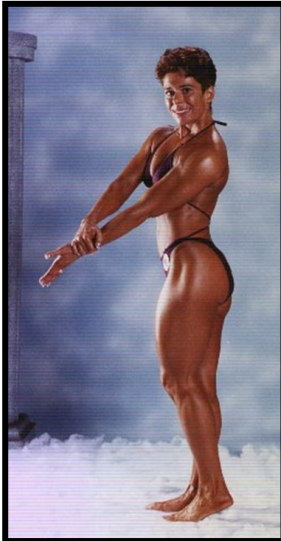


POST POLIO MATTERS

Polio Survivors Network Newsletter

APRIL 2019 Vol 9 of 12, Issue 105.

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



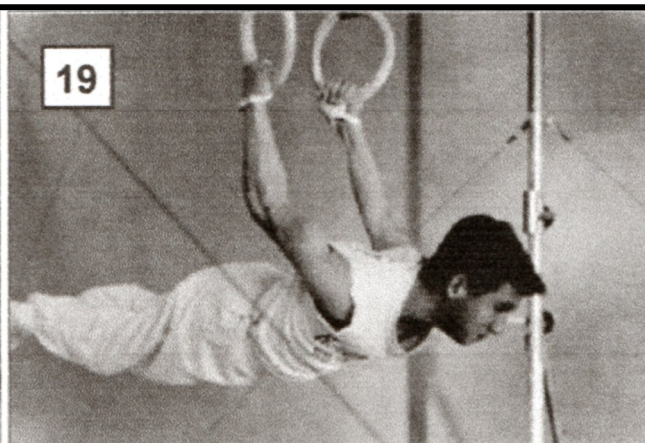
**POLIO SURVIVORS do NOT all look
as if they had paralytic polio
in their earlier lives**

[and non paralytic where paralysis not seen]

Health Professionals need your help because
they are rarely taught enough facts about
Polio and Post Polio Syndrome.

The level of invisible internal nerve damage
by the polio virus is often not seen or understood.

Gwen Hunt BSc. RN in 1995 Head Nurse of 50 bed ward
And in 2003 with Post-Polio Syndrome



**Annual General
Meeting
July 6th 2019
Lincoln**

Home of the
Lincolnshire
Post Polio
Library



Enter 100+ articles

POLIO SURVIVORS Please Help Health Professionals

PREPARE information on your Polio, Post Polio Syndrome, other medical
diagnoses, Medications, Allergies, Aids and Equipment and any prior
issues when in Hospital. Plus, as a minimum the two articles on page 18,
and a couple of photos like the above. [read more page 10]

Print this out and carry in your bag; your car; by the door of your home
large green cross on file; give a copy to friends/family members; add the
information to a USB stick on a keyring, or on your mobile phone, iPad.

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

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Page 19	Contact details
Back Page	Post Polio Matters... because "We are Still Here" Nils van Leerdam, Ambroise NL, from page 7 My Hungarian Family by Zsuzsi Snarey. Book cover Blood, Bone and Marrow, Biography of Harry Crews - from page 17 Val Scriveners' Photo Cards for sale to raise funds for Polio Survivors Network.

QUICK NOTES

Annual General Meeting has now been fixed for Saturday July 6th 2019 and will be held in the City of Lincoln.

Further information will be sent out with the Annual Report in the next couple of weeks. If you are able to join us and want information before then then please email or ring.

New Part Time Admin Officer starts on May 6th 2019, come and met her at the AGM.

Apologies for the delay in sending this newsletter due to personal issues taking energy away that was needed to complete this.

Next issue will be late June 2019 with deadline for inclusion June 4th 2019.

Remember if you see something that might be of interest to other members please let us know we would rather have it sent to us ten times than not at all.

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

Firstly I must apologise for the lateness of this issue due to a personal issue taking most of my available energy. We only have so many energy tokens a day and when they are spent there is nothing left in the kitty. Strange choice of words as I typed kitty 'Dixie Lee' jumped on the foot rest area of my riser recliner behind my laptop and settled himself down to sleep.

Annual General Meeting is being held on Saturday in Lincoln,... info here once booked...

Admin Officer. I would like to thank Simon D-S for the work that he did for PSN for six months and was sad that due to personal reasons he no longer had the time available from his University Course to extend his contract. I am happy to announce that shortly after you read this our new Part Time Admin Officer, Toni, will be in post. She is also taking the post of Part Time Admin Officer for the Lincolnshire Neurological Alliance which will be of great benefit to our Lincolnshire members. The LNA have worked for over 20 years now for better neurological services in Lincolnshire but it is the same old story.... No accurate numbers and changes upon changes of boundaries and organisation names and so many start all over again with yet another person/s charged with working on the project. The pilot program a couple of years ago for Parkinsons that was going to be for all neurological conditions pathways fizzled out. We have had meetings with the new Director of Public Health, Professor D. Ward and hope for some more news in July.

To ensure everyone seeking information about PPS from us can now afford it we have decided that **Membership is now FREE** whilst we have the funds to support this.

"Safe, effective, and potent." With these words on April 12, 1955, [64 years ago] Dr. Thomas Francis Jr., director of the Poliomyelitis Vaccine Evaluation Center at the University of Michigan School of Public Health, announced to the world that the Salk polio vaccine was up to 90% effective in preventing paralytic polio.

This reduced the number of cases of polio and as they reduced the Colleges of Medicine taught less and less facts. We learned in 1997 that for Doctors it was half an hour lecture with leprosy. How many of you have been on the receiving end of comments like 'we don't have polio in this country, do you come from a third world country? - are you sure, you don't look like it to me? - and my favourite, 'Oh yes, Post Polio Syndrome I have just learned about this new disease' and look surprised when I tell them that it was first medically recorded in 1875, is not a disease but a possible later stage following years of stable functioning. Continues page 10...

Best Wishes for Speedy Recovery. I, on behalf of all our Members, would like to wish Caroline [also BPF Secretary for the Lincolnshire Branch and East Midlands Region] a speedy recovery following her fall and operation at QMC in Nottingham. See Back Page.

PLEASE SHARE EXPERIENCES OF YOUR POLIO LIFE

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

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

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

NEXT ISSUE - Deadline June 4th 2019.

MESSAGE FROM OUR CHAIR

One size does not fit all

I have been thinking, although we are all polio survivors and share a lot of experiences, we are also very individual and different. This is true in many ways but importantly it is also true medically and psychologically. Myths pervade that try to bunch us together and that can be useful to lobby and get attention. There was a theory around that Type A personalities, go getting driven people were more likely to get polio. The truth is probably that previously illnesses were a mostly contagious diseases of the poor and working classes. Polio was different, it was indiscriminate and not just a result of poor nutrition or living conditions. The elite and powerful and middle classes were also deeply and personally affected, especially their children. As a result, more attention, funding and PR was given to polio than diseases of the poor had ever or rarely previously had. You might say we became part of some elite disability group of interest to medics, researchers and all of society. Even the President of the USA, F.D. Roosevelt was diagnosed with polio in 1921 (though we now believe he probably had Guillain-Barre Syndrome). <https://www.sciencemag.org/news/2003/10/did-fdr-have-guillain-barr>

Times change

As George Harrison put it, all things must pass. We are now largely a forgotten historical and increasing minority, and an ageing group in the west. With polio vaccines, again only groups who are poor, in war zones or problematic political environments are at risk of getting polio due largely to lack of access to vaccine. It has become much like most contagious diseases were, an illness associated with poverty and deprivation of one sort or another and, of course, war.

From celebrity to invisibility

I often feel we are not used to this down grading of polio's status, especially with professionals! It is a problem for us when we need support as we are the perfect example of diversity and the need for individualised holistic care. Today that is expensive and has increasingly given way to protocols, categorising and treatment that is only resourced if it meets a medicalised model of evidence-based practice. The problem that this requires research, and polio is no longer a sexy or lucrative subject. In addition, funding is given to research which lumps similar symptoms and conditions into treatment groups. Therein lies a problem, polio survivors do not fit into such boxes, we never have done of course, but in the past mavericks and outliers of the medical and care professions were often allowed to 'wing it' and do 'what worked' regardless. Of course, that may have been financially wasteful by today's standards but maybe we are throwing out the baby with the bath water as we shift away from holistic and individualised care and supporting difference and diversity in our healthcare system.

People not just treatments

In psychotherapy, and psychological therapies it has become increasingly accepted, if not by the government and bodies such as NICE, that it is the relationship between patient therapist that is the most important factor in the wellbeing and outcome rather than any one particular technique or intervention. It is a shame that this is something we have to fight for when I feel sure many good clinicians would welcome more autonomy and time with their patients. I fear we often forget that medicine is not just a science and not just about cure and about so but much, much more than that.

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

Chartered Psychologist. HCPC Registered Counselling Psychologist, www.sp-psychology.com

Chair Polio Survivors Network.

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

POLIO SURVIVORS NETWORK AGM - Saturday July 6th 2019 in Lincoln.

POLIO SURVIVORS BENEFIT FROM SHARING EXPERIENCES

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

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

Here are some of the other Post-Polio Resources with sharing experiences around the World.

Welcome to Sunny's Blog. - sunnyrollerblog.com

CONVERSATIONS ON LIVING WELL IN LATER LIFE—WORDS AND WISDOM FROM POLIO SURVIVORS



PolioToday.org is published by the **Salk Institute for Biological Studies**.

This website is designed to raise awareness of post-polio syndrome and to be a resource for polio survivors. Dr. Jonas Salk, who developed the first safe and effective polio vaccine, founded the Salk Institute in 1960.

Watch Videos of 14 Personal Stories, Expert Opinions by Dr. Perlman on 15 PPS subjects

Breathing and Sleep Symposium 2009 - 4 videos

Breathing and Sleep Symposium 2010 - 8 videos

Breathing and Sleep Symposium 2011 - 7 videos

polio place - www.polioplace.org

A service of Post-Polio Health International.

Preventing poliomyelitis was the focus of the work done in the first half of the Twentieth Century. Other scientists and physicians left an important legacy by developing treatments and devices during that time.

Many people have been instrumental in improving the lives of polio's survivors - the people for whom the vaccine was too late. Explore the lives of 37 notable individuals.

Facebook.

There are a variety of Post Polio Groups on Facebook where there is always someone awake somewhere in the world if you need to chat.

Public Groups are where anyone can join and the admin try to ensure that everyone respects the values of the group and will remove anyone who does not.

Closed Groups - not listed below - and where your messages cannot be seen by anyone not subscribed to that Group. Talk to your PPS Support Group for info.

The following are just a few examples of the Public Groups.

[Polio Survivors Rotarian Action Group](#)

[Polio Australia, Polio New Zealand,](#)

[Post Polio Alliance of South Florida, Polio Survivors in Ireland,](#)

[New Orleans Area Polio and Post Polio,](#)

[Land of the Sky Post Polio Support Group](#)

[The Post-Polio "COFFEE HOUSE", Polio Mom, Polio Survivors at Work](#)

ORTHOSES - Are we getting a raw deal?

My experiences with Orthoses. By Zsuzsanna Snarey.

When I had polio at the age of eight my mother refused to have callipers for me having seen the wasted limbs of the children who wore them. I managed to learn to walk again although it took a whole year before I took three steps. It took many more years before I became independent and always used a stick outdoors.

I brought up three children, became a teacher and it was not until the age of sixty that my left knee started to give me problems. When I saw the GP I was told that the waiting list to see an orthopaedic surgeon was 9 months. My husband was working at the time and his employers gave him private health insurance which meant that I had an appointment the following week. I took with me the advertisement for UTX Swing callipers from the British Polio Fellowship magazine. The orthopaedic surgeon agreed with me about the need for protecting my hyperextending left knee and immediately phoned the Ambroise representative Ken who later visited me at home, took measurements and delivered the calliper a few weeks later. He told me that I had to be seen at the orthotics department of the hospital with them where I was severely told off for "going through the back door" and jumping the queue.

In time the callipers needed servicing via RSL Steeper who acted as intermediaries with the Dutch company Ambroise. It took about two months before I received them back. So eventually I had to have another calliper to wear while I was waiting.

About ten years later I started having pains in my right knee but I was told by Robin Luff at the Lane Fox unit that it was not possible to wear two callipers. My right knee was getting more and more painful, I started to use two sticks and walk less and less. But it took me two years and several appointments with three different specialists and persistent demands before I managed to get the second calliper. First there was the problem of funding, then the fitting because an orthotist who was qualified to take the measurements had to come specially from London and once made the calliper had to be returned to Holland three times before I could use them. They were still making a dent into my leg. All this took another six months.

Finally I had two callipers for each leg but they were still not fitting comfortably. In final desperation my husband decided that we should have a short holiday and travel to Holland to resolve the problem. I contacted Nils van Leerdam CEO of Ambroise NL. www.ambroise.nl/en/team/ and we agreed on a date. He said that I would need to stay for three nights at a local hotel. I found a three star hotel (the Conferentiehôtel Drienerburght) in Enschede on the site of the University of Twente which was near the offices of Ambroise, booked a crossing at Dover and we set off on Monday morning. We spent the first night at the Premier Inn Dover where I discovered that we left my suitcase behind! We stocked up on essentials at the local Tesco.

We crossed the Channel early Tuesday morning and arrived in Enschede in the afternoon. The town is near the German border. My appointment was at 9 a.m. on Wednesday. Nils took note of the alterations necessary on my callipers and took several photographs of my legs against a graduated chart attached to the wall. This was fed into a computer to make my new callipers. We returned in the afternoon for fittings of the old callipers which took a few hours but finally they were made comfortable. On Thursday morning the new callipers were fitted. This also took several adjustments until I was told to go and try them out for a few hours. We explored the excellent Rijks Museum where we had lunch. We returned at three o'clock to sort out a few minor problems. On Friday there was still a chance of making alterations until finally all was well and we started on the return journey on Saturday, very early in the morning with a packed breakfast which in fact lasted us the whole day! We arrived at the crossing at about 4 o'clock and were home by 9 p.m. in Nottingham.

The 18th century French surgeon **Ambroise** Paré introduced modern amputation procedures and made an above knee device that was a kneeling peg leg and foot prosthesis with a fixed position adjustable harness, knee lock control and other engineering features that are still used today. His name was chosen for the company set up by Nils van Leerdam when he completed his PhD and

invented the UTX Swing calliper. UT stands for the **U**niversity of **T**wente and the X stands for **I**ntelligent **K**nee **S**tabilisation pronounced IKS in Dutch. He might have been inspired by the fact that his grandfather suffered from polio. The aims of the company are the 3C's : Control, Comfort and Cosmetics. In the reception there is a large photograph of a very attractive young lady wearing high heels and a short skirt with a UTX Swing calliper! Quite impossible to achieve for me! I am going to carry on wearing long skirts and trousers to hide them. Wearing trousers has its problems, but it is possible to put them on using a plastic bag over the shoes. Another solution is to have wide leg trousers which are much easier to put on and off with callipers. I have to rely on my callipers more and more since I first needed one 16 years ago.

Hilary's story - shortened considerably.

I had waist down paralysis at age 5 with good recovery. After a couple of operations for dropped feet I managed many sports that did not involve running.

I slipped on a wet patch on a school corridor in 1988 and this time when I got up I started to have new issues. Painkillers and physio did not help and I ended up in hospital on neck traction. I spent the next seven years going through a variety of NHS departments and always ended up with yet another physiotherapy regime. but I **just got worse**. November 1995 hearing results of MRI scan 'I am glad you are better'. I replied 'I am not better, I have continued to deteriorate. I had polio as a child has that got anything to do with this?' His reply 'Oh, there is something called the Late Effects of Polio

It took research and 2 more years and a referral to a second hospital, Queens Medical Centre, where I had a full days tests that could find nothing else and I received a letter 'confidently diagnosed the post-polio syndrome'.

I learned from other Polio Survivors online that I needed to use aids and assistive devices to reduce falls, pain and fatigue. I asked for referral to the Orthotic Department and to keep this story from running to pages and pages I have had at least seven provided by the Orthotics Department at Lincoln and, if wearable, all uncomfortable.

Thanks to my travelling to PPS Conferences I had one made in Ottawa in 1999 [thanks MF] that took FIVE hours and was comfortable from day one. It lasted 7 years till I fell and broke it for the second time and it would not glue. I met Ken from Ambrose and if I bent my left leg more than a couple of inches I collapsed. I was fitted with a left leg Utx like Zsuzsi which allowed me to walk almost normally. This was great for about five years until I was not able to walk far enough to warrant putting this on and I started using my electric scooter more often. I had also had to go back to a UK made uncomfortable AFO.

In 2008 just before we left the USA to live in Lincoln Richard went to see his Orthotist to ensure he had all the bits necessary if his KAFO broke. I found it was only £125 for an AFO. I was asked to walk backwards and forwards 10 metres with and without my shoes on. My feet and legs were then examined. Then the Orthotist picked up my UK made AFO and said, 'but there is no pressure relief for the ball of your foot'. Oh, if only I had remembered that was exactly what the Canadian Orthotist had said was wrong. The Orthotist opened his box of tricks took out the required jelly shape AFO with pressure relief space for the ball of my foot. March 2008.

2018 The strap on my right AFO needed replacing so I made a temporary repair. Then I realised that my stubbed toes and falls were because my left leg had started to drop, I had to ask GP for referral. Lincoln Hospital made new for my right leg but had to go back for alterations. They made new for left leg but it threw my knee out and caused me to fall so I went back and an appointment would be given a physiotherapist/orthotist but I have heard nothing in 3 months.

I decided to visit a Private Orthotist for an assessment. I had a thorough assessment. I was shown 7 different options to manage my dropped feet. One I could try for an idea, although it would have to be fitted. I stood walked a few paces and instead of looking at the floor I could see her face. I sat down and burst into tears. I returned a week later and now have two BlueROCKERS - www.allarduk.co.uk/foot-drop-adult/bluerocker-r. They have made a huge difference. No longer a bent old crone using a walker but almost standing straight again and using a cane. Huge benefit for my health. OK it has cost me £1450 but worth every single penny.

Hello - I am Rebecca. I am mum to David who was born with Cerebral Palsy. In 2009, following years of slow, poor quality NHS Orthotic care for him, I set out on a local campaign with other patients and carers to improve the Orthotics service in North Staffordshire. It wasn't until we had succeeded and had some national publicity, that patients from all over England contacted me to say they were facing the same challenges we had had with their Orthotic care.



Namely:

- Long waits to get an appointment to see an Orthotist
- Having one Orthotist measure you and a different one (with a different opinion!) fit it
- Devices and footwear being completely unsuitable / unwearable / ugly
- Things taking so long to come that they would be outgrown or no longer suitable by the time they arrived
- Orthotists having to rush through appointments .

So, in response to receiving some very sad stories about orthotic patient care, the campaign 'went national' in 2013. Orthotics patients and their carers generously shared their stories with us and gave their permission for us to pass them on to NHS leaders. With the help of Healthwatch we managed to get the attention of NHS England. They published a report in 2015. For some patients this report did improve their care, but for others the report joined the many other reports on the sorry state of NHS Orthotics provision that local providers and commissioners had ignored.

Some of the many reports on Orthotic Care.

- NHS Improving the quality of Orthotics Services in England
www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/orthcs-final-rep.pdf
- York Health Economics Consortium
Orthotic Service in the NHS: Improving Service Provision [July 2009]
John Hutton - Project Director, YHEC Limited - University of York [The Hutton Report]
Manjusha Hurry - Research Fellow - YHEC Limited - University of York. [July 2009]
<http://www.nsoc.org.uk/evidence/york-report.pdf>
- Centre for Economics and Business Research Ltd.
The economic impact of improved orthotic services provision
A review of some of the financial and economic benefits of a better functioning system for the provision of orthotic services
http://www.nsoc.org.uk/evidence/Orthotics_review_Cebr_report_04%2007%202011.pdf
- Report for the British Healthcare Trades Association (BHTA) Final report July 2011.
http://www.nsoc.org.uk/evidence/Orthotics_review_Cebr_report_04%2007%202011.pdf

Readers.

Please let us have your stories - good and bad. The more information we have to add to our database the easier it is to respond when we are asked at local and national meetings. We need to hear from more members and then we can provide a response in our next newsletter so that you can also use the information where you live. Contact by post or email. If you can only talk on the phone then let us know and we will arrange a suitable time.

Where the NHS excels - by Verite Reily-Collins.

When it comes to arrogance the NHS's hierarchy has it in spades. Anyone who has attended an NHS conference recently knows you just can't beat them when it comes to back-slapping and self-congratulation. But - sometimes someone stands up to their self-congratulatory committees, and recently a Lambeth nurse had the guts to do this.

Here is a video of the brave nurse who stood up to the big chiefs at an NHS Executive Board meeting, and dared to challenge them. You can see what happened on <https://aftercancers.com/challenging-nhss-back-slapping/>

Gay Lee got in to the meeting and pointed out that probably the most important problem facing the NHS today was shortage of staff. Those of us with long-term problems from polio know how difficult it is to get treatment, let alone see a consultant who understands our condition.

But instead of seriously talking about problems facing the service, all Lord Prior could do was spout self-congratulatory stuff. All gung-ho and back-patting.

Gay has worked tirelessly for the NHS for over 40 years, so when she highlighted the major problems facing the NHS such as the lack staff, workforce strategy and funding, she was on solid ground. Problems which the meeting seems to have 'overlooked.

NHS administration (those with the six-figure salaries) seem to live in a cocooned world. Grand statements about X-amount of extra staff overlook the reality that it takes years to train these staff. Therefore those heads of NHS services that were at this meeting need to be challenged on performance. But instead they have a huge staff to shield them from reality.

Now, it is even more difficult to get any adverse comment aired/ So when this video shows Gay bravely challenging Lord David Prior at an NHS meeting I am full of admiration. .

The man sitting on the right as you look at the video is Simon Stevens, CEO of NHSE - who used to be a senior executive at United Health in the USA.

Apparently the latter said nothing to Gay after the meeting and although David Prior did come up and speak briefly he left as soon as he saw that the new Chief Nursing Officer of NHSE wanted to speak to her.

As Gay says, "the bottom line is that it will take a long time....to train enough staff... and there is not even a strategy document 'til the autumn". So who is going to be the next person brave enough to challenge the NHS in public?

Verite Reily Collins

Polio Survivor, Cancer Survivor, Health Journalist, Trustee, www.aftercancers.com

Readers.

What other medical diagnoses do you have as well as Post Polio Syndrome?

We know quite a few who have Parkinsons [7 in or near to Lincoln and we know others around the world], some have MS, Cancer, Type 2 Diabetes, Sleep Apnoea, many Fibromyalgia but..

Fibromyalgia is common in a Post Polio Clinic by Trojan DA and Cashman NR - www.ncbi.nlm.nih.gov/pubmed/7763212

Polio Survivors do NOT all look... From Front page.

Gwen Hunt, BSc, RN... had paralytic polio as a child but there are no photographs of her with polio. She recovered and entered body building competitions as the picture on the left. Became a Head Nurse for a 50 bed ward then Post Polio set in and the need for a wheelchair. What did she do then, sewed a Harley Davison patch on the back of her Quickie Wheelchair, the biker bros loved it!!!

Charlie Minner, BA, BSN, MSe, CCRN (Med). Yes all three photos are Charlie, aged 10, 19 competing in gymnastics on the rings for his College Team and at 53. He built his own ultra-light aircraft, glider, his home in the mountains of Tucson and others. He was a master craftsman. Charlie loved to Fly Gliders, Watch Soaring and work at Soaring Contests. Micki Minner, a long standing researcher into PPS that I have known for many years is a committee member of Polio Epic Tucson, USA, www.polioepic.org

Please look back at the pictures on the front page. Would you have imagined that Gwen could recover from paralytic polio to enter body building contests, note she worked out poses so that any thinner limbs were not as noticeable. Even I was stunned to see Charlie's photograph on the rings and learn that he become part of his College Gymnastic Team? Did you know that

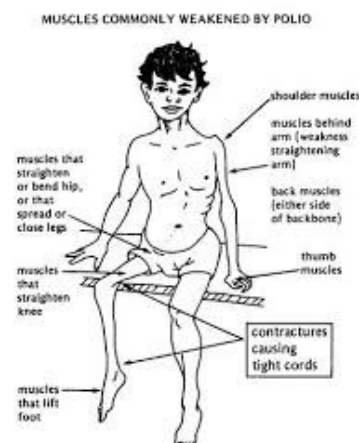


Lord Snowden, Jack Niklaus, Sir Arthur C Clarke, Mia Farrow and Alan Alda had polio?

Did you recover that well that at best recovery you had no obvious visible effect of having had polio in your earlier life?

What sort of photos/drawings do you think they show medical students about polio? Just a few examples below. When you have mentioned you had polio, have you been told that you must have had a very mild case? Have you been able to reply that you were paralysed and/or wore callipers for some years, and/or also spent some time in an iron lung?

Could this be a reason why some of us have such a hard time convincing health professionals we had paralytic polio and recovered well but now have new issues?



How do your photos change from with polio, at best recovery and now? Richard sitting in an electric wheelchair with a full leg brace and built up boots was thought to have been like that all his life till we showed the PPS Doctor a photo of him twenty years earlier with a strong muscular upper body working putting the engine of his truck back in. How about making up a tryptic of your polio life, or just two photos showing considerable ability and now with new functional decline and carry these with you. Helps health professionals 'see' more about the person in front of them.

With respect, even if you are told they know all about polio and PPS, you cannot rely on this. We have a great number of examples to show this is true. It cannot be easy meeting a Polio Survivor for the first time who has obviously got considerable knowledge and personal experience. Imagine yourself as the Health Professional meeting you for the first time. In this country I have only met one Health Professional so far who knows as much as I have learned in the last 24 years.

To make health professionals lives easier prepare some information on you, your polio and any other diagnoses that you have. Information about how you are now having to do actions of daily living in a different way than a few years ago. Ensure you have printed copies of the two best accepted by the NHS medical articles that we repeat each newsletter on page 18..

In our young lives and through our early to middle adult years we were very strong willed and determined to manage our lives to the full. Help was not needed, we could manage, If you tried telling us we could not do something we did everything possible to prove you wrong. There was no such word as CAN'T in our vocabulary.

We have achieved highly in our lives. Member Jann Hartman started a list of famous polio survivors many years ago but this is now no longer available. Wikipedia have a list under the following headings.. We know and expect there are many more to add, especially in Medicine. Acting [15], Business [11], Disability Rights Activists [6], Film television and radio [17], Literature [29], Music [26], Politics [31], Science and Medicine [15], Sports [20], Visual Arts [14] and Miscellaneous.[14] en.wikipedia.org/wiki/List_of_polio_survivors

You only have to look at this list and picture Jack Niklaus playing golf and what other sportsmen and women have achieved to realise how far people could recover and achieve from having had paralytic polio in their earlier lives.

As important are the Survivors who have used callipers, arm crutches, wheelchairs, iron lungs and respiratory machines yet still lived a full life. Richard Daggett from California [see photo back page] and Jim Costello from Post Polio Support Group, Ireland [who still sleeps in an iron lung a few nights a week] come to mind. Mums that brought up their children by finding other ways to manage tasks - one member told me she looked after her baby on a mattress on the floor to manage all necessary.

Problem is when you are diagnosed with PPS and you are asked to change the habits of a lifetime, pace and rest, use aids and assistive devices, and ask others for help you fight it year on year because that is the way you have managed up till now. Strong willed and determined polio survivors do not give up. However, those of us who have passed through this will all tell you that this is not giving up at all. In fact by taking these actions it allows you to do loads more albeit in bits [yes loads more] and less painful life doing what you enjoy. I have been asked many times should we have done less earlier? Probably, but would we? Probably not.

Even if you do not look as if you had polio and think therefore it must have been a mild case [my GP told me this because I had just told her I had been a policewoman and was stunned to find that I had been paralysed waist down] whatever damage the polio virus did to our nerves is important.

More important is charting the actions of daily living that you do each day and in separate columns writing how these actions have changed from your norm. [Remember your norm may not be the way others would do that action]. It is these changes that are the questions you can ask of health professionals. i.e. Two years ago I could walk up a flight of stairs just holding the bannister rail. Now I am having to pull myself up each step with the bannister rail and stop half way for a rest. Please can you tell me what has changed in my body causing me to do this?

How do you cope accepting the help you now need?

I am a member of the University of Lincoln, Health and Social Care Department Together Group. This is a group of service users, carers, and retired professionals who are available for Open days, interviews, planning new courses, taking part in lessons, being a book in the human library talking about your experiences, etc. Why did a group of us that had attended a Partners in Policymaking Course start doing this six years ago? Because we had given up some of our lives to attend NHS and Social Service meetings with little outcomes for us but they were able to 'tick their box they had consulted'. We believed we could see better outcomes telling students what it really is like to be on the receiving end of the services they will provide once trained. In fact we have had lots of affirmative feedback that it does.

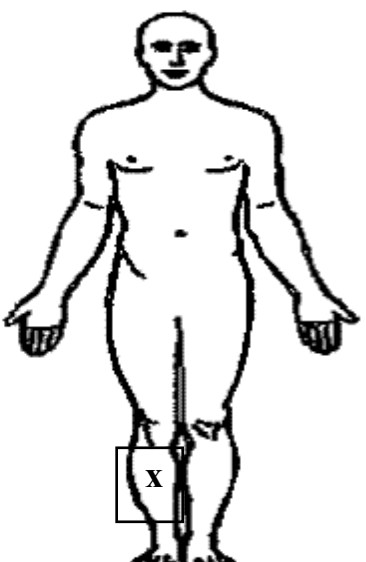
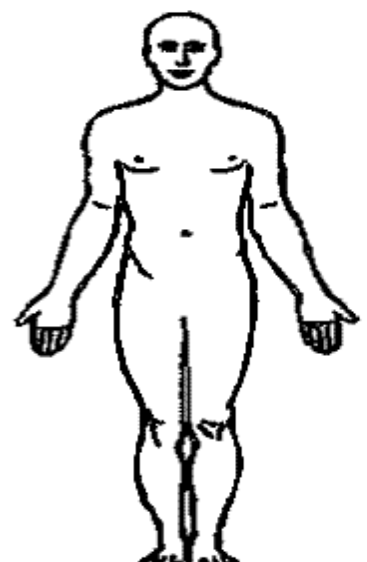
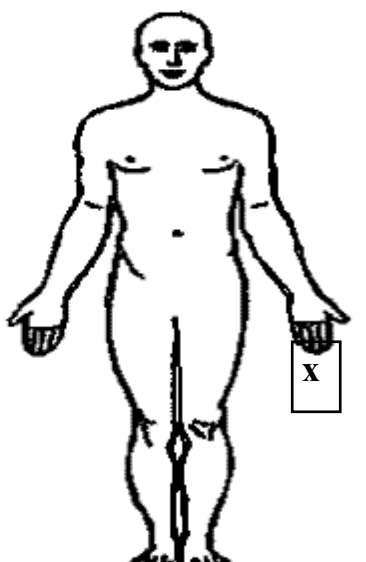
At one of the first year sessions I had a door opened for me and my scooter and I said 'Thankyou, I have got the door' but they continued to hold it open and stand in my way and I could not get past. I repeated it to no avail and struggled to pass them. This happened often and it really bugged me. During the lesson there was a chance for me to raise this as an example. After some discussion one student said 'We are trying to help you, ok I get the bit about not doing it the way you want or need it done, but if you repeat it in a stronger way, or complain, then I thought maybe rather than get it wrong I wont offer help anymore.' Further discussion took place as to how we might phrase what we said so that folks still offered. It was a very interesting discussion and it was something many of us said that this had not crossed our minds.

So how do you feel now that you need more help in the home and to get out socially and to meetings, medical appointments, etc.? I still want to be the person I was, especially in my own home, doing the things I used to do. We have had Direct Payments for some years now to employ staff to support us. I so remember the first time I saw Richards PA open the dryer and take out my undies and fold them onto a pile. I just had to get away from seeing this. I was so embarrassed. It took about a year, and getting to know him better and finding his sense of humour was similar to ours and often used to lighten the load. I told him how I had felt and he looked at me all seriously and said 'It is ok, I have a wife and a daughter and I know all about knickers [panties for our USA readers] and then he smiled and said 'hey but yours are way bigger than theirs' Oh how we all laughed.

Now some 9 years later we are needing more help and although it is 'our house' and 'my kitchen' and 'I cook this way' and 'hang the washing out like this' etc... we have to take a back seat and let those helping us do it their way. It makes me feel less of a person than I used to and want to be. I know I am getting older and I know that I have to pace and rest everything I do, and I have to listen to what I have been advising for years.

To manage our lives we have ten energy tokens a day and 70 per week and we have to work out how we can use them. Change it to money and how are you going to spend it. I cannot say do so many minutes of this and rest because it is individual for each and every one of us and for each different task and then we have to add what else we have wrong with us or have had to do the day before, etc. Take an average day and list the actions you have to do. Start with waking up and getting out of bed and washing dressing getting and eating breakfast, etc and list everything for the next 24 hours and do not forget turning over in bed.

I attended a Conference in Dublin some years back and was asked to join a panel for a question and answer session. My main focus is not on CAN we do x? But 'HOW do we do x and how has that changed? I asked the audience 'How do you roll over in bed?' Seeing the quizzical looks on their faces I explained 'I expect you will have to go back and try how you do it before you can answer this'. Many nodded agreement. With each slight deterioration we get a new NORM.

Polio at Age	Best Recovery	Date now
		
Operation. Bone cut and moved 20 degrees to straighten foot	Best Recovery at age 18 [1969] PPS symptoms age 43 [1994].	Operation. Fell cut nerve in finger. Finger removed speedier recovery.

The above is from My Polio Life - a self-assessment tool that we devised to help you collect information on your Polio Life for you to use. You can then pick appropriate information to make up a double line spacing sheet of notes, maybe couple of photos, for each appointment.

Remember this is for your use and we suggest that you keep it handy at home. You can take it with you to appointments but only refer to something in it if needed. Remember appointment times are short and large documents, medical articles, lots of notes cannot be read in the time. Why the chart of bodies gives a fast overview. Mine is 5 bodies and Richards 8 now.

The idea is to colour these in using lighter colours for mild weakness and go darker to paralysis and there are some examples on the back page to add pain, tremors, canes, crutches, little wheelchair picture, stair lift, etc.

Write in the space underneath anything that you think is important. Operation dates, other diagnoses. This is for your use so you can add anything that you think will help remind you of points to raise at other appointments.

Some have bought a hard file and broken My Polio Life down into sections and added any hospital letters or test results under Department headings, e.g. Physio, Respiratory, Orthotist, etc. Some just add copies of any of these that they think are important to this file.

Take it with you, or get someone to bring it into hospital if you are an in-patient so that you can have this by your bed to refer to if asked questions you cannot answer. From personal experience we know that any printouts you give them are just put in your file where it is never seen again, especially if yours is a few inches thick.

A couple of sheets have been included with your printed newsletter. Those emailed copies will have a pdf of the sheet attached to the email.

A laminated copy of your coloured in bodies and a couple of photos of doing something you achieved and how you are managing now can speak volumes in less than a minute.

Simon's Research Wanderings (but don't quote me!)

Guess what !

**CBT and Exercise therapy are not as effective
as claimed by many who help us polio survivors!**

Experiences and perspectives of patients with post-polio syndrome and therapists with exercise and cognitive behavioural therapy.

A study published in 2016 in the Journal BMC Neuroscience, compared the impact of cognitive behaviour therapy (CBT) and exercise therapy for patients with PPS. They found, perhaps not surprising to many of us, that the 'one size fits all' paradigm which has gradually replaced individual holistic care is so good for us. The results showed that interventions *'did NOT show a decrease in fatigue or improvement in secondary endpoints like Quality of Life and self-perceived activity limitations'*

The conclusion was 'Confirming the negative quantitative study outcome, the qualitative results did not demonstrate lasting effects on fatigue. Patients did, however, experience some benefits on self-esteem and acceptance of the disease. This study showed that it is of great importance to work with interventions that fit the patients' needs on a practical (fit into their daily routine) and psychological (fit their need for support) level.

It is interesting here to note that the measures that are collected by therapists on their interventions are perhaps showing positive result when using short term follow up and quantitative outcome measures, but the 'real lived experience of the patients' was different as any improvement was short lived and actually the quality of life measures didn't show much of an improvement. What there was, is probably what we all know, that being accepted and listened to and having some individualised focussed attention rather than ignored is what helped rather than anything actually done.

Bakker et al, BMC Neurol Feb 2016

Its not Just the UK

Polio and Post-Polio Syndrome,

viewed by patients and health professionals in primary care

Some research published in 2018 from researchers in Malaga Spain found that many people with PPS symptoms were using self-coping and managing with family and others help, but when seeking help from health care professionals:

"They presented compatible symptoms with post-polio syndrome, which remain unidentified due to the lack of knowledge of it among patients and health-care professionals. The health care provided was considered deficient due to several causes as for instance lack of involvement, communication problems.

The day-to-day polio experience is focused on personal overcoming with major roles played by family support, difficult relationships with the healthcare system and lack of knowledge of the post-polio syndrome."

So, nothing new there then!

Muñoz Cobos F Rev Esp. Salud Publica. 2018 Jun 25;92.

Watch out for Snakes!

Acute Flaccid paralysis in adults (AFP)

Interesting piece of research published in 2014 from India found that 133 consecutive cases of Acute Flaccid paralysis (AFP), so often mooted by many as being like polio may have several diverse origins. They write that AFP is:

A complex clinical syndrome with a broad array of potential etiologies that vary with age. We present our experience of acute onset lower motor neuron paralysis. The most common etiology was neuroparalytic snake envenomation (51.9%), followed by Guillain Barre syndrome (33.1%), constituting 85% of all patients. They found no cases of acute poliomyelitis in adults.

It is India remember! Ref: Kaushik R et al. J Emerg Trauma Shock. 2014 Jul;7(3):149-54

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

I don't think most kids today know what an apron is.

The principle use of Mom's or Grandma's apron was to protect the dress underneath because she only had a few.

It was also because it was easier to wash aprons than dresses and aprons used less material. But along with that, it served as a potholder for removing hot pans from the oven.

It was wonderful for drying children's tears, and on occasion was even used for cleaning out dirty ears.

From the chicken coop, the apron was used for carrying eggs, fussy chicks, and sometimes half-hatched eggs to be finished in the warming oven.

When company came, those aprons were ideal hiding places for shy kids..

And when the weather was cold, she wrapped it around her arms.

Those big old aprons wiped many a perspiring brow, bent over the hot wood stove.

Chips and kindling wood were brought into the kitchen in that apron.

From the garden, it carried all sorts of vegetables. After the peas had been shelled, it carried out the hulls.

In the fall, the apron was used to bring in apples that had fallen from the trees.

When unexpected company drove up the road, it was surprising how much furniture that old apron could dust in a matter of seconds.

When dinner was ready, she walked out onto the porch, waved her apron, and the men folk knew it was time to come in from the fields to dinner.

It will be a long time before someone invents something that will replace that 'old-time apron' that served so many purposes.

REMEMBER:

Mom's and Grandma's used to set hot baked apple pies on the window sill to cool. Her granddaughters set theirs on the window sill to thaw.

They would go crazy now trying to figure out how many germs were on that apron.

I don't think I ever caught anything from an apron - but love.

Sent in by member Janet Whitworth.

1. Johnny's mother had three children. The first child was named April. The second child was named May. What was the third child's name?
2. There is a clerk at the butcher shop, he is five feet ten inches tall and he wears size 13 sneakers. What does he weigh?
3. What word in the English Language... is always spelled incorrectly?
4. In California, you cannot take a picture of a man with a wooden leg. Why not?

What was Polio like for a 13 year old?

Richard Daggett writes....

I was born on June 14th 1940.

On July 17th 1953 I woke with a headache and stiff neck.
I was 13.

Later that day I was admitted to hospital.

In the afternoon they did a spinal tap, it was very painful.

That night my legs began to ache and shortly after
midnight I started to have trouble sitting up.

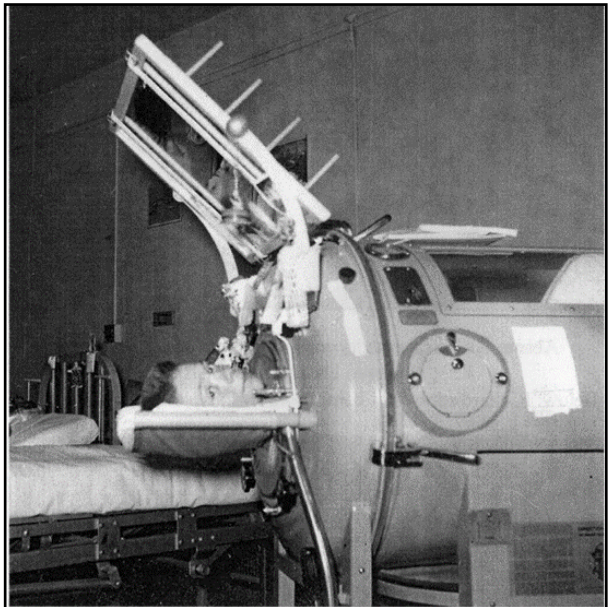
Then my arms would not co-operate.

I was given a tracheostomy under local anaesthetic with
the doctor giving a running commentary so everyone else
could understand what they were doing to me.

Everyone but me!

Then they put me in a 'Drinker Collins' iron lung.

I could not swallow so they inserted a tube through my
nose to feed me.....



Not just Polio. My Life Story

By Richard Lloyd Daggett

Forward by Jaquelin Perry MD

Available on Amazon in Hardback £16.35
and Paperback £9.95

Polio Survivors Association - [www.](http://www.polioassociation.org/Biographies.html) - Biographies - Richard Daggett

Richard Daggett is President of the Polio Survivors Association and is a lay member of the American Academy of Home Care Physicians. He is a certified speaker in the United Methodist Church and a journalist, mostly writing on the disabled condition. His articles have appeared in medical journals and medically related newsletters. Daggett caught polio in 1953 at the age of 13. He spent six months in an "iron lung" and almost three years in hospital.

Daggett was born in Los Angeles and has been a Downey resident since 1950. He studied psychology, geology, history and physics through the UCLA Extension Program. In 2010 Richard's autobiography "Not Just Polio: My Life Story" was published.

In 1974, Daggett and other severely disabled polio out-patients of Rancho Los Amigos Medical Center were discussing some of their common concerns. Among these were how to remain independent in their own homes, and how to obtain and maintain adaptive equipment necessary for their independence. This group of polio out patients decided to organise as the Polio Survivors Association and in 1975, formed a non-profit corporation to promote the well-being and improve the quality of life for severely disabled polio survivors. Mr. Daggett has led the Association since 1980.

Daggett has been honoured for his advocacy efforts by the California State Senate and the California State Assembly, as well as the County of Los Angeles and the City of Downey. He was the Los Angeles County Volunteer of the Year in 1989. When he accepted the Volunteer of the Year award he said, "As individuals, or even as a group, I know we cannot solve all of the world's problems. But, if I can improve the life of one person, then my life is enriched."

Written by Nicole Arevalo, for a school assigned, based on personal interviews.
www.polioassociation.org/Biographies.html

Hilary Boone met Richard Daggett and Dr. Jaquelin Perry in 2003 at Rancho Los Amigos, California, USA.

Two of the news items from ppn

11th April 2019.

Blood, Bone, and Marrow - A Biography of Harry Crews. By Ted Geltner; Forward by Michael Connelly.*A biography of the late Harry Crews, iconic American writer (and Polio Survivor) whom I have to admit I had not heard of until I read this absorbing story. **Highly recommended. ppn editor.*****The first biography of Harry Crews, writer of the "Dirty South" and wildman extraordinaire.**

In 2010, Ted Geltner drove to Gainesville, Florida, to pay a visit to Harry Crews and ask the legendary author if he would be willing to be the subject of a literary biography. His health rapidly deteriorating, Crews told Geltner he was on board and would even sit for interviews and tell his stories one last time. "Ask me anything you want, bud," Crews said. "But you'd better do it quick."

The result is *Blood, Bone, and Marrow*, the first full-length biography of one of the most unlikely figures in twentieth-century American literature, a writer who emerged from a dirt-poor South Georgia tenant farm and went on to create a singularly unique voice of fiction. With books such as *Scar Lover*, *Body*, and *Naked in Garden Hills*, Crews opened a new window into southern life, focusing his lens on the poor and disenfranchised, the people who skinned the hogs and tended the fields, the "grits," as Crews affectionately called his characters and himself. He lived by a code of his own design, flouting authority and baring his soul, and the stories of his whiskey-and-blood-soaked lifestyle created a myth to match any of his fictional creations. His outlaw life, his distinctive voice and the context in which he lived combine to form the elements of a singularly compelling narrative about an underappreciated literary treasure. [page 20]

2018 international meeting of the Global Virus Network | Antiviral Research.**Highlights.**

- * The GVN is an international research network comprised of 45 Centers of Excellence and 7 Affiliates in 29 countries.
- * The 2018 Global Virus Network (GVN) Meeting was held in Veyrier du Lac, France from November 28–30.
- * The theme was "Eradication and control of (re-) emerging viruses".
- * International collaboration is critical to developing new and effective viral vaccines and therapeutics.
- * The 2019 international GVN meeting will be held on June 9–12 in Barcelona, Spain.

Abstract.

The Global Virus Network (GVN) was established in 2011 to strengthen research and responses to emerging viral causes of human disease and to prepare against new viral pandemics. There are now 45 GVN Centers of Excellence and 7 Affiliate laboratories in 29 countries. The 10th International GVN meeting was held from November 28–30, 2018 in Veyrier du Lac, France and was co-hosted by the two GVN Centers of Excellence, the Mérieux Foundation and the University of Veterinary Medicine Hannover (TiHo). The theme of this 10th International GVN meeting was "Eradication and control of (re-) emerging viruses". This report highlights the recent accomplishments of GVN researchers in several important areas of medical virology, including strategies for the eradication of smallpox, measles, polio, SARS and vector-borne or zoonotic infections, emergence and intervention strategies for retroviruses and arboviruses, preparedness for outbreaks of Filo- and other hemophilic viruses, pathogenesis, impact and prevention of respiratory viruses, as well as, viruses affecting the central and peripheral nervous system. Also threats in crisis settings like refugee camps were presented.

Original Article. <https://www.sciencedirect.com/science/article/pii/S0166354219300385> [Pay to view]

POST POLIO SYNDROME EXISTS

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

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

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

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

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

POLIO PATIENTS AND SURGERY.

Information for health staff.

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

**[http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU_PDF/BROCHURER/
Polio_operation_ENG.pdf](http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU_PDF/BROCHURER/Polio_operation_ENG.pdf)**

Text copies of both have been sent to members and are available on our headed paper with permission

REMINDER FOR MEMBERS

**Have you changed your home, email address or phone number recently?
Did you let us know?**

Your Newsletter needs your stories, hints, tips and bits

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

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

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

Articles and items for Post Polio Matters

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

Deadline date for next issue is 4th June 2019

Editors Note:-

**Articles from Polio Survivors and Health Professionals
Welcome for future issues**

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

Chair - Simon Parritt - simon.parritt@poliosurvivorsnetwork.org.uk

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

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

Trustee - Verite Reily-Collins - verite.reiycollins@poliosurvivorsnetwork.org.uk

Trustee/s - Vacancies please apply for more information.

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Membership

Membership Fees

With grateful thanks to the generous legacy from Ms A Brown

Membership will now be FREE whilst our funds remain above £10,000.00

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

Overseas Members will get their newsletter by email

Use our new online membership service

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

Email - psnadmin@poliosurvivorsnetwork.org.uk

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

Donate by cheque or



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

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

Or specifically for the CONFERENCE AND MEETING FUND

To support attendance at National Meetings and PPS Conferences.

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

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

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

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

Thankyou.

giftaid it



Nils van Leerdam
CEO of Ambroise NL

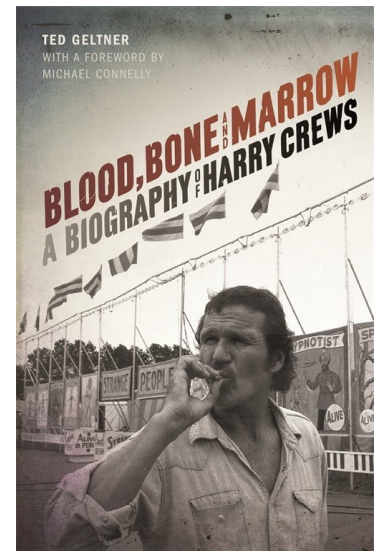
Holding Zsuzsi Snarey's
Utx swing calliper.

Read her story on page 6.



Available on Amazon £7.99 / Kindle £3.99

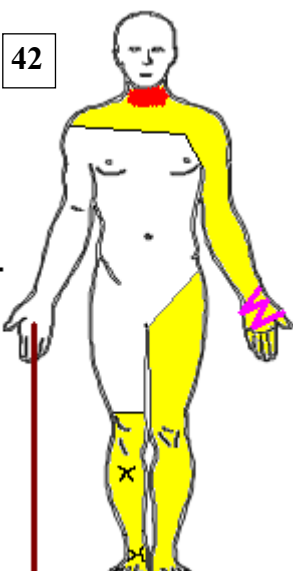
This is the story of two families,
one of them Catholic and the
other Jewish, joined by marriage
at a time when this was forbidden
by the authorities and the reason
why I came to England after having
had polio as a result of an
unsuccessful attempt to escape.



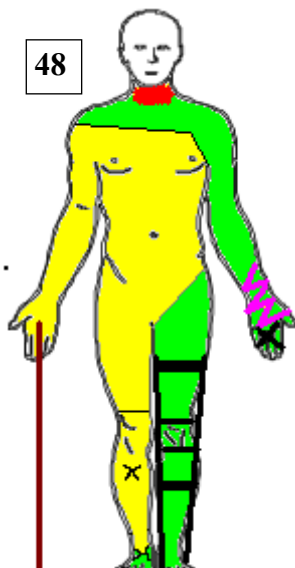
ppn item page 17

Blood, Bone
and Marrow,
A Biography of
Polio Survivor
Harry Crews

42



48



From Page 13

Looking at this is a quick way for health
professionals to see progression of issues.

You can have any number of bodies in your
chart. You could change some to photos.
These are a couple of examples of how you
might colour in your sheet.

The body on the left shows yellow mild
weakness, red is pain, pink zigzag is tremor,
brown cane, and x relates to the operation.

The body on the right has changed the
weakness to moderate and added a full leg
calliper and the x on the hand relates to an
operation as above.



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