

# POST POLIO MATTERS

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**Volume 7**  
**Issue 7**



**Book 1**  
**Pages 6,7**  
**and**  
**Book 2**  
**Back Page**

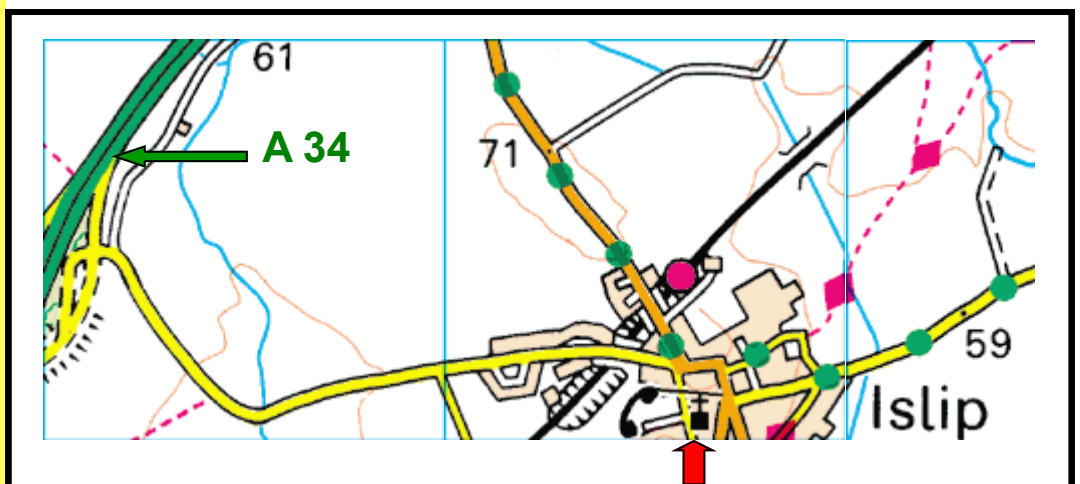
## AGM

**23 . 6. 2012**  
**Islip**  
**Village Hall**  
**Oxon**  
**OX5 2TA**  
  
**Page .4**



**Live Eels and Grand Pianos**  
**Andrew Bradford**

*Live Eels* tells the story of Kathy and Charlie's early lives, and it also tells the story of the Author Andrew Bradford's childhood



**DISABILITY  
EXHIBITIONS**

—  
**NAIDEX**

**Birmingham  
NEC**

**1 - 3 May 2012**

[www.naidex.co.uk](http://www.naidex.co.uk)

**NAIDEX SOUTH**

**17 - 18 Oct 2012**

**ExCeL London**

[www.naidexsouth.com](http://www.naidexsouth.com)

**NAIDEX  
SCOTLAND**

**18 - 19 Sept 2013**

[www.naidex.co.uk](http://www.naidex.co.uk)

**MOTABILITY  
ROADSHOW**

**21 - 23 June**

**2012**

**Peterborough**

**East of**

**England**

**Showground**

[www.mobility](http://www.mobility)

[roadshow.co.uk](http://roadshow.co.uk)

**PSN AGM**

**23rd June**

**2012**

**Islip Village Hall**

**5 miles north of**

**Oxford.**

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## New Members and Donations received.

We welcome New Member **Ann Revell**

**Thank you to all members who have recently renewed.**

Thank you to the following for donations given towards our work

Barbara Smith, Barry & Olivia Branston

Christine Darlington, Walter West, Susan Freeman,

H. Brown, N. Harvey, John Ward, Yvonne Grosse,

Lynn Hobday, Shirley Rose, and Diana Nash.

A total of **£ 104** since last newsletter.

**Plus Val Scriveners Card Sales adds another £20.00**

We have no paid employees.

We would like to recognise and thank the following for so generously donating their time. The Trustees, Chris Salter, and Bob Price

**Donations & offers of time 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

It is a beautiful sunny day without a cloud in the sky, snowdrops and daffodils in bloom, and I have just seen a Red Admiral Butterfly flit past the window.

Over the past five months I have been attending a Partners in Policymaking Course - Sharing Knowledge - at Lincoln College, five lots of two full days. For more information see page 16. Sarah Hill from Postural Care, or one of her team, will be coming to speak at our AGM and look forward to learning more about our polio issues and offering some possible solutions. ResMed UK, [they supported the Breathing Symposia in San Diego, watch on [www.poliotoday.org](http://www.poliotoday.org)— Videos] will also be presenting on ways their equipment can improve the quality of life for those of us with respiratory and sleeping issues. For more information on the AGM see front page map, and page 4.

AGM attendance slip. We have enclosed a slip with this newsletter. To enable us to plan well for the day it would really be helpful if **all** UK members [and anyone from overseas if they are in the UK of course] could please let us know if they are coming, might be coming, and are unable to come. We will be doing a full report from the speakers for the next newsletter.

I have included a report from Andrew Bradford about his book Live Eels and Grand Pianos - a family memoir. It is a really interesting read. See pages 6 and 7 for more information.

On the back page you will find information about another book written by Dr. Wenzell A Leff, a polio survivor.

Members if you read any books or articles that have anything to do with polio, polio survivors or PPS then please let us know. We would rather hear ten times than not at all.

Also included is a report of a presentation by Dr. Susan Perlman at the Southern California PPS Meeting on May 23rd 2010. It contains a lot of all round information that I hope will be of help. See pages 8 to 14.

Page 15 is information on a survey on rare diseases, and polio falls into that category, and if anyone is interested in putting forward some views on this then please get in touch.

Page 17 is some information on Raw Coconut Oil and how it might be of help in our diets.

Page 18, and hot off the press is part of a Trustee report from the Neurological Alliance regarding the Health and Social Care Bill and the National Audit Report. I will add a file with their full report to those receiving newsletters by email. Anyone else who would like a copy then please drop us a line, with an sae and we will post you a copy. PSN is a member of the Neurological Alliance.

There is much in the news almost daily about new NHS procedures, the change from Incapacity Benefits to [polio brain fog, will have to go look it up\*] Employment and Support Allowance and all sorts of issues that affect folks with disabilities. Anyone want to write things like this up for the newsletter? \* I left the polio brain fog piece in to show that if you are talking to someone and you too forget a word (and often they are the simplest words and it is so frustrating) then just describe it and move on. This method lessens the frustration. Loads of polio survivors and other folks forget words... we are not alone. You will likely remember the word later, and sometimes wake with a Eureka moment in the middle of the night!

**Members who do not have internet access** and would like more information on any subject please don't hesitate to ring and I will see how we can help.

**Financial Year** - Runs from January 1st to December 31st 2012.

### Polio Survivors Network - Meeting information

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

**AGM  
23 06 2012  
Islip  
Village Hall  
Islip,  
Oxfordshire  
OX5 2TA**

**Single Action  
Manual  
Muscle Testing**  
can be  
unreliable.

Testers are  
advised to test a  
range of  
muscles **once**  
and only do  
more testing if  
weakness is  
evident.

Problems occur  
when anyone  
can do the  
action once but  
the weakness  
starts a few  
repeats down  
the line.

“Saying ‘Ah’  
once did not  
pick up  
swallowing  
issues till I got  
them to watch  
me repeating  
‘Ah’.”

## **Message from the Trustees.**

Dear All,

The Annual General Meeting will be on 23rd June 2012. This is being held in the Midlands, as promised, at Islip Village Hall, Islip, Church Lane, Islip, Kidlington, Oxfordshire OX5 2TA.

Doors will open at 10.30am and the AGM commence at 11.00 am, with lunchtime commencing at about 12.00/12.15. We have decided that it will be far less stressful for the committee if we ask you to bring your own lunch. We will provide drinks, tea, herb tea, coffee, caffeine free coffee, fruit juice and biscuits. The afternoon session will have two speakers.

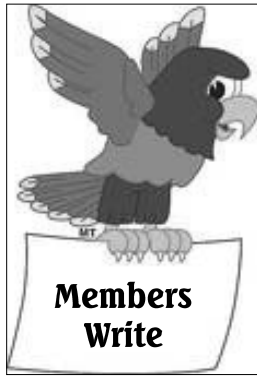
Hilary recently watched a presentation from Sarah Hill who co-wrote the Postural Care Skills Programme. As both Richard and she have some of the problems raised, especially with night time positioning, although they do not have the multiple complexities usually dealt with, they will have had a home assessment by the time you read this. We thought that others might benefit from learning more. A representative will explain that when people find it harder to move parts of their bodies that they are at risk of developing body shape distortions. Postural care is about using the right equipment and positioning techniques to help protect and restore body shape and luckily for us it is never too late to start protecting someone's body shape. Some people are having their body shape protected in the day – for example, with a wheelchair that supports their posture and braces – but getting no protection for their body shape at night. If you have scoliosis, kyphosis, lordosis, breathing or sleep problems, poor digestion, constipation for example then there may be suggestions to help us manage our lives. [www.posturalcareskills.com](http://www.posturalcareskills.com)

The other speaker will be from ResMed who will talk about respiratory assessment, their ventilators including the new S9 and more, and how professionals can see how you are doing from the downloads off the machines. [www.resmed.co.uk](http://www.resmed.co.uk), and hopefully a respiratory physiologist as well.

**Please remember single action Manual Muscle Testing**, e.g. For arms ‘grip my hand, pull against me, push against me’ does not test pattern of movement [can you lift a jug of water and pour it out with one hand like you used to] It is essential that instead of saying ‘my arms are weaker that you be more specific and say “I used to be able to cook a meal for 20 from scratch, but now I slide saucepans not lift them, I cannot mix or roll out the dough, I struggle to peel and cut vegetables, what is causing this new weakness?” This should hopefully lead the professional to test the muscles performing the actions you report. Please tell us bad instances where your reported weaknesses were not corroborated by only testing your muscles once, or when they tested your muscles a different way and confirmed what you were reporting.

**No-one** responded to our request for help with some of the tasks that we do to provide information for the members and a wider audience via our website on the internet. A couple of hours here and there could make a huge difference and more committee members would spread the workload. Please contact us for more information.

Best Wishes to you all. **Hilary, Glenna and Gill.**



**Nancy Almirall**  
**Missouri, USA**  
**Polio age 3 in 1949**  
**PPS diagnosed in 1999.**  
**<nalmirall@gmail.com>**

I'm anxious to hear how you like Nemesis; I'm reading a great book now called

"The Polio Journals: Lessons from My Mother" by Ann Gross. The author is a therapist and it took her 20 years before she read her mother's journals. It deals with the issues of anger, poor to no communication and the lack of emotional closeness that can occur when polio is never discussed in a family, or several generations. The mother had a profound disability, both legs remained paralyzed, but her mother and father and consequently, her husband and children held to the mindset that she was "no different from anyone else" except that she couldn't dance or play tennis.

In my family, polio was never mentioned and we ignored the fact that I limped, could not climb stairs etc. I grew up believing that I was defective and just not good at things like running, ballet, and so on. I know in my case, this left me with a profound feeling of being a "faker" and a deep sense of shame. I still deal with anger since being diagnosed with PPS in 1999. This book addresses these problems in detail and I have found it very helpful.

Exhaustion is my most troubling symptom at this time. I never feel rested and wake up feeling as tired as when I go to bed. I am going to try using my bi pap again. I used it for several months but would remove it in my sleep, so never felt the benefit. I spend far too many days in my robe because I am too tired to get dressed. I am depressed and in therapy and on medication for depression. I've dealt with clinical depression for many years and have never been so exhausted as I am right now.

I would appreciate any discussion on our email list or letters on these points.

English born member Janet Whitworth who now lives in Washington State in America sent this for the newsletter saying 'this feels so true'. [janhat55@comcast.net]

## Vitamin F

Why do I have a variety of friends who are all so different in character? How can I get along with them all? I think that each one helps to bring out a 'different' part of me.

With one of them I am polite.

I joke with another friend.

I sit down and talk about serious matters with one.

With another I laugh a lot.

I may have a coke with one.

I listen to one friend's problems.

Then I listen to another one's advice for me.

My friends are all like pieces of a jigsaw puzzle. When completed, they all form a treasure box. A treasure of friends! They are my friends who understand me better than myself, who support me through good days and bad days. We could pray together for each other.

Real Age doctors tell us that friends are good for our health. Dr. Oz calls them Vitamin F [for Friends] and counts the benefits of friends as essential to our wellbeing.

Research shows that people in strong social circles have less risk of depression and terminal strokes. If you enjoy Vitamin F constantly you can be up to 30 years younger than your real age. The warmth of friendship stops stress and even in your most intense moments it decreases the chance of a cardiac arrest or stroke by 50%.

I'm so happy that I have a stock of Vitamin F.

In summary, we should value our friends and keep in touch with them. We should try to see the funny side of things and laugh together, and pray for each other in the tough moments.

Thank you for being one of my Vitamins.

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

## Live Eels and Grand Pianos – a family memoir

December 2011 was UK Disability History Month. At various venues across the country there was discussion, exhibitions and performances centred on the theme of “Celebrating Our Struggle for Equality.” This theme is also relevant to more current events such as; ‘the March of the hardest hit’ in May 2011, and recent attacks on the rights, dignity and standards of living of disabled people in the UK.

My parents, Charlie and Kathy Bradford were prominent in many campaigns for disability rights in the twentieth century. Earlier this year I published “Live Eels and Grand Pianos”, a family memoir that tells their story. I was born in Edmonton, North London, in 1948. That makes me the same age as the National Health Service, and without the support of the NHS, enlightened and supportive agencies such as local authority housing departments, and self-help organisations such as the British Polio Fellowship we could never have had a normal family life.

Charlie was born in 1906 and caught polio when he was three. It left him paralysed in both legs, his left arm and he had a severe curvature of the spine that meant he had to wear a leather and steel spinal jacket that weighed over twenty pounds. Kathy was born in 1912, caught the disease when she was just ten months old and it left her paralysed in both legs.

Before the war Charlie sold sweets from a wheelchair outside the local grammar school. Kathy worked as a tailoress, but she found that she was always sacked after just one year. As *Live Eels and Grand Pianos* explains:

“When she was sacked for the third time she asked her employer why she was being dismissed, and she was told that the boss had found out that due to her disability, the employer would have to pay extra national insurance contributions, backdated to the day that she started.

National Insurance in the 1930s was a payment made by the employer to the government to provide compensation for its employees in the event of an industrial injury, and no doubt some government actuary had decided that disabled workers were a higher risk and had to pay higher contributions. Kathy’s employer said that he couldn’t afford to pay that. Somebody else could do the job more cheaply. She had to go. She therefore came to an arrangement that she would reimburse the firm for the extra national insurance stamp.

She did this for ten years until the start of World War II, and she recorded all the payments she made in a series of notebooks. In 1938 she attended one of the first meetings of what became the British Polio Fellowship, a self-help organisation for people with her disability. A few years later the Polio Fellowship submitted these notebooks as evidence to the Beveridge Commission, and the national insurance rules were changed.”

The Second World War changed Kathy and Charlie’s lives. At the beginning of the war adults with disabilities were evacuated from big cities, and Kathy met Charlie at a ‘cripple camp’ in Dovercourt, Essex. Neither of them stayed there very long, as they found the atmosphere condescending and patronising. Charlie returned to London where he found work on an assembly line, making parts for bombers. For the first time in his life, society wanted him, and needed him to play a part. He never had to peddle sweets again; he worked on assembly lines until he was sixty two, when PPS set in.





*Live Eels* tells the story of Kathy and Charlie's early lives, and it also tells the story of my childhood. While many people showed our family great kindness, others thought it wrong that two such seriously disabled people should bring a child into the world. Because we were such an unusual family we were the subject of a large number of articles on the national press. *The People* and the *Sunday Express* wrote long articles about us in the early 1950s. When the old boy who sold newspapers at the bottom of our street read the article in *The People* he verbally abused Charlie. I like to think that those days are long gone, but then I read press articles about disability hate crime today and I'm not so sure. Disabled people and their families have to continue to fight for rights and respect, and *Live Eels* is my contribution. All Kathy and Charlie ever wanted to do was to lead an ordinary family life, but to become ordinary they first of all had to become extraordinary.

I was lucky enough to inherit a wonderful photo archive of Kathy and Charlie, and the book is illustrated with over twenty black and white photographs of our family taken between the 1920s and the 1980s

To order a signed copy of 'Live Eels and Grand Pianos' send a cheque for £10.49 to the author at Belle Vue, 16 Gews Corner, Cheshunt, Herts, EN8 9BX or visit the author's website: [www.andrewbradfordauthor.com](http://www.andrewbradfordauthor.com).

# Treating Polio

## Now and in the Future

Including research from  
around the world

**With Susan L. Perlman, M.D.**

Clinical Professor of Neurology  
David Geffen School of Medicine  
University of California, Los Angeles  
Presented at the Orange County, CA.  
PPSG meeting, May 23, 2010

### **Reported by Mary Clarke Atwood**

Editorial assistance by R. Daggett  
and S. L. Perlman, MD

### **Rancho Los Amigos Post-Polio Support Group Newsletter February 2011**

Dr. Perlman has learned about PPS from her patients – more than 500 of them in the last two decades. We always look forward to this annual presentation when Dr. Perlman generously shares her time and energy with local polio survivors.

This year's review begins with patient care guidelines and includes the exciting work being done with stem cells. Although there is not yet a group working with stem cells in patients with post-polio in the United States, there has been a great deal of stem cell work in patients with other neurological disorders. What is learned from them may also apply to post-polio. Other research topics include physical and mental fatigue, pain, and predicting which polio survivors will develop polio problems and who will be spared.

## Standard Patient Guidelines

Everyone needs a good primary care doctor, a knowledgeable physical therapist, and attention to good general health practices (weight management, exercise, appropriate assistive devices, relaxation training, sleep hygiene, emotional health). If a survivor has symptoms that impinge on these areas, they can be directly attacked to improve quality of life.

These standard polio survivor guidelines of the last ten years are still valid:

Make sure your symptoms are polio related. They may be due to another medical or neurological illness or to orthopedic problems, which must be identified and treated. New symptoms in a polio survivor are only related to polio about 1/3 of the time.

Treatment of other illnesses in a polio survivor must be monitored relative to the sensitivities of PPS (e.g. surgery, chemotherapy, use of cholesterol lowering medication).

Polio survivors with symptoms of PPS must take care to modify lifestyle and use rehabilitation medicine or services to develop a program of appropriate non-fatiguing exercise and reconditioning, assistive devices, pacing of activities, and finding their own limit. They need to work with somebody who is knowledgeable about rehabilitation to address these issues.

Caution: Do not push yourself past the limiting point of pain and fatigue.



No one is talking about “Conserve to Preserve” anymore. If you are a polio survivor and are beginning to experience fatigability and weakness, nobody should recommend that you stop doing everything, to never exercise again and get a wheelchair.

## **Why Increase the Awareness of Post-Polio?**

Doctors treating polio survivors need to be aware that these patients are going to be different from patients who never had polio. Polio survivors report poorer functional status and poorer health-related quality of life than non-polios.

The life-altering effects of post-polio have not been adequately addressed by health care providers. They are not aware that they actually have tools they can use right now to help polio survivors with some of these unique problems.

Many publications indicate that polio survivors are best served in multidisciplinary clinics staffed by knowledgeable professionals. We need to make this known to others.

## **Will Healthcare Reform Make these Guidelines Achievable?**

### ***A personal experience:***

Dr. Perlman recently saw a typical polio survivor with PPS. This patient had been seen in clinic during 2007-2008 and returned two years later.

Those earlier visits included recommendations for:

physical therapy to develop a non-fatiguing home exercise program  
a sleep study for symptoms of obstructive sleep apnea possibly contributing to daytime fatigue.

However, a perfect storm of potential rationing and misinformation followed:

The patient’s HMO approved physical therapy but only for treatment of what appeared to be carpal tunnel syndrome. There were only the minimum number of treatments and that was it.

No home exercise program was developed.

No counseling about activity modification and pacing was achieved.

A sleep study was done confirming obstructive sleep apnea. But the physician in charge counseled that the mask to assist breathing would be very uncomfortable and it could take the patient a year to become satisfied. With a build up like that, the patient chose not to try it.

The patient returned to Dr. Perlman two years later with the same complaints:

symptoms of sleep apnea, daytime fatigue, plus weakness and fatigability in muscle areas - all because of potential rationing and misinformation.

There is no excuse for this, but it happens all the time. Polio survivors need to be aware and proactive with health care providers. Bring them information, but don’t overwhelm them while being firm. Show them what has been published defining the standard of care for a person with post-polio syndrome.

Will Dr. Perlman’s recommendations be provided this time? The patient has a new HMO, so time will tell.

Limited treatment and misinformation

are very frustrating because this patient could have had two years of improvement instead of continuing and probably worsening personal health status.

## Polio Vaccine

Dr. Perlman believes that polio vaccinations need to be continued because the virus is out there. Just recently in Los Angeles there has been an outbreak of mumps because some people get lazy, or are afraid, and don't get the vaccines for their children. So mumps comes back; polio will come back.

Globally, the number of new polio cases registered in the first four months of 2010 is down to 56, which is a 75% drop from the same period last year.

In Nigeria only two children have been paralyzed by wild polio virus compared with 123 during the same period in 2009.

For the first time in India, there has not been a single case caused by the most virulent polio viral type for four months straight.

### ***Editor's Note: Centers for Disease Control (CDC) - Outbreak Notice***

Polio Outbreak in Tajikistan, Cases in Russia Risk of Spread to other Central Asian Countries

This outbreak represents the first importation of polio in the World Health Organization (WHO) European Region since it was certified polio-free in 2002. As of October 14, 2010, the Tajikistan Ministry of Health has reported 706 cases of acute flaccid paralysis. Of these cases, 458 have been laboratory-confirmed as polio. Russia has reported

14 polio cases to date, five of which are linked to travelers. <http://www.nc.cdc.gov/travel/>

## Research around the World

United States, Canada, Spain, Sweden, Israel, France, The Netherlands

### Stem Cell Therapy

Lou Gehrig's disease (ALS, MND in UK) research is looking at problems of upper motor neurons, typically spared in post-polio and lower motor neurons, which are typically affected in post-polio. These neurons are both being targeted with stem cell therapies in ALS patients. The nine ongoing therapeutic stem cell trials look very promising, both in Europe and one study in the United States.

The U.S. group is spearheading an ALS trial with stem cells derived from bone marrow. These results should open the doors to similar treatment trials in post-polio because the cells are the same, the target is the same, and ideally the outcome would be the same.

Researchers in the U.S. and some scientific colleagues in Europe are working on ways to make stem cells behave like nerve cells, and to make them go to the part of the nervous system in which they are interested (spinal cord, basal ganglia, memory centers) and do what they are supposed to do.

It is important to point out that some of the fringe groups in China and Costa Rica may not have done as much advance preparation of the bone marrow or umbilical cord stem cells. Perhaps the preparation may not have been the right kind, they may not have been modified in the right way, or they

may not have been stimulated with the right growth factors. In fact, China has abandoned treating ALS patients with stem cells because that didn't work.

Although our U.S. stem cell studies for Parkinson's disease and ALS began three or four years after the Chinese, we are now working with stem cells whose behavior can be predicted and are assured they will not cause cancer.

Dr. Perlman expects to have much more information on stem cells when she speaks to this group again on Sunday, May 22, 2011.

### **Quality of Life**

A study from two post-polio clinics in Israel found that approximately 70% of the participants expressed the belief that exposure to up-to-date information about post-polio, as well as participation in social activities, might improve their quality of life. Dr. Perlman pointed out that a support group provides those things.

Reviews and reports from other large polio clinics have also shown that education and getting people to take control of their symptoms and condition definitely improves their quality of life.

This study from Israel concluded that information about the physical and mental components of polio survivors, as well as the desire to partake in specific activities for polio survivors, may serve as a basis for the operations and prioritization of service providers. Dr. Perlman recommends including the importance of this information on grant applications.

### **Fatigue**

Eighty-percent of polio survivors with

new symptoms have fatigue, or pain, or both. Dr. Trojan's group in Canada studied General, Physical, and Mental Fatigue to determine what modifying factors could be changed and which could not.

These non-modifiable factors, which seemed to have an effect on general fatigue, could not be changed:

- respiratory function

- fibromyalgia

- muscle strength

- age

- time since acute polio

In this Canadian study there weren't any non-modifiable factors which seemed to correlate with mental fatigue. However, the ongoing Mental Fatigue study at the U.S National Institutes of Health (NIH) may discover some non-modifiable hardwiring changes relating to the original polio that contribute to brain fatigue. So theoretically, if you have brain fatigue, it is modifiable.

Potentially modifiable factors account for a portion of fatigue in PPS. Dr. Perlman said the presence of these needs to be dealt with to help reduce fatigue. If you deal with stress and depression, then general fatigue scores will improve, theoretically.

### **Reducing Physical Fatigue**

Physical fatigue is the most common symptom and the most disabling in patients with post-polio syndrome. A Spanish study analyzed the effectiveness of various treatments used to improve fatigue syndrome in post-polio patients. They retrieved 396 articles, of which 23 were analyzed in detail. These treatment techniques reduced fatigue in 705 patients.

lamotrigine (Lamictal)  
bromocriptine (Parlodel)  
aerobics and flexibility exercises  
hydrokinesitherapy  
technical aids

Dr. Perlman suggests that when you pace your physical activity you should be able to manage physical fatigue. If you treat the pain, physical fatigue will improve.

### **Mental Fatigue in Polio Survivors**

The study of “Mental Fatigue in Polio Survivors” at NIH examines whether mental impairment is present in PPS patients. If it does exist, how does it interfere with self-functioning of patients?

One of the biggest mysteries in post-polio is problems with slow thinking and memory which seem to go right along with motor difficulties. Is this truly a brain mediated fatigue that affects thinking, learning, etc.? Or does it relate more to psychological or emotional factors?

The term “brain fatigue” is frequently used by patients to express problems in the areas of attention, concentration, memory, and clear thinking. Unfortunately, little is known about cognitive fatigue of PPS patients.

It has been accepted that polio survivors tend not be burdened by psychological baggage that is going to add to their neurologic and physical symptoms. If you happen to have depression it is obviously going to impair you, but it is not directly related to polio.

Polio treatment really needs to be focused on physical and neurologic hardwiring. Many studies have been done trying to sort out what is going on above the anterior horn cell, but there is

still no consensus.

### **Pain**

A study in Sweden concluded that pain is common in PPS patients; most patients experienced pain caused by an injury to body tissues. Women have pain more often than men. Older patients experience pain less often than younger patients. Age at time of primary polio infection is important for the development of pain. When neuropathic pain is present, it is important to proceed with a neurological examination to find an adequate diagnosis.

### **Orthotics for the Knee**

Orthoses play an important role in the therapeutic care of polio survivors. The aim is usually to secure the knee, preventing excessive recurvatum while respecting the patient's own gait.

A study in France by Francis Genet's group concluded:

Orthoses must be light and pressure-free if they are to be tolerated and therefore effective.

Some deformities may be helpful for the patients' gait and, therefore, corrections may worsen their gait, especially if a realignment of segments is attempted. It is therefore essential to carefully pre-assess any change brought to the orthoses as well as proper indications for corrective surgery.

In addition, it is essential for the patient to be monitored by a specialized team.

### **Impact of Age and Comorbidity on the Progression of Disability**

A study from The Netherlands concluded that despite a reduction in

muscle strength over a five-year period, the PPS patients' disability levels increased little.

Increased weakness in a quad or in a shoulder muscle really didn't have a significant impact on level of disability, as measured by disability scales.

Increased age and the other number of medical factors or surgical problems do have a negative effect on disability.

### **Predicting which Polio Survivors will Develop PPS**

Looking at the long-term ongoing studies, there is probably about a 60 % risk of developing PPS and probably a 40% risk of just living with the original deficits.

In 1995 Post-Polio Health International (PHI), an excellent website and group <http://www.post-polio.org/index.html>, established The Research Fund which is dedicated to seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases.

In 2007 the fourth PHI award was looking for biomarkers in blood and spinal fluid of polio survivors to see if they could identify a marker that would determine if a person will probably develop post-polio symptoms, or probably not develop them.

How can each group be identified? It has been confirmed that individuals with PPS have higher levels of antibodies and regulatory T cells (which are part of the immune system) circulating in the blood, compared with healthy age-

matched controls who never had polio. The immune factors that have been discussed in previous years (tumor necrosis factor Alpha, the interferons, and a few others) are definitely at a higher level in people experiencing active post-polio symptoms.

In this study a cross section was assessed. Stable polio individuals who do not have any new symptomology had variable intermediate levels...a little higher than average, but a little lower than the true post-polio population - not normal but not abnormal.

These easier blood tests are a nice first step that can be built upon. A larger prospective study of stable polio individuals over five years would probably indicate who might develop post-polio symptoms (fatigue, weakness, new atrophy) and who would not. What will happen to their blood tests over that period of time?

The final report data from the 2009 PHI award indicate that there is a low level of polio virus (PV) protein activity persisting for decades in most polio survivors. The debris is there; it is not infectious, but it is there.

The goal will be to develop a treatment for polio survivors, or survivors of other neurologic infectious illnesses, that may linger and cause problems. Perhaps an effective antibiotic will prevent PPS in the future or prevent progression.

### **Conclusion**

As PPS research in many areas continues worldwide, we look forward to learning more from Dr. Perlman in May 2011 when she presents research updates and answers personal



questions.

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This report can also be viewed at [www.RanchoPPSG.com](http://www.RanchoPPSG.com)

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### Helping Hands:

#### Monkey Helpers for the Disabled

Established in 1979 is the only non-profit organization in the world that raises and trains capuchin monkeys to provide daily, in-home assistance to people living with spinal cord injury or other mobility impairments.

[www.monkeyhelpers.org](http://www.monkeyhelpers.org)

#### An amazing 5 minute video clip called Mountain Gorilla.

Watch the expressions on the man's face as you hear his friends narration that the wild Silver Back has sat down a metre behind him with three youngsters in front of him, who feel his hair and after a few minutes they all leave as quietly as they came.

[www.wimp.com/mountaingorilla/](http://www.wimp.com/mountaingorilla/)

### Quiz for 'Bright People' - Answers will be in the next issue.

There are only nine questions. This is a quiz for people who know everything! I found out in a hurry that I didn't. These are not trick questions. They are straight questions with straight answers.

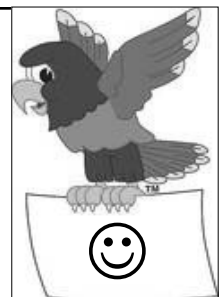
1. Name the one sport in which neither the spectators nor the participants know the score or the leader until the contest ends.
2. What famous North American landmark is constantly moving backward?
- 3 Of all vegetables, only two can live to produce on their own for several growing seasons. All other vegetables must be replanted every year. What are the only two perennial vegetables?
4. What fruit has its seeds on the outside?
5. In many liquor stores, you can buy pear brandy, with a real pear inside the bottle. The pear is whole and ripe, and the bottle is genuine; it hasn't been cut in any way. How did the pear get inside the bottle?
6. Only three words in standard English begin with the letters 'dw' and they are all common words. Name two of them.
7. There are 14 punctuation marks in English grammar. Can you name at least half of them?
8. Name the only vegetable or fruit that is never sold frozen, canned, processed, cooked, or in any other form except fresh.
9. Name 6 or more things that you can wear on your feet beginning with the letter 'S.'

A man has been having a medical problem for a couple of weeks and decides that as it is getting worse that he better make an appointment with his GP.

He rings and the Receptionist happily offers him an appointment in three weeks time. The man exclaims "Three weeks!"

The Receptionist, now not quite so happy, says "Well, what is wrong with you?"

The man replies "Now or then?"



## **UK Plan for rare diseases consultation launched - 29th February 2012**

Earlier diagnosis of a rare condition and better co-ordinated care will help improve the quality of life for people with rare diseases and their families, according to the first ever UK plan on rare diseases, published for consultation today by the Department of Health.

Rare diseases – those that affect fewer than 5 in 10,000 of the population - can affect anybody at any stage of their life, and can affect physical or mental health or both. They can range from debilitating, life-limiting conditions to manageable conditions that don't affect daily living.

The UK already has a strong record of supporting and treating people with rare diseases through dedicated healthcare professionals who provide care for complex conditions, world class research and strong patient engagement. This plan will build on this.

The rare diseases consultation:

- recommends using specialist centres to make exact diagnosis – this will make sure people are treated earlier and in some cases this could save lives
- acknowledges that all doctors should have the right training to be aware of the possibility of a rare disease
- recommends that the care of patients with rare diseases should be better co-ordinated

Health Minister Lord Howe said:

“The UK has a good story to tell about supporting and treating people with rare diseases. But we know the challenges people face and that there is always room for improvement.

“This is the first time the UK has had a coherent set of proposals on rare diseases which outlines how we can build on our strengths through improved co-ordination of services, stronger research and better engagement with patients and their families.

“These proposals will benefit patients and help the NHS to be more efficient and co-ordinated, as well as save money. A recent unpublished study has shown that better care of patients with rare neuromuscular diseases could save the NHS £31 million per year by avoiding emergency admissions.”

Bruce Keogh, NHS Medical Director said:

“I welcome the publication of the consultation document on rare diseases. It clearly demonstrates the importance the Government attaches to the treatment of patients with rare conditions.

“In England, much of the implementation of the final plan will be for the NHS Commissioning Board to take forward in its role as single, national commissioner for specialised and highly specialised services.”

### Background

This is a UK-wide consultation undertaken by the Department of Health on behalf of all 4 UK health administrations. The consultation on rare diseases has been launched today following the European Council's recommendation that every member state of the European Union should develop a national strategy on rare diseases. Responses to the consultation will inform the final plan, which is due to be produced by the end of 2013.

The UK participates in rare disease research at European level and will be actively involved in the new International Rare Disease Research Consortium.

The closing date for responses is Friday 25 May 2012.

**Editors Note: PSN will be responding to this Consultation. Any member who would like to comment please get in touch by 1st May 2012.**

## **PARTNERS IN POLICYMAKING**

**<http://www.partnersinpolicymaking.co.uk/>**

Partners in Policymaking is an umbrella name for a suite of leadership training courses for disabled adults, parents and carers of disabled children, professionals and other service providers working in education, health and leisure. It has grown over the past 10 years into further leadership courses and the development of a national network of people - champions who believe that all people should have the right to live the life they choose.

Having a disability or having a disabled child means that you may need support. The support can come from lots of different places and organisations such as health, social services, education and leisure services. Sometimes trying to get what you need and getting access to the right information seems very complicated.

Partners in Policymaking (PiP) and associated courses help people understand how the health and social care system works, organise meetings and present questions without getting frustrated. All PiP courses aim to help find solutions to improve people's lives and give participants the confidence to work in partnership to enable them or their loved ones to have choice and control over their lives.

Over the past five months I have been attending a Partners in Policymaking Course - Sharing Knowledge - at Lincoln College, five lots of two full days. We have been a cross section of disabilities - some like me with the disability and some parents of children with a disability. Hearing issues that we are coming up against from a different perspective has been really interesting and informative for us all. Now when we discuss health and local government issues we have a wider base of experience and people we can contact for more information. Not only those on our course but access to all 2000+ graduates ahead of us.

One of the speakers was Sarah Hill from Postural Care and it seemed to be just for people with multiple complex disabilities. However, I soon realised that some of the issues Polio Survivors have with the way our spines are now [scoliosis, kyphosis, lordosis] and body positioning paralysed or weak limbs at night might be helped. I discussed Richards and my issues with Sarah and we will be having a home assessment in a few days time. Sarah, or one of her team, will be coming to speak at our AGM and look forward to learning more about our polio issues and offering some possible solutions.

Another speaker was Steve McGuinness on the Autistic spectrum. Why would Polio Survivors be interested in these subjects you may be asking? We watched an 11 minute piece with snippets of animated children's drawings and video clips, with a variety of sound effects alongside the commentary. At the end of the piece we were asked for our comments, which were varied. The two people with autism explained how they saw it, so I said 'I do not have autism but had to look away from the screen to hear the commentary.' I was told this was really interesting and did I have a neurological condition. I then explained that there are times during the day that I may be concentrating on something on the computer, watching tv, reading something and I would not hear the first half of Richards sentence unless he first called me by name to break into my space. And this is when he is sitting right next to me! I had wondered if it was a hearing loss, or an inability to concentrate as I can no longer multi task, or ? Only ten days ago I had a hearing test that showed only 'mild loss'. People with autism can experience problems in a variety of ways, too much sound, too many colours, too many people in a small space, etc., and they cannot process all of this. I will be meeting Steve again to discuss this further and will let you know what I learn.

Another speaker was Phoebe Caldwell, and those with access to the Internet can watch some video clips and a full presentation on her website [Films] [www.Phoebecaldwell.com](http://www.Phoebecaldwell.com). She is an Interactive Communication Practitioner and demonstrated how to communicate with people who have difficulties in that area. My simple explanation, although the work is more complex, is that

you need to listen with all your body to how they are communicating with themselves and use that to start communication with them, e.g. Use similar sounds to those they are making but add a higher emphasis at the end as though it was a question. I came home and started to 'listen' to not only the sounds but how the cat behaves towards us at different times of the day and I have now been able to separate, 'There is no food down for me, the food there has been down there too long and I would rather have fresh, I am just saying hello, or please move your leg so that I can get more comfortable on your lap.'

These courses are started in the States and are internationally run. So if you might be interested in learning more have a look at Lynne Elwell's website.

We were asked to present our groups presentation on issues with assessments again on Monday to an audience of 90 commissioning and other staff. We used PowerPoint, role play, case history and humour to showcase a few problems and possible solutions to save money, time and stress.. We demonstrated that we were able to bat at their level, and this has made a difference.

## **Coconut Oil: Another of Nature's Miracles?**

Coconuts have received a lot of bad press in the last decade or two. Warnings about the dangers of fats had coconuts on the list of harmful foods, but no more.

There are several medical disorders that block fuel molecules from getting from the blood to the body's muscle and nerve cells. According to research, coconut converts to very small fuel molecules able to reach cells previously deprived of fuel. In this way coconut is believed to reduce the symptoms of such disorders.

The list includes: Parkinson's Disease, Chronic Fatigue, Alzheimer's and other neurological disorders. According to The Coconut Research Center studies have shown that the nut is an anti-microbial and helps protect against cancer, diabetes, thyroid problems, increases good cholesterol, and protects just about every part of the body.

Recommendation: 1 tbsp. of virgin coconut oil (comes as a paste) per day for maintenance, up to 5 per day when symptoms of a disorder are present.

Sources: [www.coconutresearchcenter.org/](http://www.coconutresearchcenter.org/),

[www.youtube.com/watch\\_popup?v=ZZOR-Qd3QSg](http://www.youtube.com/watch_popup?v=ZZOR-Qd3QSg)

[www.naturalnews.com/032727\\_coconut\\_oil\\_Alzheimers.html](http://www.naturalnews.com/032727_coconut_oil_Alzheimers.html)

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March/April 2012. [www.ppsmanager.com](http://www.ppsmanager.com)

Editors Note. The following link is an article in the Tampa Bay Times, Florida, that my daughter sent to me about six weeks ago.

October 29th 2008.

[www.tampabay.com/news/aging/article879333.ece](http://www.tampabay.com/news/aging/article879333.ece) - United States

Summary beside the picture.

After two weeks of taking coconut oil, Steve Newport's results in an early onset Alzheimer's test gradually improved says his wife, Dr. Mary Newport. Before treatment Steve could barely remember how to draw a clock. Two weeks after adding coconut oil to his diet, his drawing improved. After 37 days, Steve's drawing gained even more clarity. The oil seemed to 'lift the fog', his wife says.

I searched and found a few more articles and my husband and I decided it was worth trying. We purchased the 'Raw Organic Coconut Oil' from a health food shop then found our local Tesco stocked it. We have added a tablespoon to our morning porage, cinnamon and berries.

We gave copies of the articles to Richards Parkinsons Consultant and our Chiropractor, Dr. Darren Barnes-Heath and we will report on their views after we see them next time.

## **Member and Author Di Taylor would like to hear from you.**

I am attempting to locate all polio survivors, and their friends and families.

“I would like to include everyone who may know of any polio survivors, so I can glean their tales, and write them for others to read. From diagnosis, through treatment or operation, whatever it may have been, I would love to hear.

I contracted polio at the age of 7 months, and grew up wearing callipers on my left leg. Abandoned only when I turned 14, at the start of surgery!

Don't be shy at coming forward – you can always do this by giving a false name if you so wish.”

Stories may be published in Post Polio Matters or eventually made into a book. All doctors, surgeons, alternative practitioners, are invited to write their patients' treatments (using pseudonyms) too, as so little is known in the UK about polio in the UK.

**Contact Di at: 01444 400130**

**OR**

**Email on: [textworks202@btopenworld.com](mailto:textworks202@btopenworld.com)**

### **The Neurological Alliance - Part of the summary of the January Trustees Meeting.**

**Received 13th March 2012.**

#### **Campaigning**

#### **Health and Social Care Bill amendment on commissioning for less common conditions**

The Alliance's Health and Social Care Bill sub-group has continued to press the issue of a commissioning for people with less common neurological conditions. To add strength to our voice, the Alliance has built a coalition of 27 organisations with a similar interest, including Royal Colleges of Psychiatrists and Physicians, Help the Hospices and Pancreatic Cancer UK, to support our position.

Baroness Finlay tabled two amendments at report stage of the Bill, aimed at ensuring clinical commissioning groups will be required to collaborate when commissioning services for people with less common conditions. In advance of this we placed an article in House magazine for parliamentarians and our press release on the issue was picked up in the Observer.

As our amendments were not moved at report stage, we are currently exploring whether to table a further amendment at the Bill's Third Reading in the Lords and have discussed our concerns with the Shadow Health Team at a recent small roundtable event.

Our latest intelligence is that the Bill will pass from the Lords to the House of Commons on 20th March, where it will conclude its passage through Parliament.

Thanks to the sub group and Parkinson's UK press team for their work on this.

#### **National Audit Office (NOA) report campaign - Services for people with neurological conditions.**

Our campaign around the NAO report has resulted in over 1,200 sign ups to the e action. 77% of MPs have now heard about our campaign and 92 have signed our Early Day Motion calling for an outcomes strategy for neurology. Thank you for your support so far - please help us keep up the pressure by continuing to promote our e campaign through your newsletters, Twitter and Facebook.



# Management Committee [Trustees] and Operations Team

## Management Committee [Trustees]

Chair - Position Vacant

Secretary - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk

Treasurer - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk

Glenna Tomlin - Glenna.tomlin@poliosurvivorsnetwork.org.uk

## Operations Team

Membership Secretary - Gillian Bryan - membership@poliosurvivorsnetwork.org.uk

Phone and Email Enquiries - Hilary Boone - info@poliosurvivorsnetwork.org.uk -

Administrative Support - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk

Website Administration - Dave Eate - webadmin@poliosurvivorsnetwork.org.uk

 [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

**Friend/Supporter.** If you would like to support the Polio Survivors Network you can do so by making a yearly donation of your choice.

You will receive a yearly update of our activities and be invited to our AGM.

### Membership Fees

Individual - £ 12.50 per year

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

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

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

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

Email:- membership@poliosurvivorsnetwork.org.uk

All Forms are available on our Website, by phoning our helpline or writing to us.

## 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. Between 6 April 2008 and 5 April 2011, the government will also give UK charities an extra 3% of all eligible donations. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year.

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

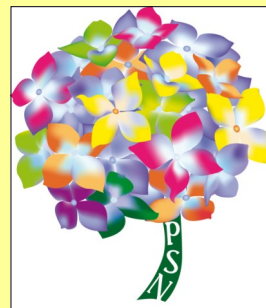
# Polio Survivors Network

Registered Charity No. 1064177

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

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



## Traveling Without A Spare

*A Survivor's Guide to Navigating  
the Post-Polio Journey*

WENZEL A. LEFF, MD

### Traveling Without A Spare:

#### A Survivor's Guide to

#### Navigating the Post-Polio Journey,

Is Dr. Wenzel A. Leff's first book [209 pages]

He was born and raised in Mobridge, South Dakota, the third of six children. After graduating from medical school at Washington University in St. Louis, Missouri, he began a long and active practice in Internal Medicine.

Dr. Leff draws on his own polio experience and his forty-plus-year career in Internal Medicine, to provide polio survivors and their families, caregivers, and healthcare team a clearer understanding of the stages and complexities of polio.

This informative book will help survivors evaluate their own bodies and condition, and empower them to make the most of their remaining strength and mobility.

WAL Publishing LLC

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