



# POST POLIO MATTERS

The Polio Survivors Network Newsletter - Volume 7, Issue 6  
n.b. Volumes 1 to 6 published under the name LincPIN.  
[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

**December  
2011  
Volume 7  
Issue 6**

**Information  
from the  
EU PPS  
Conference  
in  
Copenhagen  
31.8.2011  
and the  
Third  
Breathing  
Symposium  
at the Salk  
Institute  
29.10.2011  
Pages  
6 to 15**



**Back Page  
Cartoon and  
Page 18**



**Wickes generous donation  
enables PSN to launch our  
updated Website.**

**Wickes**  
*It's got our name on it.*

## Seasons Greetings



and

# Happy New Year 2012

# PSN AGM

23rd June

2012

In Midlands

## 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)

**Poliosis**  
is the decrease  
or absence of  
melanin  
(or colour)  
in head hair,  
eyebrows, or  
eyelashes

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## New Members and Donations received.

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

Thank you to the following for donations given towards our work  
Nicholas Harvey, John Doohan, Shirley Rose, Maureen Allison,  
Stuart Tanfield, John Finley, Dorothy Ives, J Simm, Ann Telford,  
Joy Witheridge, J Curtis, Lesley Forsyth, Victor Gabriel,  
Rosemary Staniforth, Brian Thompson, Janet Dobbie, Bridget Langdon,  
Yvonne Liggins, Sandy Yarrow, Ann Stone, Hilary Davies,  
Margaret Lamb, Winifred Hyam

### Val Scriveners Card Sales so far this year adds £50.00

Donations since last notified is **£ 454.00**

We have no paid employees. We would like to recognise and thank the  
following for so generously donating their time. The Trustees, Chris  
Salter, Dave Eate, 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  
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when permission must be gained from the original author/s.

## Editorial by Hilary Boone

**Please read Message from Trustees on page 4.**

**Info for Members not on the Internet.** In this issue I have listed a huge amount of information, PowerPoint, Video and Poster presentations and medical articles from the European Polio Union Conference in Copenhagen and the Breathing Symposium 2011 at the Salk Institute, California. We do appreciate some of our members do not have Internet Access and may not have relatives or friends who can access information for them. If you fall into this category and notice something that you want more information on then please ring or write to us and we will see what we can do to help.

**Last issue article on Gastrointestinal Problems.** I would like to thank the members who did ring or email me to discuss this/their issues. I have added some information taken from the EU Conference presentation number 28 Voiding and bowel problems on page 13.

**Financial Year** - We have changed from April to March to a full calendar year. This year will therefore only be for 9 months and the next year will run from January 1st to December 31st 2012.

**Annual General Meeting** - This will be held on the 23rd June 2012 in the Midlands. We will have at least two speakers on a post polio related issue. We will notify you as soon as the venue has been confirmed. It would really help us choose which room size if all members who would be interested in attending on that day could write, email or phone us. Thank you for your assistance.

### **“MAKING PEACE” WITH YOUR NEW FOUND HELP.**

The following was published on a polio email discussion list. I repeat this with permission from the author.

We have a new member, who has asked me a question. The question is "Does anyone have any hints as to how to adapt to using a wheelchair, after years of not needing one, and finding that a wheelchair is now desirable?"

I'll add my own two cents to this discussion by saying:

- 1) Do one of your longer, more tiring errands, using your new wheelchair.
- 2) Ask yourself, during the errand, were you able to concentrate on what you came to do, or were you thinking about "how can I get this done with the minimum of walking and effort"?
- 3) At the end of the errand, did you have energy left to do some other things you wanted to do that day? Especially fun things?
- 4) At the end of that day, were you as tired as you would have been, had you walked?
- 5) If you take pain meds, assess your level of pain at the end of the day? Better?

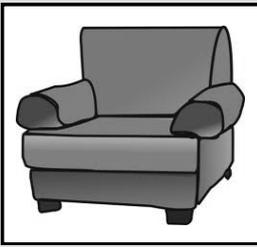
If the answer to most of these questions is that using the wheelchair made each day less tiring, more productive, and left you with some energy to enjoy the nicer things in life, then using the wheelchair was a "gift"

The more you see it as "enabling" you to do things, rather than making it harder, the closer you have come to "making peace" with your new found help

### **Polio Survivors Network - Meeting information**

The next Trustees Meeting is being held by Skype in January 2011  
If you have any matters for our attention at our meetings please get in touch via  
[info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk)

Early notification of the AGM - 23rd June 2011 in the Midlands.  
or Tel: 01522 888601 or write to us at Polio Survivors Network PO Box 954, Lincoln LN5 5ER



## PSN NEEDS U



**Dec 2011**  
**“I went to the retail park just around the corner, when I got back all the hairs on my legs were holding hands to keep warm”**

**Member**  
**John Hinton**

## Message from the [Chair] Trustees.

### New Logo and updated Website Launch.

As stated on the front page the multi coloured flower was chosen to reflect the variation in how polio has and is affecting our lives.

Your committee are doing their best to manage their PPS lives and give up what time they can to Polio Survivors Network. Publishing the Members Survey and work on our new Branding - which involves changing our Website and all Publications etc thanks to the generous donation from Wickes - has taken a lot of ‘woman’ hours and we are doing our best but must apologise for being behind our intended schedule. Once this newsletter is published and posted then we will concentrate on the other PSN publications we are working on. In the meantime please let us know what you think of our efforts and we welcome suggestions for further improvements.

### PSN Needs U

At the moment the post of Chair is vacant. The remaining Trustees, Hilary, Glenna and Gill are sharing the workload between them.

Once again we ask our members if they or anyone they know would be interested in joining PSN to share out the tasks needed to keep this organisation going whilst there are still polio survivors in need of support.

Whilst we need to increase our small committee of three you do not have to be on the committee to undertake a task. So get in touch with us if you would like to talk about how you might help. Helping with the committee work, raising funds, and some other ideas are:-

- Reading and précising medical articles, video presentations, etc.
- Letting us know what is happening in your county NHS wise. i.e. Are your Clinical Commissioning Groups up and running?
- Letting us know about any Hospital Clinics and any other health professional you see that are helping you manage your life to a greater degree.
- Sending us information for use in the newsletters:-
  - Interesting articles/items in magazines, brochures etc.
  - Visiting Naidex, Motability Roadshow your local Independent Living Centre or Disability Store. Did you find anything of interest?
- Tell us what is happening in your County in Adult Social Care.
- Help us answer our members questions. See example on the next page.
- Anything else you can think of that would benefit polio survivors.

Looking forward to hearing from you.

**Wishing all members, their family and friends**  
**Seasons Greetings and all the best for a**  
**Happy, Healthy as Possible and Prosperous New Year.**  
**Hilary, Glenna and Gill.**

## Question asked by Member Lynn Hobday.

### 'Does PSN have any new ideas how to keep our legs warmer?'

I asked for help not only on our members list but also on another Polio email list that I subscribe to. Here are the responses from the extended discussions starting with our Members.

**Hilary** says - Your legs should be warmest after you have been in bed for some time and therefore if you can - or if you don't live alone and can get help - put on items under the covers or as soon as you take the covers off and then add layers. After a warm bath is a good idea but not if the room is not warm too as it may only be the outer layer of your legs that has warmed up.

**Pat** says - Pure silk underwear - I get mine from John Lewis.

**Anne** says 'M&S thermal underwear - It has to be really hot before I discard this.'

**Dinah** - Mohair socks and a few years ago I bought a duvet called 'Climarelle' made of a man-made fibre which adjusts to one's body temperature, expensive but worth every penny.

**Zsuzsanna** - Heated insoles with rechargeable batteries from Warmawear.com [Warmawear – Fynzi Limited, Building 173, Curie Avenue, Didcot, OX11 0QG Telephone. 0800 161 3832

**Chris Salter** - Battery Heated Socks - [www.amazinghealth.co.uk/battery-heated-socks.htm](http://www.amazinghealth.co.uk/battery-heated-socks.htm). Heated Insoles - [www.amazinghealth.co.uk/heated-insoles.htm](http://www.amazinghealth.co.uk/heated-insoles.htm). Note different insole products may have different heating areas, the next url claims "New 2011 heated insoles with larger heating area are essential for anyone that suffers with cold feet." [www.blazewear.com/e-catalogue.pdf](http://www.blazewear.com/e-catalogue.pdf). Then there are the rather expensive 'state of the art' Thermo Soles!! [www.thermosoles.eu/](http://www.thermosoles.eu/)

**Beverley in USA** - a heat pad for the area of my bed where leg is coldest and my four cats and German Shepherd dog fight over who gets nearest to this.

**Eddie in USA** - told us about the Christchurch based The Merino Company and Mt Maunganui based product development company, Locus Research, have scored a major international win with a Medical Design Excellence Award (MDEA) announced in the United States for their innovative range of merino wool compression garments designed and developed in New Zealand. If you don't need a compression garment look for Marino wool underwear and socks.

### Non members responses.

**Roxann in chilly Indiana** - asked her polio group and Meg their leader has an idea. She has cold toes and can't wear two pairs of socks because they won't fit in her shoes. So she cut two to three inches off the toes of her husband's old socks and that small toe piece fit over her toes and fit into her shoes and now she has warmer toes.

**Mary Ellen in Texas** - The Hot Hands and Feet Packs hunters use and are rechargeable.

**Donnie in USA** - Flannel pyjamas with collar at night and turn collar up and layers when out and have even worn two or three hats when taking dog for a walk in really cold weather.

**Jeff in Ohio** - Using an electric blanket just to warm the bed up before I get in and only having it on a very low heat if its really cold.

**Susan in USA** - My arms and shoulders get cold at night in the winter but my torso gets too hot if I wear a full sweatshirt to bed so I wear a long sleeved t-shirt to bed but I also took an old sweatshirt, cut the body off it straight across from one underarm to the next. I wear that on top of my t-shirt. After cutting the body of the sweatshirt off it was left with sleeves, shoulders and neck only - like a shrug. Keeps my shoulders and arms warm.

**Lady at NA AGM in wheelchair** - long fingerless gloves from Dorothy Perkins are great.

### **Pat Asked - Does anyone know where a polio survivor can now get a sheepskin lined heated boot?**

**Answer** Try Columbia products by [www.columbiasportswear.co.uk](http://www.columbiasportswear.co.uk) main store is at 170 Kensington High Street, London. Tel. 0207 937 2486



**Polio Survivors Network**  
**A member of the**  
**European Polio Union**

**Post Polio Syndrome - a challenge of today**  
**European Conference, Copenhagen, Denmark, August 31st to September 2nd, 2011**  
European Polio Union [EPU] and the Danish Society of Polio and Accident Victims [PTU]

provide the following information post Conference

### **PowerPoint Presentations**

[www.poliocconference.com/Power%20points.php](http://www.poliocconference.com/Power%20points.php)

### **Video presentations**

[www.informed-scientist.org/congress/european-conference-on-post-polio-syndrome](http://www.informed-scientist.org/congress/european-conference-on-post-polio-syndrome)

### **Poster Presentations**

[www.poliocconference.com/Poster%20presentations.php](http://www.poliocconference.com/Poster%20presentations.php)

### **Abstracts in the Journal of Rehabilitation Medicine**

**J Rehabil Med 2011; Suppl 49: 1–64**

[www.poliocconference.com/Suppl\\_49\\_postpolio\\_lag%20%20FINAL%20%20august.pdf](http://www.poliocconference.com/Suppl_49_postpolio_lag%20%20FINAL%20%20august.pdf)

Numbers refer to the numbers in the programme and in the supplement of Journal of Rehabilitation medicine. Not all presenters used PowerPoint therefore some numbers are missing. Starting with PowerPoint presentations.

- 1 Progress of the eradication of polio from WHO's perspective, Rebecca Martin WHO
- 3 Post polio syndrome, overview of current knowledge, Frans Nollet MD
- 4a Improving worldwide networking to improve the lives of all survivors, Joan Headley, Director of Post-Polio Health International.
- 4b Improving worldwide networking to improve the lives of all survivors, Johan Bijttebier, President of EPU,
- 5 & 9 Pathogenesis of PPS and persistence of poliovirus genomes, Antonio Toniolo MD
- 6 Research methodology, Fieke Koopmann MD
- 7 Pharmacological treatment and medical precautions, Kristian Borg MD
- 10 Immune modulation and a potential biomarker, Kristian Borg MD
- 11 Treatment for PPS: Results from a Cochrane review, Fieke Koopmann MD
- 12 Revised EFNS guidelines for diagnosis and management of PPS, Elisabeth Farbu MD
- 13 Diagnostic tools, Laura Bertolasi MD
- 14 Electrodiagnostic studies: What, When, Why, Why not? Arzu On, MD.
- 15 Differential diagnosis, Marianne de Visser MD
- 16 Rehabilitation assessment, Frans Nollet MD
- 17 Australia's polio health and wellness retreat, Mary-ann Liethof
- 18 The warm embrace of peer support, Anne Shanahan
- 19 Disuse osteoporosis in the patients with post polio syndrome, Jülide Öncü MD
- 21 Orthopaedic surgery in polio survivors, Anders Stenström MD
- 22a Anesthesia issues for polio survivors, Professional track, Selma Calmes MD
- 22b Anesthesia issues for polio survivors, Patient track, Selma Calmes MD

- 23,24 Respiration and sleep, Speech and swallowing, Michael Laub MD
- 26 Pain in polio survivors, Katarina Sunnerhagen MD
- 27 a Impact of comorbidity, aging and lifestyle-related factors in polio survivors, Professional track, Irene Tersteeg MD
- 27 b Impact of comorbidity, aging and lifestyle-related factors in polio survivors, Patient track, Irene Tersteeg MD
- 28 Voiding and bowel problems, Lise Kay MD
- 29 a Falls among polio survivors, Professional track, Alice Bickerstaffe MD
- 29 b Falls among polio survivors, Patient track, Alice Bickerstaffe MD
- 30 Exercising for polio survivors, Deidre Murray PT
- 31 Psychological aspects of polio survivors through their life experience, Alain Yelnik MD
- 32 Participation in society, Jan Lexell MD
- 33 A needs based Rasch standard quality of life scale, Allan Tennant MD
- 34 An exploration of different coping strategies, Anne Marie Quincey, Ass. Psychologist
- 35 Never second best? Shaping and reconstruction of identity, A.K. Schanke, Psychologist
- 36 Factors influence the quality of life of poliomyelitis, Anita Atwal OT
- 37 International classification of functioning, disability and health, Frans Nollet MD
- 38 Muscle strength measurement, Anita Beelen PhD
- 40 Outcome measures for pain, Troels Staehelin Jensen MD
- 41 Outcome measures for physical functioning, Merel Brehm, OT
- 42 Outcome measures for participation and quality of life, Katarina Sunnerhagen MD,
- 43 Managing the complexity in daily occupations, Anna Lisa Thoren Jönsson OT
- 44 Resistance training in combination with IVIG treatment, Katarina Skough PT
- 45 Intravenous immunoglobulin for post polio syndrome, Emma Frasson MD
- 46 Physiotherapy as part of a multi-disciplinary rehabilitation, Susse Broberg PT
- 48 General perspectives of aging, Kirsten Avlund OT
- 49 Leg orthoses for polio survivors: Numerous innovations, limited evidence, Merel Brehm OT
- 50 A systematic seating assessment, Anna-Lene Hartvigsen PT
- 51 Role of exercise, Carin Willén PT
- 52 Role of aerobic exercises, Jülide Öncü MD
- 53 How to target aerobic exercise training in polio survivors, Eric Voorn MSc
- 54 Orthosis management Dr. Barbara Bocker MD
- 55 Light weight full contact carbon leg orthoses, Orthotist Kees Noppe
- 56 Evaluation of the function of pelvic floor muscles, Mirca Ocanhas PT
- 58 Fatigue in patients with post polio syndrome Anita Beelen PhD,
- 59 Experiences in daily occupations of immigrants with late effects of post polio, Iolanda Tavares OT
- 60 Rehabilitation in a public health perspective Claus Vinther Nielsen MD
- 61 Interdisciplinary teamwork, Jan Lexell MD
- 62 The value of investigating patient perspectives, Karen Schipper Psychologist
- 66 Cost effectiveness, Kjeld Møller Pedersen, health economist
- Summary of the conference, Frans Nollet, MD

### **Poster Presentations.**

- 68 Comparison of self-reported fatigue in Post-Polio Syndrome patients and age matched controls Charlotte Lucy Taylor, Honorary Research Assistant

- 70 Relationship between lower limb muscle strength and gait performance in persons with post-polio syndrome Ulla-Britt Flansbjerg, PhD, RPT; Christina Brogårdh, PhD, RPT; Jan Lexell, PhD, MD, Physician
- 71 Relationships between objectively and subjectively assessed gait performance in persons with post-polio syndrome Chrstina Brogårdh, PhD, RPT
- 72 The WHOQOL-BREF provides a valid measure of Quality of Life in Post Polio Syndrome Dr Ian Pomeroy, Neurologist
- 73 Post-polio syndrome and amyotrophic lateral sclerosis - similarities, differences and diagnostic dilemmas Ewa Matyja MD, PhD, Milena Laure-Kamionowska MD
- 79 Prescription of and satisfaction with the use of lower limb orthotic devices in persons with post-polio syndrome Christina Espelund, RPT, MSc
- 81 Energy cost of Walking in Prior-polio Patients Deirdre Murray, Clinical Specialist Physiotherapist
- 82 Exercise therapy and cognitive behavioural therapy in Postpoliomyelitis Syndrome: The FACTS-2-SUMMARYS study Fieke Koopman MSc
- 83 Voiding problems in a Danish population of polio survivors Lise Kay, MD; Merete Bertelsen, PT
- 84 Reported problems in relation to operation and anesthesia in a Danish population of polio survivors Lise Kay, MD; Merete Bertelsen, PT
- 85 The ventilatory threshold in patients with Postpoliomyelitis Syndrome Anita Beelen, PhD, Manger Research
- 88 An exploration of fatigue from the perspective of people with Post Polio Syndrome Samantha M Wong, Assistant Psychologist
- 89 An exploration of the impact of Post Polio Syndrome on needs based quality of life Anne-Marie C Quincey, Assistant Psychologist
- 90 A positive turning point in life. Experiences of a comprehensive interdisciplinary rehabilitation programme in persons with post-polio syndrome Jan Lexell, PhD, MD, Physician
- 91 Self-perceived impairments in persons with post-polio syndrome Jan Lexell, PhD, MD, Physician
- 92 Self-perceived participation restrictions in persons with post-polio syndrome before and after interdisciplinary rehabilitation Jan Lexell, PhD, MD, Physician
- 93 Occupations that persons with post-polio syndrome perceive difficult to perform in daily life Katja Appelin, OT, MSc
- 95 Post Polio Syndrome in British Columbia, Canada Joan Toone, President PPASS, BC
- 96 Polio Services Victoria: An Australian A Summary Approach to Effective Care for Polio Survivors through a "Hub and Satellite" Model. Blaise Doran BSc (Hons) Physiotherapist
- 98 Post-Polio Syndrome: Situation in Spain and proposals for action Jose M Amate PhD \*, Carmen Bouza PhD \*, Zuleika Saz-Parkinson PhD \*, Maayken Van Den Berg PhD Juan M. Castellote PhD

**Polio Survivors Network** have picked a few excerpts from the PowerPoint, Video, Poster Presentations and abstracts of the Conference in the Journal of Rehabilitation Medicine 2011, Supplement 49 to entice you to learn more about the widely varied issues that we experience. It is important that you read/watch the entire presentations and information provided to ensure that statements are not taken out of context. We hope this information will be of benefit when you discuss your issues with your health professionals.

# Enticing EPU Conference Excerpts

## No. 3 - Post Polio Syndrome - overview of current knowledge

*Frans Nollet, MD, PhD*

*Academic Medical Centre, Department of Rehabilitation, Amsterdam, The Netherlands*

*E-mail: f.nollet@amc.uva.nl*

### **Abstract from the J Rehabil Med 2011; Suppl 49: 1–64**

Post-polio syndrome (PPS) is the late decline in muscle function after many years of stability following the recovery of acute poliomyelitis. Although PPS has been anecdotally reported in the medical literature since the late 19th century, it was only in the early 1980s that PPS became recognized as a frequently occurring late consequence of polio when large numbers of people who had caught polio 30–40 years earlier during the large epidemics started to deteriorate in muscle function.

The diagnostic criteria that are now generally accepted are those as formulated in a consensus meeting by the March of Dimes in 2000. It must be emphasized that the diagnosis of PPS is made by exclusion, and other causes that may explain symptoms must have been ruled out.

The prevalence of PPS in polio survivors is estimated between 40 and 60%. From longitudinal studies, the decline in muscle strength is estimated at approximately 2% per year. More severe paresis has been reported as a prognostic factor for the decline in physical functioning.

The cause of PPS is not known. The most widely accepted hypothesis is that motor neurons in the spinal cord age prematurely due to the high metabolic demands and lose their ability to maintain the large motor units that were formed in the recovery phase after the acute polio. In recent years, it has been suggested that an inflammatory process might underlie PPS based on findings of raised concentrations of cytokines in the cerebrospinal fluid.

No pharmacological therapies sufficiently stop the decline in muscle function in people with PPS. Intravenous immunoglobulins have shown varying results and require further study.

Rehabilitation interventions, such as physical training and lifestyle adaptations by behaviour modification, are commonly applied to reduce symptoms and preserve functioning. Physical therapy aims to reduce symptoms of overuse of weakened muscles, to limit the disuse of non-affected muscles, and to improve cardiorespiratory condition. Physical overload in daily life must also be reduced. This might require changes in activity pattern and the use of mobility assistive devices and home adaptations.

### **Key-points:**

- The cause of PPS requires further study.
- The effectiveness of intravenous immunoglobulins needs further study.
- Randomised controlled trials of rehabilitation interventions are needed to show the effectiveness of multidisciplinary symptomatic treatment.

### **PowerPoint Presentation Slide 12 - Polio paresis a continuum!**

Beasley (1961):

‘A widespread view postulates the effects from poliomyelitis into two categories: paralytic and non-paralytic. If this were valid, quantitative muscle testing should result in two separate distributions: one at a ‘paralytic’ level far down the line from ‘normal’; the other, if truly non-paralytic, should remain within the bounds of a distribution for normal subjects.’

**‘Rather, there is a continuum in degree of paresis, with moderate amounts being more frequent than truly severe amounts.’**

*Beasley WC. Arch Phys Med Rehabil 1961;42:398-425*

## PowerPoint presentation Slide 18 Cause of post polio syndrome

Leading hypothesis:

- Loss of unstable newly formed axonal sprouts due to premature metabolic exhaustion of chronically overloaded motor neurons which had to maintain enlarged motor units for many years.

Alternative hypotheses:

Chronic inflammation in the Central Nervous System  
Virus (fragments) persistence

*Wiechers & Hubbell, 1981 Gonzalez, Borg 2002. Toniolo, 2007*

## PowerPoint presentation Slide 22 Therapy guidelines

Exercise

Aerobic exercise to maintain muscle status

Behaviour

Patient education to improve mental status and well being  
Psychosocial support to change behaviour

Other

Properly fitted assistive devices  
Weight loss  
Mobility aids and environmental adaptations

*EFNS Guideline, Farbu et al. 2006*

## PowerPoint presentation Slide 29 Care for post polio syndrome in the EU

1. PPS recognized but knowledge is low and interest questionable.
2. Specialized care is scarce.
3. Access to 'help' is bad in 50% or more of the countries for social work, psychologists, adaptations at home and work, transportation and housing.
4. Research should focus in the first place on symptom management (pain, fatigue) and therapies (medication and rehabilitation).

**PTU The Danish Society of Polio and Accident Victims  
Fjeldhammervej 8, 2610 Rødovre, Copenhagen, Denmark**

**PTU Rehabilitation Center** offers specialized multidisciplinary rehabilitation treatment for persons with polio and other physical disabilities

**The 3 week program - £ 8,500.00 - comprises:**

Assessment and treatment by neurologist, physiotherapist, occupational therapist, psychologist  
Individualized exercising programme  
Group exercises sessions  
Technical aids counselling  
Exercise and relaxation in warm pool  
Free access to the training facilities  
Free use of technical aids and use of massage chair.  
Accommodation and all meals

**For more information - [http://issuu.com/ksoptu/docs/3\\_weeks\\_treatment?mode=window&backgroundColor=%23222222](http://issuu.com/ksoptu/docs/3_weeks_treatment?mode=window&backgroundColor=%23222222)**

or contact PTU: email: [ptu@ptu.dk](mailto:ptu@ptu.dk) phone: +45 3673 9000

The diagnosis of post-polio syndrome (PPS) is made after the exclusion of other medical conditions explaining the new symptoms. Except neurological symptoms, secondary disorders of the locomotory system are quite common and may cause symptoms. Since the acute polio usually occurred at young age, most polio survivors have developed skeletal abnormalities during growth such as shortening, axial and rotational deviations of shaft bones, and hypermobile, hypoplastic joints. With age joints laxity may increase, and osteoarthritis may arise in affected and unaffected legs. Also in the upper extremities degenerative disorders are quite common due to prolonged overuse.

Secondary disorders of joints, ligaments and tendons, may hamper diagnosing PPS. For instance it can be impossible to distinguish whether weakness is due to a decline in muscle function or secondary to symptomatic osteoarthritis of the joint on which the muscle acts. Overuse of (paretic) muscles may cause symptoms of pain and cramps but do not necessarily imply that these muscles are symptomatic due to PPS. It may well be that the complaints are due to overload of muscles that compensate for other, weakened muscles during physical activities.

**[Editors note - Important paragraph regarding how Polio Survivors should be assessed]**

Since multidisciplinary rehabilitation aims to preserve functioning, the assessment of the patient focuses on the execution of activities and in this light impairments are valued. For instance, the strength of a paretic muscle is judged in view of the strength requirements to execute a task such as safe and prolonged walking. Therefore, a functional assessment of activities, such as walking, standing, transferring between bodily positions, walking stairs is necessary to gain insight in the loading of muscles and joints during these tasks. Attention should not only be given to affected body parts but also to compensatory use of less or unaffected body parts. In patients with severe polio residuals, the observation of daily activities is warranted to understand symptoms which result from overload. Clinical gait analysis may be particularly useful to objectify overuse complaints due to gait abnormalities and energy cost measurements can objectify the increased energetic demands of walking due to reduced movement efficiency. These objective tools furthermore allow the evaluation of the effects of interventions, such as braces.

**Key points:**

- Functional assessment is needed to understand the symptoms of PPS which result from overuse during the execution of physical activities.
- Multidisciplinary assessment of daily functioning is the fundament to an individually tailored therapy rehabilitation program.

**nemesis by Philip Roth. Winner of the Man Booker International Prize 2011.**

Summer, 1944. In the 'stifling heat of equatorial Newark', a terrifying epidemic is raging, threatening the children of New Jersey city with maiming, paralysis, life-long disability even death. Vigorous, decent, twenty-three-year-old playground director Bucky Cantor is devoted to his charges and disappointed with himself because his weak eyes have excluded him from serving in the war. As polio begins to ravage Bucky's playground Roth leads us through every inch of emotion such a pestilence can breed: the fear, the panic, the anger, the bewilderment, the suffering and the pain. ISBN 978-0-099-54266-1 Editors note - I could not put it down.

**Overheard two elderly men talking at our clubhouse.** One said 'I went for my hospital appointment last week and the Doctor told me when we diagnose people with the condition you have they can still live happily for ten years, but the shame in your case is we should have told you this nine years ago.' The other looked shocked till the first burst out laughing.

## **No. 12 - Revised EFNS guidelines for diagnosis and management of Post-polio syndrome**

*Elisabeth Farbu, MD, PhD; Nils Erik Gilhus, MD, PhD; Michael P. Barnes, MD, PhD;  
Kristian Borg, MD, PhD; Marianne de Visser, MD, PhD; Robin Howard, MD, PhD;  
Frans Nollet, MD, PhD; Josef Opara, MD, PhD; Erik Stålberg, MD, PhD*

*Department of Neurology, Stavanger University Hospital, Stavanger, Norway*

Some years ago, the European Federation of Neurological Societies (EFNS) decided to try to bring together peer-reviewed guidelines for the treatment and management of neurological disorders. These guidelines should be based on evidence, and where evidence was not available, by consensus of experts from different European countries.

The EFNS task force on post-polio syndrome consists of members from Norway, UK, Sweden, The Netherlands, and Poland, involving different medical specialities and a patient representative. The first guideline document was published in European Journal of Neurology in 2006 as well as in the first edition of European Handbook of Neurological Management.

The revised guideline which is presented here was published in the second edition of European Handbook of Neurological Management 2010.

Medline via PubMed, EMBASE, ISI and Cochrane databases were searched with time limits 1966–2009, and the task force reached consensus after discussion by e-mail. We recommend that The March of Dimes criteria for PPS should be used. [See opposite page]

For specific treatment regimens we found that:

- No therapeutic effects have been reported for pyridostigmine, steroids, amantadine, modafinil, and Coenzyme Q10 (Level A).
- Supervised muscular training can prevent further decline of muscle strength in slightly or moderate weak muscle groups, and can reduce muscular fatigue, muscle weakness, and pain. Precautions should be taken to avoid muscular overuse (Level B).
- There are no data evaluating the effect of muscular training in patients with severe weakness (Level B).
- Training in warm climate and non-swimming water exercise are particularly useful (Level B).
- Respiratory muscle training and early recognition of respiratory involvement with introduction of non-invasive ventilatory aids can alleviate respiratory symptoms (Level C).
- Group training, regular follow-ups and patient education are useful for the patients' well-being (Level C).
- Lightweight carbon orthoses can be more proper than metal orthoses (Level C).
- Weight loss (if adipose) and introduction of properly fitted assistive devices is helpful (Good practice points).
- More studies on Ivlg and prospective follow-up studies evaluating muscle strength and the natural course of PPS are welcomed.

### **Excerpt from Abstract of Summary 14. Electrodiagnostic Studies, What, When, Why, Why not.**

**by Arzu Yagiz On, MD, Ege University Medical Facility, Izmir, Turkey.**

Electrodiagnostic studies are of no value in diagnosing PPS. Then under what circumstances would performing these studies be justified on a patient with a history of poliomyelitis or on a patient with symptoms suggestive of PPS?

The major role of electrodiagnostic studies is to confirm lower motor neuron involvement compatible with previous paralytic polio and to determine degree of motor neuron loss. EMG will also be useful to detect the presence of sub-clinically involved muscles in the patients with symptoms suggestive of PPS. EMG would also be helpful to evaluate concomitant disorders and to identify or rule out other conditions that may cause the similar symptoms of PPS. Another situation where an EMG will be appropriate is when a patient has been misdiagnosed with poliomyelitis. In this situation, EMG will be helpful in ruling out poliomyelitis and in determining the presence of another disorder. [for more info read full article]

### **The March of Dimes Criteria for Post Polio Syndrome 2000.**

- 1. Prior paralytic poliomyelitis** with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness, and atrophy of muscles on neurological examination, and signs of denervation on electromyography (EMG).
- 2. A period of partial or complete functional recovery** after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic functions.
- 3. Gradual or sudden onset of progressive and persistent muscle weakness or abnormal muscle fatigability** (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma, or surgery). Less commonly, symptoms attributed to PPS include new problems with swallowing or breathing
- 4. Symptoms persist for at least a year**
- 5. Exclusion of other neurologic, medical, and orthopaedic problems as causes of symptoms**

### **No. 28 - Voiding problems in a Danish population of Polio Survivors.**

Lise Kay, M.D. Merete Bertelsen PT / lka@ptu.dk

[N.B. Excerpted information - for more information read the full article]

They randomly sampled 453 polio survivors aged between 40 and 89 with a questionnaire concerning the following voiding symptoms:-

Hesitancy weak stream, incomplete emptying, straining, frequency, nocturia [excessive urination at night], urgency, urge incontinence, dysuria [painful or difficult urination.], dribbling, stress incontinence and other incontinence.

During the acute polio attack 20% of polio patients experienced voiding symptoms. [Skinhø 1933 and Wreight 1936]. Theoretically these problems may return with the decline in function experienced by these patients in the long run.

Voiding problems: A thorough anamnesis, physical investigation and a drinking/voiding chart should be done. This may show the way to alleviate problems by simple means such as adjusting drinking and voiding habits or facilitating better access to the toilet. If this does not help then further investigation is needed. The final step is to carry out a full urodynamic investigation, this should be carried out by an urologist who can initiate more complex treatments.

Bowel problems: Constipation can primarily be treated by adequate balance of water and fiber content in the food, and by building up stable toilet habits. Massage of the anal region and sitting in a position with knees up close to the stomach may also facilitate bowel movement. Secondly, laxatives acting by keeping fluid inside the bowel can be used without restriction, while laxatives that push the peristaltic movements may theoretically overload the moving ability of the bowel and make things worse. Enemas can supplement oral laxatives.

The survey revealed more voiding problems than the general population. It has been shown that a reduction in functional ability is a predictive factor for bowel symptoms.

#### **Key points:**

- Voiding and bowel problems experienced by polio survivors can be relieved and if not by simple means patients should be referred to hospital departments with specialists.

### 3rd BREATHING SYMPOSIUM - 2011

## The Salk Institute, San Diego, California, USA

The third symposium was held on 29th October 2011 at the Salk Institute, La Jolla, California. Sponsored by **ResMed** and the **Salk Institute for Biological Studies**. All presentations from each of the three symposia were videoed and can be watched - and are essential viewing for anyone interested in the health of polio survivors - online at [PolioToday.org](http://PolioToday.org) - VIDEOS.

All were welcomed by Cheryl Dean from the Salk Institute with opening remarks by Angela King\*

2011 Presentations are:-

The history and current treatment of polio in China, Fang Han, MD.

Breathing A to Z - Explaining the breathing process., Joshua Benditt, MD, FCCP

Explaining the effects of Sleep Disordered Breathing, Anthony DeMaria, MD

\*Which ventilation equipment is appropriate for your needs? - Angela King, BS RPFT, RRT-NPS.

How various breathing machines work, Karyl Scott, RRT.

To give you some idea of the extent of the information you can gain from watching here are some **excerpted parts** [about 50%] of Dr. Joshua Benditt's presentation which covered the following topics. Pertinent anatomy and physiology; Different types of diseases, post polio and others, according to location of effect; Clinical approach to neuromuscular respiratory disease and Sleep and Neuromuscular disease. [If possible it is preferable to watch the whole presentation]

The Respiratory Pump, a term you will see referred to in medical literature, includes the muscles, the activating force generators that are the diaphragm and also the chest wall also the chest wall muscles and also the nerve that go to these, the motor nerves, the spinal cord and also the brain stem, the medulla and the pons and the motor cortex which for voluntary breathing is necessary. For me to be able to control my breath I need cortical input. Central Control of Respiration. Automatic breathing, when we fall asleep at night, is maintained from these four different centres of the brain stem that allow us even though we are asleep and unconscious to breathe. During the day when awake, get scared, need to talk or sing and control the breath the cortical centres on the surface of the brain function during inspiration and expiration and where we control speech.

Diseases can affect the cortex and central control of breathing.... An example of a disorder of voluntary breathing includes Parkinsons where people feel short of breath with exertion.

Examples of disorders with Automatic breathing include Polio, MS and Central Sleep Apnoea. Polio, if it was very high up in the brain stem, fortunately that was the minority of patients, but that can affect the automatic control of breathing so that some polio survivors have great difficulty during sleep not only due to nerve and muscle weakness but also due to medical control of breathing..... In polio what happens in these motor nerves is there is degeneration during the acute infection and then slowly over time the nerves grow back but not quite as strong, and what we think post polio syndrome is that as we age the nerve rootlets degenerate and we get symptoms in the same muscles groups as when we had polio.

In my clinic I see many patients with PPS. In polio, obviously there is an infection, it affects motor nerves that can be peripheral but can also be in the spinal cord and as high up as the brain stem. But there are other problems that occur in patients with polio because of the weakness of muscles surrounding the spine, the paraspinus muscles. So if you are a child and you get polio and get weakness of the paraspinus muscles and then you are growing those muscles do not support the spine and you get scoliosis. Some of the most severe cases of scoliosis i have ever seen are in post polio patients. This has an extra affect on breathing in that it makes the rib cage very rigid, very stiff and so the weak muscles have a great problem expanding a stiff rib cage. So not only nerve problems, weak muscles but also rib cage stiffness. Lastly the final operator in the chain is the respiratory muscles. This is a diagram from the side showing inspiratory muscles and

the diaphragm but there are also intercostals muscles, and the external intercostals muscles of the chest help us during inspiration. Also if you are exercising, your neck muscles and chest muscles help you to breathe. Expiration, exhalation usually is a passive manoeuvre, so if I take a breath and I relax then I exhale because the elasticity of the lungs and the chest, push the air out. But if we have to cough these exhalatory muscles which are the abdominal muscles and the internal intercostals muscles are critical and I will mention that at the end of the talk. Not only do we need non invasive ventilation but also cough assistance.

Lastly I consider the upper airway muscles, the glottic muscles in the throat to be breathing muscles and the reason I consider them to be breathing muscles is because they are controlled neurologically speaking from the same areas of the brain as the other breathing muscles and they are critical during sleep. So even though the ENT doctor would say 'Get out of my territory', I would say 'Actually they are breathing muscles'.

If you are a neurologist or physician kind of looking to diagnose where might one of these diseases be happening what we do is we look at the history, the physical exam and the lab [test results] and the neurologists are really the experts in this area. They are trying to figure out, ok is the problem up here in the cortex, or in the brain stem or is it in the muscles or the peripheral nerves and I sort of stay out of that area. I let them do that because from my point of view I need to think about three things and I need to think about that at every visit that I see them because breathing out of all the problems that these neuromuscular diseases can cause the most important, I believe, because if you cant breathe as my Respiratory Therapist told me 'if you cannot breathe nothing else matters'.

Every time I see a patient with a neuromuscular disease in my clinic I look to see if the inspiratory side of things the diaphragm and the external intercostals muscles are active. Nocturnal hypoventilation is one of the very first signs of inspiratory muscle failure. I also look for expiratory muscle failure which causes cough problems which you can easily measure that in clinic.

We look at upper airway muscle failure, so particularly for patients with ALS [MND] we are very concerned about them aspirating [food or gastric substance getting into the respiratory tract during breathing in]. When you aspirate and you cannot cough well that leads to pneumonia which is the most common cause of death for any neuromuscular disease. So when you hear about someone who has died in the hospital who had Polio or ALS probably 8 out of 10 times it is going to be because of a respiratory infection.

What do we do in the clinic? I work with a very wonderful respiratory therapist whose name is Louis Boitano, who came here and spoke two year ago. We measure the vital capacity, the biggest breath you can take, blow it all the way out as far as you can and we measure the air that comes out. We then compare it to what it should be for your age and gender and size. Sometimes we measure the maximum inspiratory pressure {MIP}, the maximum force you can breathe in, we have a little mouthpiece and we say breathe in hard and we measure that pressure. For expiratory function, how much can someone exhale, we do something called peak cough flow, I really like this, it is a very good thing to measure for people with neuromuscular disease. We also get a history about upper airway function while they are in clinic, we have a good speech and swallowing clinic where I work and we will send them there where they will sometimes do a barium swallow study to see how swallowing goes or even look at the vocal cords and upper airway.

Sleep and neuromuscular disease are intertwined as closely as can possibly be for the following reasons. When there is weakness of the respiratory and chest muscles it impairs the ability of that pump to work. Often times there is also weakness of upper airway muscles that increases the resistance to airflow during sleep, so if the muscles are weak they kind of collapse a little bit. During REM sleep [Rapid Eye Movement - our system is designed so that all muscles but the diaphragm relax so we do not move about when dreaming and might injure or kill our bed partner. If the diaphragm, either side or both are weak and with no other muscles helping the

likelihood of hypoventilation [small breaths not breathing enough] is very very high. Also because respiratory muscles associated with breathing are working hard during the day they may be fatigued and if you also have kyphoscoliosis - which many with PPS have - it can cause desaturations at night which can be enormous. Having a stiff chest wall also impacts on this.

If you look at sleep in a neuromuscular disease there are incredible amounts of pathology. Snoring, obstructive sleep apnoea, hypoventilation, central apnoea where there is little or no breathing effort at all, 'pseudocentral apnoea's which are probably severe hypoventilations. Sometimes the body protects itself and does not go into REM sleep. With desaturations if your oxygen level is going down and your carbon dioxide level going up, maybe you have morning headaches, sleepiness during the day, then you need treatment to improve your sleep quality, quality and length of life. There is no doubt in my mind that the Gold Standard method of support for people with a neuromuscular disease and sleep disordered breathing to improve their life is a bi-level device with a back up rate and humidification to reduce the dry nose and mouth effect.

CPAP is very common - used in millions of patients worldwide - provides a continuous column of air in the airway and should NOT be used for patients with neuromuscular disease. With respect, what can happen is that sleep doctors think everything looks like a bit like obstructive apnoea and patients get treated that way and we see mistakes because they have missed the fact that this patient has a more complicated situation. These patients need treating differently with a bi-level pressure device [BiPap™, VPAP™] - used in maybe 100,000 or more patients - which cycles between higher inspiratory and lower expiratory pressures and acts like a true ventilator like a machine that takes over from the fatigued breathing muscles, allowing them to rest.

Neuromuscular patients need this because obstructive apnoea can happen in them but the rest is where the muscles are weak you don't take big enough or any breaths at all and need extra assistance. Adjustments can be made during a sleep study or the daily readings from the machine can be looked at and adjustments to the settings made to maximise gas exchange and achieve Saturations >95% and PtcCO<sub>2</sub> are <50mmHg. EPAP [the expiratory setting] will be set at a relatively low level, IPAP [the inspiratory setting] will be higher and adjusted according to the results showing on the machine. A back up rate will be set so that when the patient pauses a normal breathing rate the machine kicks in. The mean setting for back up rate reported in the Mellies et al study in the ERJ 2003,22:631 of 19.2 (12 to 24) we have found is too high for our patients and may have come from the type of patients in their study. End of excerpted info. Repeated we recommend watching the whole video. Members if that is not possible then contact us and we will see if we can help.

### **Restless legs syndrome in post-polio syndrome: A series of 10 patients with demographic, clinical and laboratorial findings.**

Marin LG, Caryalho LB, Prado LB, Quadros AA, Olivera AS, Prado GF

Neuro-Sono Sleep Centre, Universidade Federal De Sao Paulo, Rus Claudio Rosse 394, Sao Paulo, SP, Brazil. luisfabianon@gmail.com

Parkinsonism Relat Disord. 2011 Aug;17(7):563-4. Epub 2011 Jun 2

#### **ABSTRACT**

**Background** - Few studies have described the occurrence of restless leg syndrome in post-polio syndrome.

**Methods** - We studied 10 consecutive patients with post-polio syndrome and symptoms of restless leg syndrome. We looked at demographic, clinical and laboratorial data.

**Results** - A remarkable finding was the concomitant onset of symptoms of both diseases, suggesting a possibly underlying mechanism. Severity of restless legs symptoms was moderate to very severe.

**Conclusion** - Epidemiological studies with larger samples are needed to better establish the relationship and the incidence of restless leg syndrome.

## **The \*12 Days of Christmas - Re-Examined\*:**

**(Please remember the reason for the season)**

In Light of Competition Global challenges require the North Pole to continue to take more competitive steps. Effective immediately, the following economy measures are to take place in the "Twelve Days of Christmas" subsidiary.

The partridge will be retained, but the pear tree never turned out to be the cash crop forecasted. It will be replaced by a plastic plant, providing savings in maintenance costs.

The two turtle doves represent a redundancy that is simply not cost effective. In addition, their romance during the working hours could not be condoned. The positions are, therefore, eliminated.

The three French hens will remain intact and we may actually expand the number of hens used. A recent time-motion-profitability study proved that using illegal migratory fowl is extremely profitable as it eliminates the company's need to provide employee benefits because the hens do not meet federal residency requirements.

The four calling birds were replaced by an automated voice mail system, with a call waiting option. An analysis is underway to determine who the birds have been calling, how often and how long they talked. Once this information is determined, the Accounting Department will deduct the costs of any inappropriate non-business calls from their final paycheck.

The five golden rings have been put on hold by the Board of Directors. Maintaining a portfolio based on one commodity could have negative implications for institutional investors. Diversification into other precious metals as well as a mix of T-bills and high technology stocks appear to be in order.

The six geese-a-laying constitutes a luxury which can no longer be afforded. It has long been felt that the production rate of one egg per goose per day is an example of their decline in productivity. Three geese will be let go, and an upgrading in the selection procedure by the Personnel Department will assure management that from now on every goose it gets will be a good one.

The seven swans-a-swimming is obviously a number chosen in better times. Their function is primarily decorative. Mechanical swans are on order. The current swans will be retrained to learn some new strokes to better enhance their outplacement.

As you know, the eight maids-a-milking concept has been under heavy scrutiny by the EEOC. A male/female balance in the work force is being sought. The more militant maids consider this a dead-end job with no upward mobility. Automation of the process may permit the maids to try a-mending, a-mentoring, or a-motoring.

Nine ladies dancing has always been an odd number. This function will be phased out as these individuals grow older and can no longer do the steps. Let me hasten to add that the company policy prohibits age discrimination. Should these individuals be asked to leave prior to their voluntary retirement, rest assured our Law Department will ensure an ironclad defence against an employee lawsuit.

Ten Lords-a-Leaping is overkill. The high costs of Lords plus the expense of international air travel prompted the Compensation Committee to suggest replacing this group with ten out-of-work congressmen. While leaping ability may be somewhat sacrificed, significant savings should result due to the number of congressmen left unemployed by the election.

Eleven pipers piping and twelve drummers drumming is a simple case of the band getting too big. A substitution with a string quartet, a cutback on new music and no uniforms will produce savings to the bottom line.

Though incomplete, studies by our latest consultant indicate that stretching deliveries over twelve days is inefficient. If we can drop-ship in one day, service levels will be improved and we can expect a substantial reduction in the use of part-time personnel.

Santa's Workshop Inc., a Limited Liability Partnership Corporation

Origin unknown



## Disabled People Against Cuts.

DPAC is an organisation run and controlled by Disabled people and was formed following the National Day of Protest on October in Birmingham. The 3rd October 2010 saw the first mass protest against the austerity cuts and their impact on disabled people. It was led by disabled people under the name of The Disabled Peoples' Protest.

DPAC believes that disabled people should not be the scapegoats for the financial mistakes of governments, should not be constantly told that there is no money to support them by millionaire politicians. We will not tolerate further erosion of our living conditions or our human rights, nor will we sit quietly while they try to take our rights away. We welcome all to join us in fighting for justice and human rights for all disabled people.

DPAC is for everyone who believes that disabled people should have full human rights and equality. It is for everyone that refuses to accept that any country can destroy the lives of people just because they are or become disabled or sick. It is for everyone against government austerity measures which target the poor while leaving the wealthy unscathed. It is for everyone who refuses to stay silent about the injustices delivered by wealthy politicians on ordinary people and their lives. Join us at Facebook - Disabled People Against Cuts or visit our web site at [www.disabledpeopleprotest.wordpress.com/](http://www.disabledpeopleprotest.wordpress.com/)

**The Crippen Cartoon** on the Back Page has come from this organisation

\*\*\*\*\*  
 \* ☺ I have been in many places, but I have never been in Cahoots. Apparently you cant go  
 \* there alone. You have to be in Cahoots with someone.  
 \* I've also never been in Cognito. I hear no one recognises you there.  
 \* I have however been in Sane. They don't have an airport. You have to be driven there. I have  
 \* made several trips there, thanks to my family, friends and those where I have worked.  
 \* I would like to go to Conclusions, but you have to jump and I am not too much on physical  
 \* activity anymore.  
 \* I have also been in Doubt. That is a sad place to go and I try not to visit there too often.  
 \* I've been in Flexible, but only when it was very important to stand firm.  
 \* Sometimes I'm in Capable, and I go there more often as I'm getting older. One of my favourite  
 \* places to be is in Suspense. It gets the adrenaline flowing and pumps up the old heart.  
 \* At my age I need all the stimuli I can get. [sent by member Janet Whitman]  
 \* - o - o -  
 \* Law of Mechanical Repair - After your hands become coated with grease, your nose will begin  
 \* to itch and you'll have to pee.  
 \* Law of Gravity - Any tool, nut, bolt, screw, when dropped, will roll to the least accessible  
 \* corner.  
 \* Law of Probability - The probability of being watched is directly proportional to the stupidity of  
 \* your act.  
 \* Variation Law - If you change lines [Queue] (or traffic lanes), the one you were in will always  
 \* move faster than the one you are in now (works every time).  
 \* Law of the Bath - When the body is fully immersed in water, the telephone rings.  
 \* Law of the Result - When you try to prove to someone that a machine wont work, it will.  
 \* The Coffee Law - As soon as you sit down to a cup of hot coffee, your boss will ask you to do  
 \* something that will last until the cup gets cold.  
 \* Law of Physical Surfaces - The chances of an open faced jelly sandwich landing face down on  
 \* a floor are directly correlated to the newness and cost of the carpet or rug.  
 \* Oliver's Law of Public Speaking - A closed mouth gathers no feet.  
 \* Author Unknown. ☺  
 \* \*\*\*\*\*

# 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)

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

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A donation has been sent to Disabled People Against Cuts - See Page 18 for more information.