

**SUPPORTING  
PHI'S CAMPAIGN**

**WE'RE  
STILL  
HERE!**  
October 10-16, 2010  
[www.post-polio.org](http://www.post-polio.org)

**JULY 2010**

## Calling all UK Polio Survivors

**Help  
research  
into PPS**

by  
completing  
this survey  
online,  
in writing  
or by phone

## That's POLIO!

**A  
Systemic  
Disease  
that  
affects  
the whole  
body.**

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# POST POLIO MATTERS

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

UNIVERSITY OF  
BIRMINGHAM



## Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions (RESULT)

This questionnaire is asking about the types of services you receive from health and social care. It is really important for us to know about your experiences of what works well and what you would like to improve. We have little information about the services people with rare neurological conditions receive.

The conditions covered in this questionnaire:- **Post Polio Syndrome**

Motor Neurone Disease; Huntington's Disease; Progressive Supranuclear Palsy;  
Multiple System Atrophy; Ataxia, and Charcot Marie Tooth Disease.

[www.haps.bham.ac.uk/primarycare/ccd/neuro/result.shtml](http://www.haps.bham.ac.uk/primarycare/ccd/neuro/result.shtml)

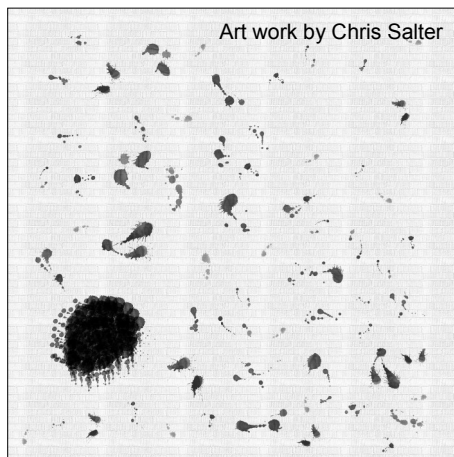


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**0121 414 8585**

Art work by Chris Salter



Dr. Alberto Esquenazi at Post-Polio Health International's 9th International Conference on Post-Polio Health and Ventilator Assisted Living: Strategies for Living Well, St Louis, MO, June 2 - 4, 2005.

### Dr. Esquenazi told the audience...

Polio is not a focal disease but a systemic disease which affects the whole body and had a larger effect in the areas where clinical paralysis and weakness were seen at the time of polio.

He described Polio as throwing a large bucket of black paint at a white wall, ending up with one large blob and lots of little blotches everywhere else. The wind changes every time you do this so the pattern for each polio survivor is different.

**That's POLIO!**

## **POST POLIO MATTERS**

**The new name for our newsletter suggested by Member Dinah Foweraker**

**Do you have concerns about the new Government changes for the NHS and Social Care?**

**NAIDEX SOUTH at London's ExCeL from September 29, 30 2010**

**NAIDEX NEC BIRMINGHAM April 5, 6, 7 2011.**

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

**MOBILITY ROADSHOW September 17 - 18, 2010**

**EDINBURGH**  
[www.mobilityroadshow.co.uk](http://www.mobilityroadshow.co.uk)

## **Editorial by Hilary Boone**

Member Dinah Foweraker suggested 'Post Polio Matters' as the new name for the Newsletter. She says 'it is functional and makes it clear what the newsletter is all about. 'Matters' conveys two ideas: firstly, that the newsletter contains articles, news and information about PPS, and secondly, that post-polio issues are important and of concern to ourselves and others.'

The changes that the Government are proposing for the NHS and Social Services with drastic cuts in spending are of great concern to the whole population. Polio Survivors are already reporting to us that they are worried about being re-assessed for benefits by health and social care professionals who have little knowledge and experience of Polio and how it affects our bodies. [more information on page 7]

I know that coping with PPS and daily life is not easy and repeatedly decisions have to be made to leave that job for another day and sometimes not do it at all. I have swept the dust 'elephant' into the corner more than once telling myself it will make a good home for spiders and save energy getting out the dustpan and brush and bending over to deal with it. Did this make you smile? I do hope so and this newsletter would love to hear from more members who can make us laugh about things that have happened in their lives. We all have trick movements, adapted ways of doing things/equipment to make our lives easier. Why not write and tell us because this information could be just what someone else needs.

### **New Members and Donations received.**

#### **We welcome new member Gillian Bryan**

Thank you to the following for donations given towards our work.

Shirley Rose, Ivor Hills, Nicholas Harvey, Val Scrivener, Barry Branston, Maureen Allison, Hilary Davies, Carol Murray, Clare Colfer, J Doohan, Margaret Edmonds, J Simm, Dorothy Ives, Yvonne Liggins, DE Shaw, Alan McKinnon, Bridget Langdon, Jennifer McGowan, Maureen Devine.

**Total received £350.00**

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, Di Brennand, Margaret Edmonds, Judy Barter, Barry and Olivia Branston, Bob Price and Anne Bennett.

**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.

Articles in this publication may be reprinted in full with acknowledgement of this Newsletter name, volume, issue and date. Exceptions are where written by an external author/newsletter when permission must be gained from the original author/s.

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## **REMAP - Helping people with disabilities to achieve independence and enjoyment of life's opportunities**

Remap is a very special charity, working through a nationwide network of dedicated volunteers. These inspiring people use their ingenuity and skills to help people with disabilities to achieve much-desired independence in some aspect of their lives, or to enjoy leisure opportunities previously closed to them.

There are, of course, many products supplied by the NHS or available on the market which are designed to make life easier for people with difficulties. However, very often such products don't quite do the job. There might be nothing that even comes close. This is when people turn to REMAP. They will either adapt an existing piece of equipment and make it work for the person concerned, or design something new and build it from scratch. Our engineers love a challenge.

Dave Eate, our new Webmaster is a REMAP Volunteer. Richard Boone has been helped by a Lincoln REMAP volunteer. PPS and the difficulties with repeating actions made filing items very difficult. Ray returned a few days later with a machine that held and moved a file backwards and forwards, leaving Richard to just hold the item.

How about a remote control wheelchair that with the aid of a model aircraft control system is able to be parked in the garage, after you have transferred to your car, and then using the garage door remote control left securely till you get home. Sue came up with the idea and the Basingstoke panel turned it into reality.

Do you have a problem that a Volunteer might be able to help you with?

To find the panel nearest you go to [www.remap.org.uk/contact-us.php](http://www.remap.org.uk/contact-us.php), phone **0845 1300 456**, email [data@remap.org.uk](mailto:data@remap.org.uk).

### **WE'RE STILL HERE Photographic competition.**

The Polio Survivors Network competition has been cancelled due to lack of entries. We are still supporting the National, European and International competition and will be publishing photographs, including the winning entry, in due course.

## Message from the Chair

Dear Members and Friends,

I was pleased to meet those members who managed to get along to our AGM on 2nd July and to meet our new Trustee, Barbara Taverner. I know all the Trustees are looking forward to working with Barbara during the coming year. AGM 2011 is June 19th, venue in next issue.

We had an interesting day with two presentations. One from Dr. Darren Barnes-Heath, who brought his plastic model brain along and gave an informative presentation about the benefits of chiropractic and post polio syndrome. [Dr. Barnes-Heath is writing an article for our next newsletter] The other from Dave Eate, our new website volunteer, who gave us a presentation about work done so far. Dave is also a Remap Volunteer and there is a little more on the activities of Remap on the previous page.

We were also pleased to meet Val Scrivener, Polio Survivor and one of our members, whose hobby is photography. Val uses her photographs to make cards that can be used as note-lets or greetings cards etc. Each card and envelope is sold at a price of 75p and every 75p is being donated by Val to Polio Survivors Network. The cards will be featured for sale on the website during the coming months.

Please visit our new website at [www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk) and if you have any suggestions about what you would like to see there we would be pleased to hear from you. If you do not own a computer most libraries have computers available for the public to use.

Sometime these areas, within the library, are called "internet cafes" and there is usually a member of staff who will be able to help you. There may also be an Internet Cafe in your local High Street or Shopping Centre.

An important role for Polio Survivors Network is to let other Polio Survivors know we are here and you could help us to do this. Enclosed in this issue you will find a yellow A4 poster about our network. If possible, we would like you to put the poster on a notice board where you live. This could be in a surgery, a Day Centre, Community Centre, place of worship, Post Office, Outpatients or Library – anywhere that people can see it. If you have more than one place in your area you think it could go please let us know and we can send you more copies. We can send it electronically if you prefer so that you can print it but we ask, if possible, that you print it on to yellow paper, please. I will be putting the poster in various places where I live during the next few weeks. No worries if you are not able to do this but if as many of you as possible can help in this way that will help to promote our network. Eventually the poster, and our new leaflets [a few enclosed for you to pass on to others who may be interested] will be available on our website.

So until next time I'll leave you with this suggestion. When you wake up, think of at least one thing that makes you smile – it can be anything, it's your thought, you don't have to share it, as long as it makes you smile. Try to hang on to that thought for the rest of the day.

Keep smiling. ☺  
Sandra Paget, Chair

**AGM**  
**All our previous**  
**Trustees were**  
**voted in again**  
**plus a**  
**New Trustee**  
**Barbara**  
**Taverner.**

**Visit our new**  
**Website**  
**put together**  
**by our new**  
**REMAP**  
**volunteer**  
**Dave Eate.**

**Promote our**  
**Charity**  
**by**  
**putting up a**  
**Polio**  
**Survivors**  
**Network**  
**Poster**  
**where you**  
**live.**



## THERAPEUTICS AND CLINICAL RISK MANAGEMENT. - July 2010.

### Update on current and emerging treatment options for post-polio syndrome

By Elisabeth Farbu,

Neurocenter and National Competence Center for Movement Disorders,  
Stavanger University Hospital, Stavanger, Norway.

[www.dovepress.com/update-on-current-and-emerging-treatment-options-for-post-polio-syndro-peer-reviewed-article-TCRM](http://www.dovepress.com/update-on-current-and-emerging-treatment-options-for-post-polio-syndro-peer-reviewed-article-TCRM)

**Excerpted Statements.** [Reference numbers have been omitted to save space]

- Post-polio syndrome (PPS) refers to the clinical deterioration experienced by many polio survivors several decades after their acute illness.
- There is no diagnostic test for PPS, and the diagnosis is based on a proper clinical workup where all other possible explanations for the new symptoms are ruled out.
- After the third decade, all healthy individuals lose both numbers of motor units and a degree of muscle strength as a part of the normal aging process. This will also occur for PPS patients, but they have a greater loss of both strength and motor units, and the clinical consequences may be greater than in healthy humans because more muscle fibers are denervated within one enlarged motor unit. The normal ageing process probably contributes to the loss of muscle strength, but does not explain all of the deterioration.
- The management of PPS is still based on rehabilitation schemes including lifestyle changes, physiotherapy, training programs, and avoidance of secondary complications.
- Weakening of bulbar muscles causing dysphagia [difficulties with swallowing], weakness of voice, and vocal changes have been reported among PPS patients, but bulbar symptoms are not among the most frequent features.
- The risk of respiratory insufficiency should be considered, because it could lead to serious complications, including increased frequency of respiratory infections, hypercapnia [the physical condition of having the presence of an abnormally high level of carbon dioxide in the circulating blood] pulmonary arterial hypertension [increased pressure in the pulmonary artery] and ultimately, cor pulmonale [enlargement of the right ventricle of the heart due to disease of the lungs or of the pulmonary blood vessels]. For PPS patients, weakened respiratory muscles in addition to severe chest deformities, such as kyphoscoliosis [Abnormal front-to-back and side-to-side curvature of the spine.] can cause respiratory insufficiency. Typical symptoms are daytime sleepiness, sleep apnea [breathing stops for more than ten seconds during sleep] morning headache, and dyspnea [laboured or difficult breathing].

**If you cannot download a copy then please contact us and we will post you a copy.**

#### IMPORTANT POINTS TO REMEMBER.

1. **Polio is not a focal disease but a systemic disease which affects the whole body and had a larger effect in the areas where clinical paralysis and weakness were seen at the time of polio.** [Dr. Marinos Dalakas, see front page and pages 12.13.]
2. **4 case histories were reported in French literature in 1875. These patients, all young men, had paralytic polio in infancy and developed new weakness, not only in previously affected muscles but also in muscles believed to be uninvolved. All had physically demanding jobs and performed repetitive activities.** [Post-Polio Syndrome : Pathophysiology and Clinical Management, Anne Carrington Gawne and Lauro S. Halstead. Critical Reviews in Physical and Rehabilitation Medicine, 7(2): 147-188 (1995) - full text of this article can be found in our Lincolnshire Post-Polio Library, [www.lincolnshirepostpolio.org.uk](http://www.lincolnshirepostpolio.org.uk)]

## **Gather information about your Polio Life before the dreaded brown envelope drops on the doormat!**

The changes that the Government are proposing for the NHS and Social Services with drastic cuts in spending are of great concern to the whole population. Polio Survivors are already reporting to us that they are worried about being assessed or re-assessed for benefits by health and social care professionals who have little knowledge and experience of Polio and how it affects our bodies and lives.

Some of our members are going through applications/reviews of 'Direct Payments/Personal Budgets' that they receive from Social Services. 'Guide to financial support for disabled people' [www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Introductiontofinancialsupport/DG\\_10020535](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Introductiontofinancialsupport/DG_10020535)

Some are on Incapacity Benefit/Income Support [quote 'If you still receive Incapacity Benefit or Income Support paid because of an illness or disability, your claim will be reviewed by Jobcentre Plus between October 2010 and 2014. The name has changed to Employment Support Allowance. [www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG\\_171894](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG_171894)

Worrying about all this causes stress and this can have a detrimental effect on our health and how we manage our lives. So what can we do to prepare ourselves for possible reviews of our benefits and/or applying for help in the future?

Prepare when we have more time on our hands rather than try to cope when that dreaded brown envelope drops on the doormat. We know that all this is daunting and produces huge black clouds when trying to understand it all, but it needs doing by you, a family member, friend, or contact a local support organisation, to make the procedure go more smoothly.

1. Make copies of any documents that you complete and if you have not done this then apply for a copy of the latest copy you sent in.
2. Members are reporting many instances where information given is incorrect. We recommend that you download or request copies of any form that you/or visiting staff may want you to complete. Before they arrive obtain and read all the National and Local Documents on the rules and regulations for the service.
3. Some members have joined their local USER group whose members have already been down this road and can help you through the procedure and lighten the stress load.
4. If you have concerns or experiences and would like to share these with other members then please contact us. Remember every tip, no matter how small, could be just the jigsaw piece someone else is looking for.

The process of applying to Social Services for a Care Assessment and the procedure and paperwork that follows is different in each county/country. For the latest information, England [www.\[your county name\].gov.uk](http://www.[your county name].gov.uk), Wales [www.ssiacymru.org.uk](http://www.ssiacymru.org.uk), Northern Ireland [www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk), Scotland [www.knowledge.scot.nhs.uk/changinglives.aspx](http://www.knowledge.scot.nhs.uk/changinglives.aspx), or contact your local government office.

To help prepare for NHS appointments we formulated 'My Polio Life—a self assessment form to help you gather information about you, your polio, what you have achieved in your life, how performing actions of daily living are changing, aids and equipment that you use/need, operations, medications and allergies, and more. If you have not already started a file of information about your Polio Life then take our advice..... the time to start this is NOW

You do not have to use our form but it might help with headings for sections of your file. You can download a copy from our website by using the Link below. If you do not use a computer then drop us a line enclosing an A4 sized Second Class Large [66p] stamped self-addressed envelope and we will post you a copy. If finances are tight please don't let that stop you asking us for help.

My Polio Life - [www.poliosurvivorsnetwork.org.uk/images/documents/mypoliolife.pdf](http://www.poliosurvivorsnetwork.org.uk/images/documents/mypoliolife.pdf) and sample answers at [www.poliosurvivorsnetwork.org.uk/images/documents/mypoliolife-sample.pdf](http://www.poliosurvivorsnetwork.org.uk/images/documents/mypoliolife-sample.pdf)

If applicable to you, you might also have to consider benefit and other assessment appointments where you are likely to be asked for confirmation of salaries, pensions, benefits etc. Some of our members are keeping a box file/concertina file of the latest of these documents so they are to hand when needed. We are going to compile a check list for the next newsletter to help with this.

### **Financial Support for Disabled People**

[www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Introductiontofinancialsupport/DG\\_10020535](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Introductiontofinancialsupport/DG_10020535)

**Disability Living Allowance** - Mobility and Care allowances. This is a tax-free benefit for people who have a disability and need someone to help look after them or have walking difficulties before you reach age 65. [At the moment this is not means tested]

**Attendance Allowance** - This is a tax free benefit for people aged 65 or over who have a disability and need someone to help look after them. [At the moment this is not means tested]

**Employment and Support Allowance** - If you cannot work because of illness or disability you may be able to get Employment and Support Allowance [ESA]. ESA was introduced on 27th Oct. 2008 and replaces Incapacity Benefit and Income Support paid because of illness or disability.

**Direct Payments - arranging your own care and services.** If you have been assessed by your local council as needing care and support services, you may want to chose direct payments. They allow you to buy in and arrange help yourself instead of receiving it directly from social services.

**Personal Budget or Individual Budget** - The money you get to pay for your support and other things in your support plan. The difference between the two is:

**A Personal Budget** is money from Social Services.

**An Individual Budget** is money that could come from several places – including Social Services, the Independent Living Fund and Supporting People.

You should know how much money there is for your Budget. You have to plan what you will do with the Budget. You have to make a Support Plan. This Plan must show what the outcomes of your spending will be – what your money will make happen. One important feature of a Personal or Individual Budget is that you can spend the money at times and in ways that work for you.

**Equipment for independent living** - You may be entitled to help towards the cost of equipment to enable you to live independently in your own home, or towards the cost of getting standard home equipment adapted so that you can use it.

**Personal equipment, prescriptions and hospital travel** - You may be entitled to help towards health costs such as free NHS prescriptions, dental care, hospital travel costs, plus equipment such as wheelchairs and hearing aids.

**Independent Living Fund** - Payments awarded from the ILF help to support severely disabled people to enable them to live independently rather than in a care home. The money is for payment towards personal and domestic care. N.B. New applications not being accepted!

## **Polio Biology XIII - Questions and Answers about Pharmaceutical Treatments by Life Member Professor Eddie Bollenbach, BA, MA**

**Polio Biology I** was published on the 28th August 1998. Eddie has kindly agreed to answer our questions, by adding to his articles featured in the Lincolnshire Post-Polio Library, to help us keep in touch with the fast moving changes in medicine. What questions have you got for Eddie for Polio Biology XIV and more.

**PSN:** Post-Polio Syndrome has been a tough opponent for modern medicine for many years. It seems trials of Insulin Type Growth factor, Prednisone, Bromocryptine, and other drugs, which have serious side effects, have shown to be of little help. Do you believe we will find things that will work to help symptoms of pain, fatigue, and other PPS related problems in the near future.

**Eddie:** Yes, I do. Every two years the knowledge and capability of bio-medicine has been more than doubling. For example, a few years ago at the Karolinska Institute in Sweden it was found that intra-venous immunoglobulin seemed to help a small group of post- polio patients but not much for others. Borg et al hypothesized that a formulation of all the immunoglobulins might need to be fine tuned to include some at higher concentrations, and others at lower or no concentrations, and that some formulation could work better against PPS symptoms. They have already had some good results with Post-Polio pain in some groups and are planning new clinical trials.

**PSN:** Several authorities have strongly argued that PPS is a mechanical problem which begins when neurons lose connections to nerves due to overwork and double duty. How could anything help if that is true.

**Eddie:** Well, even if that scenario, which is probably most widespread among clinicians, is true, you still get immune chemicals because of the inflammation. For example you get Interleukins produced. These are biochemical signalling molecules that activate parts of the immune system and foster increased inflammation and further damage. You get Immunoglobulins, like Ig M, (they are designated by letters) which were found very early in the spinal fluid of people with post-polio but was not found in the spinal fluid of those who had polio but not PPS. This discovery was very surprising and unexpected because of the physical trauma theory and because so much time had passed since the polio epidemics. Some of these antibodies to polio were just produced as some of the types of immunoglobulins against polio occur early in an infection. Yet they were present now in PPS. Interestingly, these immunoglobulins were specific for polio virus. That is, they reacted with polio virus proteins in a test tube. So we might be able to lower the number of Immunoglobulins by infusing people with different formulations of immunoglobulins. There are also chemical messengers called cytokines, which are also signalling molecules of various types which damage nerve cells. There are clinical trials going on right now and Post-Polio Syndrome has been chosen for some of the clinical trials of IVIG. The only reason PPS is being chosen is that there has been some success in palliating pain and fatigue in some early studies. We should see what happens with this soon.

**PSN:** Why are they just getting to this now. We have had PPS recognized since the early 80's by the medical community in specialists like Dr. Lauro Halstead as well as others?

**Eddie:** Well, Immunoglobulin therapy, with different formulations, has taken off in the past 5 years. Biochemists and researchers are even thinking of using them for diseases like Stroke, which is not infectious, but the damage is multiplied by the inflammation and the signalling chemicals mentioned above. So there will be clinical trials there too.

**PSN:** Since bio-medicine is moving so quickly are there other things on the horizon which may help us?



**Eddie:** I think there are several lines that may prove of use. In ten years they will be implanting stem cells into a lot of people suffering from various types of organ damage. A couple of years ago I wrote an article for Post-Polio Health International on the promise of stem cell therapy which you also published in the LincPIN [[www.post-polio.org/edu/pphnews/pph19-4p1-3.pdf](http://www.post-polio.org/edu/pphnews/pph19-4p1-3.pdf)] Since then they have improved heart function with stem cells in damaged heart muscle and have shown a variety of applications that are slowly moving through trials. Every day there is a new development in this area. Now pluripotent stem cells (which can be coaxed toward development of any type of mature cell) are being developed from blood cells and other patient tissues. This would eliminate rejection by the immune system if such cells from your body were manipulated to replace diseased or damaged cells. We really don't know how far this new approach and technology will take us. Most people that suffer from chronic diseases, and even though we are in the 21st century, we can only palliate them and help people to cope. Stem cells are one of the few developments which may have impacts on this. We are just starting but the technology is going so fast it is astonishing. It used to take a couple of days 10 years ago to develop DNA technology to identify a disease or identify someone by their blood. This involved slowly working with blood to extract tiny bits of DNA and chemically push them to multiply, and then a process for reading and comparing the DNA was used. Now this can be done in hours. That is how fast this is going. There is even progress in treating neurons to stimulate them to sprout more end fibers. This is very current. Who would think that could be done? That is tailor made for PPS. Look here: [[www.sciencedaily.com/releases/2006/07/060718073559.htm](http://www.sciencedaily.com/releases/2006/07/060718073559.htm)]

**PSN:** We don't want to foster false hopes.

**Eddie:** What you say is very true. We have to carry on with our lives. But we should realize the potential that exists and is revolutionizing bio-medicine right now. There are groups that have found success using experimental drugs to counter auto-immune problems. This is an entirely new area that is surging forward. A lot of auto-immune problems occur because there are bacterial genes and viral genes (polio for example) left over in body cells from earlier infections. The immune system begins attacking its own cells which have combined with some of these genes of microbes, and begins attacking body cells with these elements in them. Drugs like Olmesartan for high blood pressure has shown that it can modify some auto-immunity but given in larger doses than it is used for in hypertension. Biotech companies like Idera are working toward therapies and doing clinical trials right now on new agents. [[www.masshightech.com/stories/2010/01/25/daily45-Idera-moves-autoimmune-disease-treatment-to-Phase-1-trials-.html](http://www.masshightech.com/stories/2010/01/25/daily45-Idera-moves-autoimmune-disease-treatment-to-Phase-1-trials-.html)]

**PSN:** Thank you, Eddie, for your perspective. Do you have any final comments on this subject of therapies for PPS.

**Eddie:** One of our famous baseball players, Yogi Berra, used to say things that had a peculiar ring to them and that people found both funny and profound. One saying of his went: "Predicting things is difficult, especially when doing so deals with the future." I think there is a lot of momentum in biotech and I think we are likely to see some remarkable things soon. Treatments come slowly because we have to make sure they are safe and effective. So I think we are teetering on the cusp of big forward strides in medicine. The question as to whether we were born just a tad too early to realize effective help with PPS is an open question right now. I'll bet many of us will benefit even though Yogi is right. The most famous Yogi Berra quote is: "It ain't over till its over." I think that applies here too.

## References

Stangel M, Gold R. Neurologische Klinik, OE 7210, Medizinische Hochschule Hannover, Carl-Neuberg-Strasse 1, 30625, Hannover, Deutschland, [Stangel.Martin@MH-Hannover.de](mailto:Stangel.Martin@MH-Hannover.de).

**Eddie Bollenbach** <[eddie.bollenbach@poliosurvivorsnetwork.org.uk](mailto:eddie.bollenbach@poliosurvivorsnetwork.org.uk)>

**Post Polio Syndrome - a challenge of today  
European Conference, Copenhagen, Denmark, August 31st to September 2nd, 2011**

First announcement by the  
European Polio Union [EPU] and the Danish Society of Polio and Accident Victims [PTU]

**AIM**

After the large polio epidemics in the last century around 700,000 people in Europe are now suffering from polio sequelae. Many survivors have a decreasing functional level because of paralysis, fatigue and pain, and this is a big challenge for polio survivors and the professionals, who are treating them.

The European Polio Union wishes with this conference:

- To give medical and social professionals a possibility to exchange new research results and to debate relevant topics on a professional level
- To give polio survivors a possibility to achieve and exchange new knowledge on assessment, treatment and coping
- To achieve awareness on post-polio issues in the health sector and social services

**TARGET GROUP**

Professionals: Doctors, physical therapists, occupational therapists, nurses, psychologists, social advisors, orthotists or other professionals, who are involved with or treat polio survivors  
Polio Survivors and their relatives.

There will be both common and separate sessions for professionals and polio survivors. At this point we have not decided on the final topics yet. They will be depending on the incoming proposals and presentations.

Congress language will be English.

**WE INVITE YOU TO CONTRIBUTE TO THE CONFERENCE..**

- If you have a project or a proven method that you would like to present. Abstracts for parallel sessions, keynotes or poster presentations are most welcome.
- If you have a proposal for a topic
- If you are an exhibitor
- If you consider sponsoring

Details and deadlines for abstracts and proposals will be shown on our website.

**ONLINE REGISTRATION** - Will be open via the Congress website from December 2010

**REGISTRATION FEE**

|                 | <b>Before April 1st 2011</b> | <b>After April 1st 2011</b> |
|-----------------|------------------------------|-----------------------------|
| Professionals   | 3000DKK / 400 Euro           | 3500 DKK / 470 Euro         |
| Polio Survivors | 1465 DKK / 195 Euro          | 1950 DKK / 260 Euro         |

Registration fee includes participation of the sessions and catering during the conference & free admission for the Welcome reception. Conference Dinner must be paid separately.

**VENUE**

Hotel Crowne Plaza Copenhagen Towers  
Ørestads Boulevard 114—188  
DK 2300 København S, Denmark  
+45 88 77 66 55  
[www.cpcopenhagentowers.dk](http://www.cpcopenhagentowers.dk)

**CONFERENCE SECRETARIAT**

Merete Bertelsen  
PTU, Fjeldhammervej 8  
2610 Rødovre, Denmark  
+45 3673 9044  
[mbe@ptu.dk](mailto:mbe@ptu.dk)

**Festival of International Conferences on Caregiving, Disability, Aging and Technology  
FICCDAT 2011 - June 5th to 8th 2011**

**Sheraton Centre Toronto Hotel, 123 Queen Street West, Toronto, Canada**

FICCDAT is a consortium of organizations, private and public, brought together under the leadership of the two originating Co-Chairs to maximize opportunities for collaboration between two social movements - aging and disability. Andria Spindel, MSW is the President & CEO of March of Dimes Canada and Dr. Geoff Fernie, PhD, PEng is Vice President, Research at Toronto Rehabilitation Institute.

FICCDAT is growing! Building on the success of 2007 [presentations on PPS were given], we are planning six concurrent international conferences in 2011. FICCDAT 2011 will bring together six important and different conferences all focused on enhancing the lives of seniors, persons with disabilities and their family caregivers.

Between June 5-8, 2011 rehabilitation, social and health services providers, government policy makers, researchers, family caregivers, students, seniors and persons with disabilities from around the world will gather in Toronto, Canada to explore issues facing aging populations, the implications for healthcare systems and service providers, the roles and responsibilities of family caregivers and policy and how new research findings and technologies are leading new and practical solutions.

Experience the Festival! One of the unique features of FICCDAT is that, in addition to attending your desired conference, registrants will be entitled to attend sessions in any other Festival conference.

FICCDAT is an amazing opportunity for you to transfer knowledge from your experience and your research to an extraordinarily broad audience. You can submit abstracts to all six major conferences, and you can attend and present at several conferences for the cost of attending a single conference.

Call for Abstracts is open till 1st December 2010. Sign up to receive future updates.

When a patient was wheeled into our emergency room, I was the nurse on duty.

"On a scale of zero to ten," I asked her, "with zero representing no pain and ten representing excruciating pain, what would you say your pain level is now?"

She shook her head. "Oh, I don't know. I'm not good with math."

**CHECK THE MIRROR TO FIND OUT HOW MUCH PAIN YOU ARE IN.**



0 to 3 - No pain. Slight pain at rest. Slight pain with movement.

4 to 5 - Intermittent pain at rest. Significant pain with movement.

6 to 8 - Frequent significant pain at rest. Severe pain with movement.

9 to 10 - Continuous severe pain at rest. Excruciating pain with movement.

## **Should this operation have been done on this polio leg?**

A Polio Survivor is seeking information from anyone who has had a similar experience to the following.

In 2008 a female Polio Survivor was suffering a lot of pain in the knee and although experiencing difficulty with walking was able to drive and get around walking short distances wearing a calliper and using a wheelchair.

In early 2009 following an assessment a knee replacement was recommended. The operation went ahead but during the operation complications arose. The bone below the knee had splintered which led to a longer recovery time. Later our Polio Survivor learns that her foot had been set at the wrong angle and during the procedure to rectify this the bones in the lower leg shattered. The consequence of this was to be splinted for seven weeks. Our Polio Survivor was left unable to bend her leg and now unable to drive. Early this year (2010) she was admitted to hospital for treatment to get the leg to bend. She was placed on a Continuous Passive Motion machine which bends the leg little by little. A spinal tap was given to reduce pain. She received this treatment for eight hours a day for six days and 90 degrees was reached but as soon as the pain relief was taken away the pain when bending the leg was unbearable. A different Orthopaedic surgeon said that 'this operation should not have been done on a 'polio leg'.

To still be in pain, lose her independence and struggling to cope with all the emotions involved with this long drawn out saga is not easy. If you have had a similar experience or have any information or advice we could pass on do please let us know.

The questions arising from this experience are:

1. Was the original assessment done by a clinician with good knowledge and understanding of the effects of Polio on our Polio Survivor?
2. Was the post operative treatment appropriate for the effects of polio on our Polio Survivor?

**The following excerpts will give our readers more information on this subject.**

Excerpt - **New Mobility Magazine, October 2003**. Post Polio Forum. by Richard L Bruno, PhD, Adequate muscle strength is also the limiting factor when polio survivors **have total knee replacements**, as the only follow-up study shows. Pain decreased and function increased after knee replacements in 60 percent of knees where the thigh muscle had at least antigravity strength. But all knees with less than antigravity strength and 45 percent of the knees even with antigravity strength weren't better or got worse after the replacement. So knee replacements aren't a cure-all for post-polio knee pain.

**[Full article [www.newmobility.com/articleView.cfm?id=755&action=browse](http://www.newmobility.com/articleView.cfm?id=755&action=browse)]**

**LincPIN, Volume 5 - Issue 5 — August 2005, pages 10 to 18**

**Excerpts from the article Analyzing Your Gait: The Roles of Exercise, Bracing or Surgery? A Report on the presentation of Dr.'s Esquenazi and Keenan at the Post-Polio Health International PPS Conference in St. Louis, USA June 2nd to 4th 2005.**

**Dr. Alberto Esquenazi** [Director of the Gait & Motion Analysis Laboratory at Moss Rehabilitation Hospital in Philadelphia.]

...described polio as "throwing a large bucket of black paint at a white wall, ending up with one large blob and lots of little blotches everywhere else. That's POLIO."

Patients tend to overestimate the strength of their muscles and often present with pain in, say, one area. However, it is not a focal disease **but a systemic disease and affects the whole body**. It had a **larger effect** in the areas where clinical paralysis and weakness were seen.

Dr. Esquenazi went on to discuss Manual Muscle Testing, describing it as the old way that testing was done! i.e. basically grading muscles from 0 [with no muscle strength] to 5 [normal muscle strength]. “That is the way it was done and is continuing to be done in many places. We have learned now that that is not a good way to do it. We now use hand held dynamometry as a way to test strength because a grade 5 muscle - normal - could have as much as 30% weakness before Manual Muscle Testing could detect it.”

According to Dr. Esquenazi, the meat of the matter is calf weakness, and everyone needs to appreciate what this means. He explained that our calf muscles have to hold our whole body weight when we are in the stance phase, to prevent us falling. That we have to lose a huge amount of calf weakness before it is detected by strength testing. When we walk we take many steps which is what needs to be assessed, not just one step.

He explained how we also underestimate the demands that we place on our muscles every day: just sitting, keeping our head and back straight plus demands on our legs to cross them and move them around. Then add walking! Also as we get older we tend to get a little bigger, and he added that Americans tend to get a little bigger than the bigger, adding to problems and producing fatigue.....

Dr. Mary Ann Keenan [Professor and Vice Chair, Orthopaedic Surgery and Chief, Neuro-Orthopaedics Service at the University of Pennsylvania School of Medicine and Chair, Department of Orthopaedic Surgery at the Albert Einstein Medical Centre] [www.linkedin.com/pub/mary-ann-keenan-md/12/594/3a2](http://www.linkedin.com/pub/mary-ann-keenan-md/12/594/3a2)

**Joint replacement** – for polio survivors there are a lot of special considerations regarding all the other implications of the combinations of patients’ muscle strengths. It is imperative that patient and medical personnel work as a team. Patients need to understand the ultimate restrictions that this surgery will place on them. If you have already damaged a normal joint then you will wear out the metal and plastic joint in the same way unless you change how you do actions. Other leg deformities have to be corrected as well and it may be necessary to use a lower leg brace as well.

- Contracture of a joint – you don’t have normal motion. You can have laxity in one direction or the other because of stretched out ligaments and joint capsules. With little muscle strength you need to compensate.
- Bones – if you have a lot of weakness or paralysis in a limb then bones are much weaker, and there may be more osteoporosis, making fixation of the knee or hip joint challenging.

**Special considerations for polio survivors pre surgery** – because of weakness, paralysis, osteoporosis, and/or abnormal shaped bones, there needs to be a lot of work done ahead of time.

- Look at the whole person not just the leg, or both legs, and how they do actions of daily living.
- Each patient is different and we need to understand that the pattern of strength and weakness, and the compensations that have been developed over time.
- Coordinate with anesthesia team regarding anesthesia and for inter and post operative pain management.
- Coordinated team approach with rehabilitation and bracing.
- Custom joints may need to be made.

### **Save Our Shoulders: A Guide for Polio Survivors**

by Jennifer Kuehl, MPT, Roberta Costello, MSN, RN, Janet Weschler, PT.  
Investigators, Mary Klein, PhD, **Mary Ann Keenan, MD, Albert Esquenazi MD.**  
[http://www.einstein.edu/rx\\_files/yourhealth/mrri\\_sos9510.pdf](http://www.einstein.edu/rx_files/yourhealth/mrri_sos9510.pdf)

[Full article at [www.poliosurvivorsnetwork.org.uk/images/lincpin/lincpin5-5.pdf](http://www.poliosurvivorsnetwork.org.uk/images/lincpin/lincpin5-5.pdf)]

## Members Hints, Tips and Bits

### 1. Beverly Buccellato writes...

Last year was a total bummer for me. I didn't have enough strength to go out and enjoy my flower and vegetable gardens and the fruit orchards went unattended. Of course the wildlife around here enjoyed all the dropped apples, pears, plums and cherries to name a few. The nut trees were a winters bounty for the squirrels and I have found that some of the buried nuts have sprouted so I have been busy transplanting them to the woods.

Over the last winter I decided to find a way to be stronger or to just sell this place and move into town. That's a big incentive for me because I am a country girl at heart.

When my husband would massage my legs it helped to reduce the pain level and when I stretched my feet and legs I felt like my circulation was better. I asked my family doctor if she would write me a prescription for just massage and stretching sessions with a physical therapist and she agreed. I felt so much better after a few weeks that I did a few minutes on a bicycle that took almost no energy to peddle but the movement helped me. I never stayed longer than 4 minutes on the bike, I then tried a small weight around my ankles and I sat and did some leg lifts. I started out with 4 lifts and was comfortable up to 10. I did the exercises after the stretching where the therapists did all the moving of my body. I went over my limit one time and paid for it with pain and weakness for about 3 days. After that I kept everything to my comfort zone.

I am now able to go into my garden and work a little every day. I have to choose my time, do I spend it in the house cleaning up or do I go out in my garden? There are some days that I just sit and smell the roses or read in the shade. I take it all at a slow pace and it works for me. I think the stretching of my legs has improved the circulation and helped my balance. I do have a skin infection in my polio leg and it may have been brought on by my going barefoot and getting a cut on my heel. I don't know for sure. It seems that every five years or so I end up with an infection in that leg. The infection also coincides with a time of extreme stress before hand. This past Feb my sweet sister Millie passed away after many years of fighting cancer. My doctor says there may be a connection.

Next day after writing this I twisted my other knee out in the garden, just went to turn around too fast... I have just got to learn to not turn my body before my legs are ready. When I get a spurt of energy I get so excited that I throw caution to the wind. Oh well, I did spruce up the flower beds but used up too many of the next few days energy tokens... Gonna have to have a few pyjama days now.

I found my polio doctor, Dr. Michael Andary at the University of Michigan medical facilities by asking the LPPN for help. I almost fell over when I learned there was a doctor just 25 minutes drive from me. Imagine that, writing to my friends in England to find my USA doctor. Not only that but he backs up almost everything I learn from my PPS sites. The stretching of my muscles is the best way to cut back on leg pain for me. I just thank God for all you folks and all the work you have done on the other side of the pond. I am no longer in my chair except when I know its going to be a long day,

Love you all, Beverly - <bb\_dutchess@yahoo.com> Michigan USA.

A man boarded a plane with five kids. (Gutsy guy!)

After they got settled in their seats a woman sitting across the aisle from him leaned over to him and asked, "Are all of those kids yours?"

He replied, "No. I work for a condom company. These are customer complaints."

Wish I could think that quickly.

## 2. From the Southern California PPS Manager, March 2010

[www.ppsmanager.com/PPSM\\_2010/PPSM\\_03-10.html](http://www.ppsmanager.com/PPSM_2010/PPSM_03-10.html)

**IMPORTANT NOTICE - The test for Carpal Tunnel Syndrome** may show a false positive due to PPS nerve loss. Your neurologist should be aware of this before scheduling CTS surgery.

**Editors note:-** In 1989 I had Nerve Conduction Studies on my right arm that showed carpal tunnel syndrome. The surgeon wanted to operate. At that time all the pain and weakness I was reporting was in my left arm. I had no pain in my right arm. At this time I did not know PPS existed and my prior polio was not in the diagnostic equation. However, in 2004 it was found that I have extensive weakness in the supinators of my right wrist.

## 3. Value Added Tax (VAT) relief on equipment and services

[www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Taxreliefandreductions/DG\\_10028495](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Taxreliefandreductions/DG_10028495)

Some goods may qualify for VAT relief if the item has been designed, or adapted, solely for a disabled person's use. This includes some medical appliances, certain adjustable beds and hoists and some adapted vehicles.

**Motor vehicles.** If you are a wheelchair or stretcher user, you do not have to pay VAT when you buy a motor vehicle that has been substantially and permanently adapted for your personal use. A wheelchair user is defined as anyone who has to use a wheelchair—powered or manual—in order to be mobile. Any adaptation work that is done on an unadapted vehicle to make it suitable for a disabled person's condition, whether or not that person is a wheelchair user, is eligible for zero rating. However, there is no VAT relief on the purchase of an unadapted vehicle.

**Leasing a vehicle or wheelchair under the Motability Scheme.** Motability is a charity that provides vehicles and powered wheelchairs or scooters to disabled people. You don't have to pay VAT when you lease a vehicle, wheelchair or scooter under the Motability Scheme.

## 4. PHONE SCAM - <http://news.bbc.co.uk/1/hi/8263637.stm> - verified correct. [Excerpt]

**BT is warning customers to be on their guard after a series of phone scams involving people claiming to be calling from the company.**

The scammers call up their victim and warn them that their account is in arrears. They then ask for card or bank details in order to settle the account. If the person refuses or asks for proof, the fraudsters then offer to prove who they are by disconnecting the phone line then and there.

Almost duped - Once the victim puts the phone down, the scammer stays connected to their line, thus giving the impression that the customer's line no longer works.

Evidence shows that this has been happening all over the country.....

Graham Preston, the lead officer for scams at the Trading Standards Institute, admits this type of phone fraud is around.

"Scams sadly are very common, they are variations of a theme and this particular scam seems to be prevalent at the moment," he said. He warns people to be on guard. "In terms of advising people, keep your wits about you, be cynical.

If somebody calls you, mistrust them if you have to, or don't trust them," he said. "Particularly if they are asking for money, if they want your credit card details don't be afraid to say no," he added.

## Herbal remedies or what? By Karen Kenny.

Karen Kenny is the Eastern Region Rep for the National Society of Allotment & Leisure Gardeners as well as on the management team of Suffolk and Ipswich allotments where she runs a site. Karen is also an accomplished lecturer on most gardening subjects, including allotments. She is a friend of Glenna Tomlin and offered to write an article for the newsletter.

Hi folks. Just a few thoughts on what you call weeds and I call herbs that maybe can give us a bit of relief in our lives and also from history some interesting possibilities!

We have all eaten **Grass** in our lives. Remember sitting on a grassy knoll and chewing the delicious white bits at the base of the blades? Well grass (*Agropyron repens* Twitch grass, dog grass, there are many names) contains vitamin A and B, potassium salts, organic acids and starch and is frequently used as a tonic.

Used to treat cystitis and bladder diseases as well as rheumatism in the past. You can make an infusion of 1 oz dried root to 1 pint boiling water infuse for 10 mins and drink 2 cups a day and it will relieve your symptoms.

If you recall from your history lessons the majority of the peasants in 'olden times' ate bread and cheese as a staple diet, even though the bread was made of the whole wheat including the germ and husk, ground up dried grass roots were added to the mix to further fortify the bread with extra vitamins and minerals!

Grass is important as a food plant for meadow brown butterflies amongst others and is of course the main fodder food of many ruminants that form part of the human diet. So eating grass especially fresh young shoots as part of your mixed salad can only be good for you!

Talking of a salad plants *Stellaria media* (commonly known as Chickweed is a fantastic product growing almost all year round as an ethereal. Medicinally its cooling and soothing properties have been utilised for centuries as ointments and poultices. Very good for skin complains such as roseaola, ulcers and even chilblains.

Very useful too is its amazing ability to relieve constipation when an infusion is drunk! The leaves contain vitamin c and phosphorous (essential to improve the memory!) It is great in salads and also in a sandwich with marmite or steamed as a vegetable.

Now one of the best herbs that you can utilise for good health is the **Onion**. They have been used since ancient times, one of the earliest plants to be cultivated for cooking and for medicines. They are high in vitamins and as you may have figured out in sulphur compounds! It has been noted through the centuries by many famous herbalists that regular consumption especially raw will increase longevity and general health. They are antiseptic, antibiotic antislertotic [softens unnaturally hard skin] a diuretic and an expectorant. They will help to reduce blood pressure and aid digestion, heal wounds, clear the system and relieve coughs and colds. They too are high in phosphorous so with chickweed as well you should pass all exams with a super duper memory. They have been used to relieve insect stings, grated raw and applied to joints will relieve rheumatic pains, burns and migraine. Soaked in cotton wool it will relieve earache and toothache. You can rub onions on your chilblains to ease them. In winter in our household when coughs and colds were imminent Granny would cut up a lb of onions sprinkle with a lb of Demerara sugar and leave for a couple of days in a cool room for the liquid to gradually come from the onions then strain it into a bottles and serve three times a day when needed and it certainly did the trick.

In recent times it has been shown that eating raw onions helps to reduce your cholesterol. So there you are eat your onions and you may live to be a centenarian. For high blood pressure and high cholesterol are two of the main factors for heart attacks and strokes!! Think on.

For the last of our four useful herbs let's talk about **Melissa** such a nice herb.



You know her as **lemon balm** beloved of the bees. Apiarists used to rub the new hives with Melissa to encourage the bees to stay there; they do love the nectar and make delicious honey from it.

It's greatest use is for soothing tension after a long hard day you can easily unwind with a tisane of lemon balm, just take a few of the tops and crush them in a mug, pour over hot water and pop a saucer on the top to infuse for a few minutes and you will have a delicious lemon flavoured drink. You can if so desired add a smidgen of honey if you have a sweet tooth. Sit down sip slowly and relax Mmmm.

In the past it was used to cure ear ache and toothache skin eruptions and, very useful, crooked necks! For the chaps a lotion was said, if used regularly, to prevent baldness, and for the girls when made into an amulet in linen or silk caused women who wore it to be beloved and happy how good is that???

Of course it is also very good as flavouring for ice cream or sponges, dried for pot-pouris and great if you hang a bunch under the hot tap for a very relaxing and soothing lemon fragranced bath and last but not least it makes a delicious dry white wine for completely chilling out!!

### **I've finished two books in my quest for a better understanding of the polio experience...**

A polio survivor, Raymond Dinsmore, joined a Polio Email Discussion List that I am on [polio-subscribe-request@listserv.icors.org] and like Richard and I, who were six months and five years old respectively and have few memories. Raymond writes...

I've finished two books in my quest for a better understanding of the polio experience. I have several more waiting for me. As I mentioned in my first post, I have few memories of my own experience. Reading these books has been enlightening and almost cathartic.

I just finished *Twin Voices*, by Janice Flood Nichols. Janice had a twin brother who got polio at the age of six. He died within a few days. The same day he was buried, Janice also came down with polio. Her case was not as severe as that of her brother, but think of the horror her parents must have gone through.

*Twin Voices* is an excellent mix of first person accounts - her own and those who knew her at the time - and medical background on polio. It is available in soft cover and computer download. This is how I read it.

The second book is called *Not Just Polio*, and, as title suggests, is more than a polio book. One reviewer on Amazon.com wrote:

"Imagine that you wake up in a huge metal tank, with just your head exposed. A few hours before, you were a healthy and active thirteen year old. Imagine that you spend nearly six months confined to this mammoth steel cylinder, and another two years in a hospital."

Now, try to imagine how you would react. How would you cope? Richard Daggett, the author of this well-written autobiography, takes you, step by step, through this life altering experience.

But this book is more than the story of illness and hospitals. It is a recollection of life in the America of the 1940s and 50s. This was the time of black and white television, of kids playing together on the front lawn, and moms waiting to greet us when we got home from school.

I am very near Richards age, and he tells of an early life that I wish I could have shared. I highly recommend both of these books. Richard Daggett includes a contact e-mail address at the end of his book. I intend to write him and tell him how very much I enjoyed and appreciated his honest book. **Raymond Dinsmoor rdlaptop1@gmail.com**

P.S. See back page for info on the books. Hilary and Richard met Richard Daggett in 2003 [photo] and Raymond has just emailed me to say he just met Richard. An Amazing Man.

## **YOUR RIGHTS TO FLY - taken from [www.equalityhumanrights.com](http://www.equalityhumanrights.com)**

### **Air travel**

Under new European law, if you are disabled or have difficulty moving around you can receive assistance when you fly to and from Europe, including domestic flights. You do not need to be permanently or physically disabled to benefit from this service. In fact, anyone who has difficulty moving around, for example, because of their disability, age or a temporary injury, can receive help when they fly.

The law affects the whole of the air travel process, not just the flight itself. It also covers booking your flights, arriving at the airport, checking in, getting on and off the plane and leaving the airport. For more information see our step by step guide to your rights to fly.

The regulation applies to tour operators and travel agents as well as to airports and airlines. This means that tour operators and travel agents must pass on your needs to the airlines, and they in turn must inform the airports of the individual services required.

### **Before you travel**

Before you travel, consider the kind of assistance you may need. Airports, airlines, tour operators and travel agents must provide clear and easy to use information and consider the need to provide information to customers in other formats such as large print and audio. Websites should also be accessible for all users.

### **Airline safety**

Airline safety rules must always be available to the public and can be found on airline websites or by contacting them.

These rules, which may vary from airline to airline, may state that anyone unable to fasten their seatbelt, leave their seat and reach an emergency exit unaided should be accompanied. This also applies to passengers who need help with breathing, feeding, getting to the toilet, or taking medication.

On smaller aircraft, there may be limitations on the number of disabled passengers who can travel for safety reasons.

Airlines can only refuse a booking from a disabled or less mobile passenger if accepting it would break safety rules or if the size of the aircraft or its doors makes boarding or carriage physically impossible. If a booking is refused, the airline, or its agent, must inform you of the reasons why.

Your passport to a smooth journey Read our new passport style guide to a smooth journey, .

[http://www.equalityhumanrights.com/uploaded\\_files/publications/airtravel\\_miniguide.pdf](http://www.equalityhumanrights.com/uploaded_files/publications/airtravel_miniguide.pdf)

or order a printed copy by telephoning

**England 0845 604 6610 - Scotland 0845 604 5510 - Wales 0845 604 8810**

N.B. Some disabled people flying further than Europe when the required help was not forthcoming have quoted this law/had help from the EHRC in the event of an emergency.

**The Equality and Human Rights Commission** was launched in October 2007, taking over the role and functions of the Commission for Racial Equality (CRE), the Disability Rights Commission (DRC) and the Equal Opportunities Commission (EOC) and assuming new responsibilities for sexual orientation, age, religion and belief, and human rights.

Ouch! is a website from the BBC that reflects the lives and experiences of disabled people

[www.bbc.co.uk/ouch/](http://www.bbc.co.uk/ouch/)

## Management Committee [Trustees] and Operations Team

### Management Committee [Trustees]

**Chair** - Sandra Paget - sandra.paget@poliosurvivorsnetwork.org.uk  
**Vice Chair** - James [Jim] Pullin - jim.pullin@poliosurvivorsnetwork.org.uk  
**Secretary** - Glenna Tomlin - glenna.tomlin@poliosurvivorsnetwork.org.uk  
**Treasurer** - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk

### Committee Members

**Ian Hobday** - ian.hobday@poliosurvivorsnetwork.org.uk  
**Barbara Taverner** - barbara.taverner@poliosurvivorsnetwork.org.uk

### Operations Team

**Membership Secretary** - Hilary Boone - membership@poliosurvivorsnetwork.org.uk  
**Phone Team** - Di Brennand (Leader) di.brennand@poliosurvivorsnetwork.org.uk  
Margaret Edmonds and Judy Barter  
**Administrative Support** - Barry & Olivia Branston, Anne Bennett  
**Website Administration** - Dave Eate - webadmin@poliosurvivorsnetwork.org.uk

## 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.

- 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%).

**Just Giving** www.justgiving.com - Donations paid through this Website will be paid directly to our Charity Account, including the Gift Aid amount if you pay Income Tax, minus 5% transaction fee.

# Polio Survivors Network

what we have    what we are    what we do

Registered Charity No. 1064177

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

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

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

☎ 01522 888601

## POST POLIO MATTERS

because **WE'RE STILL HERE!**

I've finished two books in my quest for a better understanding of the polio experience...  
Article by Raymond Dinsmoor on Page 17

### Not Just Polio

My Life Story



Richard Lloyd Daggett  
Foreword by Jacquelin Perry, MD

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Janice  
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## Twin Voices



*A Memoir of Polio,  
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