



The LincPIN

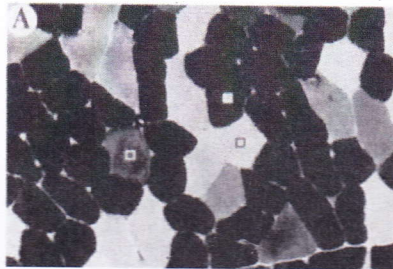
The **Lincolnshire** Post-Polio Information Newsletter
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Bio-electric Stimulation Therapy in Post-Polio Dr. Sally Sennitt

Pages 8 to 9

Control (age and sex matched)



Post Polio patient (ambulant)



Muscle Biopsy Cross Section Tibialis Anterior (Grimby et al...1996)

There was nothing I could not do,
I just had to find another way to do it
Zsuzsanna Snarey

Pages 14 to 19



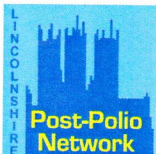
Zsuzsanna now



Zsuzsanna with her parents in 1956



Zsuzsanna in 1949



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DONATIONS

We would like to thank the following for their generous donations.
Margaret Lamb, Heather Chadwick, Vivien Holland, Stuart Barnett, Jean Simm, Barbara Bradley,
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Plus all those who work so hard for us for the time and energy they give us from their PPS lives.

Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.

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Next LincPIN Newsletter - May 2008

Articles for publication 4th April by post or - newsletter@lincolnshirepostpolio.org.uk

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Editorial by Hilary Boone.

I cannot believe that it is now nearly February 2008, time seems to rush by. When you stop working life seems to change. Weekdays were for working and Weekends and Bank Holidays for rest, relaxation and getting out and about. Now we are not working and using wheels we go out weekdays when there are less people about and stay home at weekends.

As I type an osprey is circling overhead, a lizard is sitting on the fence and bobbing his head, and a couple of sandhill cranes have just alighted next door to feed on the feeders. The lake is as flat as can be and the last orange on our tree is asking to be picked. Soaking this view up is good medicine and makes me feel better than I did a few moments ago, exhausted and aching in joints I had forgotten I had.

We got back from the Alafia River Rendezvous [a pre 1840 re-enactment] on Sunday afternoon. We bathed, needed after nine days under canvas, and sat back in our chairs and watched TV snacking on bits from the fridge. Monday we got up and expecting to be fatigued took it easily but even the tiniest bit of exertion seemed like climbing a mountain. All I managed that day was to put four loads of washing on between sleeping through five films. Richard managed to get out of bed and do his email and then he went back to bed and stayed there. Tuesday I shopped for food and slept and today Wednesday I am working on the Newsletter and have a feeling I might drop off for a few hours more during the day. From previous years we know it will take as many days as we were away to recover our energy levels but the memories are worth every ache and pain.

The memories of all the fun things we did, including coming home to the tent at midnight two nights in a row having sat round a campfire listening to the most amazing blues music made us feel normal again. On the fourth day I texted my kids to say.. '3 nights under canvas, one very hot, one huge thunderstorm and rain and one freezing.. Are we nuts?' My daughter texted back.. 'Mum, you have always been nuts, look forward to the photos'. We had a lot of help and mostly offered before we even saw we needed and without which we could not have managed. Thank you seems such an inadequate phrase to express our gratitude.

Dr. Dowsett told me many years ago that the most important thing we need to do each week is to plan something into it that will make us feel good. Something to look forward to and something to look back on and say, 'I achieved x this week', it does not matter how small. Sometimes Richard and I find ourselves getting crabby or stressed out over something and we know the best thing we can do is to get out of the house, even if it is only a drive to where we can sit and watch the world go by. However, when we do this I often think of my grandfather being brought from the Residential Home in his later years to the seaside car park where he would sit and look at the view and drink a half pint of beer and a rum. He would say it was 'great medicine' I see it as something old folks do and I don't want to think of us as 'old' yet... 20 years ago I was told you are not old till your pubic hair goes grey....

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Message from the Chair

There's no question about it – cold, miserable weather does absolutely nothing to improve the symptoms of PPS! But reading the weather reports recently, my thoughts have turned to those of you in the north of the country who may be suffering the sort of severe weather that those of us in the more temperate south have almost forgotten about. I hope that you are surviving the 'wintry blast' and are keeping as warm as possible.

Which leads me nicely to reminding you about the government's '**Warm Front**' scheme? This is a scheme that genuinely supports people who may not be able to insulate their homes adequately. Warm front grants are available to make homes warmer and more energy efficient, and the grant provides a package of insulation and heating improvements up to the value of £2,700.

To qualify, you need to be aged over 60, or be in receipt of

- Working Tax Credit (with an income of less than £15,460, which must include a disability element)
- Disability Living Allowance
- Child Tax Credit (with an income of less than £15,460)
- Housing Benefit (which must include a disability premium)
- Income Support (which must include a disability premium)
- Council Tax Benefit (which must include a disability premium)
- War Disablement Pension (which must include a mobility supplement or Constant Attendance Allowance)
- Industrial Injuries Disablement Benefit (which must include a mobility supplement or Constant Attendance Allowance)
- Attendance Allowance *Boiler - 0800 316 6011*

You can ring 0800 612 8735 for further information, or you can fill in an application form on line at <http://www.warmfrontgrants.co.uk/warmfrontgrants.co.uk/index.htm>

I took advantage of the scheme this year. I answered an advertisement in the post, and was told that an agent would call round to assess what was required. The chap duly arrived (he didn't actually look at the loft – just took my word for what meagre insulation I knew was there) and in a couple of weeks, two lads arrived with the additional loft insulation. It took about 15 minutes for them to lay the rolls of insulating material, and the difference was noticeable immediately – so with luck, my heating bills won't be quite so enormous this year.

It's also at this time of year when we're stuck indoors because the weather's

so foul, that we tend to think of holidays. For some of us, it's not been a top priority because of financial restraints, but did you know that there is funding out there to help pay for a holiday? You can approach your Local Authority Social Services Department, who will then apply to various trusts and benevolent associations on your behalf.

There is also a publication 'Guide To Financial Help Towards The Cost Of A Holiday, Respite Care or Convalescence' which was originally produced by Holiday Care (www.holidaycare.org.uk) and is now part of Tourism for All.

And of course, as Polio survivors, if you are a member of the British Polio Fellowship (sorry – british polio!) you can apply to them for a holiday grant.

But where to go? And where will you find accommodation to suit your particular needs? RADAR publishes 'Holidays in Britain and Ireland' which you can obtain from their website <http://www.radar.org.uk/radarwebsite/tabid/83/default.aspx> (£13.50) or by calling 020 7250 3222. The booklet gives information about accommodation, activities, and about advice centres and organisations that may be able to help you further.

Many thanks to those of you who managed to fill in the 'My Polio Life' questionnaire. These are now being collated and forwarded on to Dr. W. Bradley, and we will be looking forward to hearing what conclusions he comes to! If you would like your info to be included in the project and have not sent me a copy of your completed questionnaire then there is still time to do this.

Thanks also to everyone who sent in their up-to-date address details. It is important for us to keep our records up to date, so if you haven't yet told us of any changes, we'd be very grateful if you would do so as soon as possible.

Dates for your Diary

1. The Mobility Road Show Scotland - 25 & 26 April 2008

Royal Highland Centre, Edinburgh.

2. The Mobility Road Show England 12th - 14th June 2008

Stoneleigh Park, Coventry.

For more information contact:- www.mobilityroadshow.co.uk

Mobility Choice, Crowthorne House, Nine Mile Ride, Wokingham, Berkshire RG40 3GA Registered Charity Number: 1068018

Tel:-0845 241 0390 Fax:-0845 241 2136 email:- choice@gtnet.gov.uk

3. Naidex 29 April - 1 May 2008

NEC Birmingham 020 7728 3723 www.naidex.co.uk

Naidex is the UK's largest event for homecare, disability and rehabilitation, and is your best opportunity to touch, test and compare all the latest new products and services available. Registration is now open! Pre-register now for free entry to the exhibition and avoid the queues.

I so enjoyed the Mobility Roadshow last year and meeting other members was a bonus. If anyone is intending to visit any of these shows and would like to meet up with other members then please let us know so we can try and arrange a meeting point.

I'm pleased to say that we have 3 new members, and would like to welcome Andrew Doroszxowski from Buckinghamshire and Linda Mitchell and John E Wood from Lincolnshire. I hope through LincsPPN you will find the answers to many of your questions, and that you will enjoy the support of others who have a wealth of PPS experience to share.'

Sadly, I shall be out of contact for a few weeks. I am shortly to have an operation – total Arthroplasty, but without benefit of a new hip. Apparently muscle atrophy in my back hip and thigh means that any new hip would dislocate, so it is pointless to try. The surgeon and staff can give me no guarantees as to how this will affect my already very limited mobility, and the outlook is a bit worrying. However, I will be free of pain and that is the whole point of the exercise. But rest assured, I will still be working for LincsPPN to the best of my ability!

Mary McCreadie, Chair mary.mccreadie@lincolnshirepostpolio.org.uk

Members E-Mail Forum

Even I am astounded at the range of subjects that get an airing on our e-mail forum! The last few months have produced some fascinating insights into how some of our members coped with incarceration in hospital. A very lively and quite long-lived discussion evoked many memories from some of you, and made very interesting reading for the rest of us. The discussion actually caused people to remember things they thought they'd forgotten – some good, some bad – but definitely cathartic. Even the 'Grey Lady' of RNOH was remembered.... I wonder if she still walks those wards?

Other topics included The Lane Fox Respiratory Unit, is a lumbar puncture (spinal tap) necessary/advisable for diagnosing PPS?, Asda's new parking regime on Blue Badge spaces, information about Incapacity Benefit, to name but a few.

The sheer diversity of subjects, and the information that gets passed back and forth is more helpful and stimulating than you can imagine – so thanks to everyone who has posted. Keep 'em coming!

If you are a LincsPPN member and would like to join the e-mail list, please send an e-mail to join-pnl@lincolnshirepostpolio.org.uk (please include your full name in the email).

NEW ARTICLE

Actual and Perceived Activity Levels in Polio Survivors and Older Controls: A Longitudinal Study

Mary G. Klein, PhD, Leonard E. Braitman, PhD, Roberta Costello, MSN, RN,
Mary Ann Keenan, MD, Alberto Esquenazi, MD
Arch Phys Med Rehabil. 2008 Feb;89(2):297-303.
PMID: 18226654 [PubMed - in process]

ABSTRACT. Klein MG, Braitman LE, Costello R, Keenan MA, Esquenazi A. Actual and perceived activity levels in polio survivors and older controls: a longitudinal study. Arch Phys Med Rehabil 2008;89:297-303.

Objective: To examine factors associated with daily step activity, perceived activity, maximum walking speed, and walking speed reserve over time in polio survivors and older adults with no history of polio.

Design: Longitudinal study.

Setting: A research clinic and the community.

Participants: Polio survivors (n=96; 65 in postpolio syndrome [PPS] group, 31 in non-PPS group) and older adults (n=112) with no history of polio.

Interventions: Not applicable.

Main Outcome Measures: Daily step activity, perceived activity, maximum walking speed, and walking speed reserve.

Results: Results showed decreases in perceived activity over time in the PPS group. However, there was no change in average daily walking activity. Overall, polio survivors walk less and have a smaller walking speed reserve than controls. Knee strength was positively associated with maximum walking speed and walking speed reserve in all groups. Weight and age were associated with daily step activity in controls but not polio survivors.

Conclusions: This study suggests that polio survivors function with minimal physiologic functional reserve, because their normal walking speeds are very close to their maximum speeds. Although polio survivors overall perceived themselves to be as active as controls, the average amount of daily walking activity was lower among polio survivors. Daily walking activity levels did not change statistically over the 3-year study period in either postpolio group, even though the perception of activity level and the walking speed differential decreased among polio survivors who reported symptoms associated with PPS. Future analyses will focus on patterns of activity among polio survivors—specifically, the absolute and relative amounts of moderate and high levels of activity as a percentage of total walking activity. We will also investigate the association between walking activity and reported pain and fatigue symptoms over time to get a better understanding of the role activity level plays in the symptoms commonly associated with PPS.

Key Words: Postpoliomyelitis syndrome; Rehabilitation.

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Bio-Electric Stimulation Therapy in Postpolio

By Dr. Sally Sennitt, Medical Director of Kingfisher Healthcare.

At the 2006 Lincolnshire Post-Polio Network AGM I presented the preliminary results of our study of microcurrent in PPS. Our Belgian medical technology company has set up a series of studies as a world first to confirm anecdotal evidence that Bio-Electric Stimulation Therapy (BEST) does indeed have a significant impact on fatigue as experienced by polio survivors and patients with other chronic conditions. BEST and its application in PPS was explored in the BESTIPP study (BEST in Post Polio) and the results have now been submitted to peer reviewed medical journals for publication.

A number of the UK LPPN members volunteered themselves as study subjects and five actually participated for which the Kingfisher Healthcare team are extremely grateful. All credit goes to them for carrying out the protocol unaided and it was gratifying to see confirmation of one of KFH's goals – to develop handheld devices for therapies that can be self administered.

The results of the study are summarized here but more information with the relevant references can be found on the website www.kfhealth.com

The Problem

The problem of post polio syndrome in late phase polio survivors and its associated fatigue needs no introduction to the readers of this Newsletter; suffice to say that fatigue affects > 80% of the 1 million people known to be living with polio sequelae in Europe and N America and that there is very little in the way of satisfactory treatment.

Muscle affected by the polio virus has been shown to be different anatomically i.e. it contains predominantly type I fibres that are abnormally large. Furthermore, the fibres work abnormally hard, by contracting in an 'all or nothing' way, as opposed to recruiting only those fibres that are needed for a specific task. This explains why the strength is often good but they fatigue rapidly and recover slowly.

Control (age and sex matched) Post Polio patient (ambulant)

Muscle Biopsy
Cross Section
Tibialis Anterior

(Grimby et al..1996)



[In addition, there are chemical differences at the level of the cells. The major energy substance in cells is adenosine triphosphate ATP). This molecule is the energy source for all cellular processes. It supports normal cell function including muscle movement and recovery. There is substantial evidence that PP patients have an energy deficit in their muscles with high energy utilization and low energy re-synthesis. Similarly, lower oxidative enzyme capacity contributes to a lack of energy related substances

The Technology

BEST is a very specific form of electrotherapy delivering extremely small amounts of current to the body (100 times less than a typical TENS machine). It acts at the level of the cell to boost ATP production by up to 500%. This molecule is the energy source for all cellular processes so it supports normal cell function including muscle movement and recovery. The treatment is delivered by a small, hand-held device together with cables and skin electrodes that the patients can use at home. There are no known side effects and it is very simple to use.

Study Design

25 Patients were recruited from 4 different countries to treat themselves for one hour a day, 5 days a week with BEST over a period of 3 months; with another 3 month extension phase. Patient questionnaires were used to collect information on levels of fatigue, pain and endurance (based on physical activity to the point of exhaustion).

Results

BEST had a positive and statistically significant effect on all 3 end points. The average scores for the whole group showed:

Fatigue	34% reduction (p<0.0001)	8 out of 10 patients improved.
Endurance	40% improvement	4 out of 5 patients benefited.
Pain	34% reduction (p<0.0001)	7 out of 10 experienced pain relief.

Importantly, these clinical benefits were maintained during the extension phase of the study with fewer treatment sessions.

Conclusion

These results are highly significant and translate into meaningful improvements in quality of life for PPS patients. BEST seems to be a promising new tool in the management of fatigue, pain and stamina problems. In the Netherlands we now have data from patients who have been using the device for up to 2 years, and encouragingly these patients still report small but ongoing improvements.

In the Netherlands we now have data from patients who have been using the device for up to two years, and encouragingly these patients still report small but ongoing improvements.

In spite of the above, it is still early days and further experience and studies will be needed for definitive conclusions. Kingfisher Healthcare is committed to this line of research, and we are proud to have recently announced an annual award (\$ 5,000) to stimulate research in PPS. It will be named after the first Post Polio patient to have pioneered the use of KFH Energy (Marianne Liefers) and will be awarded by an independent panel, for research not related to Kingfisher products. We would be pleased to receive nominations from the GBPPA, [Greater Boston Post Polio Association] or other patient groups in the USA.

White Paper -

http://www.kfhealth.com/cms/bib/files/92_whitepaperbestippfinal2.pdf

Dr. Sennitt is the Medical Director of Kingfisher Healthcare NV, and is a Fellow of the Royal College of Anaesthetists in the UK.

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AT LAST, I FEELABLE TO ASK FOR ASSISTANCE

It was in the late summer of 1948 that I contracted polio, we as a family, (mum my sister and twin brother) would go hop picking as we lived in Kent one of the main hop picking areas of the country.

One evening, after returning home I realized that I had the most horrendous headache, I was put to bed straight away. On waking in the morning, I had been transformed from a five-year-old boy to what resembled a little old man, bent double and hardly able to walk. My mother realized immediately that I had contracted polio as, unfortunately, had her brother in the 1930s. I was taken immediately to Pembury Hospital and put into isolation, this was to be my home for the next 18 months.

In those days, isolation, meant exactly that, any visitors such as mum and dad would be allowed on Wednesday, Saturday or Sunday, but they would be outside the ward looking at me through a glass partition. The hospital was around 16 miles from our home in Cranbrook and in the years just off the war transport was not very good and money was short. This meant mum and dad cycling to see me whatever the weather and if it was really bad they would have to pay two shillings and six pence(half a crown) each for the returned bus fare.

After my prolonged stay I went home with both legs in callipers and in a wheelchair, I did not recognize my twin brother or sister as we had not seen each other for 18 months, they were told by mum not to assist me if they thought I should be able to manage on my own. Looking back on it, it was very good advice, but at the time it seemed very harsh to me and outsiders looking in. However, this did make me do things and persevere, where otherwise I would have deteriorated. I had a friend in hospital of my age, who caught polio at the same time, and was not quite so severely disabled as myself, but he spent the rest of his short life in a wheelchair being helped by his well-meaning parents. My mum had experienced a similar thing with her brother, who was spoilt by their mother and father and because of this he remained fairly disabled and unable to cope on his own.

Throughout most of my childhood. I would have many operations on my legs and feet, these were successful, but it did mean that I lost a lot of schooling as at that time it was not considered important to educate children, whilst they were in hospital, as far as I can remember. I had an old lady probably a retired teacher, visit around once a week.

When I left school, I became an engineering clerk with the local bus company as it was considered at the time that the only Job I was able to do was a clerical position. It was a good job, not too demanding and there was time for me and my colleagues to play a few games of snooker, to be honest, we did very little else, and I became quite proficient, although not up to competitions standard.

In 1965 I left to get married and moved to Cornwall, where I started work in a bakery, delivering to hotels and guest houses in the Falmouth area. This was a very enjoyable job, up to the time when a 30 ton Elm tree fell on us in our caravan one October night. Pauline my wife was able to get out and raise the alarm and two hours later I was cut out and taken to Truro hospital with a badly smashed leg and arm, this set me back a bit as you can imagine.

It was six months before I could get back to work and I did this in one full length

calliper, driving an automatic van (the boss bought this specially for me) delivering trays of cakes ,bread and proper Cornish Pasties.

All of this instilled into me the idea that if you want it done, do it your self and up to a few years ago, when post polio syndrome hit home, I did exactly that. Despite the fact that both arms and legs are affected I managed full-time employment up to a year ago. During the past 15 years I became self employed and would travel around 1000 miles a week in my car, and it was not unusual for me to drive almost non stop from Kent to Scotland to see a client.

After a number of mishaps, spillages and breakages in recent years, I was persuaded to ask for assistance in things such as getting a bag of sugar on the top shelf in the kitchen cupboard (this was particularly messy) flour and cooking oil was also proved to be very messy.

I found it particularly hard to ask strangers for assistance, but having done so. I realize that people do like to help and do so extremely willingly. Recently I needed something from the top shelf in a supermarket, there were no shop assistants available, so I asked a customer to help, he did, and then proceeded to see if I could manage the rest of the shopping. It is quite a rare thing for me to go shopping but I think people are generally very kind and thoughtful and do in fact like to be asked to help.

I now use a mobility scooter. It took my wife around three years to persuade me to have one, but it enables me to "walk" the dogs with her and get to places that I can no longer manage on foot.

I believe if there is a moral to this story it is, to do it if you can, without causing yourself a problem, but if not ask for a little help, after all most people are very nice and more than willing to help if asked.

Robin Butler - robin.butler@lincolnshirepostpolio.org.uk

My Mother taught me about....

APPRECIATING A JOB WELL DONE.

"If you're going to kill each other, do it outside I just finished cleaning."

RELIGION. "You better pray that will come out of the carpet."

TIME TRAVEL. "If you don't straighten! up, I'm going to knock you into the middle of next week!"

FORESIGHT. "Make sure you wear clean underwear, in case you're in an accident."

CONTORTIONISM. "Will you look at that dirt! on the back of your neck!"

STAMINA. "You'll sit there until all that spinach is gone."

WEATHER. "This room of yours looks as if a tornado went through it."

HYPOCRISY. "If I told you once, I've told you a million times Don't exaggerate!"

ANTICIPATION. "Just wait until we get home."

MEDICAL SCIENCE. "If you don't stop crossing your eyes, they are going to get stuck that way."

HUMOR. "When that lawn mower cuts off your toes, don't come running to me."

HOW TO BECOME AN ADULT. "If you don't eat your vegetables, you'll never grow up."

ROOTS. "Shut that door behind you. Do you think you were born in a barn?"

And WISDOM. "When you get to be my age, you'll understand."

ASDA TO FINE CUSTOMERS WHO PARK IN DISABLED/CHILD SPACES.

ASDA announced this weekend that it would be the first retailer to fine drivers for the misuse of disabled and parent and child parking bays in its car parks. All profits generated from the fines will go back to baby charity Tommy's and Motability, the national disability charity providing the leading car scheme for disabled people.

The move which will see abusers fined £60 for parking in parent and child and disabled spaces, comes into force from Monday 14th January 2008 and follows a successful trial last year in the north of England. When surveyed four out of five ASDA customers said they believed rolling out the scheme nationwide was the right thing to do.

The trial, which lasted three months, operated in six stores in Liverpool. As a result of the scheme the number of free parking spaces increased by over 60% for disabled drivers and parents with young children.

"At ASDA we have decided to take a stand to keep specialised parking spaces available to those customers that need them. Most customers using these bays without good reason don't realize their actions impact on people that rely on them to do their weekly shop." said Paul Hedley, ASDA's customer service manager.

"We are not handing out tickets to make a profit as money raised will go back to charity. Signs in all stores will clearly state that you will get a fine if you park here unnecessarily. We would encourage anyone that manages a car park to take our lead." Mr. Hedley added.

End Quote Thanks to the ME Association web site for this news item.

<http://preview.tinyurl.com/26fpxj>

Information from Mobilise on Scooter Registration with the DVLA.

We continue to receive enquiries about the registration of mobility scooters and have therefore reproduced again the current procedure for registration. Invalid carriages are separated into three categories. Only Class 3 vehicles are required to be registered with the DVLA.

Class 1

Manual wheelchairs, i.e. self-propelled or attendant propelled, not electrically propelled. These are not required to be registered with DVLA.

Class 2

Powered wheelchairs and scooters – intended for footway use only with a maximum speed of 4mph and an unladen weight not exceeding 113.4kgs. These are not required to be registered with DVLA.

Class 3

Mechanically propelled invalid carriages that are constructed or adapted to be capable of exceeding a speed of 4mph but incapable of exceeding a speed of 8mph on the level under its own power (generally powered wheelchairs and other outdoor vehicles including scooters intended for use on roads/highways). They must be fitted with a device capable of limiting the maximum speed to 4mph for use when travelling on footways. The unladen weight must not exceed 150kgs. These are required to be registered with DVLA.

<http://www.mobilise.info/InformationStore.asp?ItemId=5>

Mobility scooters and SORN [Statutory Off Road Notification]

Owners of mobility scooters and powered wheelchairs (Class 3 vehicles) must register them with the DVLA. A Statutory Off Road Notification (SORN) is also required if the vehicle is not in use and being kept off the road.

A Class 3 vehicle [see previous page for details of Classes] is registered in the "disabled" taxation class and is required to display a nil duty tax disc. Recently we were asked if a Statutory Off Road Notification (SORN) was required if the vehicle was not in use and being kept off the road. We have approached the DVLA on this issue who have advised Mobilise as follows: Class 3.

"A vehicles status should only be either be licensed (taxed) or SORN (off the road). If you do not intend on relicensing the vehicle therefore taking it off the road you should declare SORN.

SORN can currently be declared by the following methods:-

Using form V11 Vehicle Licence Application Form/SORN Declaration or V85/1 (tax application forms) This can be done by completing the relevant section of the V11 and handing it in to a licence issuing Post Office or by completing the relevant section of the V85/1 and handing it over at a DVLA Local Office.

Using Form V890 This can be done by completing the application form V890 which is available from the post office or online [CLICK HERE](#)) and returning to the DVLA address shown on the application form.

Or you can declare SORN over the telephone by calling 0870 240 0010

Please note the following:

- a) you must be the registered keeper, b) SORN cannot be backdated,
- c) SORN cannot be accepted before the 15th of the month in which the disc expires. You will also need to have your registration certificate/document with you, as you will be required to quote the document reference on it. Or alternatively your V11 for with the 16 digit number shown.

Please note DVLA are issuing acknowledgement letters on receipt of a SORN

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There was nothing I could not do.. I just had to find another way to do it.

"I was born in Budapest in September 1941 as Zsuzsanna Bozzay during the Second World War."

It was in September 1949 when I was 8 years old and my mother decided that the time was right to escape from Hungary and go to France or England. The political situation was getting worse and the borders were still not very well guarded. It was not possible to have a passport and leave Hungary legally. Many families were thinking of escaping. My father decided to stay behind because not everyone was successful at crossing the border and if a whole family was caught, all their possessions were confiscated by the authorities and they were thrown into prison. When they were released from prison they had nowhere to go.

We first travelled to the eastern part of Hungary by train for about 3-4 hours until we reached a town near the border of Slovakia and Russia. It was easier to cross here, as the border was not guarded very well. My mother found a guide who was responsible for a number of people and we all started walking together into the hilly countryside. Soon we reached some little huts where we settled down to sleep. When it got dark we got up and continued walking until we reached the border. Early in the morning we got on a train and travelled to Kassa (now called Kosice) where we found some distant relatives, who gave us something to eat and we were able to sleep in a proper bed. Next day we got on another train and travelled the length of Czechoslovakia to Bratislava. This was a very long journey, at least 10 hours. Here my mother had to find another guide.

A small group of us started off late one evening led by our guide. We left the city and headed for the country towards the Austrian border. When we approached the border we had to be very quiet and walk in a line. The guide told us that if he signals we have to crouch down and go on our hands and knees so that from a distance we would appear to be dogs. We walked over fields and just before crossing over to Austria the guide told us to sit and rest. We were sitting in a field of sweet corn about 50 metres from the Austrian border and our guide, without lowering his voice, explained that he was going to go ahead and when it was safe to follow, he would make a sound like an owl. At this signal we were to crawl one by one. As he was talking we saw two men in the distance near the horizon. They were so far away that they looked very small. It was a moonlit night, all was quiet and the guide forgot that sound travelled very well. He saw the two distant figures, but he believed that they were only smugglers returning from Austria having taken some people over. Unfortunately for us they were not smugglers, they were Czech border guards, and they heard the sound of talking and saw us in the field. They soon reached the place where we were waiting. They pointed their guns at us and shouted something in Czech, which we did not understand but we were terrified! I think they were equally terrified of us, because they didn't know if we had weapons. We were marched back to Bratislava to the police station and put in cells.

The women with children were transferred to another building the next day. There were two large rooms which were clean and pleasant. We were given some food to eat. It is possible that I contracted polio in this place because there was an epidemic at the time and it was crowded. After another day we were transferred to

the Hungarian authorities in a small van. We have been away from home for about eight weeks now and arrived in the border station where we were put in a small room, but they allowed me to go and play outside. I was questioned by one of the young border guards and answered the questions as best I could.

It was very cold, the window panes were broken although there were iron bars across it. My mother tried to warm me with her body and got up from time to time to walk up and down trying to get warm. At last morning came and my mother managed to get some warm milk for me. We were taken by train to Szombathely. My mother was allowed to take me into the orphanage, packed with children of the same fate and she also managed to send a telegram to my father to come and fetch me. By this time I was thin and weary and completely exhausted. I was separated from my mother who was put in prison. As soon as my father received the telegram he travelled down by train from Budapest, but I still had to spend a night in the orphanage. There was no bed for me so I was put in the same bed with two other girls. This was another place where I may have contracted the polio virus. I have been travelling and walking a long way during the past weeks and had little to eat. I was run down and tired. I had slept very little. It seems that during an epidemic of polio many people contract the virus but their immune system will overcome it if they are fit and well. In some cases they might believe that they had a mild case of influenza and they recover without any of the after effects which happened to me.

I was very glad to see my father. We arrived home and the next evening I remember that while my father was talking on the phone I started jumping on the settee. I could not stop jumping and then I developed a very bad head ache. My father thought it was due to all that jumping, but then he realised that I had a high temperature and he called the doctor. The doctor thought that I was seriously ill and I was admitted to hospital straight away where I had a lumbar puncture to see if I had meningitis or polio. When it was confirmed that I had polio, I was placed in an isolation ward. It was a small ward with 6 beds but I was the only occupant. My father hired a nun to sit by my bed during the day and another nun during the night. I could not sleep and amused myself by singing all the songs I had learned in school. These were mostly the communist anthems or marching songs. The poor nun had to listen to me and did not stop me! My father came to visit me after work in the evenings and it was bliss when he placed his arm under my aching back to lift it off the bed. I was in quite a lot of pain and his touch seemed to relieve it. Four times a day a doctor came to give me injections into the back of my hand. There were about 4 or 5 injections of various vitamins and also blood from a woman who had recovered from polio. They were hoping to transfer some of her antibodies against polio to me. The doctor said jokingly as he gave me each different injection "Here comes dinner, this is the starter, this is the main course, this is the pudding!" I was very brave and did not make a fuss. The back of my hand started to look like a pin cushion. Then they used my other hand.

The nurses who were looking after me were Sisters of Mercy. They had great big winged head dresses in those days and the Reverend Mother was praying for my recovery. The paralysis was gradually spreading from my left foot up towards my body. My left arm became paralysed and then the left side of my face, so my smile became lop sided. If my lungs had become affected I would have needed to be placed in an iron lung. There were only two or maybe three in Budapest and they

were already taken by other polio cases. Luckily her prayers were answered, the paralysis bypassed my lungs or I would have died. She asked my mother if I would wear the small "miraculous medal" in thanks giving. I still wear it and remember how lucky I was to survive.

My father had a very good friend who was an excellent lawyer. He pleaded on behalf of my mother to be allowed out of prison to take care of me in hospital. She slept in the bed right next to me and for the first time I slept through the night. I felt secure, calm and happy. I knew that everything was going to be fine. I stayed in hospital for about 3 weeks and when I arrived home I could not even stand, let alone walk! This did not upset or worry me because my mother assured me that she will do everything in her power to get me walking again. I don't know how she knew what to do. She started a strict regime of exercises. From 9 in the morning till 3 in the afternoon she sat by my bed and held up each leg in turn. I had to think hard and try to help as much as I could. There were several different exercises to do in different positions. To relieve the boredom of these exercises she read to me from Alexander Dumas: The Count of Monte Cristo. This exciting book gripped my imagination and I very much enjoyed it, although it was not meant for an 8 year old child. Eventually there was a faint flicker of movement, and little by little the movement came back to some of the muscles. My face recovered and the strength of my left arm returned. On Christmas Eve I was taken to have a herbal bath which was brown with dried leaves and had a strong smell and when I returned to the room there was a big Christmas tree with more presents under it than I have ever had before! There were lots of books, toys and games, none of them wrapped and among them a small children's prayer book with a beautiful picture of Mary and the baby Jesus on the cover which I still treasure. Inside my mother inscribed "May God heal you, guard you and lead you on all your journeys."

At first I could only get about on all fours, later I learned to walk leaning on the back of a chair. My legs slowly got stronger and the following year on my father's birthday on November 17th I managed 3 steps unaided. This felt a huge achievement. I was very proud of myself and my parents were very happy. This was the best present I could give my father.

My mother took me to the Pető Institute where the famous Pető was rehabilitating children who have been paralysed. The Institute had a very good reputation but it was difficult to be accepted for treatment. The great man examined me as I was sitting on the floor and said to my mother "If I stretch my thumb like this, all the muscles in my body start to work!" My mother just looked at him with disbelief, thinking that this man was crazy. We were shown round the Institute and we saw a large number of children sitting on the floor in another room singing Communist marching songs and waving their arms about. They could not stand or walk, so they exercised their arms instead. After my examination Pető said "Your daughter is accepted! She can come for treatment." He explained that I would have to be left at the Institute and my parents would be allowed to visit me once a month! My mother was shocked at this news, thanked him and turned down the offer! She was not going to leave me there on my own and not see me for a month! The family and most of our friends thought that she made a big mistake, but she was determined.

Pető, I think, realised that I was a suitable candidate to improve his image of being a great healer, because he could see that I had possibilities and would get better. That is why he was ready to take me. He was sponsored by the Communist Party.

My mother took me to several other doctors, some of them advised that I should have an iron body "belt" to stop my spine from getting a curvature, and others who recommended callipers, but thanks to my mother, I did not have to put up with any of these horrible, uncomfortable "aids" until very recently.

My leg continued to get stronger helped by a physiotherapist who came to me twice a week in the afternoon. She was trained in the United States at the famous Institute that uses the principles worked out by the Australian nurse, Sister Kenny. She disagreed with doctors who at that time kept polio victims immobilised sometimes in plaster. According to Sister Kenny stimulation of the muscles helped the nerves to regenerate. I was taught a series of exercises which had to be repeated several times every day. My physiotherapist was a very fit and athletic looking lady of about 60 years old, who wore bright colourful dresses which could have been made for a 20 year old girl.

I never thought of myself as "disabled". There was nothing I could not do, I just had to find another way of doing it. This was because my parents never showed that they felt sorry for me. Yet it must have been a terrible burden for them to see their only child so ill. I realise this now having had children of my own. There is nothing worse for parents than seeing their children unwell. But they were very positive and always gave me confidence. It was only when I saw myself walking towards a mirror that I realised that I did not walk like others. My self image was that of a normal person.

In July 1956 I went to hospital to have operations on my feet. First I had a muscle transplant on my right foot which meant that I was able to lift my foot and not trip over. It was very painful because my Achilles tendon had a zig zag cut made into it and then stretched before put into plaster. I hated the after effects of the anaesthetic which was ether. It made me feel very ill for days afterwards. So when I was due to have the next operation on my left foot, I pleaded with the surgeon to let me stay awake! I was given injections of a local anaesthetic and could watch the progress in the shiny central part of the overhead mirror. It was quite painful at times, but I did not mind as long as I avoided the dreaded ether. I was discharged from the hospital with my left leg still in plaster and I did not return to the second year of Grammar school in the September.

I was 15 years old in September 1956 and in my second year at the grammar school with my left leg still in plaster. On the morning of the Tuesday, 23rd October 1956 university students in Budapest posted flyers with 16 demands all over the city. They were demanding the withdrawal of Soviet troops, free elections by secret ballot, the removal of the hated statue of Stalin, the removal of all criminal leaders and a new government lead by Imre Nagy. More and more people joined the demonstration carrying Hungarian National flags.

We sat huddled round the radio trying to get news. The Hungarian radio station only broadcast propaganda and so to get the real news we had to tune in to the BBC or Radio Free Europe which broadcast from Munich. These stations were heavily blocked by the communists to stop people listening to them. In fact it was a punishable offence to do so and so if the doorbell went while we had one of these forbidden radio stations on, not only did we turn off the radio but we also changed the station.

The fighting continued the next day. Slogans appeared on shops and walls

"Russians go home!" Normal life stopped, there was no school and no one went to work. There were Russian tanks everywhere. They were used to frighten the people, but tanks are not really suitable for street to street combat. They are vulnerable to attack by guerrilla fighters. In the morning jet fighters flew over the city and opened fire on demonstrators. Food was scarce and my mother used what flour she had to make bread so that we had something to eat.

Saturday November the 3rd was a sunny winter day. People were returning to work, the general strike was over and the shops opened their doors for bread potatoes and other essentials. The threat of famine was over. Negotiations started about the orderly withdrawal of Russian troops assisted by the Hungarian Army. The people believed that they won a great victory. There were no Soviet soldiers to be seen in the city and there was peace. But their joy was short lived.

On the 4th November early at dawn, the tanks returned in greater numbers than before. The radio broadcast the news of the invasion. Later on in the morning the Hungarian Writers turned to the leaders of the world to help Hungary which by 8 o'clock turned to SOS! SOS! SOS! By the evening Nagy was replaced by Kadar. The leaders of the revolution were rounded up and executed. The revolution was crushed and hope of freedom vanished.

My mother decided to leave straight away, there was no time to lose. If we delayed our journey, the border would be closed and so we all left to go to the border town of Sopron near Austria, where we could stay with my father's uncle. As it was dangerous to travel and my left leg was still in plaster after the operation, we managed to get an ambulance to take us to the hospital in Sopron. Several times during the journey we were stopped by armed guards, who peered into the ambulance to check that there were no fugitives in there. We showed them a letter that said that we had to go to hospital for treatment and seeing the plaster on my leg, they allowed us to pass.

The next day my father found a peasant farmer who came into town every week for the market, and asked him to take us back to his farm and get us across to Austria. A sum of money was agreed on and a small picture was torn in half. My father had one half, and my mother would give him the other half as soon as we reached the Austrian border. He promised to get us across the border.

So we said good-bye to my father, got on the farmer's cart, our heads tied with scarves to look like peasant women. We arrived at his mud hut where he was greeted by his hugely pregnant wife, surrounded by four or five little children. He sat down took off his cap and took out a great big carving knife. He was completely bald and my mother wondered if our end had come! But he only used it to cut a piece bread and cheese for his supper. We sat in silence and waited. Later two border guards arrived with their rifles and there was a hushed conversation in the entrance. As I was not very good at walking in my plaster, it was agreed that one of the border guards should carry me on his back while the other would carry both rifles. It was getting very dark now and we were taken out and started to walk. We had several layers of clothes to keep us warm and also it was easier to carry them. We did not have a suitcase. When we got to a barrier on the road, the soldier put me down and pointed us in the direction of a small building.

"That is Austria, carry on walking that way!" My mother thanked them and handed over her half of the small picture.

So we set out into the dark night, along the bumpy road. I managed with the plaster by holding on to my mother's arm and of course using my stick. The worse of it was the darkness! Eventually we reached a building and my mother cautiously crept up the stairs and peered in. She listened to the voices inside. They were speaking Austrian! She went in and asked for help. We were taken to a school building where several people were lying on the floor for the night. We settled down with them when three men entered the room.

"Who would like to sleep in a hotel in Vienna tonight?" said one. Of course everyone wanted to go! They were all asking to be chosen. We had just arrived and were lying on the floor nearest the door where they entered, so they took us.

We went out into the night and got into the back seat of a small black car. I tried in vain to read the road signs. Were we really going to Vienna? Were they taking us back to Hungary? What will they do with us? We were very worried and hardly dared to speak. It was after midnight that we arrived in Vienna. One of the men got out and made some phone calls. "I am sorry but I can find no beds for you in a hotel."

My mother and I got out of the car and thanked them for bringing us so far. We started walking down the street. Then my mother found a hotel, we went in and we did get a nice clean bed for the night. It felt like heaven to be in a lovely room and we soon fell asleep. The next morning she telephoned some friends who came and paid for the room. My mother phoned her brother in England. He told her to go to the British Embassy immediately and ask for asylum to come to England.

At the Embassy there was a long queue of people all waiting to come to England. As my mother could speak English and use a typewriter, they asked her to help with taking the details of the refugees. Eventually we were put on a bus to take us to the train station. The train started off and we settled down for the long journey. At several stations the train stopped and there were kind people who gave us food, such as chocolate bars and fruit. There were numerous tunnels on the way and lovely views of the Rhine. Then we had to cross the Channel by boat and finally arrived in Dover. The journey took nearly two days.

Member Zsuzsanna Snarey <zsuzsi.snarey@googlemail.com>

POINTS TO PONDER from Members.

1. Don't forget to smile when passing a mirror. It is an instant face lift. Vivien Holland.
2. The way to a happy older age for everyone must include the ability to embrace and even positively encourage change. Gillian Weldon
3. I have learnt there is little advantage of wasting my time worrying or feeling sorry for myself even when I have cause to be. Len Van Zyl
4. Never having found aids that have really solved any major problems for me, apart from my wonderful husband. Hazel Coleman
5. Oh how I would love to post polio.. If only I knew where to send it. Hilary Boone.

Please send us phrases or sayings to print in future newsletters.

'Taking control' campaign for neurological conditions

STOP PRESS from THE ME ASSOCIATION - <http://www.meassociation.org.uk>

According to new research, 82% of the 10 million people with neurological conditions in the UK do not have as much information as they want about their condition.

Furthermore, four in 10 – 41% – are not treated with respect by healthcare professionals and less than half (44%) believe they are receiving adequate care.

The Neurological Alliance, the Association for the British Pharmaceutical Industry and Ask about Medicines have joined forces to launch the 'Taking Control' campaign.

The campaign calls for people with a neurological condition to expect, as a minimum:

- To be treated by healthcare professionals who attach priority to giving information to patients.
- To leave the appointment at which they receive their diagnosis with an 'information prescription' including contact details of a relevant patient organisation.
- To have a single, well informed and accessible point of contact for on-going information about their condition and treatment.

For more information on 'Taking Control', contact Charlotte James, tel: 07771 568 915.

Do not put all your 'eggs' in one basket.

1. For some time, I have thought that lumping all one's conditions under the portmanteau of PPS might be a mistake.

In filling in official questionnaires I have always differentiated between LEP [late effects of polio] and PPS, and also between them and aging problems that are exacerbated by my polio history.

In this way, I avoid them being able to turn me down by a simple disbelief in PPS. They have to argue against each set of symptoms separately, which means there is less chance for simple prejudice to have a negative effect.

Now this is probably obvious to many of you, but it is very easy to say "I've got PPS" and leave it at that. I usually approach it from the non-PPS symptoms end, while at the same time pointing out that "polio is for life" and can seriously increase the effects of simple ageing and age related conditions, such as arthritis, ON TOP of the new problems of additional weaknesses caused by PPS.

From 'Hermit' aka Robin Brierley <munzly_hermit@BTINTERNET.COM>

2. We have 52 hens and 2 young roosters that we bred last summer who will have to go as we prefer the hens have a more "peaceful" life. I dare not leave the gate open as we have some foxes roaming the farm and as you know, if they got into the run, they would kill them all in a frenzy.

Last night at dusk I was trying to get a stray hen back into the run. She was hysterical watching the other hens going into the henhouse and was trying to get through the fence. After half hour I gave up trying and had to watch how and where she went to roost. Just as well as she thought a good place was to stick her head into the compost heap with her entire body sticking out. That's when I managed to grab her from behind and get her to her mates.

From Len van Zyl <leonard.van-zyl@SKY.COM>