

APRIL 2011

# POST POLIO MATTERS

The Polio Survivors Network Newsletter - Volume 7, Issue 4  
n.b. Volumes 1 to 6 published under the name LincPIN.  
[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

**STOP  
PRESS**

**Professor  
Catherine  
Sackley**

**Speaker**

**18th June**

## PSN AGM Saturday 18th June 2011

Venue:- The Pinsent Mason Suite 2,  
The MAC Birmingham, Canon Hill Park,  
Birmingham B12 9QH



AGM 1.00 pm

Speakers 2.00 pm

Verite Reily Collins, Polio Survivor, Travel & Health Author

Professor Catherine Sackley

Primary Care Clinical Sciences, University of Birmingham.

Speaking to the RESULT Study and PPS Component.

### It does exist!

World Health  
Organisation  
Code for

POST-POLIO  
SYNDROME

is

**G 14**

and

**WE'RE  
STILL  
HERE!**

October 9-15, 2011  
[www.post-polio.org](http://www.post-polio.org)

**SUPPORTING  
PHI'S YEARLY  
CAMPAIGN**

**August 31st  
to  
September  
2nd 2011  
in  
Copenhagen,  
Denmark.**

### EUROPEAN CONFERENCE ON POLIO - Page 10



**POST POLIO SYNDROME**  
- a challenge of today

COPENHAGEN // AUG 31 - SEP 2 2011

*Paul and Trevor Corr visit Lincoln*

*To present PSN with the fantastic sum of £900*

*Donated by Family and Friends In memory of Life Member*

*Janet Corr*



Post-Polio Health Care  
Considerations  
for  
Families & Friends

Pages 6 to 9

Page 10

**European PPS  
Conference**

**Polio World  
2011 Poster  
Competition**

**Have you  
been and  
looked at a  
Changing  
Place Toilet?**

**£900.00  
Donated in  
memory of  
Life Member  
Janet Corr  
Page 13**

**NAIDEX**

**GLASGOW**

14/15 Sep 2011

**LONDON**

**EXCEL**

19/20 Oct 2011

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

**MOBILITY**

**ROADSHOW**

June 30th to  
July 2nd 2011

East of

England

Showground,  
Peterborough

[www.mobility  
roadshow.co.uk](http://www.mobility<br/>roadshow.co.uk)

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**New Members and Donations received.**

**We welcome new member Donna Jean Kornerup**

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

Nicholas Harvey, J Stevens, Val Scrivener, Ivor Hills,  
Christine Darlington, Lynn Hobday, Diana Nash,  
Olivia and Barry Branston, Dianah King, Hilary Boone, J Dobbie,  
Stuart Barnett, Norman Jones, Lesley Forsyth, Clare Colfer,  
Audrey Brown and Bob Price.

We also thank the family and friends of Life Member Janet Corr  
for their In Memoriam Donation of £900.00

Total since last newsletter is **£ 1,178.50**

We have no paid employees. We would like to recognise and thank the following for so generously donating their time. The Trustees, 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 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.

## Editorial by Hilary Boone

What a winter, not seen so much snow since the year I was born. OK, ☺. I do not remember March 1947 but was told 'Your mother had to walk to the end of the road in London to get on the ambulance' and some folks in the Wolds in Lincolnshire told me they were able to use the telegraph wires as hand rails the snow was that deep and it took six weeks before their town was reachable by road. It was a week before we could get someone to dig our drive out but even then we could not use our electric wheels as the pavements and car parks were not treated. When we got to our Dental appointment adjacent to a GP surgery we were horrified to see the car park was one sheet of ice an inch thick. Very difficult to get from car to door. We need to be better prepared for this winter.

**Page 10.** New Northern Ireland holiday getaway for disabled is unveiled. I am sure our members will have found other holiday places that are accessible. Why not write and tell us about them?

2011 Polio Poster Competition Information. Please let us know if you submit an entry.

### **Cuts in Council Spending could affect some of our members.**

There is much on the news about which services Councils are going to cut. The BBC's 'Council Spending: Making it Clear' survey estimated Adult Social Care spending would fall by 4.7% to £3.4bn in the North in 2011/12 and rise by 2.7% to £3.33bn in the South.

Lincolnshire spent £140m on services such as home care and day centres in 2010/11 but this is being reduced to £130.6m in 2011/12, **a fall of 7%**. What is happening where you live?

Do you have Direct Provision or Direct Payments or a Personal Budget from your County's Social Services? Maybe you might need help in the future. The government define four levels of need, Low, Moderate, Substantial and Critical and each Council defines which of these levels they will support. [1]

If you need to apply for help to manage your life from Social Services the first step will be a Social Worker (SW) or Community Care Officer (CCO) should come and see you and determine your eligibility for one of the above levels. This will involve the completion of a questionnaire/form. To help you be prepared for what you are going to be asked you could ask for a copy before the meeting.

Until recently Lincolnshire County Council (LCC) have been supporting people eligible from moderate level upwards but now are consulting on their 'proposal' that they will no longer support awarding Direct Payments/Direct Provision or Personal Budgets to those on moderate level. This affects 2,899 people in Lincolnshire. Some counties are already only supporting substantial and critical need, and some only critical.

Do you know what is happening where you live? Will local cuts affect you adversely.

Reference - [1] Prioritising need in the context of *Putting People First: A whole system approach to eligibility for social care.*

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113154](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154)

**Government information for Disabled People** - <http://www.direct.gov.uk/en/DisabledPeople/index.htm>

Click on Financial Support, third option - more about financial support.

**Highlighted Item** - Government responds to the consultation on Disability Living Allowance reform

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

Annual General Meeting is on Saturday 18th June 2011

**At the MAC, Canon Hill Park, Birmingham, B12 9QH, from 1pm to 5pm.**

[www.macarts.co.uk/plan-your-visit/getting-here/](http://www.macarts.co.uk/plan-your-visit/getting-here/)

The next Trustees Meeting is being held in the Midlands in July 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)

or Tel: 01522 888601 or write to us at Polio Survivors Network PO Box 954, Lincoln LN5 5ER

**Any idiot  
can rise  
to a  
crisis,  
it is day  
to day life  
that  
wears  
you  
down.**

**Anton  
Chekov.**

**Life  
you know  
is rather  
like  
opening  
a tin of  
sardines.  
We are all  
looking  
for  
the key.**

**Alan  
Bennett,  
Playwright  
and  
Actor.**

## **Message from the Chair**

Dear Members and Friends,

Our Annual General Meeting is almost here and we, at HQ, are working hard to make sure an interesting meeting takes place. This year we are in Birmingham at the Midland Arts Centre. Verité Reily Collins has kindly agreed to speak and we hope that a researcher from the RESULT Study will be able to come along as well. I know PSN members participated in this study and the Final Report will be available shortly.

We need a few more members to help manage PSN. Although, always welcome, this need not be as committee members. For example, we need someone to help source charities and Trusts that PSN is eligible to apply to for funds. If you are interested in research and patient information, you might like to help update our website information.

The time for these activities can be as much as you can spare, e.g. half-an-hour a day or a week, an hour a week, half a day a week, all day, everyday etc.- you get the idea I am sure. All that is needed is, You, a computer and a comfy chair and, perhaps, tea and biscuits.

The responses to our members' survey are providing some useful information. For example, of those responding to the question asking whether you have other medical conditions, 70% replied "yes". Some of the conditions reported are common such as, cardiovascular disease, diabetes, asthma and high blood pressure. Conditions you might expect to find in the general population but what might not be expected in the general population is post polio syndrome as well. This is an important issue in view of advice given for lifestyle changes for these conditions such as increase activity levels, reduce weight, go for a brisk walk for 30 mins 5 times a week. And with the knowledge of Verité's, Hilary and Richard's experiences we have to work better during the next year to educate and inform clinicians and service providers.

The survey also asked about your "experiences" and these will provide the beginnings of a databank (anonymous) for us to refer to. We need to add to this continually. If you have any health experiences you would like to add please send them to me. Particularly, if you are invited for a health screening test. Your experiences are important because You are important.

On my notice board I have a postcard sent to me about 10 years ago. On the front in multi-coloured lettering is the an observation by Margaret Mead, who was an American anthropologist:

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."

I believe that do you? Polio Survivors may not be able to change the whole world but the bits that affect you will change when you make the change happen.

Looking forward to seeing you at the AGM!

Sandra Paget Chairperson

sandra.paget@poliosurvivorsnetwork.org.uk

Tel: 01494 729373

Mob: 0777 294 0905

# POLIO SURVIVORS NETWORK ANNUAL GENERAL MEETING

**SATURDAY JUNE 18TH 2011**

**Pinsent Mason Suite 2,  
The MAC Birmingham, [Midlands Arts Centre]  
Canon Hill Park,  
Birmingham B12 9QH**

**1.p.m. To 5 p.m.**

## **Bridges Café Bar**

Offer a tempting selection including daily specials,  
breakfast: hot and cold sandwiches,  
pastries, delicious cakes, main meals and jacket potatoes.

9am- 11pm (Hot Food available 9am - 8.30pm, snacks available until 11pm)

Arrive early and have a snack or lunch in the Cafe Bar, time to chat with others.

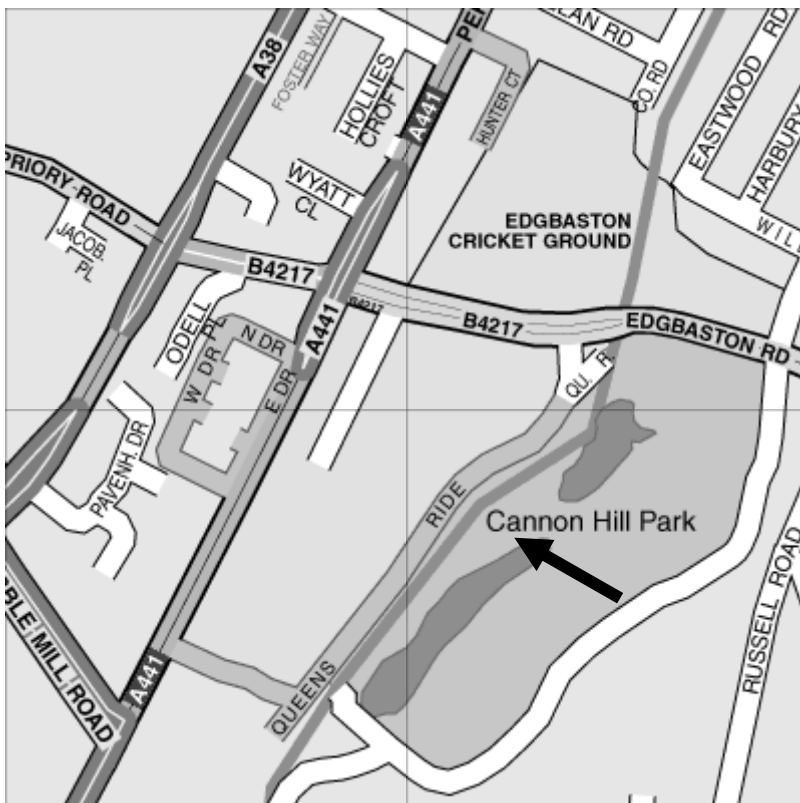
Room opens at 1.00 p.m. AGM commences at 1.20 p.m.

Followed by Speakers Verité Reily Collins and Professor Catherine Sackley

[See AGM Block on Front Page]

Tea Break and Raffle, and Q&A session

Hotel info near the MAC - <http://www.skiddle.com/hotels/Birmingham/near/Mac/ent-e5419/>



**MAC** is located in  
Canon Hill Park,  
Birmingham,  
opposite the  
County Cricket Ground  
on Edgbaston Road,  
off Pershore Road (A441)  
and Bristol Road. (A38).

Buses

1, 35, 45, 47, 62 and 63.

# Post-Polio Health Care Considerations For Families & Friends

Joan L. Headley, MS - Post-Polio Health International, St. Louis, Missouri  
Frederick M. Maynard, MD - Physical Medicine and Rehabilitation, Marquette, Michigan  
With

Stephanie T. Machell, PsyD - International Rehabilitation Center for Polio, Framingham, Massachusetts  
Holly H. Wise, PT, PhD, Associate Professor, Division of Physical Therapy,  
College of Health Professions, Medical University of South Carolina, Charleston, South Carolina

PUBLISHED BY Post-Polio Health International [www.post-polio.org](http://www.post-polio.org)

[EXCERPTED CHAPTER - more details about this document at end of Chapter]

## III Late Effects of Polio: The Psychosocial

Is your family member struggling with finding out that he or she has PPS? Does he or she appear to be in denial about what seems to you to be obvious changes in his or her functioning? Many polio survivors have difficulties adjusting to new disabilities. Some people with PPS find that they are now reliving their childhood experiences with polio and that can be traumatic and even terrifying.

Because of the relatively small number of polio survivors, many physicians see very few, if any, and know very little about PPS. Some still believe that the condition is only in their patients' heads. People with PPS often depend on their own resources to help them cope with this condition, because there is a lack of proper medical and psychological advice.

Fortunately, PPS continues to gain attention in the medical community. A growing number of health care professionals understand PPS and can provide appropriate medical and psychological help. In addition, there are PPS support groups, newsletters and educational networks, such as Post-Polio Health International, that provide up-to-date information about PPS while offering individuals the knowledge that they are not alone in their struggle.

### A. Polio: The Experience

Many polio survivors have never shared their experiences with anyone, even their children. You may not have known that your parent even had polio until he or she began to experience the late effects. Why would your family member never have talked about something that seems so important?

The polio experience was a difficult one. Polio carried a stigma similar to HIV/AIDS in that others were afraid to associate with children with polio and their households. It was common for polio survivors discharged from the hospital or rehabilitation to be discouraged from talking about what they had experienced. If they were able to pass as non-disabled, polio soon faded from their awareness. Many didn't feel that polio had really affected them very much at all until they developed PPS.

However, it did affect them. Acute polio was an extremely painful disease. Along with the pain, the patient would have a high fever and become unable to move parts or all of his or her body. He or she may have developed difficulty in breathing, and even been placed in an iron lung. Children and adults who were hospitalized and contagious were kept in isolation from family, and even when rehabilitating allowed few visitors.

Professionals thought young children did not need an explanation of what was happening to them. Young polio survivors were confused and afraid, sometimes believing they had done something bad to make their parents leave them. There were few mental health professionals on polio wards to help patients deal with their emotions, and those who did do such work didn't acknowledge the psychological effects of the illness.

The experience, of course, affected children in many ways. For some, especially those who had

polio before the age of 4, it became hard to trust and connect with others. Some became mistrustful of doctors and medical treatment. Certain sights, sounds or smells may bring back the polio experience years afterwards.

When it was time to go through rehabilitation, polio survivors were encouraged to work as hard as they could, often pushing themselves past the point of exhaustion to regain as much mobility as possible. They learned to do whatever they could to function in a society that would make no accommodations for their disabilities. Wherever possible they were encouraged to give up braces and crutches as soon as they were able. Essentially, the message was that if they worked hard enough they could be successful at whatever they wanted to accomplish.

Polio survivors, especially the youngest ones, often returned to the hospital for surgeries for many years afterwards. Some children spent every summer in the hospital having "corrective" surgeries that often did little to improve their functioning. Many came to dread summer. Some felt they were in constant need of "correction" and that they were never good enough as they were.

Polio survivors often became stubbornly independent because of these experiences. They learned to be self-reliant. They exercised and exercised out of a belief that doing so would allow them to preserve their abilities. For many, PPS has felt like a betrayal, because what was helpful then has turned out to be harmful now.

More ...

Emotional Bridges to Wellness (*Post-Polio Health*, 2001)

A Guide for Exploring Polio Memories (*Post-Polio Health*, 2002)

Improving Quality of Life: Healing Polio Memories (*Post-Polio Health*, 2002)

## **B. Models of Disability/Identity Issues**

After polio, survivors learned to cope with their disabilities. Researchers identified three coping styles that polio survivors used during the initial rehabilitation. Men and women with mild disabilities who could give up their braces and crutches could "pass" as nondisabled. Persons who couldn't do this played down their use of crutches or braces and magnified physical or personal strengths, thereby "minimizing" the more obvious effects of the disease. Persons who used wheelchairs or ventilators faced the architectural and attitudinal barriers of the times. They couldn't pass nor minimize, and so fully "identified" with their disability. Many identifiers became leaders of the independent living movement that resulted in changes in society, including the passage of the Americans with Disabilities Act (ADA).

How your family member deals with PPS depends on how they coped with their original polio. Identifiers don't question who they are now even though they are distressed by new disability. The changes brought on by PPS distresses mostly minimizers and passers. They may experience a sense of being a different person now, and may have to deal with what it means to be a person with a disability. For some, counselling or psychotherapy can help with these concerns.

## **C. Coping with Stress and Physical Changes**

Is your family member having trouble coping with PPS? Individuals who are coping well focus on what they can do, rather than on what they cannot do, and play an active role in their lives, rather than respond as passive victims. They participate in areas of life seen as worthwhile and meaningful. They may have problems, but they are not overwhelmed by them.

People who are coping well appreciate their accomplishments and do not deprecate them because they do not meet some "normal" standard. They participate in valued activities and enjoy doing so. When they have problems, they solve them by making changes in their physical and social environments, such as eliminating architectural barriers in their homes and making new friends. They do not wait for a "cure" to fix everything.

To cope well with increased limitations, polio survivors may need to make important realistic value changes. They cannot deny their disability. Persons who successfully cope with their disability enhance their ability to change and to maintain relationships.

The late effects of polio can be complex and distressing as it may arouse painful memories that may interfere with the need to make major lifestyle changes. However, survivors often realize that changes, at their own pace, are manageable. They can use their coping skills to adjust.

Working hard to meet goals and surmount adversity are characteristics of the "polio tradition." Your family member has coped with many difficult life experiences. With support, he or she can cope with these new challenges.

#### **D. Relationships: Families and Friends**

As family members become more disabled, they may become more isolated from you, other family members and friends. They may be less able to attend functions or engage in activities. Others in your social circles may not now know how to deal with a person with a disability. If your parent has cognitive changes, this makes communication harder. Polio survivors' independence can also pose challenges for those around them.

Everyone needs support from family and friends. If you can help loved ones keep their relationships, and even find new ones, you will help them to have the best possible quality of life. Offer to help them find ways of getting together with friends and family, such as using senior or paratransit services, or provide rides yourself. Encourage them to have friends or family over. On the other hand, help your family member use other means of connecting, such as the telephone or computer. Aged parents might enjoy getting out to the local senior center. There are many activities for all interests and usually transportation. Support groups for PPS or other issues might help them feel less isolated.

Every relationship is unique, but for any relationship to succeed, both individuals will need to cope with any disability. This requires a realistic acceptance of the disability with an emphasis on what one can do, rather than one what one cannot do.

Caring for an aging parent or spouse can strain a relationship. Here are some suggestions on how to keep a relationship healthy.

- Accept yourself and your family member. He or she is probably not going to change at this time of life.
- Be actively concerned with each other's growth and happiness.
- Commit to the relationship and to the other person.
- Communicate clearly with each other.
- Deal with feelings.
- Provide freedom and time away from each other.
- Be realistic about demands on each other.
- Be flexible and adaptive in confronting new challenges.
- Be prepared to accept new roles.

If you are having difficulty with a family member or your role as caregiver, or if these ideas bring up new issues, seek professional help. Support groups for caregivers are available and can help family feel less isolated. [End of Chapter]

[Editors Note - This 40 page document has a Flowchart.

Visit [www.post-polio.org/edu/healthcare](http://www.post-polio.org/edu/healthcare) to view the information about your loved one's post-polio care considerations by using the flowchart and answering the questions "yes" or "no" then reading the sections that apply to your polio survivor's needs.]



MEMBERS NOT ON THE INTERNET can purchase copies of the 40 page document at \$10 each [£6.25] plus postage and packing (figure unknown at the moment). If you would like a copy then please get in touch BY THE END OF MAY 2011 when we will place the order. To give you a little more information I have included the Outline.

## OUTLINE

- I. Considerations for Hospitalized Polio Survivors
- II. Late Effects of Polio: The Medical
  - A. Polio: The Disease
  - B. New Symptoms after Stability
  - C. Post-Polio Syndrome
  - D. Aging with Polio
  - E. Maintaining Health and Wellness
- III. Late Effects of Polio: The Psychosocial
  - A. Polio: The Experience
  - B. Models of Disability/Identity Issues
  - C. Coping with Stress and Physical Changes
  - D. Relationships: Families and Friends
- IV. Management/Treatment Ideas
  - A. Pain
  - B. Weakness
  - C. Fatigue
  - D. Breathing and Swallowing Problems
  - E. Depression and Anxiety
  - F. Trauma
- V. Evaluation of Options within the Family
- VI. Professional Assistance
  - A. Family Physician
  - B. Health Care Specialists
  - C. Coordination of Care
- VII. Plan for the Future – Don't Reinvent the Wheel!

<http://www.post-polio.org/edu/healthcare/PostPolioHealthCareAll.pdf>

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### **PHONE, PEN AND EMAIL PALS - Chat and Share Life and Times with your Peers..**

We have suggested this quite a few times in the past but it has never really taken off. We have members who now live in Residential Homes, alone and/or find it increasingly more difficult to get out and about and not everyone has or wants a computer.

Some members who have computers are subscribed to our Members Email Discussion List where much gets discussed. [contact [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk)] We have had information and questions/discussions on polio, post polio, numbers of survivors, other allied conditions, different pieces of equipment, news articles, incapacity and disability benefits etc and personal good news items. We know how beneficial this can be, so why not help those who do not have computers. Whilst I know our lives are pretty full trying to manage our own PPS lives, can you spare a half hour now and then to chat or write to another member or carer to carer?

Contact us by phone, letter or email if you are interested.

## 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]

### 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

Congress language will be English. Online registration. [www.poliocconference.com](http://www.poliocconference.com)

### REGISTRATION FEE

	Before April 1st 2011	After April 1st 2011
Professionals	3000DKK / 400 Euro	3500 DKK / 470 Euro
Polio Survivors	1465 DKK / 195 Euro [£165.09]	1950 DKK / 260 Euro [£220.13]

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.pccopenhagen Towers.dk](http://www.pccopenhagen Towers.dk) [rooms from £104 a night]

### CONFERENCE SECRETARIAT

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

## BBC Northern Ireland News Item April 21st 2011

### New Northern Ireland holiday getaway for disabled is unveiled

From the Strangford Bay Lodge Website [www.strangfordbaylodge.com](http://www.strangfordbaylodge.com)

As summer approaches, getting away will be just a distant dream for some families as they can be put off leaving home in case their destination can't meet the needs of their family. Because if you have a member of the family with a disability, getting away is not as easy as it sounds. But that's about to change with the opening of Strangford Bay Lodge. "Looking after a loved one can be hard and if anyone deserves a holiday or a short break, it's the thousands of selfless carers who look after their loved ones full-time, and wouldn't have it any other way." *Laura Dunlop.*

Paul Toner's vision is simple: "I want to create a place where able and disabled people can come together, with no distinguishable differences made for either visitor. There's no big blue and white toilet marked 'disabled' here; everybody uses the same luxurious wet rooms. The space and the surroundings are to be a place where you can come and relax, get away from it all knowing all your bathroom and accommodation requirements will be met discreetly."

Included is N.I. Sixth Changing Place Toilet and the first privately owned one adjacent to the Breakfast Room.

Strangford Bay Lodge, Abbacy Road, Ardkeen, Portaferry, Newtownards, BT22 1HH

Phone: (028) 4272 8350

Email: [strangfordbaylodge@hotmail.co.uk](mailto:strangfordbaylodge@hotmail.co.uk)

**WE'RE STILL HERE**  
**2011 POLIO-WORLD POSTER COMPETITION**  
**Organiser Micki Minner.**



You are invited to send us photographs to show  
your individual history of Polio.

We are looking for three photos:

- the first showing Polio,
- the second depicting Living with Polio
- and the third Adapting to Post-polio.

We will use the photographs to create an awareness of Post-polio and to show the world that WE'RE STILL HERE!.

To participate,

send your submission to [Mickiminner@msn.com](mailto:Mickiminner@msn.com)

Three photos and with a description of 50 words of less.

Please put Polio-World in the subject line, your description in the email and attach your photographs.

You can design the whole poster yourself if you wish.

Have a look at the back page to see some examples of last years Posters.

Deadline is September 1st 2011.

[Editors Note:- Last years winner was on the front cover of Post Polio Matters December Issue. Any member without a computer who would like to join in, post the information to our main address and we will forward it for you.]

**CHANGING PLACES - <http://www.changing-places.org/>**

**Each Changing Place Toilet provides:-**

**The right equipment**

- a height adjustable adult-sized changing bench
- a tracking hoist system, or mobile hoist if this is not possible.

**Enough space**

- adequate space in the changing area for the disabled person and up to two carers
- a centrally placed toilet with room either side for the carers
- a screen or curtain to allow the disabled person and carer some privacy.

**A safe and clean environment**

- wide tear off paper roll to cover the bench
- a large waste bin for disposable pads
- a non-slip floor.

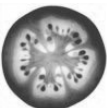
Editor's Note:- To date there are 200 in England, with 8 in Lincolnshire, 3 in Lincoln City.  
56 in Scotland, 13 in Wales and 6 in Northern Ireland.

## God's Pharmacy is Amazing.

[It's been said that God first separated the salt water from the fresh, made dry land, planted a garden, made animals and fish... all before making a human. God made and provided what we'd need before we were born. These foods are best and more powerful when eaten raw. God left us a great clue as to what foods help what part of our body! The Manataka American Indian Council website but Gods Pharmacy is Amazing is on many websites]


A sliced Carrot looks like the human eye. The pupil, iris and radiating lines look just like the human eye... And YES, science now shows carrots greatly enhance blood flow to and function of the eyes.



 A Tomato has four chambers and is red. The heart has four chambers and is red. All of the research shows tomatoes are loaded with lycopine and are indeed pure heart and blood food.


Grapes hang in a cluster that has the shape of the heart. Each grape looks like a blood cell and all of the research today shows grapes are also profound heart and blood vitalizing food.



 A Walnut looks like a little brain, a left and right hemisphere, upper cerebrums and lower cerebellums. Even the wrinkles or folds on the nut are just like the neo-cortex. We now know walnuts help develop more than three (3) dozen neuron-transmitters for brain function.

Kidney Beans actually heal and help maintain kidney function and yes, they look exactly like the human kidneys.

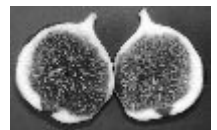



 Celery, Bok Choy, Rhubarb and many more look just like bones. These foods specifically target bone strength. Bones are 23% sodium and these foods are 23% sodium. If you don't have enough sodium in your diet, the body pulls it from the bones, thus making them weak. These foods replenish the skeletal needs of the body.

Avocados, Eggplant and Pears target the health and function of the womb and cervix of the female - they look just like these organs. Today's research shows that when a woman eats one avocado a week, it balances hormones, sheds unwanted birth weight, and prevents cervical cancers. And how profound is this? It takes exactly nine (9) months to grow an avocado from blossom to ripened fruit. There are over 14,000 photolytic chemical constituents of nutrition in each one of these foods. Modern science has only studied and named about 141 of them.




Figs are full of seeds and hang in twos when they grow. Figs increase the mobility of male sperm and increase the numbers of Sperm as well to overcome male sterility.




 Sweet Potatoes look like the pancreas and actually balance the glycemic index of diabetics.

Olives assist the health and function of the ovaries.



 Oranges, Grapefruits, and other Citrus fruits look just like the mammary glands of the female and actually assist the health of the breasts and the movement of lymph in and

 Onions look like the body's cells. Today's research shows onions help clear waste materials from all of the body cells. They even produce tears which wash the epithelial layers of the eyes. A working companion, Garlic, also helps eliminate waste materials and dangerous free radicals from the body.



[Editors Note:- I thought this was interesting and added it to the newsletter then thought I better check it out on the Internet in case this is a Hoax and found 'Health through God's Pharmacy' by Maria Treben which has been on the top of the German Best Sellers List for years selling several million copies. Published by Ennsthaler October 1993.



Janet Corr, a Life Member, passed away a few weeks ago at the age of 61. Husband Trevor and son Paul travelled to Lincoln to hand over a donation in her memory. On behalf of all our members we thank their family and friends who donated the fantastic sum of £900 towards our work.

I asked them to tell me about Janet.

Her most loved fact was that her birth certificate stated that she was born in the 'Cock and Pheasant Pub' in Bollington in Cheshire.

Janet caught polio when she was six months old but like many other polio survivors got on with her life. She left school and worked as a machinist and then joined ICI as a packer on an assembly line. When they came to her with a Green Card 'Registered Disabled' she told them in no uncertain terms that she did not need or want that!

She met and married Trevor and continued to work for another 13 years till son Paul was born. It was not long before she started looking for other ways of adding a few pennies to the pot. She loved children and became a child minder taking on two sets of twins amongst others. When Paul was a little older she decided to look for other work. On top of looking after her family, she worked as a cleaner in the morning, then dinner lady at lunchtime, more cleaning in the afternoon and took in ironing to do in the evenings! The children at school loved her and she was soon also helping with sewing and making cakes. She was always on the Go.

About 12 years ago Trevor noticed that the number of tasks she could manage each day got less and less, although she never mentioned it.

Two years later he decided it was time to discuss this and she eventually agreed that maybe it was time to visit the doctors for advice because after all 'I am only 50'. After an assessment she was awarded High Rate DLA Mobility and found out that PPS existed. She joined our organisation and Trevor said she enjoyed getting the newsletter and all the information we provided which helped her manage her life.

The family had always caravanned with the Caravan Club, organising many rallies. Six years ago they decided to buy a new caravan and travel the country all year round. Trevor remembers one rally in Lancashire where a lady, known for always complaining regardless of where her pitch was fixed, started to complain yet again. Janet sorted it out and came back and frustratingly said 'I am fed up with all this, I have a good mind to go home..... oh I can't because this is our home' and laughed.

Paul told me that at a Christmas Rally his mum made a Santa Sack covered with presents, wired it open with coat hangers for him to wear and he won the Fancy Dress competition.

Janet was loving her 'travelling the country life' when a few weeks ago she started to have more headaches and breathing problems was admitted to hospital but sadly passed. Trevor told me, I have lost my best friend, a great cook and organiser. In fact I called her my 'Tour Operator'.

Why is it that writers write but fingers don't fing,  
Grocers don't groce and hammers don't ham? I  
If the plural of tooth is teeth, why isn't the plural of booth, beeth?  
One goose, 2 geese. So one moose, 2 meese?  
One index, 2 indices?  
Doesn't it seem crazy that you can make amends but not one amend?  
If you have a bunch of odds and ends and get rid of all but one of them,  
what do you call it?

# MAKING ONE MORE EFFORT TO PUT OVER OUR POINTS

By Verité Reily Collins

Lying on the floor of Chelsea and Westminster Hospital, I thought “Oh Bxxxxxx - why won't they listen to patients?” I was frozen (hospital heating wasn't working) my feet had lost all feeling, and when I got up to go to the loo, I crashed into drip stand, chairs and assorted NHS furniture.

Five years ago I started to try and get this hospital to listen to simple things that we need: warmth, sensible handling, and padding in right places when we have to lie down – in other words, what we are always being promised ‘we care about patient comfort’.

Huh! I had been to see the nurse in charge of their Medical Day Unit (MDU) in advance of a full-day infusion. Tried to explain simple things that I would like – a comfortable chair to sit in: “we don't have cushions – bring your own” (so much for hygiene). But never thought to say we need warmth. Silly me.

It was a warm early-summer day, but inside the MDU the air-conditioning had broken down five days ago, and was blasting cold air so that even nurses were complaining. I was supplied with three blankets, but new NHS ones are made of slimy cotton, cold to touch, and so heavy they cut off my circulation. When I stood up my feet had no feeling and I crashed on top of drip stand and chairs.

I was picked up, asked if I felt OK, and like an idiot said yes. So was left alone. Shortly after I had a headache, felt woozy and had a dry mouth, so tried to attract attention of nurse – who eventually gave me a cursory glance. Began to feel worried, so asked what could be done, and was crossly told a doctor would be called. Hallelujah!

After doctor had come and given me a thorough examination (luckily no lasting damage as I'd only hit my thick head!), I took matters into my own hands, phoned down to Estates and Maintenance and told them to get a move on. Then phoned Supplies and got them to send up a heater – and started to warm up. But why Sister in charge of unit hadn't thought of keeping a polio patient warm before this all happened, heavens knows. Falling on top of medical equipment is never a good idea. And if the same thing happens to you, it is no use expecting nurses to phone Maintenance – they don't have time; you as a patient phoning them is a novelty, so they do something.

The end of the story is that when I asked for a glass of water nurse said to me “you have had enough attention today”.

The week before the Government had said it will be consulting with patients as to what we want for NHS - and my local hospital was chosen to start the ball rolling. The government has found that it is earning ‘brownie points’ for putting on these meetings, so, desperate for popularity, are organising more.

## How can we change things?

Well what we did. We dutifully answered the invitation to turn up at Chelsea and Westminster Hospital to meet 'a Minister', then endured ten minutes of political speech from Nick Clegg - who turned out to be 'The Minister'. He had bought along Paul Burstow (Care Minister) and Prof. Steve Field, a GP.

For anyone who is organising any more of these 'consultations', some observations might be useful.

- Make sure questions you are asking concern what is in the Health Bill. This covers a wide remit, but it helps if you phrase it within ‘Health Bill’ proposals.

- Don't involve Governors. They are the great Gods of their hospital and won't see anything wrong with it.
- So - ONLY patients - and no more than a dozen. There were over 30 in the room; many people had come miles and didn't get a word in.
- And no-one to be allowed a second question until everyone has had a go - one participant tried to hog the whole meeting.

Afterwards another patient said it would be much more helpful if we had been invited to listen to a half-hour explanation of what the Bill is about, and then when the Minister arrives, we could get straight in to questions. And - there should have been some form of follow-up - many patients have good ideas about where money could be saved, but weren't given a chance to suggest them.

The Governors got in their plug for the 'excellent care offered by the hospital, etc', (to indignant snorts from patients near me), but patients were concerned with what they see is already happening:

- losing nurses and front line staff
- what was going to happen with GPs holding the purse strings - already tests and operations are being 'held over' in Chelsea and Kensington, and the 2-week wait for cancer patients has been changed to 'first appointment only'.
- What is happening re 'care packages'

Remember, there are more people who survived the effects of the polio virus than most people realise. It could be about 120,000 but there are no official figures so no-one can challenge you. [See Chair's comment at end of article, page 16]

## Getting a question in

I managed to ask Paul Burstow (Care Minister) why hospitals were being fined for placing patients in a mixed ward, with the fine going to the PCT - so making this just a paper-shuffling exercise. Why didn't the patient get the money? They had had to put up with the indignity.

Surprised looks all round. No-one had an answer. I was promised someone would look into this. Realising that no record was being kept, I made sure I got hold of a business card from one of the Dept. of Health officials, emailed a copy of my question, and full marks - this afternoon an email popped into my inbox asking me where Mr. Burstow could send his reply.

But you MUST follow up your question. With this 'informal' meeting you won't be guaranteed a reply unless you chase it up yourself.

## Worries

Concerns were expressed at units being closed down, and Frontline staff were already being made redundant. That was of great concern to those patients acting as carers to disabled relatives, who needed continuity of care. Burstow did explain the new system of grants and support for the disabled, but sadly there wasn't time to go in to this.

As the meeting went on it was obvious that GP commissioning was a major concern. Patients had already been told they couldn't have 'normal' procedures; drugs that 'suited' them were to be changed for something cheaper, etc.

## In future

I looked up Prof. Steve Field, and discovered he was representing **NHS Future Forum**. This supposedly represents views of staff, patients, GPs, etc. helping to shape the future NHS.

Does it surprise you that amongst the FORTY-FIVE members of this forum, there is only ONE patient representative? So much for consulting with patients. But if you would like to tell them what you think, you can contact them on

<http://healthandcare.dh.gov.uk/listening-exercise-how-to-get-involved/>

But be warned. The website is cleverly designed, and trying to find how to navigate it is difficult!

Hopefully the Dept. of Health team will take on board that we don't need 'protecting' from reporters covering the event (in fact we were delighted to say what we felt), but we DO need a calm sensible forum where we can put to Ministers just what WE want from the NHS.

And if the idea was for Ministers to learn and take on board what we had to tell them (as Clegg emphasised) I wonder why there was no recording ? I asked for one afterwards and was told this was not being done. Strange.

It's OUR money that funds NHS - we should have a say and be listened to.

## **How can YOU be involved?**

There is still time to find out if there is an event near you, and apply to go.

<http://www.regionalvoices.net/2011/04/nhs-future-forum-listening-events-programme-hosted-by-regional-voices/>

If not, contact your MP and ask them to arrange for a Minister to come to your hospital or patient group

And go armed. Get two or three other invitees together to decide on YOUR most pressing question that needs answering, then work out how you can ask about this subject, but phrasing it differently each time so the Minister doesn't say they have already answered.

If they are going to 'use' patients for a face-saving exercise - it's up to us to play them at their own game.

Good luck. Verité Reily Collins <verite@greenbee.net>

Editor: [www.after-cancer.com](http://www.after-cancer.com); [www.healthspanews.com](http://www.healthspanews.com)

Member Chartered Institute Journalists; the Sports' Journalists' Association., & the Association. Guild Health Writers

## **Sandra Paget, Chair, Comments. [1—Experiences and 2 Polio Numbers]**

### **1. Experiences.**

The experiences described above by Verité, and Hilary, Richard & Maureen [on page 18] raise an important issue and one that is often overlooked :- What happens to people when being treated for something other than their neurological condition, including health screening? Quality Requirement (QR 11) of the National Service Framework for Long Term Neurological Conditions (NSF-LTNC) which was published in 2005 with a ten year implementation period covers this aspect of health experience.

QR11 addresses the provision of care in other settings, for example, during treatment for non-neurological health problems. Good planning can ensure that the management of the neurological condition and the person's self care are not compromised.<sup>[1]</sup>

Towards the end of last a year a Systematic Review: Access to Health Care for disabled people by Dr Jeremy Gibson, Royal Derby Hospital and Dr Rory O'Connor, Leeds Institute of Molecular Medicine was published in the Journal of Social Care and Neurodisability. Sixty studies were reviewed, many of which were in the USA, no randomised controlled trials were identified. The review suggests that disabled people are restricted in accessing health care and report less satisfaction with their medical care.<sup>[2]</sup>

**More awareness, more education of clinicians and more research is urgently needed.**



If you would like an electronic copy of the NSF-LTNC we can send you one on request.

#### References.

1. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4105361](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361)
2. Systematic Review: Access to Health Care for disabled people, Gibson, J. and O'Connor R., Social Care and Neurodisability • Volume 1 Issue 3 • November 2010 © Pier Professional Ltd

## 2. Polio Numbers.

Trying to give an exact figure of how many polio survivors there are living in the UK who are experiencing PPS seems difficult. The Health Protection Agency (HPA) has published all notifications of cases of polio in the UK between 1912 - 2008<sup>1</sup>. The information given by NHS Choices<sup>2</sup> is that Post Polio Syndrome (PPS) affects approximately 20% - 66% of people who have had polio with symptoms developing between 10 and 40 years after the initial illness. Symptoms can take an average of 30 years to develop.

Taking the total HPA notifications between 1920 - 1998, the year of the last notifications given, of 65,658 and using the NHS Choices' figure that PPS affects approximately 20% - 66% of polio survivors there may be 13,131 - 43,334 people experiencing PPS today.

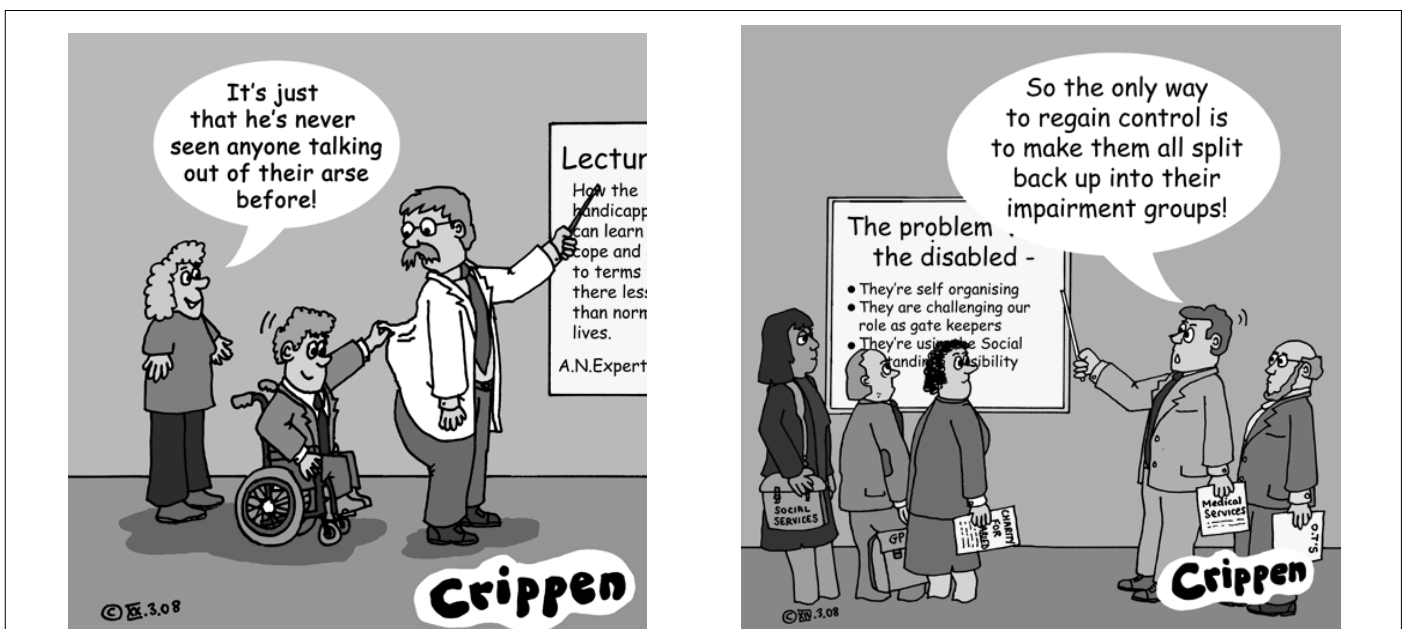
In a paper published online in July 2010 it was suggested that 15% - 85% of polio survivors may go on to develop PPS<sup>3</sup>. Using these percentages and based on the HPA notifications between 1920 - 1998 there may be between 9,848 - 55,809 people experiencing PPS today.

Some of the potential PPS population are fairly young. For example those who caught polio in the 1959 epidemic, aged 1 are, today 53 years of age. Our youngest member is about 13 years of age. At the same time our oldest members are over 80. And we have within our membership 7 U.K. members who caught polio abroad, who may not be included in the HPA notifications. It is also possible that there are polio survivors among the UK's ethnic communities that are not included in the HPA notifications because they were not living here when they caught polio but may go on to develop PPS.

References: all available online, Ref. 3 is an Open Access free to download document.

1. <http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/Polio/EpidemiologicalData/>
2. <http://www.nhs.uk/conditions/Polio-and-post-polio-syndrome-/Pages/Introduction.aspx>
3. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2909497/>

Sandra Paget, Chair.



## **Polio Survivors - your experiences are valuable.**

Please send info for this page by email or letter. We know that may be difficult for a few members who are welcome to ring. Deadline for next issue is June 15th.

1. Richard was rushed into hospital with a suspected intestine blockage one evening in mid February and despite all our documents, knowledge and experience the five days were a nightmare. Ensure you have ready any medical equipment and spares you might need, copies of your What you Need to Know about Me form completed, any medical reports that contain any valuable information about your conditions, copies of your prescriptions, a few days supply of the actual tablets, and phone numbers of your health professionals and any support group/help that you might need. I expected some lack of knowledge about Polio, PPS, Bi-level ventilators and masks but not almost NIL. Richard also has Parkinsons and there was a similar lack of knowledge except when the Neurologist was on the ward on two fifteen minute occasions. One doctor arrived round the curtain saying to me 'I have come to see your father... Because to him a Parkinsons patient is usually an elderly person. He was a bit taken aback when I said I was his wife and he is younger than me.

If your physical limitations before or with the current reason for your admission are such that you need help throughout the day, e.g. not being able to move very much and operate the call system, your voice level going so low you cannot call for help, etc. then it is advisable to have someone with you at all times to remove that added stress level. I stayed with Richard the whole time and was able to provide valuable information to the constantly changing of staff, twice preventing the wrong treatment, and help him with needs as they occurred throughout the day and night. It was exhausting, and I did not think to ring the Parkinsons Support Group till he was improving on the fourth day. The relief of talking to someone who understood what we were going through and was able to offer some help was great. We now have that number added on our WYKTN form and on our mobile phone. I do not regret one minute of helping Richard but those five days took their toll and lowered my available energy levels. If you have family or support workers who know you well enough to take some shifts then it would be a good idea to go through all this with them now just in case.

2. Maureen, a member rang and told me that she had recently gone for a blood test at a hospital and the nurse taking the sample had told her to move her arm. She explained that she could not as she had polio. The response was 'Why on earth did you not get the vaccine'. She explained she caught polio in 1947 and the vaccine came out in 1955!!

3. Zsuzsanna:- I often slide down to the bottom of the bed because my left ankle has been fixed and if I try to sleep on my stomach it is uncomfortable so I stick my foot off the end. As I am only 5ft something (depending which leg I stand on!) my husband often says to me 'What are doing half way down the bed!'

Robin replies:- I have a foam mattress and to stop sliding down I put a thick folded bolster under the mattress to make a sort of traffic bump under the upper thighs. I have a foam wedge at the head of the bed so I sleep propped up. I also have a monkey pole and a pair of metal loops standing up either side of the bed about level with the bump. These I have covered in pillowcases and folded pillows, mostly to stop me rolling out of bed if I turn the wrong way at the edge of the wedge. All seems to work well.

Wendy replied:- before we had the electric beds I also had a problem with sliding down the bed and the OT provided me with a foot plate and I put two thick pieces of foam on it. I still slid down a bit as I am only 5'2" but in the least not out of the bed and it was soft on my feet. At the time I thought of having a monkey pole but after trying one, it was not for me.

MEMBERS. We need more items for page/s like this.

## 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

Gillian Bryan - Gilltcs@aol.com [Co-opted to the Committee]

### Operations Team

Membership Secretary - Hilary Boone - 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.

**NEW** →

**Val Scrivener is supporting us by making photo greetings cards for you to purchase**

- 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

what we have    what we are    what we do

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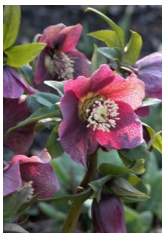
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Email - [info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk)

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THREE ENTRIES FROM THE 2010 POLIO WORLD PPS POSTER COMPETION - WE'RE STILL HERE.  
<https://picasaweb.google.com/110818555619380325259/PostPolio#>

Audrey King, Toronto, CANADA

1950's: 500 in hospital

1952: Polio left Audrey tags to wheelchair & ventilator dependent with some hand use. At age 15 she returned to school, graduating from University with her BA in 1961 & working for 36 years at a children's rehabilitation center.

1980's: Working as a psychologist

1990's: Canoeing on the Ottawa

Advocate, Artist, Advisor & Author, Audrey traveled to many countries during her career years. Six decades later, she declares "although my body no longer listens to my head, the BEAT GOES ON. Life may be lived in a different way now but there is still much to do and every moment is worth it."

I had polio at 18 months in England in 1948. My husband and I came to live in Australia in 1967. The warmer climate made life easier. I have two children and three grandchildren. Have kept active until post polio problems set in over the last few years.

Polio

Living with polio

Post Polio

Charlie Minner, Tucson, AZ USA

Flying in any way I can

Polio - 1955

Living with Polio - 1967

Post Polio - 1998

Charlie Minner passed over on the evening of 12th May 2011.

Our thoughts go to his wife, Polio Survivor, Micki Minner Polio World's 2011 Polio Poster Competition Organiser.

Help tell Our Story by entering Information - page 11.