



# POST POLIO MATTERS

The Polio Survivors Network Newsletter - Volume 8, Issue 2  
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[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

**December  
2013**  
Vol 8, Issue 2

**Meet our new volunteer, Mrs. Polly O'Lyffe**



Enter 100+ articles

What is this?

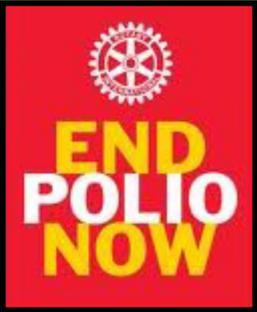


Answer page 16



**Wishing  
You  
A  
Merry  
Christmas**

Donated by  
Barbara  
Taverner



**Remembering Nelson Mandela 1918 – 2013**

I learned that courage was not the absence of fear,  
but the triumph over it.  
The brave man is not he who does not feel afraid,  
but he who conquers that fear.

“Madiba”, as he was reverentially known, was instrumental in kicking off South Africa’s polio eradication efforts in the mid-1990s. On World Health Day in April 1995, he announced that South Africa was throwing its support behind the notion of a world without polio. The following year, he was there to launch the ‘Kick Polio out of Africa’ campaign. Commending the efforts of health workers across Africa for the work they had done in reducing polio case numbers, he urged them to keep going until polio is defeated.

**POLIO  
in 2013**  
WPV1  
31.7.13 - 170  
INCREASES  
as of 4.12.13  
to 355  
PAGE 5



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Support PSN - buy Val Scrivener's Photo Cards.

**New Members and Donations received.**

**Welcome new members David Marris and John Keating  
Thank you to all members who have recently renewed.**

Thank you to the following for donations given towards our work  
Family and friends of Dinah Bass, Steve Clynch, Jean Simm,  
Ann Telford, Diane Taylor. Joy Witheridge. Victor Gabriel.  
Susan Freeman, Joanne Curtis, R Barry. Hilary Boone,  
Janet Dobbie, Wendy Grimmitt, Susan Freeman,  
Sandy Yarrow, Winifred Hyam, Margaret Lamb, Stuart Jupp,  
Helene MacLean, Jenni Paulger

Membership donations are	£786
Family and Friends of Dinah Bass	£600
Donations towards the cost of the AGM	£498
Val Scriveners Card Sales	£100

**GRAND TOTAL to 30th November £ 1,984**

This publication is provided as a service to those seeking such information and is not intended as a substitute for professional medical care. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Polio Survivors Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

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## Editorial by Hilary Boone

I would like to thank member Barbara Taverner for the donation of a Build-a-Bear teddy complete with wheelchair and crutches. Mrs. Polly O'Lyffe has a blank biography at the moment. She wonders if any members would like to contribute pages about 'her polio life', using your experiences of medical appointments, applying for benefits, managing at home, etc. Anything that will inform others of the issues we have and come up against, plus of course if you can make us laugh at the same time it would make good reading for the newsletter. Remember hearing others stories, hints tips and bits is so much easier to relate to than being told 'you must or should do this by a medical professional'. It is not that we don't want to listen and take their advice, it is just hard to change the habits of a lifetime of pushing ourselves to achieve. Jak who is five years old visited us yesterday and asked 'Why does the Teddy Bear need a wheelchair?'

Short reports from the European Polio Union AGM in Tullamore, Ireland, 18th to 21st October 2013 and the Neurological Alliance AGM in London November 26th 2013 on pages 10,11 and 5.

It was with some sadness when Robert Bass rang me to tell me that his wife Dinah had passed. He then told me that family and friends were donating £600 to Polio Survivors Network - a huge boost to our funds and so gratefully appreciated. Read more about Dinah on page 15.

Linda Donahue's article on transitioning to a wheelchair, pages 6 to 9, was reminded to me recently on the Post Polio Facebook page. When I saw the date I realised that I had actually been at this presentation 13 years ago, the first time we met in real life, we meet again in 2014.

We have received 100 copies [more requested] of the PTU [The Danish Society of Polio and Accident Victims.] leaflet POLIO PATIENTS AND SURGERY. Information for Health Staff. The leaflet was also produced in English so that it could be used by English speaking PPS groups and the Scottish Post Polio Network have already done this. PTU are European PPS Conference Partners and provide excellent clinic facilities for polio survivors. [We will start with members not on the Internet and then anyone in outlying areas. I asked at the EPU AGM if it was possible to have a pdf version to print ourselves and they said they would look into this.]

We have kept the membership costs to £12.50 p.a. despite the cost of everything going up year after year. We know that in hard times some things have to go and we don't want that to be your Newsletter. We have only been able to do this because yearly members that can add a few pounds more, or a book of stamps, with their membership fees. Some Life Members have also donated funds, some specifically for the Annual General Meeting costs.

However, PSN still need to raise funds to provide more information to a wider audience and to provide some expenses towards attendance at national meetings and post polio conferences. To date PSN have not been able to offer Richard and I anything towards the costs of our trip to Ireland in October to the European Polio Union AGM. Next year we are making a trip to the States and Canada to see family and have tied this in with the date of the 4 day PHI Post Polio Conference in St. Louis. I have been invited to be part of the Assessment Presentation Team - through My Polio Life. While part of the trip is of a personal nature there are additional expenses solely associated with attending the conference. I will also be submitting a presentation abstract related to self assessment for consideration to the 3 day EPU Conference in Amsterdam. A colleague of mine in Lincolnshire Neurological Alliance recently offered to help us raise funds and this is now underway and we hope to have some success. However, if any members are able to donate something towards the costs of attending conferences it would be appreciated. For example the costs of hotel rooms at the conference venue in central Amsterdam are €200 per night, [4 nights] plus conference fees of €275 per polio survivor and carer.

### Polio Survivors Network - Meetings

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

## MESSAGE FROM OUR CHAIRMAN - Simon Parritt

### APPROACHING A MILESTONE

More years ago than I care to mention, like many of you, I contracted polio. This was of course devastating for my parents and very scary for all those around me, no doubt in those days contamination fears were rampant. I was quite a small child at the time, so I think back and realize that the optimism and naivety of childhood played in my favour. I survived in fact I did better than most who had the type of polio that involved total paralysis, ending up independent and mobile to a large extent for many years. Now years later I am approaching an age, when I may fall into the pensionable age category. I have over the years coped with my impairments and dealt with my disability status in varying ways and degrees of success. But being a disabled younger working person was a priority status that focused attention on my needs as a disabled person.

The problem I now face is a system and attitude that divides society into elderly or not, before it was disabled or not, now disability has a danger of being dropped from my identity. As my impairments have increased and as PPS has progressed over the last decade or two, the support I need has increased. True some of this is also about the natural ageing process, but most not. But I, like many of you perhaps, now face the problem that many of my support needs and issues overlap with those who are elderly and having age related problems such as mobility and reduce functioning of muscles and skeletal systems. However they are quite distinct in origin from others who are non-disabled. They require different assessment and treatment and distinguishing between the two is important, not just from a physical point of view but also, for me at least, a political, rights and identity point of view.

The moment I am classified as elderly, I will be treated differently. I will for instance be lucky to have the same attention in hospital. I will be funded and treated differently by social services and even charities and voluntary organizations. Whilst I am 'younger' and often the younger the better, I am considered a priority and worth investing time and money in ensuring independent living and expert medical attention. As an elderly person with mobility etc needs I am part of an ageing population problem.

The minute I cross that magic age of 60-65, I am no longer treated as a disabled person BUT an elderly person with illnesses or conditions. You might say that the issue of altered status impacts on everyone, disabled or non-disabled, but this isn't quite true. I deeply resent this change of status because, unlike our non-disabled people, I have struggled against my impairments and a discriminating work and social environment. I have also struggled to be disabled and embrace what that means in terms of identity and rights and being true to myself. I am still and always will be a disabled person to my core first and foremost, it is in some ways my cultural identity, and the approaching new struggle to be disabled first and elderly second does not fill me with much excitement but quite a lot of irritation.

I guess this is something that many of you may have different experiences of, having been diagnosed later in life or not felt yourself have 'disability' as such a core identity for so long, if at all. However, maybe you have experienced people treating you differently in social situations and the different choices, access and treatment you have received. It would be good to hear from any of you about this issue of growing older as a disabled person with PPS.

**On behalf of the Trustees I wish all members, family, friends and readers**

**A Merry Christmas and a Happy New Year**

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

Chartered Psychologist

HCPC Registered Counselling Psychologist

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## Neurological Alliance Annual General Meeting November 26th 2013



Simon Parritt and Hilary Boone attended the AGM and Afternoon speakers which included Dr David Bateman appointed by NHS England as the first National Clinical Director (NCD) for Neurological Conditions.

Dr Bateman is currently a consultant neurologist in Sunderland at City hospitals, He spends three days a week doing his hospital work and gives up two days a week to his post as NCD.

It was so refreshing to hear a neurologist talking about community neurological services [which he has provided in the past at previous hospitals] and how much the provision of these would help us manage our medical conditions to a far greater degree with less need for medical emergency admissions.

He asked the members of the Neurological Alliance to provide him with samples of issues that our members have with numbers of how many so that he has more local knowledge when he attends meetings around the country, e.g. no knowledge of polio and or pps, no multi disciplinary assessment, any issues with equipment/wheelchairs/orthotics, no therapy available, etc.

**Please email, write or ring if you have any difficulties with the other methods. We will use the results ourselves and pass the information to the Neurological Alliance.**

### Polio cases on the increase in 2013

	31.7.13	3.12.13
Pakistan	22	70
Nigeria	40	50
Afghanistan	3	11
Somalia	95	183
Kenya	10	14
Ethiopia		6
Cameroon		4
Syrian Arab republic		17

### Polio Eradication reports....

The 'high season' for polio transmission is seeing a dramatic expansion of polio in Pakistan. Over the past four months, 45 cases of wild poliovirus have been reported since August, with evidence of widespread geographic transmission across the country. By contrast, 25 cases had been reported for the period January to July.

The situation in Pakistan is increasingly worrying to the global eradication effort, especially in Federally Administered Tribal Areas (FATA) which remains the main transmission zone in Pakistan. **This area is also affected by an outbreak of circulating vaccine-derived poliovirus type 2 (cVDPV2). The risk of spread within the country and internationally is high. [43 cases with first case notified 31st August 2012 and 43rd on 27th October 2013. 4 cases in Cameroon, 4 in Chad, 3 in Afghanistan and 1 each in Niger, Nigeria and Kenya]**

By contrast, cases during the 'high season' are on the decline in Nigeria. Since August, 8 cases have been reported, primarily from Borno and Kano states, compared to 42 cases for the January to July period.

[www.polioeradication.org/Dataandmonitoring/Poliothisweek.aspx](http://www.polioeradication.org/Dataandmonitoring/Poliothisweek.aspx)

ppn

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

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

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

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

## Transitioning To A Wheelchair: An Exploration of our Fundamental Fears

*Linda Wheeler Donahue*

When the late Christopher Reeve sustained his spinal cord injury in a horse riding accident, his transition from Superman to Man in Wheelchair was instant. In contrast, we polio survivors usually go through a lengthy, angst-ridden decision making process before we plunk ourselves down in one.

We listen to the recommendation of our physicians and we sheepishly explore the idea with our loved ones. We recognize that using a wheelchair would keep us from tripping and falling. It would help us conserve our limited energy and sure would make daily life a lot easier. Why, then, is this decision so emotionally intricate and agonizing?

**You were paralysed by polio, do not be paralysed by society.**

Let's go all the way back to the beginning. Like many of you, I contracted polio as a baby and endured a long hospitalization. I was separated from my family at the tender age of 18 months, and still have psychological wounds from that trauma. I emerged using braces and crutches for mobility. However, doctors encouraged eliminating these aids so that I could walk like "normal" people. Does this sound like you?

Many polio survivors made an impressive recovery, walking unaided for decades, only to find that about thirty years later, they had excessive weakness, fatigue, and pain. At that point, many of us were diagnosed with post-polio syndrome. We were now told to go back to using a cane or braces and crutches to walk.

**Life is much more difficult with PPS.**

At a very young age, striving to walk as "normal" people do taught us that reaching that goal, that high ideal, spelled success. Therefore, it is understandable that many of us equate our new muscle weakness, and need for adaptive equipment, with failure. That could not be farther from the truth! One of the biggest obstacles to our self-acceptance is realizing that when we embrace our wheelchair or our braces, in essence we are embracing ourselves. When we conserve our strength, we succeed in the task of being whole, much more so than when we push through the pain and fatigue.

**"The only way to make sense out of change is to plunge into it, move with it, and join the dance." Alan Watts**

Are you declining activities that involve walking? Do you sit back and reluctantly stay home, unable to do some of the activities you once enjoyed due to increased weakness, pain, fatigue, fear of falling, and lack of endurance? ***Do you choose to stay home?***

Did you once adore pops concerts in the park? But decline to go now because walking on uneven grass is far too difficult? ***Do you choose to stay home?***

Did you once savor the fun of cruising the mall with your daughter-in-law? But now decline to go because that much weight-bearing and walking is far too painful. Do you choose to stay home

Did you once thrill to walk the boardwalk at the beach absorbing the sights and sounds of the ocean, but decline now because the length of that long, winding boardwalk is too much to manage without pain and fatigue? ***Do you choose to stay home?***

Have your polio medical professionals recognized that the time has come for you to use adaptive equipment for most of your mobility needs? Does the thought of ***appearing in public*** appearing in public in a brace, crutch, or wheelchair fill you with dread? The key phrase there is "appearing in public." Alone in your home, you may love the way a wheelchair allows you to move smoothly, gracefully, and without pain and fatigue, but the image that most terrifies you is the thought of using a wheelchair ***out in public***. Your emotions overflow with panic and anxiety. Why? You realize on a rational level that using a wheelchair or other assistive device would be very liberating. However, that rational base is overpowered, indeed almost buried, by the negative

emotional overtones that shout: “No! No! No medical equipment for me!” We bought into the biases of our fitness conscious culture. We got the message early in life that society applauds people who have no observable abnormalities who are physically fit.

Persons with strong personal development and inner autonomy tend to rise above ideas of contemporary culture. They may observe folkways but are not controlled by them. In other words, confident persons with disabilities are able to transcend the environment rather than just cope. In psychological terms, this is called “resistance to enculturation.” And it’s a good thing.

### **Society places an inordinately high value on walking.**

#### **Let’s examine the underlying origin for this resistance.**

- ◆ As a child, you received considerable praise for your attempts to walk unaided.
- ◆ Society places an inordinately high value on walking.
- ◆ The wheelchair makes it virtually impossible to be a “passer,” that is, to pretend you are able-bodied.
- ◆ Indeed, it is the image of a wheelchair that is the universal symbol of disability.
- ◆ Much of your positive self-esteem is wrapped up in the fact that you are still able to walk.

These are some of the contributing factors in your resistance to using a wheelchair. However, we have only examined the surface reasons.

The deeper overriding reasons for your reluctance stem from a negative association of ideas. Think of it like an algebraic equation: YOU are on one side of the equation and DISABLED is on the other side. Especially if you have been walking unaided, or “passing,” you do not feel like you belong on the DISABLED side of that equation. Your association of that side is laden with shameful emotional overtones. Why?

One reason is that historically people with disabilities have been stigmatized. They occupy a low rung on society’s ladder. I remember the various social cliques in high school. Back in the 50’s, teenagers were ranked in hierarchical order as “Preppies,” “Jocks,” “Greasers,” and “Nerds.” The most popular kids were the Preppies and the least popular were the Nerds. The terms today have changed, but the hierarchy remains very much intact.

Very few handicapped kids land in the popular crowd. In a time when adolescents are learning how they fit into society, the message to many disabled kids is “you don’t belong.” We absorbed that message like water into a sponge. As we grew up, society’s hierarchical classifications undergo various transformations. The discrimination is not as overt, but is still there. I have a sense that most of us still long to belong to the “popular crowd” and for many, the ticket in is pretending you do not have a disability.

Our resistance to using a wheelchair is intimately connected to our unwanted view of ourselves as disabled. We have integrated the societal message that it is better to be ambulatory than to be in a chair.

Often that message is reinforced in our everyday interaction with the world. For example, there could hardly be a greater medical triumph than getting someone “up out of a wheelchair.” Consider the hidden negatives in our language: “wheelchair bound,” “confined to a wheelchair.”

Almost universally, people who are not totally wheelchair dependent, make too little use of the wheelchair, if they are willing to use it at all. Likewise, people who are gait impaired but not crutch dependent, make far too little use of crutches, if they are willing to use them at all. “I’m not *THAT* disabled.” or “I don’t *NEED* them,” are rationalized as sufficient reasons to forgo the enhanced function, ease, safety, and health benefits they could have from using adaptive aids.

When a polio survivor chooses to transition to assistive equipment, he/she faces emotional, interpersonal, and social issues that can be deeply troubling and anxiety producing. Phyllis Bottome wrote “There are two ways of meeting difficulties: you alter the difficulties or you alter

yourself meeting them.” We cannot alter our polio deficits but we sure can alter our way of getting through the world. We can use a wheelchair or scooter and liberate ourselves.

In my walking years, I always moved with a severely compromised gait, but as long as I was walking, I too saw myself on the opposite side of the disability equation. How my heart pounded with dread and self-consciousness the first semester I wheeled into a faculty meeting. That wheelchair gets the credit for “outing” me. I now had to admit to the world, and more importantly, to myself, that I was, indeed, a Person with a Disability. However, ever since that day . . . oh, the liberation that has been mine!

***....Oh, the liberation that has been mine!***

It is an important healing step to incorporate the belief that is OK to be YOU. Know that the consumer driven, stereotypical images of “attractive” and “popular” are oppressive falsehoods rather than the truth. It is stunningly attractive and appealing for a person with a disability to exhibit confidence and self-acceptance. We all admire people with confidence... Including people with disabilities. We have the power to change some of the prejudices and false perceptions of our society. Most of society is not used to seeing confidence and self-assuredness in someone who is disabled. Do not accept that preconception. Be as full of life in your chair or with your brace as you were when you walked unaided. That exhibition of confidence is our best weapon to break the old mold and to change prejudices.

When you live with confidence and self-acceptance, it is amazing how easy it is to transition to adaptive equipment and make the changes that will add so much to the quality of your life. When you live your life “out” in the open, you will witness people around you change their preconceived notions of disability. When you see their positive responses and you realize that their response is to YOU, as you are, you will be freed. You will receive positive reaction to the real you, not despite your disability, nor because they are unaware of your disability, but to the whole YOU. You will shed a burden you may have carried for most of your life.

***The good news is that the stigma is diminishing.***

Societal attitudes about people with disabilities are vastly more accepting today than they were in the doo-wop era of the Fifties. Are you still suffering from antiquated tapes playing incessantly on your inner self-talk tape recorder? If so, it is time to erase those old tapes. You can trade in your negative thought patterns for powerful new positive beliefs. I have discovered that the more comfortable I am with my disability, the more comfortable others are with me. You can liberate yourself and claim your rightful place in society.

If you love the comfort and ease of using assistive devices in private, but dread the thought of using these out in public, you can use the power of your human consciousness to restructure your perceptions and free yourself. You may not have control of your body but you certainly do of your thoughts. If we want society to change its idea about people using adaptive equipment such as wheelchairs, we have to start by changing our own thoughts. All you have to do is change your mind... That may sound simple, but it is very powerful. You will be amazed at how easy the rest falls into place.

***All you have to do is change your mind***



Think about sitting proudly, head held high, in your sleek manual chair or perhaps zipping around in your sporty power-chair. Visualize yourself manoeuvring gracefully over the uneven lawn at the pops concert in the park. How lovely the grounds look when you are no longer fearful of tripping. How sweet the evening air, as the melodic musical sounds touch your heart.

Picture yourself on a swift mobility scooter at the shopping mall with your favourite friend, scooping up bargains. You don't have to shop 'till you drop; you will still have energy left over to go out to dinner at the end of your day.

Envision yourself traveling the length of the boardwalk at the ocean. Your senses overflow with the ambiance of the seashore. Since you have no pain or fatigue, you are much freer to hear the seagulls, smell the salty sea breeze, and celebrate the sheer joy of an outdoor experience.

***I know that this is still a difficult decision.***

One of the toughest suggestions for a person with post-polio syndrome to comply with is to accept the need to begin using a wheelchair. Nevertheless, one is often necessary especially for those who had very little neuronal reserve after their initial polio episode. The benefits of wheelchair use are many, such as conserving energy for other activities, preventing injuries from falling, avoiding fatigue from ambulation, and preventing arm and shoulder overuse. In addition, there is one more benefit that the ladies will certainly appreciate: you can wear stylish colourful shoes! Throw out the “sensible” clodhoppers and don a cute flat, which will look adorable on our wheelchair footplate.

I believe that our able-bodied counterparts admire people who are comfortable with their bodies. Our pride, holding our head up as we sit in our wheelchair draws others to us and then, when they see our happy spirit, our curiosity, our contentment, and most of all, our acceptance of ourselves just as we are, then a newfound friendship bursts into bloom.

The key to solving your disability equation is confidence and self-acceptance. Dread of using durable medical equipment is based on old emotional baggage. If you choose, you can toss that baggage out like a sack of old trash and fill the void with acceptance as you wheel forward with pride. You will be an inspiration to all who encounter you.

Generally speaking, we are still in a climate where the mobility-impaired person has to swim upstream against self-imposed inner conflict. We have stress from well-intentioned family and friends, caught up in the “use it or lose it” mantra. Yes, there are many pivotal issues along the journey to the usage of a wheelchair: hope, joy, release of past fears, confronting stigma and then finally, the joyful arrival of acceptance and reclamation of freedom. If we are to take optimum advantage of adaptive equipment, we need a lot more people willing to swim upstream, proudly and confidently, to change that climate. Won't you join me in the swim?

And now I leave you with this quote by Helen Keller.

*Character cannot be developed in ease and quiet.  
Only through experience of trial and suffering can the soul be strengthened,  
ambition inspired, and success achieved.  
~ Helen Keller*



Linda Wheeler Donahue, Professor Emeritus of Arts and Humanities, President, The Polio Outreach of Connecticut USA [poliooutreachct.com] and Editor of their Polio Sentinel newsletter, is a polio survivor, writer, and speaker. Her first wheelchair sat in the corner of the kitchen gathering dust and disgust. She now wheels with pride in her speedy powerchair.

Linda has been a strong and consistent voice for disability rights. As a result of her grassroots advocacy work, President George H. W. Bush, Sr. invited her to the White House Rose Garden signing of the Americans with Disabilities Act on July 26, 1990. She welcomes feedback and can be reached at LinOnnLine@aol.com.

Linda originally presented this essay at the International Polio Network's Eighth International Post-Polio and Independent Living Conference, St. Louis, Missouri, June 8-10, 2000.

**'Creating the Spectacle!' Part 1. Finding Freedom.** Watch Sue Austin take a magical journey in her summery dress and long flowing hair as she navigates the tranquil sea around a coral reef in her wheelchair..... <http://www.youtube.com/watch?v=1atfF5mt0dk>

## Information from the European Polio Union

### EPU AGM 19<sup>th</sup> October 2013, Tullamore, Ireland by Hilary Boone.

There were 25 representatives from Belgium, Denmark, Finland, Germany, Italy, Ireland, Netherlands, Norway, Switzerland and surprisingly I was the only UK representative. Apologies received from Johan Bijttebier, Board Member due to illness and nine other European polio organisations including the BPF. Observing were Joan Bradley and Jim Costello founder members of the Irish Post Polio Support Group [it was great to see both of these pioneering polio survivors again, I had attended their PPS Conference in 1999.]

The minutes of last years AGM in Janské Láznia. Czechoslovakia were read and approved with no matters arising.

**Activity Report excerpts**..... the intention to appoint a representative for the EPU in Brussels had not been achievable mainly due to finance.... The finance that had been applied for, prepared by PPSG and BPF, under the EU Health Programme rare disease category had been unsuccessful as it did not meet the definition of rare under their terms. An appeal failed as the age demographics were too concentrated and that the % definition of rare should be counted in the target age group... that with lessons learned a suitably refined bid would be entered under the 2014 criteria....., EPU are involved in the organisation of the PPS Conference in Amsterdam next year.. Els Symons had represented EPU at the European Federation of Neurological Societies in Vienna and had met many medical professionals a large number of which denied either knowledge or the existence of PPS in their countries.... John had attended the BPF AGM in Glasgow with presentation by Prof. Gareth Williams of Bristol University about his book 'Paralysed with Fear' [featured in earlier Post Polio Matters] and he has been invited to give an address at the opening Plenary Session at the Amsterdam PPS Conference in 2014.

Any other business included thanks from Daniel Peltzer, Belgium, for the wonderful open arms and every assistance given to them by the Paralympic Organising Committee after EPU requested assistance. Erika Gehrig, Switzerland had attended a WHO conference in Geneva looking at the ongoing polio eradication programme. Robert Bassi, Italy, reported that after a prolonged campaign and negotiation the withdrawal of funding for the Hospital in Malcesine, Lake Garda, where there is a PPS facility, had receded.

2014 EPU AGM will be held on the afternoon of 24<sup>th</sup> June in Amsterdam in the NH Grand Hotel Krasnapolsky. [ahead of the PPS Conference]

## European Commission.

### Seeking healthcare in another EU member State: your rights

#### Did you know?

You have the right to receive medical treatment in another EU Member State and the right to have your home country cover some or all of the costs.

You have the right to be informed about the treatment options open to you, how other EU countries ensure quality and safety in healthcare, and whether a particular provider is legally entitled to offer services.

Look inside 4 page A5 leaflet to find out more...

One paragraph 'Your home health system must provide you with a copy of your medical records to take abroad with you. Once you have received your treatment, it must provide the same follow-up care it would have provided if you had been treated at home.'

[http://ec.europa.eu/health/cross\\_border\\_care/docs/cbhc\\_leaflet\\_en.pdf](http://ec.europa.eu/health/cross_border_care/docs/cbhc_leaflet_en.pdf)

For more detailed information on your rights please see [www.europa.eu/youreurope](http://www.europa.eu/youreurope).

John McFarlane, Chair EPU reports:-

The Netherlands has transposed the directive into national law, one of the minority within the EU.

**Please ring/email Polio Survivors Network if you would like a full copy of this leaflet.**

**From John McFarlane, Chair EPU**  
**EPU website is [www.europeanpolio.eu](http://www.europeanpolio.eu)**

Next year, 2014, see elections across the 28 member states of the European Polio Union and this is YOUR chance to get your voice heard by politicians. We are attempting and still in negotiation with the EU parliament secretariat about a motion to discuss the plight of those with PPS and polio survivors in general being tabled for discussion but with the elections things are rather full on the calendar– that is not to say we shall not keep trying to achieve the goal of a full discussion in the EU Parliament.

However, as I stated all the EU political parties are gearing up for next year' elections and will be preparing political manifestos to try to gain as many votes as they can from national electorates. EPU have prepared a political manifesto [ring/email Polio Survivors Network] if you would like a copy] that they would like members to send to all the political parties in our country who will be, or may be considering, to fight for seats in the EU Parliamentary elections due to be held between 22nd and 25th May 2014.

**EPU Political Manifesto Excerpts**

...Objectives: Our vision is of a Europe where people with polio and Post Polio Syndrome have all the resources they need to lead full active, independent and integrated lives and of a world where polio is completely eradicated....

... In addition, demonstrate your commitment to disabled citizens we ask that your Party sign up to the following **vision statement** for your European Parliament Election Campaign 2014:

A **vision of Europe** where society values every disabled citizen, where the fundamental freedom exists to exercise the rights reflected in the EU Charter of Fundamental Rights, the European Disability Strategy 2010-2020, and more specifically the UN Convention on the Rights of Persons with Disabilities, where people can choose to live the life they want to live, free from discrimination and where they are permitted to enjoy the full entitlements of being an EU citizen, regardless of disability.

**ASPECTS OF POST POLIO SYNDROME** by Dr. Peter Bauer, information in earlier **Post Polio Matters**. Read couple of pages on **Breathing and Sleep Disorders** on this link [www.polio-selbsthilfe.net/en/extract/](http://www.polio-selbsthilfe.net/en/extract/)

**PUBLIC BROADCASTING SERVICE - USA - THE POLIO CRUSADE**

The Public Broadcasting Service, funded by the US Federal Government, commissioned and broadcast a series of programmes on polio and its medical, social & psychological effects on those it infected and affected in the middle of the 20th Century.

To read transcript of the USA DVD \$19.99 [Remember there can be Zone issues on DVD's check before buying that you can watch it in your country].

[www.pbs.org/wgbh/americanexperience/features/transcript/polio-transcript/](http://www.pbs.org/wgbh/americanexperience/features/transcript/polio-transcript/)

**Hilary writes..** Meeting representatives of the other European countries including Ireland was great fun, specially during meals and in the bar. So many laughs on translations of phrases. Great to swap information on issues experienced in our countries. Look forward to more contact.

It's a small world..... Sunday lunch on a table of nine. An Irish polio survivor with a husband with Parkinson's mentions Florida... Richard who also has Parkinson's said 'I lived in Florida and Erika from Switzerland said we have friends with property in Florida we stay with. Would you believe they were all talking about Sarasota in Florida. Later that day I talked to the daughter of an Irish Polio survivor and she asked me where I came from. I told her 'Lincoln' She replied 'You wont believe this but my father is the polio survivor, lives in Ireland but supports Lincoln City Football Club.' She called him over, he was very disappointed that I did not follow my local club..

# Diary of a Benefit Scrounger -

A site to share information on Welfare cuts, illness, disability and general, current, political thought.

<http://diaryofabenefitscrounger.blogspot.co.uk/>

**24th November 2013**  
**Open letter to Andrew Marr**

Dear Andrew Marr

On the Marr show this morning you said you had "a greater understanding of disability" since your stroke. Yet when the story was mentioned that Ian Duncan Smith is thinking of getting rid of the Work Related Activity Group of ESA, the group that is supposed to help people back into work when they get instantly and terrifyingly sick, just as you did, you barely flickered a benevolent eyebrow.

What you actually meant was that you have a greater understanding of disability for wealthy people.

I wonder, has anyone talked you through what would have happened if you had been poor? Had you not enjoyed the great good fortune and success that you have? Immediately, I imagine a part of you just bridled - "Good fortune? My success is down to hard work and determination." But refuse collectors work hard, nurses are determined.

Just for a moment, humour me and imagine you were working for minimum wage in the local factory. You worked there for years. But you have no official contract and hours can be patchy over winter. Your wife works too, but between you, you don't earn enough to pay the bills. You get tax credits and a little housing benefit to make up the shortfall. You're still 54.

That morning you woke up on the floor would have been just as terrifying. The precious candle flame of immortality would have blown and guttered, just the same. The look on your wife's face would have been just as frozen with fear and the dazzling blue lights just as disorientating.

When you got to the hospital, the care would have been the same. Thanks to our wonderful NHS, worry and fear would have been contained in the instant. Will they make me better? Will I live? Will I walk again? Will I work again?

But you would fear for your family - how will they eat if I can't work? Will there be a job if I do recover? How will I pay the rent?

For those first few insecure days those fears would have hovered in the background, pushed aside by the fight for simple, vital life. But soon, as the days wore on, the luxury of self absorbed terror would have lifted. Practicality would start to matter just as much as survival.

And so, your wife would have arrived at the hospital one morning with a clutch of forms. Endless, confusing, demanding forms. 20, 30, 40 pages long. Forms for employment and support allowance. Forms for housing assistance. Forms for care. Between you, through clouds of fear, you would have started to fill them in, agonisingly, nervously, a sense of guilt and failure hanging heavy in the room.

After days of wondering which words they want to hear, what magic keys might unlock a door to security and support, together, you would have sent off the forms and waited an anxious wait. Much as you would have been hoping you would be Andrew Marr again, more, you would have wondered if your wife and children would get through this crisis without hiding the gas bills from you and eating simple, joyless meals in the kitchen while you sat in bed oblivious with the best they could give you, praying a little nutrition would speed you back to join them.

The claim comes back and they tell you they will consider it. They will pay you £71.70 per week - not nearly enough to cover the bills. You worry even more. But months pass. You spend them gritting your teeth, just as I'm sure you did, fighting with every last ounce of will to be the Andrew

you left in bed that fateful night before your world turned upside down.

Time drags on and on and still you hear nothing. Your wife sells the car, then cashes in a little savings scheme you had set up for your funerals. But it's never enough. The bills keep flooding in and the money keeps flooding out and you still can't walk across the room or speak clearly. There are days of anger, fury that after all the years you worked, now you are left to pick up the pieces of your life alone.

When that brown envelope finally falls through the door, it tells you that your claim has been "successful". You have been placed in the Work Related Activity Group. Letters explain that you are expected to work again at some point, and as such, you will receive £100.15 per week, but you will be expected to attend "Work focussed interviews". The letter is stark. If you don't attend, you could lose your benefits. If you don't do all you can to get better, you will lose your benefits. If you don't return forms on time or jump through whichever hoops the agency feel are appropriate you will lose your benefits.

You want to scream. You want to shake someone until their teeth rattle. "I HAD A STROKE" you want to shout. My life was turned upside down! I'm doing all I can to be Andrew again. If I could turn back the clock to that night, not do so much exercise, not eat so much of that rich sauce, not drink that strong coffee. But I can't. I didn't ask for this to happen, I've never been off work in my life. Why is it all so hard? Why do I feel such a failure? But most of all, don't they realise of course I'm doing all I can to get better? Of course I want to walk again and talk again and play with my children?

It's six months now since you woke up on the floor, helpless and confused. You can walk a little, slowly. You can make yourself understood. But your wife has lost weight. You can see it every day as she cares for you, lifting and dressing and washing, as she cares for the children all alone, as she rushes from one job to the next, desperate to keep the family together.

You call your old boss. "Can I come back?" But he says you're just not ready. His insurance won't cover you. He can't afford you there if you can't do the job.

The work related activity begins. The letter says you must attend a centre right across town. It takes 40 minutes on the bus. You can't get there. You certainly can't afford a taxi and your wife sold the car weeks ago. You phone them to explain, but they say rules are rules. Whatever the rules, you can't get there. The next letter explains that you have been sanctioned. You will lose all of your support for two weeks. Again, you want to scream "BUT I HAD A STROKE!! I CAN'T WALK!

Your wife sells the x-box and the kid's bikes. You can hear them downstairs, angry and resentful, they don't understand why they have to suffer because Daddy got ill. You cry quietly upstairs terrified someone will come in the room, but unable to hide away.

After 7 months, exhausted and ashamed, you go back to work. You're not ready. The doctors say you shouldn't go back, the physio says you need more time. But there is no more time. Time has run out. If you don't go back to work you'll be evicted and you simply can't let that happen.

This is the reality of life in the UK today if you happen to be poor and random life throws you into crisis. Still you might not believe me. You might say I'm exaggerating, that no system could possibly work the way I just explained in a developed democracy. A part of you might allow yourself to think you tried harder, you're stroke was worse. You didn't and it wasn't.

You simply had the cushion of a comfortable life propping you up. Without that cushion, you would have been astonished, appalled by how you were treated. Your view of being disabled in the UK today would have been very, very different.

Finally, just in case I made you think, even a bit, imagine there was no wife. There were no children. No family or friends close by. Who would have washed you and fed you and encouraged you then? Who would have filled in the forms and kept things afloat while you dribbled and hobbled your way back to health?

If you think the answer is the state, think again. And if you think you know what the vast majority of sick and disabled people go through, think again.

All you had to do was concentrate on getting better.

I thank God that you are and for the care and support you had to get there. But perhaps, now and then, you could read the odd article about how it might have been very, very different.

<http://www.stroke.org.uk/news/working-stroke-survivors-struggle-most-make-ends-meet> - Stroke survivors struggle to make ends meet on ESA

<http://www.derbytelegraph.co.uk/Hundreds-Derbyshire-win-victory-sickness-benefits/story-16337459-detail/story.html> - Derbyshire stroke victim wins victory in benefits protest. ....

<http://www.theguardian.com/society/2012/may/29/benefits-system-fit-for-work> - "following a severe stroke, Jan Morgan was shocked at how she was treated by the benefits system....

Update : When a post goes viral, you think of the one thing you should have said.

I had a stroke. Luckily, it turned out to be a TIA - a transient ischaemic attack. A stroke that fades away with little effect. I have the most imperceptible left sided weakness from it. If you look at a picture of me, you'll see my smile lifts a little less on the left than the right.

But for 30 minutes, I went totally blind, lost the power of speech, became totally paralysed down one side and I had no idea if it would last or pass. I was locked away in myself for 15 of those 30 minutes, absolutely knowing that I was having a stroke. Mentally, functioning exactly as always, but unable to express myself in any way. It was without doubt the scariest 30 minutes in an otherwise fairly grade A scary life.

Please with just a few days to go, would you all sign the WOW petition <http://wowpetition.com/> and share it amongst your friends and family. [Closes 12.12.13]

### 30th November 2013

WOW Petition - Over a hundred thousand people have signed a petition calling on the Department for Work and Pensions to look again at all cuts affecting sick and disabled people.

#### **The achievement means the issue must be considered for debate in the House of Commons**

Editors Note:-

Time and again members of PSN and LNA and other disability organisations that I see at the variety of meetings I attend is that the people who make the decisions on issues that relate to our lives most often have absolutely no idea of what it is really like medically or financially.

Back in 1995 having had to go on long term sick, as a single mother with two children, I received a letter from the DWP that said, the government had decided that I qualified for £200 per month to live on. It did not even pay the mortgage and rates... Prior to this I had earned £1100 a month. Now I was not only coping with nearly seven years of new issues of fatigue, pain, and really worryingly constant decline of abilities with NO medical diagnosis at all but this massive reduction in funds... how was I going to manage, pay the bills, heat the house, feed the children, etc.

November 22nd 1995 - I mentioned my prior polio and at last it was in the equation. At last a diagnosis and I would get the help I needed. Or would I?



Yes, it became a little easier to claim benefits but it took months of envelopes and forms; appeals to obtain more benefits and 2 more years and a second hospital for letter to my GP stating 'confidentially diagnose the post polio syndrome... but there is no money for treatment.' 1997

It is now 2013 and there is almost no help from the NHS, a little more from Social Services via a Personal Budget. But every time a brown envelope appears on the doormat I dread opening it.. Black clouds descend.., will it be yet another form to complete.

**M.P's pay rise is 9.25%. Is this EQUALITY?**

## Memories of Member Dinah Bass 1945 to 2013.



I was nearly five when Dinah was born on June 13th 1945 in Bootle.

I remember visiting the hospital and seeing this little red, wizened face peering out of a large shawl. I was not impressed!

We grew up to be good friends as well as sisters. Our childhood was a very happy carefree one - in spite of many moves from Bootle to the Isle of Man - Llangollen - Leamington Spa - Llangollen again and back to the Isle of Man. My memories are that the best times were spent in the little cottage in the hills above Llangollen - no water or electricity and a toilet down the garden! The countryside there gave us such freedom. Joan and I would shove Dinah and a picnic into an old pram and push off for the day. In one of mum's old diaries she wrote "The Health Visitor called today but the children had disappeared!" I was 7, Joan 5 and Dinah only 2! Would we have been taken into care today?

Holidays after the war were a month in a seaside bungalow at Abersoch with friends and relatives. We moved back to the Isle of Man in 1949. Dinah started school at St. Johns. By 1953 our Dad's health was becoming more of a concern and he died two years later of TB. Around this time Dinah contracted Polio and her life changed dramatically. She had to leave the island for the orthopaedic hospital in Gobowen, where she spent many months and many more afterwards wearing a contraption called a Milwaukee after all the operations on her back. I cannot remember her ever complaining, but can picture her clambering over the rocks at Glenmoye in that contraption but still thoroughly enjoying herself.

Her days at Secondary school were not her happiest. After school, having shed the Milwaukee she worked in Douglas at a travel agency where she met Freda. One summer they both went off to Scotland to work in a hotel until they both got sacked! She tried nursing in Liverpool then came to stay with us near Cambridge where she tried a number of jobs before going to Training College and finding her vocation teaching infants for 20 years at Kings Hedges in Cambridge. Having gone to stay with friends Jane and Chris for a "couple of nights" and she stayed sixteen years! By 1992 Dinah's breathing difficulties became much worse and she retired from teaching and found herself in Papworth Hospital where she met Robert her future husband. Here began twenty-one years of happiness for them both. They went on many holidays together all over the country in their little 2cv between doing up their house before selling it and buying an unfurnished bungalow at Trefenter in the wild west of Wales. How they enjoyed the garden she created with birds and badgers outside the French doors at night. After a few mishaps they moved to Castle Caereinion in December 2010 on the day the snow began falling. New neighbours called round and they soon made new friends.

Dinah lived life to the full, no matter what it threw at her. She had a strong will and you soon knew if she didn't want something... "can't be doing with that" she would say. Dinah was cheerful and brave, quirky, caring and strong. She was an inspiration to us all. She will be missed by us all.

Dinah we love you.

I'm good friends with 25 letters of the alphabet..... I don't know why...  
I can hear music coming out of my printer.... I think the paper's jammin' again  
What is faster Hot or cold?..... Hot, because you can catch a cold...  
How do you get down off an elephant..... You don't you get down off a duck...  
What do you call an elf that sings? A wrapper!  
What do snowmen eat for lunch? Icebergers.

## Excerpt from *Escape from Communist Hungary* by PSN Member Zsuzsanna Bozzay. [Snarey]



At the end of the war in 1945 Hungary became part of the Russian buffer zone. In fact it was now under Russian occupation, as decided by Churchill, Roosevelt and Stalin at the Yalta Conference. Hungary was once again punished for being on the wrong side of the war.

There were food shortages just like in other European countries but there was no rationing as in England. People had to queue for basic foods and often when they had reached the end of the queue there was nothing left to buy. We had all lost a lot of weight and felt exhausted after the long months of bombings, getting little sleep and constant worry. Many members of my mother's Jewish family disappeared in the concentration camps although her brother Feri just managed to survive by some miracle. He was found by a woman doctor when the concentration camp was liberated by the Russians. She noticed a flicker of movement in his eyes as he lay barely alive among a pile of dead bodies. She lifted him up and carried him out. He was suffering from typhus and was skin and bone, so emaciated that even his own wife did not recognise him...

In 1947 a coalition government was formed after the elections. The Communists had very few votes, which did not please the occupying Russian forces, who wanted the Communists to be in power. It took two years to achieve their aim by starting a reign of terror; deporting, imprisoning and executing leaders of the opposition as well as ordinary people.... These were the methods of intimidation developed in the Soviet Union which were used by Lenin and continued by Stalin who invented the term an 'enemy of the people' to eliminate dissidents and hold people in terror, fearing for their lives.

It was not possible to get a passport in Hungary during communist times and without it we could not leave the country, but my mother was determined to escape from the regime and to go to London where her brother lived. The only way to get out of Hungary was to walk through the border illegally which was very dangerous, especially crossing into Austria...

It was late afternoon by the time we arrived at the border town of *Sátoraljaújhely* near Czechoslovakia and close to the Ukrainian border. At the station we were met by a guide who knew the terrain and offered to smuggle us across the border for a fee. We followed him through the quiet town, until we reached open fields. We continued through a forest climbing up a slope and reached the top of the hill where he showed us to a small shepherd's hut. There was straw on the floor and a piece of sacking for a door, which was flapping in the cold October wind. There were three other couples already settled in there.

'Make yourselves comfortable, but be very quiet. I'll be back after dark and show you the way across the border,' the guide said as he left...

<zsuzsi.snarey@GMAIL.COM> Available on amazon.co.uk in print and Kindle.

**What is this from Front Page.... It is Frosty the Snowman's first baby picture.... 😊**

### **Your Newsletter needs your stories, hints, tips and bits**

A way of doing something, or aid, that helps you might help someone else. Tell us.

**How about a recipe that tastes great on the lips but not on the hips.**

**CARERS** - Are you a Carer and would like to write and tell us how we might help Carers understand what you go through helping us manage our lives.

**Articles and items for Post Polio Matters**

are always welcome, by post, by email and by phone if writing is not easy for you.

**Deadline date for next issue is January 25th 2014**

# **Polio Wars, Sister Kenny and the Golden Age of American Medicine** **By Naomi Rodgers - Oxford Press, 2014**

Naomi Rodgers, associate professor of the history of medicine  
and of women's, gender and sexuality studies

"Polio Wars" is the story of Sister Elizabeth Kenny — "Sister" being a reference to her status as a senior nurse, not a religious designation — who arrived in the United States from Australia in 1940 espousing an unorthodox approach to the treatment of polio. Kenny approached the disease as a non-neurological affliction, championing such novel therapies as hot packs and muscle exercises in place of splinting, surgery, and immobilization. Her care embodied a different style of clinical practice, one of optimistic, patient-centered treatments that gave hope to desperate patients and families.

## **Review by Professor of Microbiology and Polio Survivor. Mike Kossove** **Touro College in New York**

I've read almost everything out there on polio. When I was told about this new book, I went to Barnes and Noble to buy it. They didn't have it, so I ordered it. Two days later it arrived in the mail.

I am an avid reader, and when I begin to read a book, I can usually finish it in a day or two. The print in this book was so small I found it very hard to read. The author jammed so much information into this book, I guess the print had to be this way to get the story into the 450 pages. It was very slow reading for me, and I had to put it down numerous times to rest my eyes. Determined to read it, I would pick it back up and continue, several times a day. I never had such a difficult time reading a book. After each chapter there were pages and pages of bibliography documenting her information. Now, most readers might not care about the bibliography unless they were historians who might investigate her comments further. Had she put the bibliography's at the end, noting the chapters, it would have been better. However, the small print still made it lengthy and difficult to read.

Sister Kenny was a "bush nurse," trained in the field with neither formal nursing education, nor degree, and who in her lifetime, did numbers on the traditional practices of treating polio, and drove the medical establishment crazy. Women in medicine were almost unheard of at that time, and nurses were assistants, not main players. The book was very interesting as it told the story of her trials, tributes, Although scorned by the medical profession, she never gave it. How dare a "bush" nurse lecture to physicians. Unheard of in those days. It took almost two decades to realize her methods were correct. For the public, Sister Kenny is a person of the past, probably unknown to a majority of the public who are not associated with polio. But, for us, she was one of the most important figures in the treatment of polio.

Suggestion: Perhaps, to keep her name alive, support groups, and conferences directors might establish a Sister Kenny Memorial lecture, or award, so that we can keep her memory from fading into eternity.

Available on [www.amazon.co.uk](http://www.amazon.co.uk) in print and on Kindle.

## **A BALANCED WAY OF LIVING**

### **Practical and Holistic Strategies for Coping with Post Polio Syndrome**

By Polio Survivor Vicki McKenna. Available as an e book on RANDOM harvest

[www.postpolioinfo.com/balanced\\_way.php](http://www.postpolioinfo.com/balanced_way.php)

This book was featured in the LINCpin Vol 2, Issue 3, February 1999

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

Another article in LincPIN Vol 1, Issue 10, pages 14 to 18

...The Transforming Power Of Illness by Vicki McKenna, BA Lic Ace MBAC

## Sky News Sunrise Program 8.15 am. Friday 8th November 2013.

Sky News rang Hilary late on Thursday asking if we had any members who lived near enough to the studio for a taxi pick up who would speak about their polio life on a News item about the polio outbreak in Syria the next day. Simon, our Chair was on holiday so nearest members were rung and Yash Airth, a long serving Life Member, agreed to get up early to do this. Yash writes..

Dear Members,

Thank you for giving me the opportunity to speak on behalf of the Polio Survivors Network on Friday 8 Nov 2013 when I appeared on Sky News. It was a very early start and I hope I got some more awareness out there about post polio syndrome. Typical PPS symptoms, I had to rest for the next two days to recover from my adventures! Fatigue and probably polio fog kicked in and I didn't get to mention the amazing sports club that Greg and I belong to: SportsAble in Maidenhead which is a club for people of all abilities, including paralympians, so I'm making my plug in your newsletter! Greg and I started the creative therapies group and a few months later the golf section, both of which are going strong.

Don't know about the rest of the members but the only exercise I can do is in water and I tend to do aqua aerobics at least twice a week. This has led me to work on a new exercise regime called aquabhangra. Bhangra (Punjabi folk music) is very invigorating and uplifting, check out my website [www.aquabhangra.com](http://www.aquabhangra.com). If there is a dance teacher/choreographer/aqua aerobics instructor who enjoys bhangra out there why not give me a call on 07710745183, as I'm currently looking for instructors.

I hope I managed to do some good through my interview, thanks again.

Warm regards Yash

## RETIRED PERSON HEALTH MESSAGE ☺

As I was lying around, pondering the problems of the world, I realised that at my age I don't really give a rat's ar\*\* anymore.

- .. If walking is good for your health, the postman would be immortal
- .. A whale swims all day, eats only fish, drinks water, but is still fat.
- .. A rabbit runs and hops and only lives 15 years while
- .. A tortoise doesn't run and does mostly nothing, yet it lives for 150 years.

And you tell me to exercise?? I don't think so.

### Editors Note:-

Remember that we need to keep our joints and muscles as supple as we can within our daily energy level limitations. Don't just dismiss exercise. Daily living must come first and for some of us there is nothing left on some or all days.

Stretching, which can also be done to you if you can find a physiotherapist or alternative therapist with time to do this to you as this does not use your energy up is beneficial [we have a great manual from [www.stretchingusa.com](http://www.stretchingusa.com)] as is whatever level of exercise you can manage around your daily life activities. Ask your GP to refer you to a Neuro physiotherapist - preferably with some knowledge of how polio and post polio affected and now affects our bodies who can help you work out some exercises you can do. Even a couple of repeats of some actions when you can manage them can make a difference.

Yash is right exercising limbs under the water is much easier because the buoyancy of the water puts less stress on our joints. Remember you are also using energy to get dressed, get to the pool, undressed, showered, dressed again and home. Get all the help you can to do those parts of 'going swimming' so that you get benefit from the time in the water.

# Management Committee [Trustees] and Operations Team

## Management Committee [Trustees]

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

Secretary - Hilary Boone - [hilary.boone@poliosurvivorsnetwork.org.uk](mailto:hilary.boone@poliosurvivorsnetwork.org.uk)

Treasurer - Gillian Bryan - [gillian.bryan@poliosurvivorsnetwork.org.uk](mailto:gillian.bryan@poliosurvivorsnetwork.org.uk)

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

Trustee - Dorothy [Dot] Ives - [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)

## Operations Team

Membership Secretary - Gillian Bryan - [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk)

Phone and Email Enquiries - Hilary Boone - [info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk)

Administrative Support - Gillian Bryan - [gillian.bryan@poliosurvivorsnetwork.org.uk](mailto:gillian.bryan@poliosurvivorsnetwork.org.uk)

Printing and Website - Elpeeko Ltd, Lincoln.

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

## Membership

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

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

### Membership Fees

UK Individual - £ 12.50 per year

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

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

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

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

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

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

<http://www.poliosurvivorsnetwork.org.uk/joinus.html>

## Donations

*giftaid it*

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

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

Some members send us a few postage stamps

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

**The Gift Aid scheme.** Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year.

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%).

If you have not filled in a current Gift aid form please contact us and we will post you one. Thankyou.

# Polio Survivors Network

Lincolnshire Post Polio Network - Registered Charity No. 1064177

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

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

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## Escape from Communist Hungary

By Polio Survivors Network member Zsuzsanna Bozzay [see page 18]

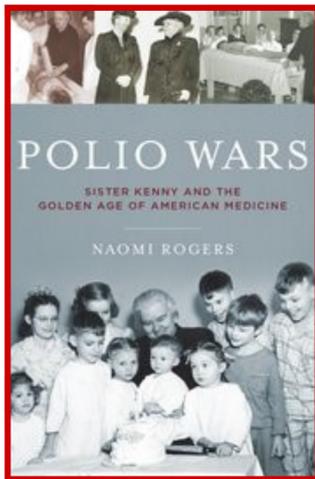
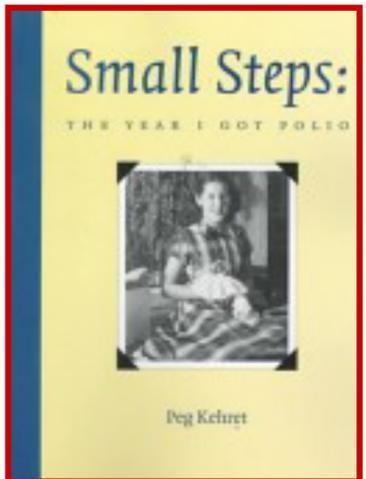
At the end of the Second World War Hungary became a Russian 'protectorate' without the consent of the people. Communism was established by stealth and it was not possible to leave the country legally with a passport. The only way to escape was to cross the border on foot which was both illegal and very dangerous.....

In the late autumn of 1949 after our failed attempt at escaping I lay paralysed by polio in an isolation ward while my mother was in prison.

After the Hungarian Revolution of October 1956 was crushed by Russia and all hope of freedom vanished, thousands of people fled their homes to cross the Austrian border. My mother realised that she now had an opportunity to leave Hungary...

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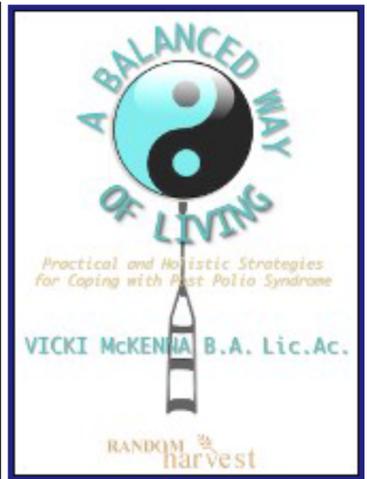
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