



The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 4 - Issue 4 - June 2003

WebSite - <http://www.lincolnshirepostpolio.org.uk>

**JOIN US FOR OUR
ANNUAL GENERAL MEETING and SPEAKERS**

**Aaron Mattes, MS, RKT, LMT.
Dr. Ali Arshad, Consultant in Rehabilitation.**

**OCTOBER 11TH 2003
ANCASTER DAY CENTER,
BOUNDARY STREET, LINCOLN.**

More information on Page 23

A REALLY WHEELY NEWSLETTER



Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. Although it does not provide an endorsement, it is provided as a service to those seeking such information.

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

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Membership Information

Renewal dates are the first of the Months of Feb, Apr, Jun, Aug, Oct, Dec.

Please make cheques payable to 'Lincolnshire Post-Polio Network'
post to Membership Sec, 78 Heron Road, Larkfield, Aylesford, Kent ME20 6JZ, UK
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Other Countries please contact membership@lincolnshirepostpolio.org.uk for details.

Next LincPIN Newsletter - August 2003

Articles for publication mid July 2003 by post or - newsletter@lincolnshirepostpolio.org.uk

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Editorial by Hilary Hallam

Annual General Meeting - Info on page 23. Dr. Ali Arshad has now confirmed as a Speaker. He is a Consultant in Rehabilitation with a multi disciplinary clinic at the Haywood Hospital, Burslem, Stoke on Trent, Staffordshire. He has been doing research into PPS for some years now and looks forward to sharing information. Aaron Mattes, from the U.S.A. will be demonstrating, his stretching therapy, doing join in sessions and will be with us all weekend. A chance not to be missed. We have already heard from 20 of you that you will be joining us on this day. We need to hear from the rest of you please and would appreciate your completing and returning the enclosed slip, or email us the information.

This newsletter is my 40th LincPIN and trying to complete it has not been easy - as I am still in considerable pain three weeks after my accident - page 6. I know some of you will already have read this on our members email list, and some might just want to skip reading more about me, but this has led to many polio survivors coming forward with incidents that have happened to them. There is an email list for PPS Newsletter Editors and we have agreed that we should pass on the stories to forewarn you of what might happen. With thanks to those who have agreed to have their incidents in more Squeals on Wheels starting on page 8. Strangely the poem on page 18 was already in the file for this newsletter before my accident. Read members Jann and Marcia's stories of their travels. In fact this has turned into a Really Wheely newsletter.

I am a Speaker at the 'Aging with a Disability : The Late Effects of Polio' Conference in San Francisco on September 19th. Page 17. Not only is this an honour but another chance to meet more PPS Health professionals and share their information with you.

It is the sharing of information worldwide on PPS and allied problems that is moving things forward. How can you help move things on faster. How about writing to us with your problems, the names of health professionals who have helped you, equipment that has made your life easier, tell us how you have devised a new way of doing an action, how you or your family feel about PPS and how its affecting your lives, etc. If you would like to see other subjects

covered then let us know. In fact put pen to paper, or fingers to the computer keyboard and add the info to your return slip for the AGM. We appreciate that not everyone will be able to get to the AGM but we would be more than happy to take your questions for our Speakers - so why not add one, or two.

A fairly new member took the plunge this week and rang - she was fed up, tired, exhausted, worried, struggling to cope with family not understanding, struggling with medical appointments that continue to be unproductive. How many of you can relate to this, nearly everyone I expect. We chatted, we had some laughs, we swapped how we both felt on different issues, it was good to talk to someone else who can genuinely say, 'I know what you mean, I know how you feel'.... We continually suggest that you might like a pen or phone pal or even to meet another member over a coffee, but few respond. Many members are on the internet and on our members email list - if you are not, or have changed your email address and not let us know then please email either Robin or Hilary - yet the level of discussion on subjects remains small. Letters to the Editor are almost non existent.

Your committee and others who share the workload are already giving up a large amounts of their available energy and time to doing the work necessary to keep the organisation running. All this work is voluntary, mostly using our own equipment.

Our last request for help brought forward some great folks to join the team and take a share of the workload. If there is anyone else who has an hour or two a week, or more, then get in touch with us. Suggest what you might be able to do for us, or ask what can I do in my area? You can be sure of a great welcome and remember we are in the same boat as you. If you start to help and then find you cannot manage to continue to help for a short time or have to give up all together we will understand. In the meantime OUR NETWORK NEEDS YOU.

THE HESSING SAGA - soon to be serialised on TV

There once was a man called Hessing,
Whose parents named him after his birthing,
As they shook on the talcum
They named him Malcolm,
Not Michael - my errors are causing much mirthing.

A BIG THANKYOU FOR THE DONATIONS RECEIVED FROM

**W K Turpin, Kay Preece, Barbara Dickinson, R M Owen,
Philip Dalton, Bob Price, Angela Johnson, Hilary Ambrose,
Kathleen Burrell, Di Brennand, Herman Erlichson,
Lady Phillipa Dunally, Sylvia Fortune and Anne Brown.**

Let's Be Enabled, Not Disabled

by Your Membership Secretary, Robin Butler,
robin.butler@lincolnshirepostpolio.org.uk

It began with a conversation I was having with Hilary concerning problems that were becoming more acute as time goes by. Such as eating a boiled egg or soup or even drinking a cup of tea all difficult or messy. Hilary told me about the Mary Marlborough Lodge Centre at the Nuffield Orthopaedic Hospital in Oxford that she had visited some years ago. [LincPIN Number 3 January 1997.]

I asked my GP for a referral and shortly after I had an appointment to see Professor Derick Wade who is a Consultant of Neurological Disability at the Center for Enablement at the Nuffield Hospital in Oxford. The appointment came through quite quickly and we duly arrived after driving for a couple of hours from Kent. The receptionist realised we had had a bit of a journey and she brought us a cup of tea whilst we were waiting to see Prof. Wade (in my experience it is not the usual procedure in an NHS hospital)

I had about half an hour with Prof. Wade who knew about PPS and the problems many of us are experiencing. He made copious notes (from which he produced a six page report for me, my GP and Hospital consultant) saying they would be in touch ASAP to assess me and my abilities in greater depth.

A week or so went by and an appointment came through. We arrived in good time not knowing quite what to expect. A young lady arrived and whisked us off to an office upstairs. Whilst sitting waiting for a short while I noticed the door was marked "Speech and Language" I said to my wife, "Crumbs they want me to learn French or some other language" On checking with the lady therapist she then realised I was not her patient. She had wondered why I was so improved as last time she saw me I only spoke a word or two. We were then taken back to reception by a rather embarrassed young lady who will probably check who is who in the future.

We were now with two Occupational Therapists who quickly gave us a cup of tea. They watched as I had to lift my right arm with the left one to drink it. I then went on to explain the problems I am experiencing when eating, I have a good appetite but unfortunately my energy levels quickly run out. I explained that "I am no longer a two egg man", as I am exhausted before I have finished the first. Another example is that I have not managed soup for many years as after two or three spoons I find most of it down my shirt and to me soup is not the same from a mug,.....or a shirt.

The therapists said they could help with this problem and produced a glide along chair with a bracket fitted to the frame on the right hand side. Into this bracket they fitted a stainless steel frame with a number of bearings and an arm rest. I sat in this contraption and to my surprise I was able to move my right arm on its own and by lowering my elbow my hand was raised to mouth level. To those of you with full movement of your arms this will not sound too exciting, but for those of us who have struggled for years to do the most simple arm movement it is truly amazing. I was like a kid, pointing and moving my arm as never before (having had polio at 5 years of age in 1948)

Then we went onto discuss the problem I have with reading a book as it is not possible for me to hold one for more than a min. or two. A "V" shaped cushion [the sort you normally put behind you] was produced and placed on my lap with the point forward, this gives a good resting place for my arms and takes the pressure off my shoulders. On this they placed a tray with a bean bag base that could be tilted so that a book could be placed on it.

We broke for a sandwich and resumed later with a couple from the mobility section. We spoke about my car and a few problems that I am experiencing. Unfortunately their solution was to buy a new car, not quite what I wanted to hear. I was then taken to see an array of scooters a couple of which I tried, very interesting but I am not quite ready to go down that road just yet.

The computer room was our next port of call, where I was shown some attachments to fit to my desk that will take the weight off my arms and I am sure will make using the keyboard much easier. As yet I have not bought these but I do intend to do so.

We concluded with the sports and recreation dept. where there were many good ideas and strange but useful looking gardening tools to look at and where to buy them.

We ended up where we had started with the two therapists and to our surprise all the items we had looked at were there ready to be loaded into my car. I had assumed we now had to now fight to get hold of these, but no they were there waiting for us. All in all a very productive day spent with a great team of thoroughly professional people who care and it certainly shows. What a change from the NHS beurocuracy that lets you believe you are almost there only to have another insurmountable object thrown at you. I am not trying to get at the NHS as there are many very good people working for them but it is not as good as it once was, of that I am sure.

All of this was because Hilary and I had a chat about some of my difficulties. As the advert says "its good to talk"

The new Oxford Centre for Enablement offers a wide range of disability services, including respite care, wheelchair provision, prosthetics, orthotics and neuro-rehabilitation. Clients are given the opportunity to move between the services and pick and mix those that best meet their needs.

<http://www.noc.nhs.uk/index.html>

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Windmill Rd
Headington
Oxford
Oxfordshire
OX3 7LD

Main Reception - 01865 741155

Fax - 01865 742348

It seems like only last week that I put finger to

Treasurers Thoughts

keyboard to write the last article for the magazine. In fact it's nearer to nine weeks (each time I run closer and closer to Hilary's deadline). Quite a lot has happened since I last wrote.

Christmas Labels

There will be more information (and probably designs) in the next newsletter, but at the committee meeting last week we decided on a fund raising campaign of selling labels which can be attached to your own Christmas cards saying you support the charity. There will probably be three different designs on each sheet of 12 labels. The cost is likely to be £1 per sheet plus a small amount for the envelope and postage.

Whilst we expect this to generate only a small amount of income from the sale of labels it also serves the benefit of providing publicity for the charity and may enable more people to contact us.

Chartered Society of Physiotherapy

Because we are members of the Neurological Alliance we have the opportunity to place a half page advertisement in the Chartered Society of

Physiotherapists' Autumn Supplement which goes to their 41,000 membership. In addition our logo will be on all the literature and advertising to promote a reception organised by the Society at the Labour Party Conference. This also exposes our message to ministers MPs, peers and councillors. The cost of all this publicity is only £100. Your committee felt this was too good an opportunity to miss and Hilary is designing the advertisement as I type this article.

It's all in the timing

I have now been treasurer for almost 11 months. For the whole of that time we have been short of money, but Hilary has always consoled me with the fact that the majority of the subscriptions come in after April, i.e. they are sent out with the last newsletter.

I have recently been away and as I laid on my lounge in the sun I thought of all these cheques waiting for me when I returned, I had visions of not being able to open my front door for envelopes. But when I got home there was one cheque, just one cheque, for £10 waiting for me. As an aside I should say that, not only do committee members give their time, they are also expected to provide their own equipment. Robin's printer broke down just as he was about to print out the subscription notices and as a result they didn't go out with the last magazine. They have gone out now. I would like to express my heartfelt thanks to those of you who have already paid and especially to those who added a donation, words cannot express the joy each of these cheques brings to my heart. If you haven't paid I wondered if it could move up your priority list?

It is also gratifying that so many of you are now returning the Gift Aid Declarations as this enables us to claim back tax for the present, the past and the future.

Auditor Required

Our constitution requires us to have our accounts audited. In earlier years this has been done by a member; unfortunately he is unable to act for us this year. The job should not be too onerous, the records are well kept and complete. The accounts will be prepared and will comply with all accounting and charity guidelines. The work ideally needs to be done between late August and mid-September. The records (and anything else you require) will be brought to you – so if any member can help us out I would be exceedingly grateful.

I would be interested to hear any comments you have to make, please contact me:

jenni.paulger@lincolnshirepostpolio.org.uk

A Cautionary Tail!

by Hilary Hallam
hilary.hallam@lincolnshirepostpolio.org.uk

Friday the 6th June 2003 with blue skies, loads of sun, a few fluffy white clouds and the ripples on the nearby sea shining like diamonds. Richard and I had arrived 24 hours earlier to visit with my father and were now recovered enough to take up his offer of a meal at a nearby hostelry.

From his front door we can look down his drive across the car park and over a few roofs see the top floor of the hostelry. This is built against the cliff at the bottom of Seaside Hill and has no car parking for customers. Before PPS it was no problem, just a few minutes walk of about 400 yards. We could see all the car parking spaces on Seaside Hill were taken so we decided to use our electric wheels. Dad and I on our electric scooters, Richard on his Jazzy and we joked that Dad's carer Ann would have to put her running shoes on to keep up with us.

Dad's bungalow is at the top of a plot on the hillside with a sloping drive to the small road at the bottom bordered on the south side by the stone wall of the main car park. In previous years we had unloaded and loaded our electric wheels at the bottom of the drive, but Dad had had some work done at the top of the garden and there was now space to park at the top of the garden on a sloping gravelled area.

For the first time I found myself unloading our wheels with my vehicle on a sideways slant and with the hoist groaning a bit and my having to hold the wheels away from the back of the car I managed to get them both out. Thinking to myself that I would not park this way on again! I shut the back door of the car and gratefully plonked myself down on my scooter seat and unexpectedly found myself moving forward. Sheesh I thought, I haven't put the brake back on – having had to take it off to move the scooter in the back of the car – and I reached round and pulled the lever under the seat.

Horror hit me full in the face. Instead of stopping as I expected I started to move faster on the gravel and then down the steep drive heading for the wall. I was in Free Wheel Mode! I do not remember much as I started to move down the drive, although I am told I screamed at the top of my voice. My only remembered thoughts were to try and turn left at the bottom of the drive onto the small road and try and miss the WALL!!!

My next memory is lying on the road in the recovery

position – all that First Aid Training when a Lifeguard must have triggered something in my brain. I was alive, I had hurt my head, apparently grazing it along the wall as I turned. I had half a ton of gravel digging into my face and right arm, and my right ankle. The bottom of my back was hurting – I later learned that the scooter had landed on my back. I could hear many voices expressing concern as they hurried to get to me from nearby houses. Shocked as we are when we fall, the last thing we want to do is move, so I stayed put trying to collect my thoughts. I had just decided they would have to call for an ambulance when a first aider arrived and after a few quick questions and short examination confirmed yes call an ambulance. Thoughtfully a small towel was fetched and placed between my face and the road and to my relief I was told that unbelievably my head was not bleeding only bruised.

Family voices desperately asking how I was, children's voices telling everyone in earshot 'she careered down that drive on that and her brakes failed', and at last the sound of the ambulance. Looking up the road I could see two ambulance men walking towards me with oxygen and I thought, well I won't need that. They quickly assessed the situation and someone went with one of them to bring the ambulance round to the other end of the road and nearer to me. The other man carried on with his examination and questioning and told me how they intended to move me. Embarrassment set in about now, being six foot tall and no lightweight I thought now I really will look like a beached whale. The second ambulance man returned and soothingly told me to grip his hand tightly – I opened my eyes to check him out, and said so. All I can remember is that he was going bald, but his face and eyes sparkled with laughter as he told me I was cheeky. Great medicine.

My spine with a few congenital fused lower vertebrae and some kyphoscoliosis meant that lying on a flat board was almost impossible. To lie like this I need my legs bent and a pillow under my head and that does not quite equate with being strapped down to a spinal board. They rolled me onto the spinal board but my head would not go down, and my legs had turned as they were with my knees bent. As I was able to give them factual information of my problems and had no pain in my upper spine they placed a pillow under my head and strapped me on with my left leg bent. My right ankle was badly grazed and they said it would be better to take my pop sock off so that it did not cause problems with the wound. Off came my now badly scuffed leather trainer and AFO and I was able to straighten that leg. 'A classic broken ankle' said one ambulance man. 'A classic dropped foot' said I, 'and my ankle is normally swollen in front of the bone, look at the other one.'

'Maybe, maybe not then' replied the ambulance man in a light-hearted way. They really were very professional but knew how to lighten the situation and stress.

Strapped down I was lifted onto the stretcher and up a ramp into the ambulance. I felt as if I was going to slide off and got told swiftly to 'cross your arms on your chest and keep them there'. This was to make sure I did not bang my arms but all I could think of was 'you do that to dead people and I had fallen far enough already'.

There were two ways to the hospital and knowing them both I said take the shorter but bumpier route as I could take the pressure off my back slightly as my left leg was bent up. The thought of getting stuck in traffic using the other route was not something I fancied.

Richard came with me in the ambulance, he was really worried but relieved to be able to be with me and talk to me. The ambulance man started asking me a few more questions for the records and up came Post Polio Syndrome – something they had not heard about. Richard joked, 'well you soon will' and I told them about PPS and it did help to take my mind off the situation.

We arrived at the hospital and into A & E. I was relieved to be there, now I would find out what I had done. I was moved onto a trolley and a doctor came and they rolled me onto my side. I was a little surprised at the cursory feeling down my spine – at first some inches away and I had to say this – but the main pain was at the bottom..... 'Your coccyx' I was told. [I got to see my lovely ink stain bruise 4" by 1" today, using two mirrors with great difficulty]. X-rays were prescribed and I was pushed to x-ray. I was a bit surprised at being asked to move from the trolley to the x-ray table as I was still flat on my back in terrible pain and moving normally like this would have been hard, but now it felt like a nightmare. With some difficulty I managed to get into the positions asked and my head, back and ankle were x-rayed. One picture had to be taken again and I was then pushed back to my cubicle. Richard now came and joined me. It was nice to have company.

The doctor returned and told me that my head was OK, my back OK, but I had cracked a bone in my ankle. Some time later a nursing aid came to clean the graze on my ankle, dress it and then she brought out a huge roll of cotton wool and some crepe bandages. She managed to push my jeans up to my knee – I was surprised that they had not been cut or taken off to check me out. I said, 'If you put that on I won't be able to get my Ankle Foot Orthosis on', so she checked with the doctor and came back and started

wrapping me up in cotton wool. By the time she had finished my leg was twice its previous size. Richard passed me my shoe and I saw my AFO was cracked in three places [its now been glued up]. They gave me some arm crutches and told me I could go once mobilised.

Thinking about it now I think the doctor must have thought I just fell off the scooter whilst going along the road, and did not realise that I had been going downhill at a rate of knots towards a stone wall, or that the scooter had landed on me. He may also not have known much, if anything, about Post polio syndrome but having had to move about – and still without any pain relief, despite asking - I was in far too much pain to think straight. All I can remember him asking relating to polio in any way, was 'which is your weakest leg'?

The title is A Cautionary Tail.

CAUTION - I have told this story so that it can be passed around in the hope it will prevent others having the same problem. I remember some years ago another PPSer telling her story – Always take your crutches out with you no matter how short the trip if you need them to get out of your chair, when her wheelchair broke down on a rail track! If you have to take an electric scooter out of a vehicle on a slope or hill ensure, if at all possible, that this is done so that you are at right angles to the slope. Plus if you have to release the brake at any time - as I have to to push my scooter right into the vehicle to get Richards wheelchair in behind - then **before you sit on the scooter Check the Brake is back in the ON position.** I have now stuck a coloured sticker on the tiller to remind me.

TAIL – well that's the bit that I am trying not to sit on as I type this!

© Hilary Hallam, polio survivor of 1952,
Founder and Chair, Lincolnshire Post Polio Network,
UK – June 2003.

This tale sent over the Internet brought back to me many stories of other incidents. Many PPS Newsletter Editors have agreed that it would be really helpful if we passed the information on.

Forewarned of possible problems could mean your having extra information that you can use to get you out of, or better still, not get into the situation in the first place.

More Squeals on Wheels

From Ellen Riddle.

I got my chair while still living in Oregon and our house was on a street that was a steep hill. I took it out for a 'walk' along the store fronts at the bottom of the street. Started out very slow until I got a feel for it, taking my hand off the joystick and yep., steep or not I stopped. Once I knew that I started really enjoying those hills! LOL...[laughing out loud]

Funny I felt safer on the side streets in Oregon with the hills than I do here in our San Antonio development. Too many cars parked along the curbs and too many teen drivers who don't do the posted low speed limits.

Oh and sidewalks are a joke! They are narrow to start with and then everyone's mailbox sits smack dab in the middle of them. Some with the lovely brick surrounds take up the entire width of the sidewalk. Oh well....

My own story is from when I first got my chair and went to the outlet mall. I was in one of the clothing stores and had my speed dial on low as it was a bit tight navigating between the various racks. I made a note that the racks were extending out further than the feet of them. I went merrily from one to the other. Well, there was one that was the reverse of the others, the feet extended out. I caught the foot and my hand over reacted (I hadn't learned yet to simply take it off the joystick) and the next thing I knew I was part of the display.

Of course other customers and help came to my assistance. I was so embarrassed (now I would just let the staff know it was their fault for having things so tight in the first place.<Grin>) I was fine and left. It was only much later when I got home that I realized I had bruised my left leg and somehow my right arm.

I think there is a learning curve with these things. We have a bunch of minor incidents in the beginning as we get used to how they work. Then we know it all. This is when we are probably most vulnerable because then it's easy to keep the speed control higher and be over confident.

The thing I keep doing is when I wheel around the part of the house I can (and anywhere that is tight) I find I push my feet back so I'm more on my toes, to protect them. No, I've not banged them yet, but I've heard stories of others who have so I guess I'm just careful, and glad I can do it. You would think they would make the foot rests long enough to protect one's feet... and I have tinier feet than most!

From Jen. I have had a powerchair for almost 5 years now. I use it 24/7 and can tell you going down hills are fun. However, if they are too steep I take them backwards. I take curbs and other obstacles backwards also for more traction, power and safety. Ramps especially, at the zoo, for the trams and also for really steep ones.

The only experience with the wheel brake for freewheeling has been when my husband was taking mine apart each time and loading it in pieces into our van before we got the rear gate lift. He would push the wheel gear off so he could move the chair and then it wouldn't re-engage.....ughhhhh! He was so mad!. He finally got used to it, but I was scared all the time it would come loose and I'd be stuck somewhere. We got a new wheel assembly and now the only thing is you can't keep it un-engaged now to move it about off power! We have the lift now so have never un-engage the motor now.

Oh, I nearly forgot, I sometimes don't put my short legs and feet up on the footrest (I have a one piece front one) all the time and run around with them dangling. It's also easier to do dishes if your footrest is folded up so you can get up closer to the sink. Well, I was doing dishes last year and turned the chair to pop some things in the dishwasher and caught the sleeve of my pj's on the joystick and the chair went forward into the cupboards. I felt the side of my foot catch between the front wheel and the side of the baseboard where it meets the cupboard. I just thought I had scraped it good and would maybe need a band-aid.....until I felt this cold stuff run down into my slipper. I looked down and there was blood on the floor, opps..... I called for Dave, my husband, and he didn't hurry he thought I wasn't hurt badly either till he saw the blood. We got a clean washrag and pressed it hard on the side of my ankle below the bone on the inside where the bolt from the front wheel had cut my foot. He held my foot up while I slowly ran the chair and me into the bathroom (that was a funny sight) He held my leg up over the sink and washed it off. "We need more than a band-aid" was his remark, so on with my clothes and a quick run through my hair with a brush and some make-up (can't go to the ER without make-up now can we)

It was Saturday mid-morning, not many folks waiting. We got into a room and what a time getting me onto a table. Luckily we had the oldest son with us and he helped get me up there. I hate exam room tables more than anything, they are way too high. The Doc had a look and inserted 11 stitches. Luckily I didn't hit any nerves or tendons. It took a long while to heal and now I am VERY careful about running my chair with my legs dangling and when I do let them dangle to do dishes I turn the chair OFF.

From member Jennie Bedford in Canada,

I managed to have an accident with my scooter when Mattie went one side of a road marker pole and I went the other. Before you say it, I know we're not meant to walk dogs and scoot at the same time - but that's a fact of life, the dog needs to be walked. Anyhow, the retractable lead went to its max length in nanoseconds but I was still doing 4+ mph. The next thing I knew was that my left arm had nearly been wrenched out of its socket backwards, my body was snapped back (felt like over the back of the seat). The lead was ripped out of my hand. Then wham, forward I went. Of course, somehow I'd managed to hang onto the handlebars of the scooter with my right hand - the thumb of which was in contact with the Power. The next thing was that the scooter jack-knifed to the right, catching my right foot and ankle under it. I was unceremoniously dumped into the middle of the road. Luckily it was a very wide residential street and there was no traffic at the time. Being on my own, I had to calm 12-week-old Mattie down (she was frantically licking my face!); get myself, the scooter, and Mattie out of the road, and then get home. I learned my lesson well....keep the pooch on a locked, short leash and in your line of sight at all times....and train the dog to react to the "Left" and "Right" commands (this she does beautifully now).

In response from Margaret Davis in Arkansas.

In order to have no need of pushing that arm back into the socket, before attaching the leash to the ring on the dog collar/harness, attach the leash to the wheelchair base by slipping the metal attachment end through the hand loop and tightening it to the w/c base. Next, snap leash to dog collar/harness. By attaching the leash to the side away from the Joy Stick, I still use my hand on the leash so the dog will learn to respond to the feel of my gentle tugs as well as oral instructions. When training a dog to lead, the dog is prone to Pull, when they do this. I let the leash slide through my hand so the dog is pulling against the w/c and not against my strength, which would not be strong enough to hold the dog anyway, and I just sit still. When the dog gets tired of the struggle which he is loosing, he will stop struggling, at that point I slowly move the w/c forward. My dog Lady learned this quickly and almost never tightens the leash.

From member Jann Hartmann,

I haven't had an accident with my scooter or any of my wheels (knock on wood), but I have run into trouble as I am losing upper body strength. I used a full leg brace (KAFO) since I was 6 years old, and was very good with crutches. I had great strength in my arms until recently and depended on them.

Luckily, while traveling in Europe (when I spoke at your AGM), we were able to get me and my scooter on most older trains with the sissors lifts provided at most all of the train stations. Later, in Germany (where the lift wasn't working), I fell flat on my face trying to go up two large steps into the train. We've decided not to travel that way ever again. I will only go on trains with a level entrance or on one we took here that had a permanent ramp at the train station for loading passengers. I now call and ask lots of questions.

But, the scariest thing that happened to me was when we took an escalator from street level to an underground train. We now tend to look for an elevator, but didn't this time. I hadn't been on an escalator in years but used to do just fine. Since I did have my crutches with me, John took the foldable wheelchair down in front of me and I stepped onto the escalator and grabbed the moving handrail...no problem. But, fear gripped me as I realized the handrail was moving down at a faster rate than the moving steps pulling me off balance (never a hard to do). As I was falling onto the steps I'm remembering that clothing can get caught at the bottom so I am preparing to lunge forward when we get there. I was successful and landed on the dirty floor clear of the escalator hoping not to get run over by any people coming down behind me. Luckily, there was no one behind us except one man who offered help and showed us where the elevator was located for the next time!

I was very lucky not to have been hurt (other than my pride), and I learned that I must take the time to find the elevator and never take shortcuts. I used to be smarter, I think! But now I remember the old PA Dutch saying, "We grow too soon old, and too late smart!"

From member Ginger Ottonello. Another incident occurred at Home Depot and knocked a "chunk" out of the back of my chair. I was simply trying to get out of the way so a man could get by and backed into a metal bar used to hold wood - there went a nice chunk out of the plastic - super glue to the rescue, I hope!

Another caution for people. I was visiting Fort Laramie, Wyoming, with my niece one on an on again, off again, rainy day. We had taken my little Shi Tzu with us and he was on one of those spring type leashes. We were cruising right along and I didn't pay attention to the leash cord, which was quietly wrapping itself around my rear wheel axle, until I came to a screeching halt.

I tried reversing but that got us even more tangled up. In the meantime it started to rain even more and there

we were. The chair wouldn't go. The dog was upset because he couldn't "go", and my niece had no idea what to do - nor did I, because guess where my crutches were - in the car. I had to stay in the chair and that did complicate matters. I had also forgotten that you could tip the chair back on it's end and that would let us get to the wheels.

Finally, a young man and his sister saw our predicament and they got the leash undone. I owe them a large thank you because that young man held the back end of the chair up in the air while his sister unwound the leash. I was able to get to a bench so they could do that but it still took some time and we all got a good soaking.

I am now very careful to keep an eye on what Ewok is doing whenever the two of us are connected by that leash. The easiest solution is to let him ride with me, which is exactly what he wants.

From Carol Lewis.

OK, here's mine -- but about a manual wheelchair, not power. In September of 1984, scarcely three months after the death of my husband, my very young twins had been playing on the ramp from my front porch to the sidewalk. I strongly reminded them that they had to get EVERYTHING off of the ramp when they were done. They really did an excellent job for five-year-olds. BUT, they neglected one little thing -- a small rock. I was running late the next morning on the way to work and was flying down the ramp -- a ramp that was much too steep to begin with. My front wheel hit the rock, and the wheelchair stopped but I kept going. I landed on my knees and immediately flipped over to a sitting position. After swearing at the kids under my breath for a few moments, I started to straighten up my limbs in order to try to climb back in my chair. Uh oh, moving my left leg just wasn't going to happen. As you might guess, I shattered the knee when I landed on it.

My oldest boy had already taken the twins to school (kindergarten) and went on to school himself -- or so I thought. So here I sat on the sidewalk, in business attire, with my briefcase next to me -- long before the advent of cell phones. I had to wave at every car passing in front of my house in an effort to flag someone down. A woman finally stopped and I gave her my house keys so she could use my phone to call an ambulance.

Later, my next door neighbor went over to the school to let my oldest boy (then 12) know what happened and not to expect me home that evening. Hmmmm, he wasn't in school and hadn't been for a week! She found him down by the creek, hiding in a tree. He had cut school one day, and realizing that he would

need to have a note to get back into class, didn't know what to do. So, he just kept on not going to school. Lord knows how long he would have been out if I hadn't broken my knee! Thanks to my misfortune, he finally got himself back into classes. The boys laugh about it to this day -- almost 19 years later.

From member Larry Kahout.

Before I went into the power chair I used a power attachment to my manual chair. We had christened it Go-mobile because compared to wheeling I could really move around quite comfortably. The attachment is called a Roll-Aid and is made by Stand Aid of Iowa. With some brackets on your manual chair you simply roll the chair over the power attachment and it hooks onto your chair and you become a powered tricycle with the casters of the chair off the ground and the tiller coming up between your legs.

You can reach the handles on the tiller quite comfortably and your thumbs very naturally rest on either end of a paddle switch. When you press on the right end with your right thumb you move forward, when you press on the left end with your left thumb you move in reverse, very simple. That is very simple until you put something in your lap and accidentally lean forward.

If you use a chair or a scooter you realize that you almost always put things in your lap to carry them around. Shortly after I started using Go-mobile I was moving around at work and needed to go through a closed door. I had my organizer laying in my lap on top of my laptop computer. I pulled up at the appropriate angles so that I could pull the door open, leaned forward, and the computer or my organizer pressed firmly against the "forward" end of the switch and drove my left foot solidly against the door.

It took me a second or more to get myself back upright and off of the power and backed away from the door. The fact that I am on anticoagulants did not help the situation either. By the time I got home my foot was swollen so badly I thought I was going to have to cut the shoe off. Luckily it was simply a severe bruise and nothing was broken.

But you would think I would have learned my lesson, wouldn't you? Not so. Two weeks later, before my left foot was healed, I got out of the car at night and headed across the garage toward the elevator in one of my effervescent moods, and managed to do exactly the same thing to my right foot. At least this time I did not bruise it nearly as badly. As I recall both my right and left foot managed to heal up at about the same time.

Although it is much more difficult to do with the joystick on a power chair, I have learned that it is not impossible.

Larry (a slow learner but always well balanced)

From member Nancy Almirall.

I am by nature very careful and methodical, or rather, I used to be. Now I forget things that used to be second nature to me. I know that I must turn down my wheelchair speed before going up the ramp in my van. The first time I forgot to do it I went sailing off half of the ramp and was dangling over the edge in a grocery store parking lot with groceries in my lap.

I think that I'll never forget again and then I find myself doing a wheely right into the van, saying "oh ****" like the sundance kid. I have experienced that horror of zooming right for a wall at full speed. it's horrible and so helpless. I can't blame PPS for my

situation because it happened in 1990 while I was in nursing school. I was riding a friends dirt bike, (motorized and fast) and forgot how to slow it down. I started squeezing the grip on the handle bar tighter and tighter toward me and of course the bike just went faster and faster. I did a 90 degree turn at a barbed wire fence and both the bike and I flew into the air and then landed with the bike on top of me. The only thing broken was my right hand and fortunately, i'm left handed. I thought I would be kicked out of nursing school for lack of good sense, but alas I remained. I was old enough to be the other students mother and they must have felt protective of me because when I needed to take a blood pressure or do anything that required 2 hands, one of them would zip into the room and lend a hand.

I think the sticker on the tiller is a great idea, perhaps I should put one somewhere that i will remember to look, maybe at the bottom of the ramp.

GINI Aging and Late Effects 16 Page Survey from the University of Michigan

A series of questions covering the topics of basic background information, physical functioning and activity, life satisfaction, mood, your polio history and late effects symptoms you may be experiencing.

Section A - Who you are - Section B - Your Health
Section C - Your Mood - Section D - Polio History and Late Effects.

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If you are not on the Net then tick the box on the AGM return slip and we will post you a copy.
FOR MEN

<http://www.lincolnshirepostpolio.org.uk/downloads/surveys/GINI-Survey-Intro-Men.pdf>
<http://www.lincolnshirepostpolio.org.uk/downloads/surveys/GINI-Menop-Polio-Quest-MEN.pdf>
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<http://www.lincolnshirepostpolio.org.uk/downloads/surveys/GINI-Survey-Intro-Women.pdf>
<http://www.lincolnshirepostpolio.org.uk/downloads/surveys/GINI-Menop-Polio-Quest-WOMEN.pdf>

Too Have and Too Old by Richard Armour

The bride, white of hair, is stooped over her cane
Her faltering footsteps need guiding.
While down the church aisle, with wan toothless smile,
The groom in a wheelchair comes riding.
And who is this elderly couple you ask?
You'll find, when you've closely explored it,
That here is that rare, most conservative pair,
Who waited 'til they could afford it.

<http://ylcf.org/gretchie/romance/weddingsnmarriage.htm>

Ahhhh.. Comfortably Sitting in a Wheelchair

Last year I finally got my first powerchair.

A year later as I sit in comfort in it I find that I am grateful for some advice I was given before I got it. I want to share my experience so others might go directly to comfortable sitting as I did.

When I was talking to some of my friends who have been using their chairs 24/7 or close to it I asked them for their suggestions. (Even though I knew I'd only be using it outside the house to start with).

Each one told me the importance of having a physical therapist or an occupational therapist fit me for the chair.

Another gal, who knows me really well, went further. She shared from her own experiences. Her first chair she brought "off the rack". She got one with the upholstered sitting and standard arm and foot rests. Her thinking was that the only reason she was going from the manual chair to a power was because her arms couldn't handle the work of pushing her around any longer so she didn't "yet" need a more elaborate chair.

She laughed as she told me she soon discovered how wrong she was. But, with insurance (Medicare would be the same) she had to wait a few years to replace her chair with what she really needed.

She told me the type of cushion to ask for and a lot of other little things that had to be written into the script for insurance or Medicare to cover them.

When I went to my doctor to ask for the script for my first powerchair I went armed with all of this information.

First of all, I didn't walk in using my cane. With a few failed attempts at trying to get other doctors to write my script I had learned that when I was ready I had to be in a manual chair with someone pushing me. (If I could still manage to walk in then the doctor was very hesitant to write the script as "technically" I was still walking. (Even with a cane, even with a limp, etc.)

My MNL wheeled me into his office. He knew right away why I was there. Before I even asked him to write the script he said he would. Then, it

was my turn.

I told him all the things that needed to be in the script.

Here is my list:

1. A gel Jay cushion for bun [behind] and back support.
2. Adjustable arm rests (this should have been obvious as my left arm bends much higher than my right). I would recommend this to anyone though as I change the height of my right arm rest frequently depending on how it feels and what I am doing.
3. Some kind of back support system.

He did this and then told me that I really needed to be evaluated for my chair so I would get all I needed in it. So he also wrote a script for me to go to a rehabilitation hospital he worked with to be evaluated and fitted for my chair.

If anyone asks me about this I tell them that if their doctor doesn't automatically write a script for a PT evaluation to insist on it.

Here's what I found out when I had my evaluation done.

The pt had me walk, sit, stand and checked over my body posture with great care and detail. She felt I should get and use my chair most of the time, as opposed to my view of using it just outside the house.

I knew I needed the seat and good back rest. I didn't know that I also needed good side support. I would not have done this on my own even though I tilt to the left when I'm tired. (I've done this for many years now so didn't even think it "not normal").

We went with the medium side support to start with and she showed me what looks like small paddles that I can order down the road if my left side starts calling out for more support.

Then we talked about my generic leg rest. You know the one that both feet sit nicely on and you lift it up to get on and off.

I had had a more generic (upholstered seat with standard arms and single foot rest) chair for two weeks to "play with". I readily agreed to better arm rests, seat and back. But I wanted the single foot rest. Then she asked me the revealing question. How many times did I really lift it up when getting off/on? None...

So we added the regular swing away leg rests. With a simple touch on the side of them they swing out and are easy to swing back.

Yes, I am happy with this too, as getting in and out of my chair is much easier and far safer.

Because of the fact that my chair gives me the support I really need and is so comfortable just a year later I find I am using it almost as much as I should. I wouldn't think of working at the computer in my old office chair as I get fatigued much faster due to lack of support. I use it outside as much as possible. On the occasions that I don't I find I can't wait to get back to it simply for the comfort. It feels that good.

I don't use it inside the house other than in my office and bedroom as this house is simply not accessible enough. But, I dream and am praying for my totally accessible home. At least I sit in comfort while I dream and plan.

I hope that if you contemplating either getting your first chair or upgrading your existing one you will keep these tips in mind for comfort and support:

- 1 Insist on a professional evaluation (not the one at the wheelchair supply store... they don't really know what we may need as a good PT/OT will)
- 2 Ask for a gel cushion
- 3 Ask for adjustable arm rests
- 4 Ask for back support.
And one thing I didn't get and will be going back for soon
- 5 Ask for a high enough back with a neck rest. Last year I didn't think my neck was that bad. I am wishing I had more neck support more and more and am hoping it will be an easy upgrade. I can't wait for four more years.

The good news is that since my back rest is separate from the chair. All I have to do is replace it. Not the whole chair. Pretty cool?

Oh, and don't forget the swing away leg rest. Yes, they are on the ugly side, but so much better.

Ellen M. Riddle - Texas USA.
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CHANGE OF NAME TO POST-POLIO HEALTH INTERNATIONAL

Gazette International Networking Institute (GINI) has changed its name to Post-Polio Health International and has developed a new membership structure. Post-Polio Health International will continue to respond to the needs of ventilator users through its affiliate, International Ventilator Users Network.

The new name, Post-Polio Health International, clearly focuses on living with the late effects of polio and reaffirms an ongoing interest in international issues. Post-Polio Health International is meant to project the broadest meaning of "health," encompassing the physical, emotional, social, psychological, and spiritual aspects of individuals' lives.

The new membership structure is designed to strengthen Post-Polio Health International's ability to advocate for its constituents.

Current newsletter subscribers are automatically members of Post-Polio Health International and/or its affiliate International Ventilator Users Network.

Not already a subscriber?
Check out <http://www.post-polio.org/order.html> to become a member today.

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The Lincolnshire Post Polio Network
are members.

Marcia writes... Accessible Alaska

I know Alaska is a long way from London, but it's not impossible to do. The question is – is it worthwhile to go there? The answer is a resounding 'YES'! If you are looking for the trip of a lifetime – to a place where they still speak your language, this definitely qualifies. We just returned from a nearly 2 week long visit to Alaska and I found it to be the friendliest, most wheelchair accessible place I ever visited.

How do you get there? I would suggest the following route (a travel agent would be glad to help you find the cheapest fares): fly from London to Vancouver, British Columbia, Canada or perhaps to Seattle, Washington. Both are great places to visit and you may want to spend a night or two to get over jetlag as there will be an 8 hour time difference. After you've rested up a bit either city has numerous sights to see – but I want to tell you about Alaska so I'll not go into any detail.

From Vancouver or Seattle fly to Anchorage, Alaska. This is a 3 to 4 hour flight and only a one hour time change is involved, so you'll be ready to do a bit of sightseeing or shopping on the day you arrive. There are many hotels in Anchorage. We stayed in an accessible room at the Anchorage Marriott Downtown Hotel at \$135/night (about 82 Pounds). There are many other hotels and most have w/c accessible rooms. Once again, a travel agent – or the internet – can help you find the best rates which will depend upon when you visit and how long you stay. Remember too that 1 British Pound will get you about \$1.60 US dollars so prices are not nearly as bad as they first appear.

I would suggest that you spend at least three or more days in Anchorage, but it would be easy to spend even more time there. In Anchorage there is w/c accessible public transit system. You can buy a day pass for a reasonable sum and use it to get to various attractions. Or you can rent a car which makes things much easier but also requires that you remember to drive on the right and spend extra dollars doing this!

Shops and stores – there are lots of them carrying all kinds of neat souvenirs from the ridiculously expensive to the plain ridiculous – are w/c accessible. All the sidewalks have curb cut downs and drivers are courteous and patient while you cross the street. I use an electric scooter and was constantly amazed that I had no problems getting into restaurants, stores, hotels, museums and many, if not all, general

tourist attractions. Equally good to know is that there are w/c accessible toilets everywhere and they are truly accessible. There is room to transfer from a w/c; there are grab bars, a raised toilet and lowered washbasin and towel dispenser

Here are just a few of the many things open to wheelchair users in the vicinity of Anchorage. The Alaska Native Heritage Center – a wonderful place with shows by the 5 groups of natives (4 Eskimo cultures and 1 Athabaskan Indian culture). There are craftsmen working on native crafts and you are free to join in and make some yourself. There is a very large outdoor area which has full size replicas of the houses used by the native people of Alaska. Alas, in summer the temperature is not too different from that in Great Britain and hence there are no igloos! Knowledgeable and charming people staff the center and they are happy to answer questions and to tell you about their own people and their own personal histories.

Anchorage also has a very fine Museum of Art and Culture that depicts the settlement of Alaska beginning with the native people who arrived during and just after the last ice age some 10,000 years ago and continuing with the Russian fur traders, settlers and priests and winding up with the gold rush to the present day. The art portion of this museum has some paintings that are not to be missed – even if you are not normally attracted to art museums.

Drive or take a taxi to visit Earthquake Park, just across the bay from downtown Anchorage. In 1964 Anchorage and southeast Alaska was battered by a 9.2 magnitude earthquake. The main shopping street in Anchorage was split right down the middle. One side of the street dropped 18 feet in a matter of moments. Earthquake Park commemorates a housing development that slid into the bay, killing 9 people. Here you can see how the land surface broke into chunks as chasms opened and closed and you can see the mud flats that are all that remain of the houses that were built on a once high bluff overlooking the bay. There is a small, w/c accessible, earthquake museum in downtown Anchorage. It is kind of tacky and the video they show is not terribly well done but it's still worth visiting to see and hear the survivors tell about their own personal experiences in the earthquake.

You need a car to visit some of the other sights. A short drive over a 4 lane highway out of Anchorage will take you to Hatcher Pass – one of the few ways that natives and gold miners

could use to get from the ocean to the inland area. When we were here in mid-May the pass itself was still under 10 feet of snow and not open to cars. Later in the summer you can drive over the pass for some spectacular views. Just before the pass is the Independence Mine State Historical Park - a fully preserved gold mine from the 1940's. There are also two places to have lunch or coffee and one of them is above the tree line with a lovely view of snow covered mountains.

Near Hatcher Pass is a musk ox farm - don't miss it. Musk ox are one of the few animals surviving from the last ice age. They were contemporary with the woolly mammoth and the saber tooth tiger! Here you will have to travel over some uneven lawns to visit the musk ox in their pens, but it is quite do-able in a scooter or a w/c with wheels capable of taking on grass and gravel surfaces.

You can continue on to the small town of Palmer which has not changed too much since the 1930's. It is a pleasant place to visit, have lunch and perhaps take in the small museum nearby. But you might want to cut this short and continue along the main highway between Anchorage and Fairbanks which at this point is a narrow, somewhat unkempt two lane road. It has the virtue of some unsurpassed vistas as well as access to the Matanuska glacier.

Driving to the Matanuska glacier is a bit of a test of nerves and vehicle control - but well worth doing. To reach the glacier you turn off the main road onto a steeply inclined dirt road which is actually more like the slightly widened path of a mountain goat. You carefully make your way down to the bottom of the valley avoiding fallen (and falling) rocks, pay a fee to use a gravel road and head off across the huge, dry riverbed to the foot of the glacier. The Matanuska glacier, like virtually all glaciers, is receding quickly. However there you can drive almost to the foot of the glacier and if you've got a really tough scooter or wheelchair, you can take a path right to the ice. I chose to sit in the warm car and admire the glacier from a good vantage point while my husband braved the cold to trek to the glacier.

Of course while you are in Alaska you should go on a whale watching cruise. Some of the best of these leave from Seward which is about a 2 hour drive from Anchorage but the easiest way to get there is to take a package tour which includes a bus from Anchorage as well as 4 or 8 hours on a whale watching boat. On the longer tour the boat will go to a glacier that is 'calving' large

icebergs into the ocean and if you are lucky you'll be there to hear (a very LOUD sound) and see this event. You are virtually assured of seeing whales as well as sea lions, seals, porpoises and various marine birds including the funny little puffins. Most of these are wheelchair accessible but check before you book because it will depend upon the bus, the boat and the weather!

You might want to take a 6 hour train ride to Denali Park and spend one or two nights in one of the luxurious lodges within the park. Mount McKinley, the highest point in North America, is located here although it may well be shrouded in clouds so that the peak is not visible. No private cars are allowed in the park. Instead there are buses that will transport you through the park to points of interest. Arranged mainly for hikers, they are also a good way to see this vast expanse of land. There are enough grizzly bears and moose in the park that you well may get a chance to see one from the bus.

If you are looking to complete your visit in affordable luxury, I suggest you consider taking a cruise ship from Seward to Vancouver. It's a seven day trip that will take you to visit more glaciers on the way south. We traveled with the Holland America Line on the S.S. Statendam and had a w/c accessible cabin with a roll-in shower. The cruise is probably not too different from other cruises - but the places you will visit are definitely unique. The ship stopped at Sitka, a town of about 14,000 people that 250 years ago was called the "Paris of the North". Sitka was the heart of the Russian fur trade and the attempt to Christianize the native Indians. There are only a few buildings remaining from this era but the town itself is charming. Unfortunately Sitka has no harbor and so you have to go ashore on tender boats. They cannot accommodate heavy wheelchairs, and if the sea is rough, they will not take mobility impaired guests due to the dangers involved. Fortunately the sea was calm when we were there and they were able to take my lightweight travel scooter on board the tender as well as giving me enough help so that I was able to make it as well.

The other two towns, Juneau - which is the capitol of Alaska, and Ketchikan do have regular docking facilities and hence are w/c accessible AND wheelchair friendly. In both places there are a variety of things to see and do. We took a whale watching tour out of Juneau and went to see a wonderful Athabascan Indian village, Saxman, as well. If you go to Ketchikan, do not miss visiting Saxman and seeing the vibrant show that that depicts native songs and dances.

On board the cruise ship most things were w/c accessible – and the crew were unfailingly pleasant and helpful! A few of the forward outdoor decks are not accessible because of raised door sills for the watertight doors. This is a shame because it is fun to be at the front of a moving ship. We were able to lift my travel scooter over these obstacles and so I could get out on the decks. However the promenade deck and the deck chairs were all wheelchair accessible. Probably the main hazard of cruising is gaining weight. There is always food available and it ranges from good to utterly delicious! I'm afraid I put on a few pounds. Why are they always so much easier to put on than they are to take off?

I could go on at great length about other things to see and do in Alaska. I was constantly surprised and pleased by how easy it was to get about and how kind and patient people were to me. If you are planning any sort of extensive holiday – think about going to Alaska! I know it's cold, and sometimes it's rainy – although we had quite a lot of sun – but you will enjoy it anyway. I guarantee!

marcia.falconer@sympatico.ca

Travels with our Trailer

by member Jann Hartman

John and I both come from families who enjoyed camping and travelling all over the US and Canada. By the time I was a pre-teen my family had been to all 48 states in the US [that's all there were at that time]. Then, in 1960 Alaska was added; and, in 1961 they added Hawaii. John comes from a family that is widely travelled, too. While we vacationed in Newfoundland the first summer after we were married, we just got to the lower part of Alaska a few years ago. Now, we only have Hawaii yet to visit!

We love to vacation in the Canadian Maritimes on the east coast of Canada (New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland) and love to tour the lighthouses and the old forts. New Brunswick even has the longest covered bridge in the world in Hartland. Nothing beats the awesome feeling at Niagara Falls which we have visited several times (even once in the winter). In Spring 2001, we finally got to the west coast province of British Columbia as well as Alberta, Saskatchewan, and Manitoba.

While I dearly loved the Rocky Mountains in the US, I thought the Canadian Rockies were even more beautiful with the creaking blue ice glaciers and beautiful waterfalls. We hope to someday take the train up to Churchill on the Hudson Bay to see the Polar Bears.

A few years ago, we finally bought a new caravan for the very first time. Our Sunline Travel Trailer is just over 20 feet long. It's just big enough to have a bed that stays made plus a bath and sit-in shower with a handheld wand. It has a fully equipped kitchen with a propane gas stove and oven, large refrigerator with separate freezer, and even a microwave. We added a stool for me to sit on while in the kitchen, and from it I can reach the sink, stove, and refrigerator without getting up. There's also a swivel chair and sofa bed for relaxing along with a foldaway table.

Many people seem to enjoy a motorhome where you can go from the front (driver or passenger) to the back without getting out of the RV (recreational vehicle). But, we like to be able to unhook the trailer from our truck to tour the area. We have also put a mattress in the back of the truck and can sleep there in a pinch or for a nap. As with all things I find I need a variety of options so I can choose what fits my particular needs on any given day.

There are several companies that make RVs that are accessible for those with disabilities. Ours is too small to have a roll-in shower. Since I am still able to use crutches on a limited basis, this trailer works well for me. It seems smaller is better for me at this time. But, there options that work well for people with other needs. Luckily, there seems to be something suitable for everyone.

We do plan to trade this RV in for one just a bit larger someday. By just adding 4 or 5 feet, we can get a roll-in shower and a ramp or a lift with a wider front door. That really makes it ideal for anyone with wheels. These caravans are much more affordable than the large Winnebago-type RVs which cost more than any house we've ever owned. Besides, I just don't need that much room. So unless we inherit a large amount of money (not likely), we'll stay with our smaller, but wonderfully liveable smaller sized caravan.

I was surprised to find out that there are several travel clubs just for people with disabilities. And, I am pleased that the National as well as State and Provincial Parks in the US and Canada are becoming much more accessible. They are making trails with no barriers for those using

wheels and bath houses with ramps or level entry. Many campsites are level and some are designated as accessible. They are usually close to the bath house, have easily navigated paths, accessible picnic tables, and often even a raised cooking grill.

While many historic areas and buildings are inaccessible, some places are making an effort to provide alternatives. There are places where ramps just cannot be installed. I don't know any way to get up to the top of a lighthouse without climbing the many steps (which I did many years ago). Hilary did find an accessible 2-story lighthouse in Florida on the internet. They have installed an elevator (lift) to take a small scooter to the second floor. But, for my money, I much prefer the Ponce Inlet Lighthouse below Daytona Beach on Florida's east coast. They have done a lot of work over the years and all outbuildings are ramped and accessible. It's very easy to get around and there is plenty to see.

Even President Roosevelt's cottage on Campobello Island on Canada's Passamaquoddy Bay is only accessible to the first floor. But, they provide a nicely done video for anyone who can't get up to see the second floor. The Welcome Center and beautiful grounds are all accessible. After seeing the movie "Sunrise at Campobello" I wanted to visit the place where FDR got sick with poliomyelitis. I enjoyed it very much!

After many wonderful years of tent camping with our boys, I realized once they were grown that I no longer enjoyed "roughing it." I really needed some "creature comforts." So, while we will be back in Canada again for our vacation this summer, we are already dreaming about another trip to England. Since we can't take our RV with us, we thought we might hire a Campervan in England in order to tour around the beautiful country where we got to spend only a few days. Thanks to Hilary for taking us on a personal tour of the area around Lincoln. Hopefully, we will see more of the UK on our next trip!

Recommended Book: about a Travel Odyssey
"Climbing Kilimanjaro: An African Odyssey" by
Helen Bergan [polio survivor]
[http://www.bioguidepress.com/
climbing_kilimanjaro.htm](http://www.bioguidepress.com/climbing_kilimanjaro.htm)

Recommended Video about FDR
Sunrise at Campobello (1960) copies are often
available on eBay or Amazon.com
arojann@yahoo.com

'Aging with a Disability: The Late Effects of Polio'
September 19th 2003
Oakland Marriott Convention Center
Oakland, California

Hosted by Kaiser Permanente Foundation
Rehabilitation Center/Kaiser Foundation Hospital,
Vallejo, California.

In co-operation with

The San Francisco Bay Area Polio Survivors
The Northern California Rehabilitation Advisory
Board, The KP Aging Network,
The Northern California Diversity Council,
The Institute for Culturally Competent Care,
The KP National Diversity Department

1. Aging with a Disability: Epidemiology, Health Care Services and Health Policy - Fernando Torres-Gil, PhD, Association Dean, Academic Affairs, School of Public Policy and Social Research UCLA.
2. Post-Polio Syndrome: The Provider Perspective - Susan Perlman, MD, Neurological Services, Associate Clinical Professor of Neurology and director of Post-Polio clinic UCLA.
3. Post-Polio Syndrome—The Survivor Perspective - Hilary Hallam, Founder and Chair Lincolnshire Post Polio Network, UK..
4. Research Panel - Tessa Gordon PhD, University of Alberta Neurosciences Center; Spencer Wang, MD, Director Electrodiagnostic Medicine, Kaiser Foundation Rehabilitation Center, Vallejo.
5. Late Effects of Polio: The Evaluation and Management of Respiratory Disorders - Edward Anthony Oppenheimer, MD, FCCP, Pulmonary Medicine, Kaiser Permanente, Los Angeles
6. Late Effects of Polio: Anesthetic Agents and other Medication Considerations and Contraindications - Selma Calmes, MD, Chairperson, Department of Anesthesiology, UCLA School of Medicine
7. Rehabilitation Interventions: Home and Community - Grace R Young, MA, OTR: Susan Watkins, PT, Anna Von Reiche PT, Maggie Randle, SLP, Kaiser Foundation Rehabilitation Center.
8. Rehabilitation Interventions: Vocational Settings - Ana Verran, OTR, Jeffrey Symonds, Project Threshold, Center on Aging and Disability, Rancho Los Amigos Rehabilitation Hospital. Each session has a Discussant to facilitate a Question and Answer Session.

For more information contact:
USA—Phyllis Hartke, President, San Francisco Bay Area Polio Survivors, on Phartke@aol.com
Kaiser Permanente—Cristine.Richards@kp.org
UK—Contact our offices.

Edie Gonzalez

She was a lovely old lass was Aunt Edie
And it fair brings a tear to me eye
'Cos she had such a passion for living
You'd think the last thing she'd do was to die
 She was as fit as a lop was Old Edie
 And was always so kind and polite
 Doing favours and shopping for neighbours
 On the go from morning 'til night
 The sea air, she said, had been good for her health
 She took it in every day in deep breaths
 In fact the folks of the town were so healthy
 The undertaker, poor lad, starved to death
 When she got into her nineties she started to slow
 She always said it would happen one day
 She was put in a wheel chair 'cos her legs were no use
 Well, no use as legs anyway
 But she still got about as best as she could
 There was nothing would hold the lass back
 All her housework was done when the home help arrived
 And she'd even been round with the vac
 She used to bowl herself out and sit at the gate
 Cos she always liked a bit crack
 She would talk to the folks on their way to the shops
 And catch them all on the way back
 She was famous in Amblemouth, Edie
 There was some people one day walking past
 They said "You must be the oldest inhabitant?"
 She says "No, he died the year afore last"
 She was a mine of information was Edie
 She remembered things most would forget
 They'd say "Have you lived here in Amblemouth all of your life?"
 She say's "No love, I haven't. ...not yet!"
 One Monday, at her lunch club, up at the Mem'
 In her wheelchair on account of her knees
 It was Roast lamb and Jersey potatoes
 Mint sauce and a few garden peas
 They had best butter to put on their taters
 She says "ooch, thanks. I'll have some o' that"
 But she dropped some on the brakes of her wheelchair
 She went downhill pretty quick after that
Now after they'd all had their dinners
In come this old bloke in a cap
He took her home in a sitty up ambulance
Just in time for her afternoon nap
 It was just when they'd lifted her out of the bus
 And she was getting her key from her pocket
 Her wheelchair was sat on the path by the gate
 But she flew off down the bank like a rocket
 With her front wheels in the air like a dragster
 Nought to sixty in five seconds flat
 With one hand trying to pull on the brake thing
 And the other hanging on to her hat
 She was heading for the newsagent's window
 And young Norman was washing the sign
 He shouts "Your Peoples Friend isn't in yet"
 "That's okay" she shouts "some other time"

She spat on her hand and slowed down the left wheel
 And she swerved under his ladder with skill
 She shouts "It's a good job I'm not superstitious"
 As she accelerated off down the hill
 There was a tyre mark round the bend by the Pork Shop
 And another up Higgins's cat
 There was a big scrape down the side of the Library van
 And a hedgehog, poor bugger, squashed flat
 She swerved in and out of the traffic
 She was getting good at this cornering lark
 But she still couldn't stop, she went up the grass verge
 Crossed the A1 and into the park
 They found her face down in the duck pond
 And they think she must somehow've flown
 'Cos her wheel chair was stuck in the railings
 She'd done the last fifty yards on her own
 So that's the sad tale of Aunt Edie
 But she wouldn't want her loved ones to weep
 She was thoughtful to the end 'cos at this time of year
 You can get a big bunch of flowers quite cheap

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Web Site: <http://www.toontoons.com>

IF I CAN DO IT, SO CAN YOU

I've been sitting in a wheelchair for more than 30 years,
 And though outside I'm happy, inside I hide the tears.
 When I think about the folk who gripe of things they can't do,
 It brings me to the thought: If I can do it, so can you.
 Of course there's things that I can't do, but a lot more that I can,
 So I try to do those things as well as any other man.
 Like a little smile or a word of cheer to help folk on their way,
 It doesn't cost a cent to say, 'Hi! Have a happy day.'
 For life is what we make it and the lucky ones it seems,
 Are those who face life as it is; though we too have our dreams.
 But we don't look for sympathy, so we're ahead by miles,
 Although not rich in money, we're millionaires in smiles.
 The birds, the sunshine, rain and flowers belong to everyone,
 At time we take for granted the things that God has done.
 So do with pride what you can do and you'll find, every day,
 No matter how hard pressed you are, with will you'll find a way.
 For regardless of what handicap we're saddled with, it's true,
 Just stop and realise that your main handicap is you.
 For you can laugh and you can smile, just the same as me,
 So share these gifts with others and pretty soon you will agree.
 That it's great to be a giver, so give... and give again,
 Give your love and give your smiles, give anything you can.
 For in every cloudy sky, you're sure to find that patch of blue,
 And I know it... so come on now, let's show it, if I can do it, so can you.
 Think it over, you know it's true,
 If I can do it, so can you.

Written and recorded by Colin James on his album, *Save Another Day*.
 Reprinted by kind permission of Yeldah Music.

Both items are with permission and from Polio Survivor Viola Pahl's forthcoming 8th book
 How to be Incompatible and Love it
 [Especially if Grandpa has Income and Granny is Patible} viola@pahl.ca—or write a letter via us.

HINTS, TIPS AND BITS FROM POLIO SURVIVORS.

From Debbie

I am 52, and I can still walk. I use a cane most the time, or crutches when I get really dragged out. I have good days and bad days. On my good days, I am no where near what I used to be as far as energy and strength.

You have to stop thinking that you can do more now because you are not working. You can only do so much. My doctor explains it to me this way. You get \$10.00 of energy per day, it's all up to you how you spend it. I used to have tons of energy, I couldn't sit still for anything. Now I do more sitting then anything.

Sweetie don't feel guilty about the SSD [American Benefits], you deserve it. We all know, that we would all be working if we could. God knows we could make a lot more money then what SSD pays. Just think of it as this is YOUR time in life, to finally relax.

I make small goals every day for myself. Small projects I know I can usually accomplish. Sometimes it take me two days. I never set my sights higher then my ability. Or I should honestly say, I rarely set my sights too high. The trick is to pace and rest, that way you can keep an even amount of energy going. You must avoid exhaustion and pushing yourself beyond your limits, as this will suck the energy out of you for the next couple days.

Every morning when you wake up, just stretch and say, I'm on vacation today, I can relax and be lazy. This is my time in life to just slow down and notice all the things I was to busy to notice when I worked.

We have conditioned ourselves that we have to do all these things, but we really don't. It's a matter of changing your thinking. Changing your priorities in a day. I know that isn't an easy task to do, but it's not impossible. Just take a deep breath every time you start to feel yourself working up into that "work" mode, and tell yourself "I'm on vacation now, I don't have to rush anymore"

From Mary Ellen

I know many of you claim you wouldn't have done anything differently if you had know PPS was coming...but I think awareness is better than naivity. If we had known to recognize the first PPS signs, perhaps we would be in better physical condition today.

From Dianne Sandau

Mary Ellen, if I would have known I would have done a lot of things differently. Save money while I was working is the one big thing I would have done. I banked on having 10 more years of working to save for my retirement. But that was taken away from me, so here I sit, NO retirement. I make do with what I can. Of coarse no sense crying over what isn't, but I can tell you I was pretty angry at first.

I'm fortunate that I worked desk jobs. That was a blessing in disguise for me. I would have made preparations earlier in life. I would have been more conscious of my weight, instead I just let it get out of control. I just figured I'd exercise it off when I was ready, not realizing that I would not be able to vigorously exercise anymore.

I don't know if I would have stopped going to sport games, however. That was always a lot of walking, and of course I can no longer walk that far, or I should say I don't want to push it anymore. I think even if I knew, I would have continued to go just as I did, but I may have tried to be a bit more conservative.

If I would have known however, I may have taken a few more trips while I could walk. I have places I wanted to see that are not accessible, that now I can't. However I am grateful for being able to go to the places I did get to go.

I feel PPS has changed me quite a bit. In a spiritual way it has been a positive change. In the physical way it has been a negative change.

I used to jog, and take steps two at a time. Now I can't even walk fast, and I struggle to get up one flight of stairs. So my physical ability has decreased tremendously.

Having the decrease in physical ability, has caused my life to slow down considerably and I had a chance to look at things differently. I had time to connect with myself more spiritually.

Even though I am more at peace with myself then I have ever been in my life, I still miss being physically able. But I think I have accepted my disability, and feel I am adjusting fine. I look at my life and acknowledge and be thankful for what I can still do, and try not to worry about what I can no longer do.

The invisible part is the worst. NOBODY can understand what we go through except another with the same problem. I gave up trying to explain even to my family because they just don't get it.

From Linda....

I know Dave has just decided that certain chores are now his responsibility. But if I get them done that day then he gets a break. So a lot of the adjustment comes from changing what chores we think we polios still must do ourselves. Example: After my siege last fall Dave kept the chore of emptying the dishwasher and expects to have to do that nightly when he cleans up the dinner dishes. But if I feel up to it I do that now so he gets a bit of a break. Seems to work well for us.

From Mary Hemby

I was planting six tiny cacti in concrete pots - holding onto my cane with my left hand, and troweling them into little holes I'd cleared.

Several differnt neighbors yelled over "glad to see you're feeling better. " Now who the h-ll told them THAT? It took me an hour with a cup of tea and my feet up to get back to where I started!

From LaVonne Schoneman, How to Cope books

An AIR HORN is a good thing. About 5 years ago my husband got one and some other joke things attached to a cane and hat (his son and grandson thought he was getting so old...)

Well, I absconded with the LOUD!, RAUCOUS!! horn (like for a kid's trike) and put it under my wheelchair to toot when I really need him and my voice won't carry (he spent a lifetime around jet engines and can't hear some sounds or tones now). This really gets his attention and means "I need your help NOW!"

It always works and is only used for emergencies. This TOOTING SOUND even penetrates when he wears his beloved radio headphones to listen to the talk radio shows I hate. Works for us.

From Sandi...

The worst experiences I had with medical personnel was during 2000 when it was not unusual to go to ER 3 times a month. Sometimes I would be admitted, but most times I was just released from ER. The frustrating part was each time I went there, I had to reteach intern and other medical person about PPS. I didn't break my legs. I didn't injure my back. The pain of laying flat wasn't due to any type of injury just experienced. My dearest hubby became quite an expert on me and PPS. He made sure that I was kept very warm and relieved of all the pain. Once the medical personnel realized that, my interaction with them went much better. But, it became more dangerous to go to ER than to stay home.

By the Way, I keep a one page sheet of the important stuff like my Doc's info, my family and phone numbers. I also listed all surgeries, all injuries, all illness and all medications. That one sheet of white bond made my life so much easier. It has now become a 2 page info sheet explaining what I will and will not allow. I explain briefly possible scenarios and what I must have done in conjunction with PPS. With a living will, I know that my husband and family already know what I need.

I also contacted my local Fire Dept to find out if they have a program where I can send them my information and they can store it in their database or something so that if I should need them (911 Emergency) again and no one else was here, they would have it. In addition, I needed to let them know that I have a service dog in the house and that should I be transported in an ambulance, they should contact the people I listed to come and properly care for my dog from ER where the dog will be unless my condition is too critical.

Fortunately, I found out that our local Fire Department along with others in my area have a program whereby they sent me a large pill container with a special decal on it and an decal to put on the refig. door. The pill container is to be fill with medical instructions for me and info about my service dog. The decal is to be put on the door of the refrigerator and the medical info container is to be kept on the shelves. I was really glad about that because I had already had an episode where ER came here and my blood pressure was dropping very fast. Since I had this happen before, as it started dropping I was smart enough to call 911 but by the time they got here, my b/p had dropped to the point that I simply couldn't answer them back. Fortunately again for me I had called my husband (night time driver) and told him what I was doing. However, he would get home long after I was gone. He called the Fire Department and told them what I was going through and what to do.

Other places I have this paper is in my glove box, my wallet, my picture wallet, my folder and other various places and in thing I might have or be. I have lots of them in a folder so that hopefully, someone will look into because I always have them in the folder because where I go so do my dog and folder.

Thankfully, when I have had to use them such as at the hospital outpatient department, other doctor's office, etc. I don't have to keep answering all those questions over and over again,

**Congratulations to Lynn Singleton & family
On the birth of her first grandchild
Hannah Joy.**

Report on Neuro Alliance Meeting

On May 13th I attended a Neurological Alliance Members Meeting at The Glaxo Neurological Centre in Liverpool, as a representative for Lincolnshire Post Polio Network. This meeting was held to disseminate information about the progress made by the Alliance since it was set up over 10 years ago. I was a little surprised to find that not many other polio survivors, if any, were in attendance. However, because of this I felt it was even more important to take notes and to come away with some information which I could feed back to LincPIN and its members.

The meeting was attended by a mixture of people managing conditions, voluntary groups, G.P.'s, carers and others involved at various levels of health management. A sizeable portion of the meeting was taken up by a report from Diana Whitworth who is the Chair of The External Reference Group (ERG) for the National Service Framework for Long-term conditions focusing on Neurological conditions and Brain and Spinal Injuries. The Framework is a government strategy generated by the Ministry of Health (with consultation) for monitoring and treating a range of neurological conditions in a modern health service. Diana stated that many different groups had been consulted in the process of devising the strategy, and in her role had attempted to make those groups as representative as possible of the wide variety of needs and issues around managing long-term neurological conditions. She emphasised that she was confident the ERG report was comprehensive, but that its *implementation* could prove to be the most difficult task of the ERG's work.

Comments and questions were invited from the floor, and one of the key issues which came up was how the mental health of those who are managing a physical impairment was dealt with by health professionals. There were no easy answers to any of the questions, but it was interesting to hear what some of the issues were and how they were being presented to government by the ERG.

This was followed by an update by Maureen Kelly, Chair of the Neurological Alliance. Maureen reported that several new Alliances were being formed around England and a new North West Alliance had recently formed and is planning to hold a North West Forum in October 2003 (date to be determined). This Alliance has

members in Lancaster and Morecambe, (where I also live) and I was given the name of a local contact who I am hoping to meet shortly. When I do I hope to make some contact with both polio survivors and others managing a variety of neurologically related conditions and will be happy to report an update then. This is an exciting development for me, as I do not know many other people in my area who are managing post-polio conditions, and I rely a lot on the dissemination of information from places like LincPIN and from friends I have on the internet. I feel that I have something to offer to a local group and I will be happy to report further developments as they happen.

The welcome at Liverpool Glaxo Neurological Centre was friendly and warm, and the building is open planned and was purpose built for the use of people managing a range of neurological conditions and their families. It was a very refreshing experience to walk (with the aid of my crutches) into a disabled friendly environment, with wide entrances and colour coding in the toilets to aid those with a sight impairment. It was obvious that a lot of thought had been put into its design. It has extensive Meeting and Conference Facilities, and plans to put a map of its whereabouts on to its website (which should make it a lot easier to find!)

Their web address:

<http://www.glaxocentre.merseyside.org/>

Their phone number, if you're not on the web, is: 0151298 2999.

Contact them if you want to know if there is a local neurological alliances in your area. We know meetings are taking place in a number of areas with a view to starting alliances. You will be surprised—we are all saying virtually the same thing.

If you are in my area of the country then email me or contact the office by phone or letter to pass on your contact details.

Mary Kinane - Lancaster

marykinane@marykinane.free-online.co.uk

NEW BOOK IN OUR LIBRARY.
The Association
of British Pharmaceuticals Industry
have sent us a free copy of their very
comprehensive new
Medicine Compendium

**LINCOLNSHIRE POST POLIO NETWORK
ANNUAL GENERAL MEETING
SATURDAY 11TH OCTOBER 2003
ANCASTER DAY CENTRE, BOUNDARY STREET, LINCOLN
[Boundary Street is on the A1434 - South Lincoln]**

Room opens at 10.00 a.m. - AGM will commence promptly at 10.30

**Nominations for posts of
Chair, Vice Chair, Secretary, Membership Secretary,
Treasurer, and Committee Members
Are requested
Please complete sheet enclosed.**

**The AGM will be followed by
Coffee for Polio Survivors in the main room,
family members and friends in another room.
Discussions will be led on 'How PPS has affected our lives'.**

Buffet Lunch 12.30 p.m.

**Afternoon Session 1.30 - 5.00
with break for tea and raffle.**

Speakers

**From the U.S.A.—Aaron Mattes, MS RKT LMT
The Benefits of Active and Assisted Isolated Stretching
Demonstration including 'Join in, if you want to, from your chair session'
and**

**Dr. Ali Arshad, Consultant in Rehabilitation,
Multi-Disciplinary Clinic,
Haywood Hospital, Burslem, Stoke on Trent, Staffordshire.
The benefits of a multi disciplinary care plan**

**Tickets AGM only FREE
Full Day with lunch £10.00 - £7.00 with no lunch.**

**Join us both Friday and Saturday nights in the
Bar of the IBIS Hotel, Lincoln.**

**Share info, share laughs, network, enjoy.
IBIS HOTEL**

**TEL 01522 698333—Mention LincsPPN when you book.
£29.95 per room—continental breakfast extra.
Snacks served—Take-Aways can be ordered.
Full meal service at Pride of Lincoln next door
Also Frankie & Bennie's Italian Eatery next to that.**

**CONTACT US IF YOU ARE INTERESTED IN SHARING A ROOM
OR SHARING TRANSPORT**

BRUNO PULLS OUT JULY 12TH TELFORD CONFERENCE CANCELLED

Statement from Simon Lawrence and Peter Ruberry (Co-organisers).

It is with deep regret that we have to announce the cancellation of the Conference co-organised and co-sponsored by the 25% ME Group and Shropshire & Wrekin ME Support. An email from Richard Bruno on Friday 6th June stated that according to his Senator, who happens to be on the Senate Intelligence Committee "New warnings will be issued regarding our Independence Day - July 4th - and the weeks afterwards, specifically regarding attacks on historic sites and air transport". He goes on to declare that he has no intention of flying under these circumstances. He did offer "I can provide my slides in PowerPoint format or other materials if they would be useful. Maybe {another speaker} could talk on PPS using my slides?"

According to another paragraph he quotes his publisher Time Warner PR people, "After all of these months neither they {nor I} have found one person in the UK media who is interested in the Conference. The Polio Paradox, ME or PPS." This is not correct, as he is aware that arrangements have already been made with Radio Shropshire to carry an in-depth interview with Dr. Bruno via a live link from London in the week before the Conference.

Following their AGM on Saturday June 7th Shropshire & Wrekin ME Support's Committee of Trustees met to discuss the implications of this bombshell. A range of alternative strategies was discussed, including Bruno's presentation on video, on PowerPoint with taped commentary, live conference link and inviting other speakers to participate. All such suggestions were ruled out on grounds of cost, the short time scale and inability to guarantee top quality presentations. But the overwhelming feeling was that morally and legally such changes would constitute a breach of promise to those who have booked tickets in good faith to see Prof. Bruno in person. Such a move would require us to offer refunds to all concerned and invite applications on a new prospectus. Lack of confidence in our organisation could well result in so many withdrawals as to make the venture financially unviable. It was therefore decided that we had no option but to cut our losses and cancel the Shropshire Conference immediately.

Betty Dowsett and Simon Lawrence were immediately informed of this decision. Both agreed that unfortunately this is our only viable option. Inevitably we shall have to live with the **heavy financial loss** and considerable wastage of manpower resources we have already devoted to this venture, which we believed was a vitally important event. This announcement will be posted as widely and as soon as possible, and all who have purchased tickets or made applications will receive a personal letter and refund cheques as soon as possible. Thank you all for your support and good wishes, which has kept us going over the last six months.

We regret the disappointment and upset to all concerned, who were looking upon this as an opportunity to learn and disseminate the truth about rehabilitation for sufferers of ME and PPS. WE have all been badly let down by factors outside our control.

Is this yet more collateral damage from Gulf War II? or is there a hidden agenda?

Yours in sorrow, Simon Lawrence and Peter Ruberry.

The Lincolnshire Post-Polio Network have been in contact with Simon, Peter and Dr. Dowsett and expressed our sorrow that the Conference has been cancelled. An out of Conference meeting had been arranged with Richard Bruno by the Scottish Post Polio Network which we and other Polio and Post Polio group members were attending. We were booking into the same hotels to facilitate further get-togethers, and arranging meetings with ME and other similar condition groups attending.

The Cancellation of this Conference has given all groups even more impetus to work together, swap newsletters, and those not already part of local or national neurological alliances to join. The symptoms and problems of those with neurological conditions overlap to such a large degree that

Together We Will Become Stronger and Stronger