

# POST POLIO MATTERS

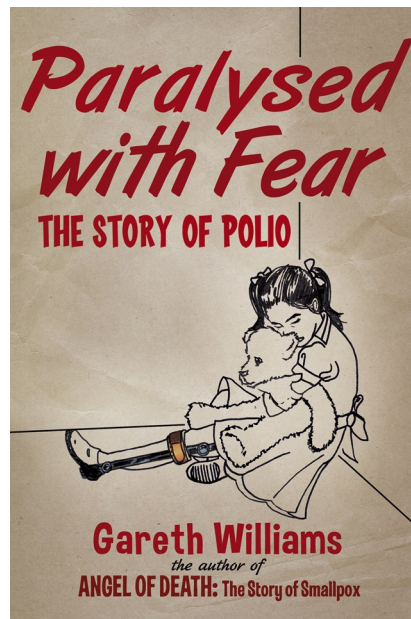
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[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

**MAY  
2013**  
Vol 7, Issue 12

**P.S.N.  
Annual  
General  
Meeting  
now  
September  
14th 2013  
in  
Lincoln**

**Post-Polio  
Health  
International  
PPS Conference  
31.5 to 3.6 2014  
St. Louis  
Missouri, USA  
Page 12**

**WE'RE  
STILL  
HERE!**  
October 6-12, 2013  
[www.post-polio.org](http://www.post-polio.org)



From the critically-acclaimed author of *Angel of Death* comes **Paralysed with Fear**, the story of polio a powerful and engaging narrative of mankind's battle against polio.

Excerpt from the *Lancet*, 25th May 2013  
Volume 381, Issue 9880, Pages 1805—1806

By Paul Offit

"Williams doesn't shy away from the science. He begins by detailing the discovery of poliovirus and its method of spread in a manner so dramatic that we can't wait to turn the page, even though we already know the ending"

<http://preview.tinyurl.com/oyzeqpk>

Polio, with its haunting images of disabled children and the iron lung, was one of the iconic diseases of the 20<sup>th</sup> century. In the 1950s, only the atomic bomb frightened Americans more than this debilitating scourge which could break into any home and paralyse or kill a healthy child. Now, vaccination has pushed polio to the brink of extinction – but its complete eradication may still elude us.

Mankind's struggle to defeat polio was one of the grand challenges of modern medicine. It was also a battleground between good and bad science, powerful personalities and warring ideologies. The result is a compelling story, rich in twists and paradoxes.

Gareth Williams takes an original and uncompromising view of our journey with polio, from the first descriptions of 'morning paralysis' to the no-holds barred race to develop a vaccine and the front line of today's eradication campaign. *Paralysed with Fear* is the first comprehensive history of polio for over 40 years. It is an enthralling story which will grip the reader from beginning to end.

Gareth Williams is Professor of Medicine and former Dean of Faculty at the University of Bristol, UK. He has written or co-authored over 20 books, including the *Textbook of Diabetes* (BMA Book of the Year, 1997) and has contributed to more than 30 others, including the *Oxford Textbook of Medicine*. Inspired by the life of Edward Jenner, Gareth wrote *Angel of Death: The Story of Smallpox*, which was shortlisted for the Wellcome Trust Book Prize in 2010.

Palgrave Macmillan book publisher are offering Polio Survivors Network members a special discount of 20% off ***Paralysed with Fear*** [hardback published 27th June 2013, £20.00 down to £16.00] when you order the book direct from [www.palgrave.com](http://www.palgrave.com) and enter promotional code **WORLDPALGRAVE20**

**MOTABILTY  
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**Welcome to New Members Philip Walker & Peter Thwaites**

**Thank you to all members who have recently renewed and  
to all those who have made donations towards our work.**

[We apologise but names and total amount of donations  
are unavailable due to a computer glitch with a file that  
could not be sorted before the deadline to take to printers.

The information will be included in the next issue]

### **Val Scriveners Card Sales**

Help our funds by ordering - info on back page.

We have no paid employees.

**Donations & offers of time, no matter how small,  
towards our work are always welcome.**

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

Simon Parritt has kindly agreed to take the role of our Chair and Dot Ives has taken over the role of minute taking. Barbara Taverner offered to become a Trustee then had to undergo a major operation which takes a few months to recover from. As soon as she is back on track and able to join us she will be in touch. On behalf of members I wish her a speedy recovery.

The date of the AGM [Annual General Meeting] has been changed to Saturday 14th September at a venue in Lincoln. Actual times will be fixed when we hear back from you as to how many members think they would be able to attend and how far they have to travel. Following the AGM and a buffet lunch we will spend the next two hours providing information - from up to two speakers - with question and answer time and reporting in the Nov. newsletter. The theme will be ways to help manage a PPS Life. As soon as we know how many members will need accommodation we will arrange this and as in previous years we will join together Friday and Saturday evenings. [Please complete the sheet enclosed with this Newsletter and return it to us - address label provided - by June 20th 2013. We are not asking you to make a firm commitment to attend, but the information will help us plan the day more easily. Thank you]

**Front cover.** We were contacted by Publishers Palgrave regarding a new book from Gareth Williams, *Paralysed with Fear*, the story of Polio. We have an advanced copy and finding it fascinating reading. Note the quote from today's *Lancet*. We have also been sent a pre copy of another book on Polio due to be published in October, more information on this in the next newsletter. **More on books.** One of the PPS groups on Facebook referenced two new books "Limping through Life: A Farm Boy's Polio Memoir by Jerry Apps" which I have just finished reading on my iPad. A great read. I have just downloaded Kindle version - £3.35 from Amazon. "Too Early for Flowers:- The story of a Polio Mother" by Kurt Sipolski. I remember almost nothing about my polio, age 5, and recovery years. When I first raised the issue of my PPS with my parents they were horrified and did not want to discuss it. They lived in North Devon on a hillside. Off to the bakers I stopped to get my scooter out of the car and my mother said "surely you don't need that thing to get to the shop?" I said, "No, but I will need it to get back up the hill" When I saw a photo of parents carrying a limp child into hospital, I realised that I was opening their closed box of memories. PPS is tough for many people not just us.

**Back Cover.** Dr. Jacquelin Perry. The Grande Dame of Orthopaedics and an expert on Polio and Post Polio Syndrome passed away on March 11th this year. At 94 and suffering from Parkinson's she had retired but still saw 'my polio patients' at the Friday Clinic. Read Richard Daggett's personal tribute starting on page 6. I met her on four occasions at three PPS Conferences and when Richard and I stayed at Rancho Los Amigos in 2003. It was good to thank her in person for the help she gave us prior to Richards Rotator Cuff Surgery. See Page 10 and 11 for information on her medical articles in the Lincolnshire Post-Polio Library and how we have benefited from her knowledge.

Have you noticed how many of our newsletter articles over the years are by Members and Polio Survivors and from contacts we have made with other PPS Groups. This issue, Simon Parritt a Chartered Psychologist and PSN's new Chair. [pages 4, 5] Life Members Professor of Biology Eddie Bollenbach. M.A., [pages 6,7] and Jann Hartman [page 13] Jann has presented at one of our AGM's and at many other PPS Conferences. Dot Ives, a new Trustee and Early Support Inclusion Co-ordinator, introduces herself [page 4]. Past issues have included articles from many other members including Dr. Marcia Falconer, Ph.D., a Virologist, Dr. Ruth Bridgens a Medical Sociologist, Zsuzsanna Snarey, BSc MSSCh MBChA, a Surgical Chiropodist. How many other members have qualifications, hobbies, or would just like to share the story of their polio or anything else of interest to members? Deadline next issues is August 1st.

### Polio Survivors Network - Meetings

If you have any matters you would like us to discuss at our meetings please get in touch via  
hilary.boone@poliosurvivorsnetwork.org.uk  
or Tel: 01522 888601 or write to us at Polio Survivors Network PO Box 954, Lincoln LN5 5ER

## **MESSAGE from Polio Survivors Network's New Chair**

### **Simon Parritt, on behalf of the Trustees.**

The past year has been challenging on a number of fronts and PSN has been reviewing its role and future direction. As a members' organization it continues to provide advice and information where possible to its members and others who have had or think they may have had polio and are experiencing problems now. This has been through the newsletter and also personal responses to enquiries. It is regrettably still true that, although there is a body of knowledge about post polio, it is often not disseminated amongst to professionals who we come into contact with.

Our membership has remained more or less static over the past year and the kinds of issues that have arisen have been the basis of a proposed project for the coming year. The project would attempt to address the paucity of knowledge around polio assessment and rehabilitation amongst health professional through short video teaching modules on specific areas that are the most often, not well understood. We intend to work with other professionals to build up an expert patient led teaching and information resource that will begin to redress the lack of knowledge around such issues as manual muscle testing and respiratory issues.

We hope that the past year's reflection and examination of our role and function, will form the basis for a focused project that will directly impact on health professionals knowledge and understanding of polio and will therefore benefit our members and other polio survivors.

Simon Parritt, [simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)

[See article on opposite page]

### **Meet Trustee Dorothy [Dot] Ives.**

I was born prematurely in 1955 in Salford, Lancashire and weighed the grand total of 2lb 1oz. In 1956, I was rushed to hospital with suspected meningitis, as this did not materialise I was sent home as a 'fussy baby'. When I didn't learn to walk or fell over when I attempted to at around two years of age my family discovered that I had one leg shorter than the other. Back to the hospital who belatedly diagnosed poliomyelitis. Fast forward to 8 years old where I had 'tendon replacement' surgery. This was successful and I went on to lead a 'normal' life, no more limping, wearing built up shoes and having scabby knees from falling over!

As far as I was concerned I was cured and forgot all about polio and my 'gammy leg', mind you, I was still prone to falling over!! During my late twenties I slipped a disc in my back as a result of lugging playgroup equipment in and out of a church hall cupboard. Many years of back pain, sciatica, bursitis, tendonitis ensued with increasing fatigue and failing muscle strength. This was put down to my age! I was only in my mid 40's. From being able to swim at least 30 lengths I can now barely manage a length!

I had never heard of post polio syndrome until I attended a muscular skeletal clinic in 2006 with my back problems and the Consultant muttered about my scar on my right ankle and how I had classic 'polio feet'!!!!!! The rest as they say is history!!

In spite of smashing my 'good' left ankle in 2009 along with getting breast cancer I still manage to work full time and hobble along with my two bulging discs.... Sciatica...etc etc. I guess I am still one of the 'in denials' really when it comes to PPS and stubbornly carry on. I recently became a trustee of PSN and am still very much a novice! I know though, that when I was diagnosed with PPS I could not have managed without the valuable information from PSN and the Lincolnshire Post-Polio Library.

Dot Ives, [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)

## **IN BETWEEN TWO WORLDS**

As a psychologist and a polio survivor I have been on both sides of the divide. Working in hospitals and with GPs and social services, as a psychologist, I know what a delight it is achieving the best and how frustrating not to be able to offer the best for my patients. I know that some patients get the best, whilst others can be victims of their condition, circumstance or lack of knowledge of how to access what they need.

As a patient myself for nearly 60 years, I know what a difference it makes to, not only to my physical health but my sense of well being and quality of life when I am lucky enough to be in a collaborative, honest, and open relationship with my doctors and healthcare professionals. In contrast to the situation I face when needing to accept help and treatment from those with limited experience of polio and very poor interpersonal skills. I wish the later were the exception.

To be fair, I am only too aware that health professionals have limited time and constrained knowledge to offer. I understand it but also feel frustrated and scared by it. Being at the mercy of a service, a physician or a team who you sense are going through a protocol but not listening to me as a person doesn't help my anxiety. Failing to explain the whole picture and worst of all an inability to admit their level of 'not knowing' further frustrates and annoys me. I find this a very uncomfortable place to be. Does being a psychologist help? Maybe but sometimes I wonder, as I sit in the waiting room or come away from hospital with my feelings of frustration and anxiety raised.

I wanted to say something personal about how it feels to experience being a psychologist with declining physical abilities and also cope with input and advice from people who in other circumstances would be my friends and colleagues. Do I raise my hand and say, "hey, hold on its me, I'm not just a patient!" And then I think what I am saying "NOT JUST A PATIENT".

I find it hard to manage these feelings whilst also being 'The Expert' on myself, so important in today's healthcare environment. I am only too aware how to approach medics and assessments with the confidence of self knowledge whilst also being open minded and ready to hear and accept the professionals' opinions about my health and prognosis. But losing abilities so hard fought to regain years ago involves sadness, disappointment, feeling of failure and often anger. I might say as a psychologist that the cognitive and feeling part of me, make uneasy bedfellows in the medical setting.

Emotions do not comfortably fit within the medical approach to disability. I know this from working as a psychologist in hospitals. Questioning medical logic, diagnosis and expressing physical concerns are seen as somehow less valid when delivered from an anxious or emotional patient than when from a calm and compliant one. Am I paranoid that showing, let alone discussing my anxiety in the consulting room, places me in a more vulnerable position?

And finally, if I do chose and am able to cover up my emotional side, how much do I exercise my medical and polio knowledge? How many health professionals are able, or want to, work collaboratively with a patient whose knowledge may be quite extensive, without feeling at best irritated or time pressured or at worst threatened and de-skilled ?

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

Chartered Psychologist

HPC Registered Counselling Psychologist

[www.sp-psychology.com](http://www.sp-psychology.com)

What do you call a dinosaur with an extensive vocabulary. A Thesaurus.

Broken Pencils are pointless.

What does a clock do when its hungry. It goes back four seconds.

When you get a bladder infection. Urine trouble.

I stayed up all night to see where the sun went. Then it dawned on me.

## **POLIO, CHOLESTEROL AND CARDIOVASCULAR RISK**

### **By Life Member Professor Eddie Bollenbach, Connecticut, USA.**

There are new and potentially valuable developments in the area of prevention of cardiovascular disease. This has special importance to polio survivors because of our additional risk factors due to our age, sedentary lifestyle, and in many, obesity along with its consequent problems. Despite our risk many of us have a high cholesterol number and are intolerant of statin drugs due to their effect on muscles, particularly overused muscles.

We all know that high cholesterol, particularly the fraction of low density lipoprotein (LDL) in cholesterol, is a risk factor for cardiovascular disease. We also know that LDL alone, particularly if it is not inordinately high, is not a foolproof way to predict who will develop coronary artery disease or stroke. It is also true that some people with a normal or low cholesterol can have a heart attack and have significant cholesterol clogging their arteries despite low cholesterol numbers. So high numbers are associated with more heart disease but there must be other factors at work.

The more risk we have the more valuable lowering cholesterol is to us. For example, for a person with no risk factors the number of people needed to treat to save one individual with statins is 50 people. But for someone with a 50% chance of developing a heart attack in the next few years the number needed to treat to save one individual is only 4. So, given the difficulty some have with statins and their value to an at risk population we should all be aware of new research which may help us prevent cardiovascular disease.

### **RED MEAT AND HEART DISEASE**

A new study at the prestigious Cleveland Clinic this April may shed some light on an additional factor that, according to researchers, is predictive of the development of cardiovascular disease with 10 times more accuracy than cholesterol numbers. But no sooner was their work published this April than some inconsistencies threw doubt on their findings.

Here is what happened. Mice fed red meat had more atherosclerosis than they normally do. Also, retrospectively, humans who eat a lot of red meat are more prone to heart disease. The researchers found that a unique chemical shows up in the blood of both mice and humans after consuming red meat. The chemical is TMAO, short for Trimethylamine oxide. The amount of this chemical in the blood is 10 times more predictive of heart disease than cholesterol alone. Mice fed red meat develop atherosclerosis and have high TMAO numbers and when a human eats a good steak TMAO quickly shows up in the blood. There are other absorbing aspects to this story. The researchers found that in both mice and humans TMAO is not produced in vegetarians after a meal, even a meal of red steak. They also found that TMAO is produced by bacteria in the gut that chemically digests red meat. When they gave the mice, or humans, antibiotics to remove much of the gut bacteria subjects did not respond to red meat by producing TMAO. Also, as mentioned above, vegetarians who were given red meat did not produce TMAO. The researchers surmised that the type of bacteria in the gut of red meat eaters is different than the bacteria in the gut of vegetarians, and in vegetarians the bacteria that work on digestion are different than the bacteria at work in the gut of meat eaters. The bacterial flora in meat eaters produces TMAO but the bacterial flora in vegans does not, even when they are fed red meat. Red meat here is beef, pork lamb, mutton, duck, and venison. TMAO is much lower in the blood when fish or chicken is eaten. All of this points to better prediction of risk for heart disease. The researchers pointed out that there is currently no clinical test for the levels of TMAO in the blood but, if their study results are confirmed, there soon will be.

### **THE CARNITINE CONNECTION?**

Now comes the mysterious part of this riveting saga. Researchers mapped the chemical steps required to produce the TMAO by bacteria in humans and mice. A substance in meat called carnitine (carn for carnivore referring to red meat) was tagged as the culprit. So, a person who

eats red meat and has bacteria in the gut that digests red meat digests more carnitine than those who don't eat red meat. Vegetarians have much lower carnitine intake as do mice fed a vegetable diet. The researchers expressed concern about people who take carnitine supplements or drink energy drinks which have carnitine in them. But, mysteriously other unrelated studies have shown that carnitine is actually beneficial to the heart, it sometimes is even helpful in maintaining a proper rhythm after an acute myocardial event. And, strangely, despite the above study, people who take carnitine supplements generally benefit from those supplements as far as heart disease is concerned. So which is it? Is carnitine good for the heart or not? A new study in the April 25 New England Journal of Medicine showed that metabolism of Lecithin is the culprit in the production of TMAO but more studies are needed.

These kinds of mysteries are always interesting. Obviously carnitine itself appears not to be involved in the production of deleterious TMAO. Or, something else in red meat (lecithin), together with carnitine, may result in TMAO production. Or, the researchers interpreted their data incorrectly and must go back to the drawing board. It will be interesting to follow this development to see where it goes.

There are two other chemicals associated with TMAO in the blood of meat eaters and are thought to be associated with atherosclerosis: betaine and choline. The scientists also warned against eating lecithin, a component of meat and eggs because it too can lead to the production of TMAO indirectly.

So, although exciting, the research has to be reproduced in other labs. Then we may know that red meat should only be eaten in moderation and if we are careful of our intake we may protect ourselves better knowing this and also keeping a low cholesterol number. Time will tell.

## **NEW POTENTIAL CHOLESTEROL DRUGS**

There is also new work being done on lowering cholesterol with two drugs other than statins. These drugs are in development and are now being used in clinical trials. They inhibit the expression of a gene for making LDL cholesterol. Statins have an adverse effect of causing muscle soreness and muscle disease in some people. It remains to be seen if this new approach will also result in muscle problems. The introduction of these new interventions may allow people to get to lower cholesterol numbers to reach goals without the use of statins.

The second approach is by interfering with cholesterol receptors in the body. By altering receptors on various surfaces in the body researchers found that more cholesterol can be removed from the blood. Currently the goal of individuals who are advised to lower cholesterol is to get below 100 for LDL. With these two new approaches it may be routine to lower LDL even more. In indigenous people, like aborigines, LDL cholesterol is around 38 and they do not get heart disease. So it may be possible to lower cholesterol with or without statins to much lower levels. Since competitive athletes and polio survivors develop muscle problems with statins more often than those who do not use their muscles as intensely, these novel ways of lowering LDL may prove invaluable. So some questions remain but the outlook for risk reduction is more promising than it was even a couple of years ago.

**Ingestion of red meat may be more important in heart disease than cholesterol itself. And, there are two new ways to lower cholesterol without statins. Stay tuned, we will soon see more on all of these issues.**

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# Jacquelin Perry, MD

May 31, 1918 - March 11, 2013

Physician – Mentor – Advocate – Friend

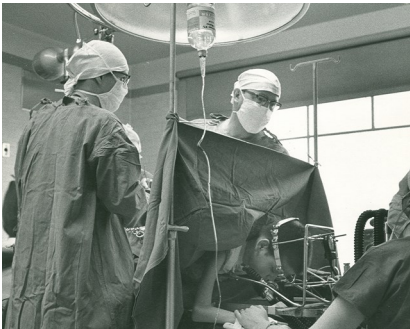
A personal tribute by Richard Lloyd Daggett

I join with others of the polio community in mourning the loss of an irreplaceable treasure, Dr. Jacquelin Perry, who died at her home in Downey, California on Monday, March 11, 2013. She had no immediate family, so I believe I may have known her longer than anyone. I'd like to tell you a little about her life, and why she had such an impact on polio survivors.

Dr. Perry joined the Army in World War II and trained to be a physical therapist. She later said, "When I started out, I had to convince the Army that I was completely unable to write, because if they thought I could write they would have made me a secretary." She said she enjoyed being a therapist, but her real desire was to become a doctor.

After the Army, she used the G.I. Bill to enter medical school, completing a residency in orthopedic surgery. Dr. Perry wrote the Foreword to my autobiography, and in it she wrote, "*Dr. Affeldt, as director of the (pulmonary) unit (at Rancho Los Amigos), also had concern for loss of limb and spine function and, especially, the patient's inability to sit erect. He recruited an orthopedic surgeon and former classmate to assume the task of finding a solution. Dr. Vernon Nickel agreed to come to Rancho but, because of his busy private practice, he would need help to accomplish this goal. His brother, Eldon Nickel, also a physician, recommended one of his classmates who was just finishing a residency in orthopedic surgery and was not inclined to open a private practice. I was that person. I was pleased to join the orthopedic staff at Rancho in July 1955, and my involvement continues.*"

I was a fifteen year old patient at Rancho when she joined the staff, and I can tell you that she scared the bejeebers out of me. It was obvious that she knew her craft, and that her goal was the improvement of her patients, but she was completely focused on the task at hand. I was apprehensive around all orthopedic surgeons, but Dr. Perry was at the top of my "avoid at all costs" list. When she added instructor to her many talents, Dr. Perry continued to be an intimidating presence. Many of her former students, including doctors, therapists, and allied health professionals, have remarked on her insistence for perfection.



In November 1955, Dr. Perry and Dr. Vernon Nickel operated on my spine, fusing most of my vertebrae. This was before these two doctors perfected the "halo" apparatus they designed for spinal fusions on polio patients, and now used on many other patients. Their halo device allowed surgeons to stabilize the spine of the patient and provide for some correction of a curved spine. The photograph shows Dr. Perry, left, and Dr. Nickel, right, operating on the spine of a young polio patient wearing a halo device.

Without the halo they could not correct my curvature, but they stabilized my spine sufficiently for me to walk unaided. I described the surgery in my autobiography: "*As I was wheeled into surgery I saw Dr. Nickel and Dr. Perry. I vaguely remember someone feeling my arm and asking for a size 18 needle. In my sedated state it sounded to me like he asked for a needle 18 inches long. I thought, 'Where could they put a needle 18 inches long in my body that wouldn't stick out the other side?' If I had been able, I would have run out of the operating room so fast that nobody could catch me.*"

When Dr. Perry read this, she smiled and told me, "Richard, if you had gotten up from that operating table and started running, I would have run out of the room with you."

During the 1960s and 1970s, Dr. Perry would occasionally ask me to be a "model" for various classes she was teaching. She would use me to demonstrate the benefits of a particular



treatment. I think she picked me because I lived close to Rancho, and I was so thin that my bones, and what few muscles I had, were clearly visible.

Dr. Perry was dedicated to her patients. We polio patients who were fortunate to have her treat us would sometimes remark, "Once you are Dr. Perry's patient, you are always her patient." She remembered all of us, and she remembered every person she operated on.

After the polio vaccines reduced the number of new polio cases, Dr. Perry used the skills she mastered treating us to treat other devastating injuries and illnesses. She studied the mechanism of human movement and wrote several books and articles on the subject. She authored the classic textbook on gait analysis. If you needed to read one book on this subject, it would be her book. She is fondly known among her peers as the Grande Dame of Orthopedics. Dr. Perry's curriculum vitae (list of professional degrees, honors, and accomplishments), is 72 pages long. She was one of the first medical professionals to recognize the late effects of polio and publish articles in medical journals.

"We didn't anticipate anything like this," she said in an interview. "The people who tried hardest to be normal, and pushed hardest, have been hit more with post-polio."

Rancho Los Amigos continued to evaluate post-polio patients in the outpatient clinics, and Dr. Perry was a constant presence. One colleague was quoted, "She would arrange her very busy travel schedule so that she would miss as few polio clinic appointments as possible. She would have the taxicab from the airport drop her off right in front of the polio clinic so that she could see the patients who were lined up and waiting to see her."

In 1996, the *Jacquelin Perry Neuro-Trauma Institute and Rehabilitation Center* was opened at Rancho. This impressive three-story, state of the art facility is Rancho's primary inpatient care and treatment unit. At the dedication Dr. Perry said, "It amazes me that I should be honored for doing the very things I enjoy."

As Dr. Perry aged, and Parkinson's disease began to take its toll, she cut back on her activities. But she still saw "my polio patients" in the Friday polio clinic, and she spoke to the Rancho Los Amigos Post-Polio Support Group a number of times. Her presentations were always helpful. Dr. Perry's *General Information Letter for Polio Survivors* is still one of the best overviews of post-polio.

Also, as she became semi-retired, I perceived a more open and mellow person. She stood by my side at her 80<sup>th</sup> birthday celebration, and I invited her to lunch a number of times. She graciously accepted my offers.

In 1996, I was able to arrange a one hour television special about Rancho for Huell Howser's "California's Gold" program. Dr. Perry and Hazel Adkins, a retired physical therapist, agreed to provide the onscreen medical perspective of the polio years at Rancho. This was a very special experience for me.

Many of her friends and colleagues addressed Dr. Perry simply as "Jackie."

I just wouldn't be comfortable calling her anything other than Dr. Perry. She was my Physician, Mentor, Advocate, and Friend.

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### **Excerpt from the Southern California "PPS Manager" Newsletter Summer 2013.**

Editor Rick Van Der Linden writes... "When I presented Dr. Perry with the Charles D. Siegal award in 2010 her alertness was obvious. After I presented her with the award she lectured me from the podium, in front of 300 plus folks, about how I should not be "over doing" since she had diagnosed me with PPS in 1997. A true Polio and Post Polio Syndrome Pioneer, she never had any doubts about whether PPS was "real."

## Medical articles by Dr. Jacquelin Perry in the Lincolnshire Post-Polio Library.



### Title: **Gait Analysis Techniques**

[www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/perry/gat.html](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/perry/gat.html) or  
<http://preview.tinyurl.com/ptyavt3>

### Title: **Findings in Post-Poliomyelitis Syndrome.**

[www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/perry/findingsinpps.html](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/perry/findingsinpps.html) or  
<http://preview.tinyurl.com/ovmpcth>

### Title: **The Postpolio Syndrome - An Overuse Phenomenon**

[www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/perry/thepostpoliosyndrome.html](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/perry/thepostpoliosyndrome.html) or  
<http://preview.tinyurl.com/qgpfjyq>

### Title: **Postpoliomyelitis Syndrome: Assessment of Behavioral Features**

[www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/perry/behavioral.html](http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/perry/behavioral.html) or  
<http://preview.tinyurl.com/okeks4z>

**Editors Note:-** I first met Dr. Perry, with Lynn Singleton, at the Irish Post Polio Support Groups Conference in March 1999.

I showed her two medical reports on me the first from a neurologist stating 'on neurological examination of the legs the left hip knee and ankle are normal' and the second from a physiotherapist 'Quads Muscle Grade 5, Normal' and explained that my left leg and particularly my quads had always been weak since polio. It took less than a minute, in the bar!, to examine my left leg and say 'Your quads are a 3 at best a 3+ but I would need to examine you properly to state which.' **{\*\*see below}**



Getting confirmation from one of the most highly respected PPS specialists that the medical examinations of me had not correctly graded my muscles was such a relief. I was not making it up!

In 2000 Richard was scheduled for Rotator Cuff Surgery and where else could I seek the best advice but to contact Dr. Perry through Rancho Los Amigos PPS Support Group. It was not long before I received a reply.

Dr. Perry advised that we needed to see the Post Operative Physical Therapist pre operation so that she could see how Richard moved about, and in particular used his arms, now. Next she recommended that we should isolate that arm in a sling and work out and practice how he was going to achieve all the basic actions of daily living needed post op with just one arm! It took some working out but the advice was invaluable... post operation there is pain and to have to work out how then would have been far far harder.

### **SINGLE ACTION MANUAL MUSCLE TESTING can over grade your muscles.**

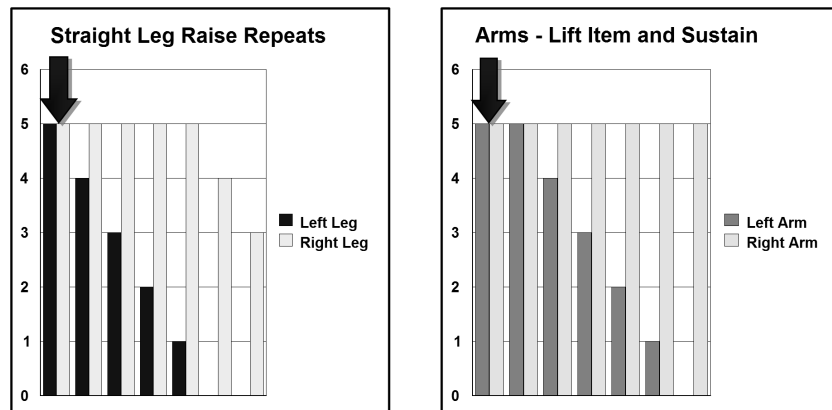
It was not long after talking to Dr. Perry that a light went off in my brain. 30 years earlier the doctor that examined me for my medical in 1969 for the police had passed me fit when I could not run or rise from a squat. I was stunned because I thought I would fail the medical, I never queried how this had happened.

But now another medical professional had done the same thing and I knew that no health professional would state anything he did not believe to be true. I applied for my medical records and found many more instances. I was being told there was nothing wrong with me because the single action test was not picking up the weakness reported. This is why we suggest that you are more specific and give an example of an action that you are now having to do in a different way that you believe is because of new weakness in some of your muscles.

Manual Muscle Testing was developed by physical therapists, Florence and Henry Kendall (Kendall & Kendall, 1949), to evaluate muscle functions for diagnostic, treatment, and insurance purposes. It is a method used worldwide. I did some self test repeated actions and demonstrated to myself that whilst I could do it the first time I could see deterioration on later repeats, time of

sustaining an action. I did some more research looking for medical articles and asked two eminent PPS doctors for comment. I put this information into my PowerPoint slides.

**My self tests in 1999 - Lying down and lifting legs into the air  
Seated and picking up a jug of water from the middle of a table.**



Manual Muscle Testing done a single time did NOT pick up my reported weakness

### CONFIRMING STATEMENTS by email and on Medical Articles.

**Lauro S. Halstead MD - May 2002** - Director of Post-Polio Program. National Rehabilitation Hospital, Washington DC, USA - Replied ' If done only a single time, it can give an erroneous idea of the true muscle strength and endurance'.

**Fred Maynard, M.D. - May 2002** - Marquette, Michigan, USA - President Board of Directors, Post Polio Health International - Replied "You have done a brilliant job of describing a real problem for polio survivors and professionals that is, the limitations of the Manual Muscle Testing

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

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

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

### Polio Viruses affected the whole body to varying degrees.

4 case histories were reported in 1875 by Carriere, Raymond & Cornil and Lepine. 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 physically demanding jobs and performed repetitive activities.

Prof WJW Sharrard in the 1950's found on autopsy that up to 44% nerve damage was seen in muscles where **NO** physical weakness had been found on physical examination at the time of Polio.

### HEALTH PROFESSIONALS

Please ask us HOW not CAN we do an action when you assess us so we can tell it like it really is.

**POLIO SURVIVORS PLEASE SEE OVERLEAF**

## POINTS TO PONDER

From our research over 18 years we have learned that the amount of information on polio, its effect of our lives and now post polio syndrome provided by Colleges of Medicine has reduced over the decades as the numbers of people catching polio reduced. Responses to our 'How much do you know about polio?' were from 'its not been mentioned through 'a half hour lecture with leprosy.' The best example is the registrar that contacted us for help after three years of seeing many of his hospital colleagues without results broke into the conversation to say 'but I only had it in one leg'.

Do you tell EVERY health professional [including alternative therapists, dentists and pharmacists] that you had Poliomyelitis [other terms are bulbar or spinal or bulbar/spinal polio, infantile paralysis, polio encephalomyelitis] in your earlier life and that you are diagnosed with or might have the Late Effects of Polio or new issues most commonly termed Post-Polio Syndrome? Any of this could impact on the way you:-

- a. Perform actions of daily living now compared to your best recovery level, that you
  - i. Have, or could have new weakness in muscles known to have been affected
  - ii. Now have or could have increased weakness in areas of my body not thought to have been previously affected

That this includes how you move muscles and joints, singly and as patterns of movement and could also involve how you swallow, breathe and/or sleep.

- b. May react to some medications (including anaesthetics) in a different way especially those with muscle relaxant or sedative properties. [Polio survivors have recorded a huge variety of issues and whilst you may not have or get the same response discussing this further can put your mind at rest]
- c. Found and/or still find it hard to acknowledge the changes that are happening to yourself, to the health professional, but also to your family, friends and work colleagues.
- d. Find any suggestion of returning to or using equipment for the first time, asking for extra help, applying for benefits/increased benefits, the total opposite of how you have managed your life during recovery and stable period of function and it is extremely difficult to accept that you have reached this stage, let alone start what the health professional is recommending.
- e. Try to ignore it but are concerned about what the future holds not only for yourself but for your family and you find it hard to broach the subject with them.
- f. You now realise that your current level of ability has reduced to such that you now need some support and should consider applying to Social Services for an assessment of these needs. [We know this is not an easy step to take because it seems like a downward step but our later response to this, using aids and asking for help etc., is usually "I now have a better quality of life and wish I had done this earlier"]
- g. Have applied and qualified for support from Social Services, completed the scoring process [RAS, Resource Allocation System - method of scoring the amount you will be allocated for the year] been through the writing and costing your support plan [how you will spend the money to achieve the outcomes allowed] and the financial assessment. Whilst thankful for the benefit this has made to managing your life did you find the process took far longer than you expected and was stressful?

The government has decreed four levels of need. Low, Moderate, Substantial [some counties have split this into two] and Critical. Each county decides the level for which they will provide funds and this can change. 2 years ago Lincolnshire decided to no longer provide funds for anyone whose needs were assessed as Moderate. Paperwork and procedures are different for each county based on national documents. Our best advice if you do not live in Lincolnshire is to contact a local User-Led Organisation in your County where you can get support from people already using the system.

## Tips and Tricks on Travelling as a PPSer by Life Member Jann Hartman.

Here are some tips and tricks that I have learned along the way to help you be prepared, no matter where your travels may take you, near or far! I have travelled by air, in an RV, by ship, and on a train thru Europe and in the USA. I have had four different scooters [2 were given to me], and now use a lightweight travel scooter. Getting the right assistive devices is important for us all.., at home or for travel.

- Be very specific when explaining your needs.
- If a destination cannot meet your needs, you may need to make alternative plans.
- Have your equipment serviced before your trip, Small tweaks or replacement parts may help you avoid problems later.
- Carry a basic tool kit, in case small repairs are needed.
- Bungee cords or zip-ties can also come in handy!
- Personalise your mobility equipment in some way so people do not assume it is offered by the airport or attraction. I like to use post-polio stickers that I got at various conferences. I also have name stickers under the seat {engraved would be really good for ID}. Ensure that all pieces that come apart are named with contact details including your mobile phone number. Some craft people have decorated their devices, added beads, painted canes - featured in LincPIN some years ago by Ellen in Florida.
- Whenever you travel things are bound to go astray in one way or another, It is always good to maintain a good sense of humour! Ensure you have details of where you can hire a suitable alternative en route with you.
- The proper adaptors are important. Using the wrong adaptor can ruin electronics. (Amigo recommends a power converter that is rated at 200 watts minimum). Read your equipment manual, it may be online too!. [Editors note: We can vouch for that having forgotten at the end of a long flight to the UK and plugged the power lead or Richards Jazzy directly into the mains in the UK. Phht!... We needed to plug this into a power convertor first, but luckily were able to use the connector on the controls instead. Would have been a costly repair.]
- Duct tape - it can fix a variety of problems!
- Check your electric wheelchair or scooter when it is delivered to you at baggage claim. One time they brought me my base/seat/tiller but not my battery! It is important to double check everything and make sure you have all the necessary parts before you leave the airport, just in case. [Editors note last trip to USA the baggage handlers put Richards electric wheelchair on the luggage conveyor belt and it got stuck in the entrance flaps to the Baggage Hall!!.
- Drive slowly - many places that seem accessible at first glance may have hidden dangers. Power can get you into trouble. Better to go slower and stay safe!
- One more thought. I like to travel to destinations more than ever. I enjoy meeting with friends in a suitable place {AGM in England, BransonGoers yearly in June in Branson MO, USA) or a cruise (with the Miami PPS Groups) to somewhere - or even nowhere. It is nice to go as a group or meet up somewhere so you can do things with others but remember you must include rest breaks.

Will be at the Post-Polio Health Conference May 31st to June 3rd 2014 in St. Louis, Missouri, USA. Be great to meet more members, do let me know if you are going to be there too.

[www.ricksteves.com](http://www.ricksteves.com) (esp. Graffiti wall posts on Senior Savvy and others)

[www.cruisecritic.com](http://www.cruisecritic.com) (just read, or register to post and talk to other people)

[www.gimponthego.com](http://www.gimponthego.com) (my article on cruising and other trips)

Jann Hartman - [arrojan@yahoo.com](mailto:arrojan@yahoo.com)

# EUROPEAN POLIO UNION MEETING & ANNUAL GENERAL MEETING

in Tullamore, County Offaly - IRELAND 18<sup>th</sup> – 21<sup>st</sup> October 2013

## 18<sup>th</sup> October 2013

Latest arrival date in Dublin, EPU will arrange transport for delegates from a designated point (probably the airport, but yet to be confirmed) to Tullamore and your hotel. Ordinary delegates will have a free evening. Further transport details to follow.

20:00 hours EPU Board Meeting – EPU directors only

## 19<sup>th</sup> October 2013

08:00 – 10:00 hours Breakfast  
10:30 hours – 13:00 hours European Polio Union Annual General Meeting  
13:00 hours – 14:30 hours Lunch  
14:30 hours – 17:00 hours European Polio Union Annual General Meeting (continued)  
17:00 hours Close of European Polio Union Annual General Meeting  
19:30 hours EPU Annual General Meeting Dinner – to be confirmed

## 20<sup>th</sup> October 2013

10:00 hours – 13:00 hours Presentations from EPU Member Organisation – to be confirmed  
13:00 hours – 14:30 hours Lunch  
15:30 hours – until late Join in the Irish Post Polio Support Group Celebrations with music & fun

## 21<sup>st</sup> October 2013

Departure from Tullamore by EPU provided suitable transport to Dublin & airport. Departure time will depend entirely on the flight times for delegates. It would be most useful if delegates could arrange their flights for mid to late afternoon so that the transport and delegates do not have to be leaving from hotels in the early hours of the morning.

### General Arrangements

At this time it is not possible to give accurate times for coach transport and the suitable transport provided will include provision for wheelchair users.

Delegates are responsible for meeting all flights costs and taxes from their home country, including transfers where needed, and meeting the cost of hotels, meals (excluding hopefully an EPU AGM dinner on night of 19 October 2013). Lunch costs are included in the EPU events and evening meals are available in the hotel at the special rate of €19.95 per person.

It is essential that you inform the EPU by email ([jmcfarlane1@iolfree.ie](mailto:jmcfarlane1@iolfree.ie)) of your finalised transport arrangements to and from Dublin by the end of June, if it all possible, at the latest so that we may be able to coordinate in the most cost effective and efficient manner onward transport to the AGM venue and the return journey.

It is anticipated that there will be a number of Polio Survivors and those with Post Polio Syndrome who will attend the weekend from non-member countries. It has always been the intention of EPU to extend and to reach out into eastern European countries and other sub Saharan countries. It is intended that at every opportunity people from the non-member countries will join us and observe our work and methods of collaboration. It is to be hoped that some may be able to observe the EPU AGM but will have no active part in its working or any vote that may be taken there. If any member organisations object to this will they please let me know so that any possible embarrassment may be avoided. No invitations to observe the work of the EPU AGM have been issued at this stage and therefore any objections would be appreciated by the end of May at the latest.

Negotiations are still ongoing at the present time with the various agencies linked to the 2013 EU Presidency regarding the provision of translation services. Whilst every effort is being made to provide these services at the AGM currently no firm promises can be made. You will be kept informed of progress in the weeks to come.



## MAY 2014

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
25	26	27	28	29	30	31 PHI's

## JUNE 2014

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
1 Promoting Healthy Ideas	2	3	4	5	6	7

**11th International PPS Conference**  
**Promoting Healthy Ideas**  
**St. Louis, Missouri, USA.**

[www.post-polio.org/net/confs.html](http://www.post-polio.org/net/confs.html)

Hilary and Richard Boone - health permitting - are taking what might be our last opportunity to cross the pond, visit our daughter, son-in-law and by then 3 year old grandson in Canada and then fly to St. Louis for the Conference and then just 70 miles down the road to see Richards family. Hilary and Richard attended and Hilary presented at the 8th Conference in 2000 and the 9th Conference in 2005 and will be giving a presentation at this one.

Jann Hartman and other USA members, and polio survivors you might know from Facebook are making arrangements to attend this Conference. Any UK members, or readers of this newsletter, who think that they might be able to attend, then please get in touch. PPS Conferences are not only informative but the sharing of experiences and meeting knowledgeable PPS health professionals, and Polio Survivors you know from the Internet in real life plus the gales of laughter at times makes this a date not to be missed if you can afford the finances and energy.

### **What is the Gift Aid form and envelope enclosed with this newsletter?**

#### **Why is it so important to us?**

Gift Aid is a system where our 'generous' government allows certain charities, such as PSN, to claim back an extra amount where certain criteria are met.

For all of the payments you make to PSN (both membership subscriptions and donations) we are allowed to claim an extra 20% from HMRC (Her Majesties Revenue & Customs).

So if you just pay your membership subscription of £12.50 we can claim an extra £2.50. There is no cost to yourself or PSN at all!

The only requirement is that the person who makes the payment MUST pay income tax to at least the value of the claim.

So, if you meet the requirements, please complete this form as soon as possible.

If you have any queries concerning Gift Aid please contact:

Treasurer and Membership Secretary

Gillian Bryan – [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk)

## All You Need Is A Web Browser To Read POST POLIO NEWS [ppn]

Twitter, Newspaper and RSS feed can all be browsed without requiring extra tools or subscriptions.

Go to [www.post-polio.org.uk/](http://www.post-polio.org.uk/) and check out the "Tips".

**An online news cutting service from Chris Salter  
that specialises in news relating to polio and post polio issues**



### 'Our Brains Matter' survey

Are you living with a neurological condition? If so, we want to hear about your experience of being diagnosed; find out about taking part in our new survey.

What is the 'Our Brains Matter' survey? For people with neurological conditions, quick and accurate diagnosis is vital to enabling access to the care, support and treatment that they need. Unfortunately, however, the time between experiencing first symptoms and getting the correct neurological diagnosis too often takes far too long.

To mark Brain Awareness Week 2013, we are launching **Our Brains Matter** survey to develop a clear picture of the experience of being diagnosed with a neurological condition in the UK. With the evidence we gather, we will push for improvements in diagnosing all neurological conditions.

<https://www.surveymonkey.com/s/D585LX6> To take part in the survey online. Anyone without internet access who would like to complete this please drop us a line.

Peter Brauer

Aspects of the  
**Post-  
Polio  
Syndrome**

POLIO Selbsthilfe e.V.

PSN apologises for the problem with our P.O. Box in that we did not receive the orders when posted. 9 copies have now been posted to members. If anyone else would like a copy then we need to know by June 10th 2013 when we will re-order from Germany.

Comments so far.. "The book is helping me collect my thoughts together on how to cope" "Please can I have another copy as I am going to send this one to my surgeon" "Reading a book by a doctor who is a polio survivor and has PPS was helpful because he knows what it is like from our perspective" "The translated German to English had a couple of terms I was unfamiliar with but found the English version on Google."

## Your Newsletter needs your stories, hints, tips and bits to make us laugh..

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 August 1st 2013.



## **Wild poliovirus in the Horn of Africa**

**22 MAY 2013** - The Horn of Africa is currently experiencing an outbreak of wild poliovirus type 1 (WPV1). A four-month-old girl near Dadaab, Kenya, developed symptoms of acute flaccid paralysis (AFP) on 30 April 2013. Two healthy contacts of the child tested positive for WPV1. They are the first laboratory confirmed cases in Kenya since July 2011. Investigation into this outbreak is ongoing. In addition, a case of WPV1 in Banadir, Somalia was confirmed on **9 May 2013**.

In response to the outbreak, the first vaccination campaign, reaching 440 000 children began on 14 May 2013 in Somalia and a second round of vaccination is planned for 26 May 2013 in synchronization with the affected parts of Kenya.

The risk to neighbouring countries is deemed as very high, due to large-scale population movements across the Horn of Africa and persistent immunity gaps in some areas. Dadaab hosts a major refugee camp, housing nearly 500 000 persons from across the Horn of Africa.

An alert for enhanced surveillance for polio has been issued to all countries across the Horn of Africa, highlighting the need to conduct active searches for any suspected cases. All countries are urged to rapidly identify sub-national surveillance gaps and to take measures to fill the gaps.

In 2005, polio spread east across the African continent, and into Yemen and the Horn of Africa, resulting in over 700 cases. Since then, international outbreak responses have been adopted and new monovalent and bivalent oral polio vaccines have been developed, which can significantly reduce the severity and length of polio outbreaks.

Some areas of Somalia (south-central) are also affected by an outbreak due to circulating vaccine-derived poliovirus type 2 (cVDPV2), which has resulted in 18 cases in Somalia since 2009. In 2012, this strain spread to Dadaab, causing three cases.

WHO's International Travel and Health recommends that all travellers to and from polio-infected areas be fully vaccinated against polio.

### **"ATOS, ESA & Polio" - by Chris Salter.**

"Most Atos HCPs [Health Care Professionals] are not doctors, they are usually nurses or occupational therapists. There are some conditions that will mean you need to be assessed by a qualified specialist nurse, or a doctor and you can ask for this."

"List of conditions judged by the DWP and Atos Healthcare as suitable only for assessment by doctors:" and the list includes Polio.

The above is specific to ESA. Whether it will apply to PIP I cannot say and bear in mind that PIP assessment contracts have been awarded to Centrica in addition to ATOS.

The list appeared in two recent blogs by one kittysjones and are based on information supplied by Joyce Drummond, a Scottish nurse originally employed by ATOS and who has since apologised to ATOS assessment "victims" and submitted evidence to the Scottish Parliament Select Committee on Welfare Reform.

What you need to know about Atos assessments.

<http://kittysjones.wordpress.com/2013/04/18/what-you-need-to-know-about-atos-assessments/>  
or <http://preview.tinyurl.com/c5ovzab>

Essential information for ESA claims, assessments and appeals.

<http://kittysjones.wordpress.com/2013/04/21/1560/>

Chris Salter - [chris.salter@post-polio.org.uk](mailto:chris.salter@post-polio.org.uk)

**MEMBERS** who are in the age range and affected by ESA/PIP are asked to please let us know how you get on with the assessment and decisions. Sharing information helps us help you

Patients receive the best care when they work in partnership with doctors. This guide explains how you can help to create a partnership with your doctor. Much of it is simply common sense, but following it should help you get the most out of your time with your doctor. It is based on the standards the General Medical Council (GMC) sets for doctors in our core guidance. *Good Medical Practice*.

## **Doctors must provide good care.**

The evidence suggests that the vast majority of patients have an excellent and trusting relationship with their doctors. With respect and understanding on both sides, you should be able to develop such a relationship.

The support and feedback that patients provide is vital for doctors in helping them work effectively and in continuing to improve standards of practice.

From the outset, to provide you with the best care and treatment the doctor will need to find out what's wrong with you.

They must listen to your explanation of why you have come to see them, and take into account your previous and current health and illnesses, as well as your lifestyle and your views.

They should examine you physically where necessary.

It is important to be as frank and open as you can. You may find it helpful to make some notes beforehand to take with you, so you do not leave out some information that will help the doctor understand your situation.

## **What will my doctor tell me?**

They will offer you advice, medicines or other treatment based on the best available evidence. Many of us find it difficult to take in all the information our doctor is sharing with us and it is important to ask for clarification if you need it.

In particular, you should understand whether you need to prepare for the treatment or any tests, and that you are clear on the instructions for taking medicines.

Again, do ask your doctor if you are not sure of anything he or she has said, including when or how you should take any medicine or why you need to have any tests.

If you feel your doctor has not made the right diagnosis or is not offering the right treatment, you can ask for a second opinion from another doctor.

## **Helping to train students and doctors.**

Everyone who sees you should introduce themselves and explain how they fit into the team looking after you. Training the next generation of doctors is a key part of any healthcare system. Medical students cannot learn all they need to know from books and will, at times, be part of the team. If you for any reason you would prefer not to help in medical student training, you have the right to decline.

Email: [gmc@gmc-uk.org](mailto:gmc@gmc-uk.org)  
Website: [www.gmc-uk.org](http://www.gmc-uk.org)  
Telephone: 0161 923 6602

General Medical Council, 3 Hardman Street, Manchester M3 3AW

[http://www.gmc-uk.org/static/documents/content/What\\_to\\_expect\\_from\\_your\\_doctor\\_-\\_a\\_guide\\_for\\_patients\\_-\\_English\\_0413.pdf](http://www.gmc-uk.org/static/documents/content/What_to_expect_from_your_doctor_-_a_guide_for_patients_-_English_0413.pdf)

# Management Committee [Trustees] and Operations Team

## Management Committee [Trustees]

Chair - Simon Parritt, [simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)  
Secretary & Newsletter Editor - Hilary Boone - [hilary.boone@poliosurvivorsnetwork.org.uk](mailto:hilary.boone@poliosurvivorsnetwork.org.uk)  
Treasurer - Gillian Bryan - [gillian.bryan@poliosurvivorsnetwork.org.uk](mailto:gillian.bryan@poliosurvivorsnetwork.org.uk)  
Trustee - Chris Salter - [chris.salter@post-polio.org.uk](mailto:chris.salter@post-polio.org.uk)  
Trustee - Dot Ives - [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)

## Operations Team

Membership Secretary - Gillian Bryan - [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk)  
Phone and Email Enquiries - Hilary Boone - [info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk) -  
Administrative Support - Gillian Bryan - [gillian.bryan@poliosurvivorsnetwork.org.uk](mailto:gillian.bryan@poliosurvivorsnetwork.org.uk)  
Printing and Website - Elpeeko Ltd, Lincoln.

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

## Membership

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

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

### Membership Fees

UK Individual - £ 12.50 per year  
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 to keep costs down.  
Email:- [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk)

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

## Donations

*giftaid it*

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

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

Some members send us a few postage stamps

- Some members take their newsletter via the internet saving us printing and posting costs.
- Others add a donation amount to their yearly cheque, or Standing Order amount.
  - UK Taxpayers can Gift Aid their subscription and donated amounts.

**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. [See page 15 and enclosed new Gift Aid form]

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

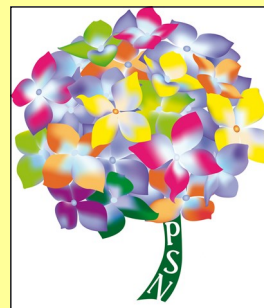
# Polio Survivors Network

Registered Charity No. 1064177

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

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

P.O. Box 954, Lincoln, LN5 5ER, U.K.



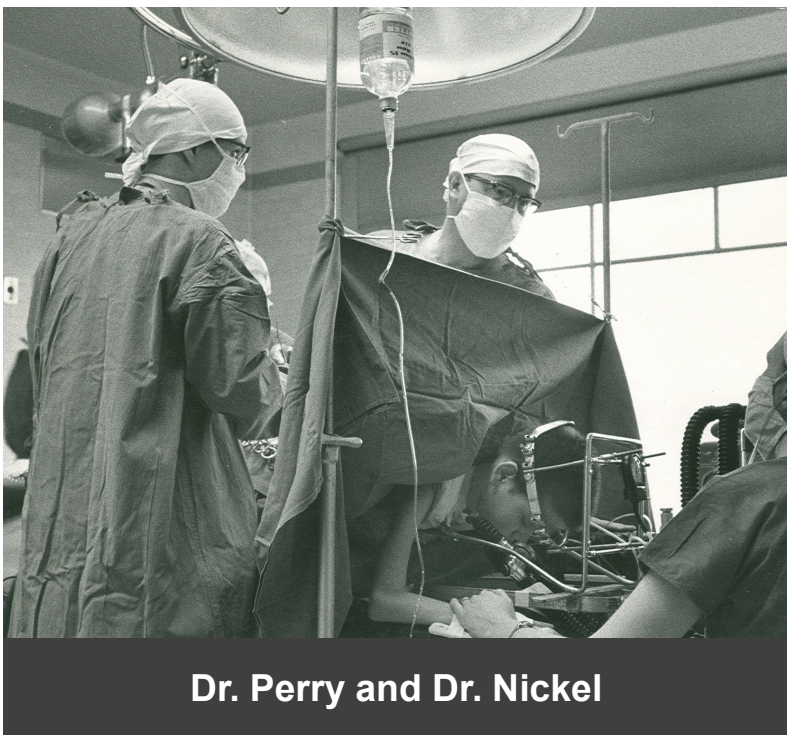
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**POST POLIO MATTERS** because **WE'RE STILL HERE!**



Dr. Perry

Richard Daggett



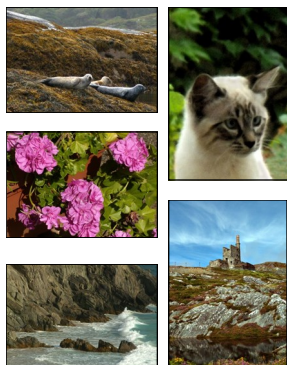
Dr. Perry and Dr. Nickel

**Jacquelin Perry, MD The Grande Dame of Orthopedics**

**May 31, 1918 to March 11, 2013**

**Physician, Mentor, Advocate, Friend**

**A personal tribute by Richard Lloyd Daggett, Pages 8 to 11**



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