



# The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**  
Volume 5 - Issue 3 — April 2005

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



## SHANG-HAI MOBILITY!

After Xian, a short flight to Shanghai, a modern bustling city with modern skyscrapers on the one hand, and tiny shacks for some of the residents on the other.

*Alan Russell visits China  
in*

*TRAVELS WITH A WHEELCHAIR—Page 21*

## LONE RANGERS FIRST KISS

As readers of the Herald American adventure strip know very well, the Lone Ranger, masked avenger of the plains., doesn't go round kissing girls. He is far too busy foiling rustlers for that sort of thing. But today at Mercy Hospital star of International Amphitheatre rodeo made an exception. He couldn't resist a smooth with Ellen.

*Ellen—Our Texas One Arm Bandit*



*Happy 100th Birthday  
30th March 2005*

*to*

*Bessie "Gertrude" Brooks  
of Vicksburg, Mississippi, U.S.A.*

**97 years a Polio Survivor!**



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

**Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177**

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### WE WOULD LIKE TO THANK THE FOLLOWING FOR DONATIONS RECEIVED TOWARDS OUR WORK.

Ewan Peddie, Jenny Rayner, Sylvia Fortune, XX Lightfoot, Jennie Paulger,  
Mrs. B. Bowles, L Wood, W.K.Turpin, Michael Fisher, Kay Preece,  
Yvonne Grosse, Yvonne Webb, Raymond Owen, Angela Johnson,  
Bob Price, Helga Dale, Sherrye Parr,  
Sheila Dunnett, Denise Carlyle, Hilary Hallam, Mary Kinane, Robin Butler and Di Newman.

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**  
**UK Membership** - Life Member (LM) £150 or £5 x 30 months S.O. - Member £10 a year.  
All UK Memberships payable by Standing Order - Forms from Membership Secretary.

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**European Membership** - LM E300 - Member E25 a year.

**USA** - LM US\$375, Member US\$25 a year - **Canada** - LM C\$550, Member C\$40 a year  
Other Countries please contact membership@lincolnshirepostpolio.org.uk for details.

#### Next LincPIN Newsletter - June 2005

Articles for publication 15th May by post or - newsletter@lincolnshirepostpolio.org.uk

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# Editorial

This is Issue Number 51 and I would like to thank Ellen for stepping in and providing the content of the last newsletter. Ellen prepared more on similar lines and we will be using that in the months to come. Thank you to other PPS friends and the rest of the Committee and Operations Team who have been there for me whilst we have coped with the side effects from drugs/and side effects from the drugs for those side effects!!! given to Richard. I am pleased to report that he is now off these drugs and on the mend.

Remember that polio survivors often tolerate much lower doses of many drugs and Richard and I are now taking the advice given to the members of the Parkinson's Support Group in Sarasota by Dr. J Terry Petrella, Neurologist.

Non-emergency.

- \* Never start more than one drug at a time.
- \* Always check with your Pharmacist before taking any new drug. If you are taking any other drugs or vitamins that are not on his computer then give him/her this information.
- \* Discuss with the prescriber your starting on a quarter of the lowest dose and increase schedule if you do not get any side effects from the drug or detrimental change in your condition.
- \* Likewise if told to stop taking a drug discuss a reducing schedule rather than stopping it immediately—unless there is a reason for this.

Emergency

- \* Carry copies of a CARD; detailing your medical conditions, drugs and vitamin schedules, allergies, intolerances, past reactions and contact information for all your health providers, with you.
- \* If you or someone who is with you are unsure about treatment being offered then be polite but say so and why and ask for more information.

REMINDER

**Ninth International Conference on  
Post Polio Health and  
Ventilator Assisted Living:  
Strategies for Living Well  
Saint Louis, Missouri, USA.  
June 2nd, 3rd and 4th 2005**

## **HOW SELF ASSESSMENT CAN HELP YOU IN OBTAINING BETTER CARE FROM HEALTH PROFESSIONALS**

Hilary Hallam  
Denise Carlyle, BA, MA, PhD, LRAM  
Mary Kinane, BA, PGCE  
Lincolnshire Post-Polio Network, Lincolnshire,

Jann Hartman is a Life Member and was a speaker at an AGM a few years ago.

## **EATING BETTER FOR BETTER HEALTH WITH YOUR FAMILY AND FRIENDS**

and

## **SCOOTERS AND POWER CHAIRS**

### **The Care and Feeding of a Scooter or Power Chair**

John and Jann Hartman - Baltimore, Maryland

Members Phyllis Hartke and Stella Cade with three colleagues from the San Francisco Bay Area PPS Group are attending. Anyone else attending please let us know as there are often SIX options to choose from. We would like to report back on as much of the Conference as we can. A few of the other subjects are:-

- \* Anaesthesia precautions for people with neurological conditions.
- \* Integrative medicine approach to Post-Polio Syndrome Management in Practice.
- \* Assistance from Allied Health Professionals:-
- \* Falling: Fear, Risks, and Practical Strategies
- \* What OT's and PT's can (and can't) do for Polio Survivors.
- \* The Right Ventilation at the Right Time
- \* Analyzing your gait: The roles of exercise, bracing or surgery.
- \* Research1: What is being done? What needs to be done?
- \* Solutions for overuse and disuse weakness
- \* Analyzing Your Sleep. Is it Apnea, Hypoventilation.. Or Both.. Or Something Else?
- \* Spinal Bracing & New Technology in lower extremity orthotics.
- \* Exercise—Part 1, A Debate about the Debate and Part II, What Steps to Take.

More info:-[www.post-polio.org/conf9th/prog.html](http://www.post-polio.org/conf9th/prog.html)

# Message from the Chair

"Hello everyone,

Welcome to edition no 51. We hope the collection of snippets from former articles printed in the last newsletter was helpful and informative. I certainly found it to be so, and thank Ellen Riddle again for her unique contribution to the LincPIN.

We continue to seek positive solutions to keeping the organisation afloat and addressing issues relevant to our members. Our able Treasurer Denise Carlyle is addressing you all with important questions regarding membership which will determine the direction of the newsletter in the future. I urge you to respond in any way you can to this questionnaire and send it back to us so that we have an idea of what our members really want.

This month (April) sees the beginning of Mental Health Week (27th March - April 2nd) and MIND, being England & Wales' biggest mental health charity, is sponsoring a series of events and web-based publications of interest to all who have concerns around good mental health. This is an area which we don't always associate directly with being polio survivors, but were we to monitor anecdotal evidence more closely, we might find that a substantial proportion of polio survivors have had dealings with the mental health system in one way or another. The use of anti-depressant drugs is one example of the PPS'ers quest for solutions to the manifold problems experienced as a polio survivor in today's world. We take the view that individuals are best suited to make informed decisions around managing PPS and associated symptoms (assuming good information is available) and we DO NOT make any judgements about those decisions. Unfortunately, all too often users of anti-depressant prescription medicines do not have the full choice to exercise decision-making in this area, and anti-depressant drugs can be over-prescribed for our group. We encourage our readers to read the article and to visit the websites quoted at the end.

It is with sadness that we have to tell you of the death of member, Gerald Perkin of Surrey. Our condolences to his family and friends.

We wish all our readers and their friends and families good mental health and continue in our endeavours to provide up-to-date and thought-provoking articles on topics relevant to polio survivors.

Best wishes  
Mary Kinane. Chair  
[mary.kinane@lincolnshirepostpolio.org.uk](mailto:mary.kinane@lincolnshirepostpolio.org.uk)

# Treasurer's Thoughts March 2005

## Your support.

*giftaid it*

Your generosity continues. In the first six months of this financial year, donations came to over £800. Over 65 of our members have now completed Gift Aid Declarations. Once again Jenni Paulger will complete the necessary forms to reclaim tax through the Inland Revenue.

Gift Aid provides a great opportunity for all our members to increase the value of their donations to LincsPPN. The only people who should not return a form are those who pay no tax, or always give through a scheme, such as CAF, where tax has already been reclaimed. If you give £10, covered by a declaration, the taxman will add £2.80, making your gift worth £12.80. If you have not already done so, please fill in a form. Completing a form is *not* a promise to give to LPPN, but it allows us to increase the value of anything you do give us in the future.

## Fundraising.

We were unsuccessful in our bid for Section 64 funding for 2005 despite the many hours it took to compile the application. We will continue to pursue alternative options. If you would like to assist us in future funding bids, have any suggestions of sources of funding, or could offer a few hours a month, we would welcome your help.

## Jenni Paulger.

Our previous treasurer Jenni Paulger will soon be off to live in sunnier climes and will no longer be able to continue in her role as independent examiner of our accounts after the summer of 2005. We are very grateful to her and wish to thank her for all her hard work over the past few years. We wish her well in her new life.

This means we are seeking someone to help with the independent examining of the annual accounts. If anyone out there has accounting qualifications and would like to know further what this task entails, I would be glad to hear from them.

I would welcome any suggestions/comments you might like to make. You can contact me via email:

denise.carlyle@lincolnshirepostpolio.org.uk  
Denise Carlyle.

## Front page story—Happy 100th Birthday

Bessie "Gertrude" Brooks of Vicksburg, Mississippi, USA, just celebrated her 100th birthday. Hitting the centenarian mark is quite a feat for anyone, but even more so for a survivor of Polio (once called Infantile Paralysis). Bessie, who was born March 30, 1905, got polio when she was 3 years old. She married, and went on to have 7 children (all by natural childbirth according to her grand-daughter, Karen in California). Unfortunately, her husband died when the children were still young, so she raised them by herself. Karen's mother and her Aunt Vi have been the primary caretakers for this wonderful woman. Many others visit and take good care of their Mamaw, as they lovingly call their grandmother.

As far as anyone can discover, Bessie, is the oldest living Polio survivor. There was a report of a Mr. Remaley from Pennsylvania, who was born in 1904. Even if he is still among us, Bessie could still be the oldest woman who survived Poliomyelitis. That is quite an accomplishment! I'm looking forward to the next year when Bessie will celebrate 101 years. As one doctor from South Africa said in an email message to Bessie: "Happy Birthday, Bessie! May you have as many more birthdays as you desire."

Written by Life Member Jann Hartman, Baltimore, MD, USA—arojann@yahoo.com  
Polio, 1953 and living with PPS since about 1985

### *Center for Enablement*

In October 2002, after talking to people at the LincsPPN AGM, I asked my doctor to make an appointment for me at the Centre for Enablement at the Nuffield Hospital in Oxford. He had never heard of it but being a forward thinking man he agreed to write to them. Even the name gave me a boost. ENABLEMENT not DISABLEMENT.

The appointment came through for November 2002 for me to see a Professor Wade. It's a reasonable journey from where we live in Kent to Oxford and we arrived early. As soon as we walked through the doors we received our first shock. No dinghy waiting room with people rushing about making you feel as though you shouldn't be there, no awkward steps and doors to negotiate and no queue to see the receptionist. Were we really in a clinic? There was a wide hall with plenty of room and lots of comfortable but easy to get out of chairs, all door handles and light switches were set at a sensible height for wheelchair users; even the receptionist's desk was quite accessible.

I gave my name and the first thing they asked was whether we would like tea or coffee, milk and sugar. We couldn't believe our ears. Had we wandered into the foyer of some expensive hotel by mistake? No. This was definitely the clinic. We hadn't even finished our tea when a man walking past asked if I was Robin. He was Professor Wade the man I had come to see. Complete with cups of tea we went into his office and he went through my Polio history.

I was having trouble with my feet becoming numb if I stood for any length of time but after an examination Prof Wade was of the opinion that this was not caused by

my Polio at all but by the narrowing of the canal in my spine. He told me there was an operation I could have to correct this or a drug called Neurontin I could try. We came home very pleased with our progress and waited for our next appointment to come through.

Unfortunately the Neurontin did not work with me and I had some very unpleasant side affects but that is another story.

Our second appointment came through for March 2003. We knew what to expect this time, we thought. The same format. Welcome by the receptionist and cups of tea all round then we were whisked off upstairs to an office. My wife couldn't understand why the notice on the door said Speech Therapist. I don't have trouble with my speech. I joked and asked if they were going to try and teach me French. A little confusion ensued but it ended up with us all having a laugh. The therapist had collected the wrong patient from the reception. She said she thought my speech had improved a lot. More like a miracle.

We saw Jan Keating the Occupational Therapist who asked a lot of questions about how I managed at home. As I cannot lift my arms above waist height without supporting one arm with the other this makes eating very tiring. Two boiled eggs can wear me out. A wheeled glide-about chair with an attachment to support the arm was tried out and seemed successful as was the neck cushion that could be used in many ways especially in conjunction with the lap tray to support a book.

I was then passed on to the wheelchair department where I was able to try out various scooters for the first time. Since then we have purchased a scooter that we are able to fit into the car and it has proved invaluable. There was a room where I was given advice on computers and even a lady who advised us on gardening tools. Nothing was too much trouble. Whatever problem I asked about there was some-one who could come up with a suggestion.

When we returned to the reception there was the chair, arm support, neck cushion and lap tray all waiting to be loaded into the car. We couldn't believe our eyes. After years of having to fight for every little thing the NHS was showering us with equipment. My wife had been carefully making drawings of the cushion and the tray so that she could make something similar and we were going to inquire where we could get the chair but there it all was. All provided.

Since then we have had a home visit from Jan Keating to make sure that everything was working OK and to iron out any other problems we might be having. She even came up with an idea to make fastening the waist band of my trousers a bit easier. Sadly she has now left the department but the rest of the team are still there providing their excellent service.

Nuffield Orthopaedic Centre, NHS Trust,  
Posture, Independence and Mobility Service, Oxford Centre for Enablement,  
Oxford, OX3 7LD. Telephone: 01865 227600

Robin Butler - Membership Secretary.  
membership@lincolnshirepostpolio.org.uk

## *Wheelchair Upgrade, Assessment and Mobility Centers and Hoist*

I needed to upgrade my powerchair from a Phoenix Invacare to one which would lift me up to reach high shelves, and also tilt-in-space to relieve pressure. I called my local wheelchair supplier and he brought a couple of models to my house to try out. I had to immediately discount the one which also fully reclined as it was much too big and heavy to hoist into my car. The other one was the Invacare Spectra Plus. I gave it a little run up and down the road and it felt comfortable. It had all the bells and whistles I needed, but I was reluctant to part with a lot of money without having more choice. So I thanked the salesman and said I would think about it.

I had chosen my original chair after a full assessment at the Queen Elizabeth Banstead Mobility Centre, Damson Way, Orchard Hill, Queen Mary's Avenue, Carshalton, Surrey M5 4NR (Tel: 020 8770 1151, Fax: 020 8770 1211).

In view of the several thousand pounds I would be spending I considered that another £75 was worth it for a second assessment. To the delight of my supplier, the assessor and I agreed that this particular model was indeed the right choice for me.

Because I needed the chair urgently, my supplier phoned the centre to get the specification rather than waiting several weeks for the report to come through, and he came to me the following week for another trial with the chair. We spent a long time getting the exact requirements and he will also fit the necessary brackets so that my hoist will lift it into my Renault Kangoo. I hope to take delivery in a week or so, and it's costing £4,600. By the way, he advised against fitting front and rear lights, as did the assessor, because they are expensive, easily broken and a good torch or lamp on my lap would do the job just as well. I don't intend using the wheelchair on the road or at night unless absolutely essential.

By the way, I am delighted with my new Kangoo - it is automatic, has power steering, and has double doors at the back so that I can open it easily. However, it had to be ordered specially from France as no-one in this country stocks this model, only the hatchback version which would be impossible for me to open.

I can thoroughly recommend my mobility firm to anyone who lives near them - they are TechMobility (Sussex), Unit 4, Crosspost Industrial Park, Bolney, West Sussex RH17 5QU, Tel 01444 882233 [sales@techmobility.info](mailto:sales@techmobility.info) They are most friendly and helpful, and their Maxi-hoist is brilliant. They supplied and fitted armrests which have made such a difference to my comfort now that my arms are losing strength. They also fitted a reversing aid for me as I find it difficult to squint out of the back window now, and the wheelchair partly block the view anyway.

Member Anne Wood  
Anne <poglet@beeb.net>

## *Babysitting with PPS*

For the past 16 months I've been babysitting my grand daughter, who was one on Dec 24, 2004 and my grandson, who was born Dec 22, 2004... Whewwww, I hear you say. I thought maybe we could swap tips on how we manage this.

I started early on teaching Katie to do small things for me to save my energy. She began walking at 10½ months. I started out by making a game of putting her toys away and now she does it all on her own just by my asking. She also will throw the little fella's diaper in the trash, pick up his pacifier and give it to him and put his bottle back in his mouth if it should slip out. She's started bouncing him very gently in his bouncer seat and getting me his diapers, powder, and baby wipes. She loves to help her Grammy.

It took some doing but I now have them on a schedule where they both nap at the same time, her naps consist of 3 to 3½ hours and his are approximately 2½ hours in duration. This allows Grammy to nap also and re-energize. I keep all their items within my or Katie's reach so as to save much energy during the day.

I have a step stool with three steps on it and only have to hold Katie's hand and she can get in and out of her crib on her own for naps. She has a baby doll she just loves and will go get her baby and go to the bedroom door when she is ready to nap on her own and actually gets all excited about nap time. Stomps her little feet and laughs, which is something I've never seen before and I've raised 4 youngins. I started out by telling her to get her baby and she'd look till she found her.

I've also taught her to go up and down steps on her own so I don't have to help her when going outside to play. Am in the process of having a fence put up attached to the porch so she can push the storm door open and go outside and come back in when she wants to. She just loves being outside. Most of her drinks and her lunch are on the lower shelf of the fridge and she gets them by herself and crawls into her high chair, (again have a small step stool there) leaving me only to have to put the tray on it. She also puts her own bib on as it's one that pulls over her head.

She has been a very easy child to deal with as we say "Yeah, Katie" and clap and get all excited when she does these things. Making a game of daily activities has made my life much easier, and she wants to do things.

As for her little brother, when watching a small baby one of those battery operated swings is a God send. Their Mom puts him in it in the morning and it is only 2 ft from the floor, with the tray lifting up it's very easy to put him on the floor and to re position him back in it. Again he's an exceptionally happy baby, as she's always been. And since he's only 3 months he sleeps most of the time, so far.

Guess the best advice I can give anyone with PPS caring for small children is to look at every aspect of each thing needing doing separately and to always utilize compensatory techniques to preserve energy, just as we do for ourselves, but in easier steps for our grand babies.

Member Sue Kearnes, Pennsylvania SEKEARNES@aol.com

# *Freeze that person, problem or worry out of your life!*

From the Texas one armed bandit.. Member Ellen Riddle [Elmari@lonellen.com](mailto:Elmari@lonellen.com)

It happens to all of us. One thing goes wrong, then another and along with dealing with the challenges of PPS we quickly reach the boiling point. What can be even more frustrating is our ability to speak up and handle things in a very positive, productive way seems to be leaving us when we seem to need it most.

As anger and frustration builds up within us it affects not only our mood, but now can increase our already increasing fatigue levels, rob of us saved energy tokens, and snowball into other unwanted problems.

Getting so upset and staying so is fast becoming a thing to be avoided.. it falls under avoiding stress which will pull us downward with our pps problems.

So it is that I have dusted off a very effective symbolic way to get rid of these feelings that simply have lost any positive results they may have once provided.

When someone (from a near by person to one of those so very irritating bureaucratic pencil pushers making decisions that affect either my life or that of someone I care deeply about); an event (something I have no control over and feel helplessly caught up in), or just a culmination of small things growing into an mountain I once again take steps to freeze them out of my life.

Its really quite simple to do and surprisingly effective. I take a small piece of paper and write down the name, event, or group that is causing me so much turmoil and frustration.

I fold this up to fit into a small medicine vial. I fill this with water and place it into my freezer. As I do the last step I tell the person, event, group, whatever, that I've had it and they are now going to be frozen out of my life. As I slam the door shut (sometimes when my emotions are high enough) I say it out loud..... so and so you are now frozen out of my life.. and then I let the freezer worry about all of it.

If the person or problem persists to be bothersome it may take two or three freezings, but trust me eventually it does work!

It works in that once I do the above I am able to let go of the wasted emotions I've been investing in the person or problem. Sometimes this clears the way for a real solution to pop forward, other times it simply helps me accept the part of the Serenity prayer that is the most difficult.. accepting the things I can't change. And, magically at other times within a very short time of freezing it out of my life things change.. the person is no longer irritating, the problem will literally solve itself, the mountain sinks back into the sea. Once again I can sit back and enjoy the sea that is now so deliciously calm.

You could always add a little fruit juice or flavouring and sell them as popsicles 😊

**A blind man**, deaf man and a lame man went on a pilgrimage to a healing spring.

The blind man washed his eyes with water from the spring and exclaimed "I can see! I can see!"

The deaf man washed his ears with the spring water and exclaimed "I can hear! I can hear!"

The lame man drove his wheelchair into the water and out the other side, yelling "I got new tires!"

**A paraplegic man** who was having some problems with his bowel program went to his doctor for some help. His doc told him that he had to drink warm water with Epsom salts one hour before breakfast. At the end of a week he returned and the doctor asked if he was feeling better.

The man said that he actually felt worse.

"Did you drink warm salt water an hour before breakfast each day?" the doctor asked.

"No," replied the man sombrely, letting out a sigh. "I could only manage about 15 minutes!"

**There's a deaf guy** who became a scuba diving geologist. He works with two deaf friends and they get a lot done at their dive sites as they can communicate easily under water with sign language. He has made it his business to measure the relative sizes of the rises, drops, cavities and undulations of coral formations. Of course this can only be done in the summer months so he takes the winters off to avoid the frigid air.

You may tag him as  
a frost-free reef ridge rater.

**Sara was having trouble** with her power chair. She called her tech, Old Charlie. Old Charlie had been a wheelchair repairman for 35 years and was only two years from retirement. He had seen it all and wasn't impressed or dismayed by much.

"Thank goodness you're there. How long will it take you to fix it?"

Now Charlie had had nothing more than the sketchiest description of the problem but he replied without hesitation, "Oh, about 15 minutes."

"Great!" replied Sara. She transferred to a chair in the lobby.

After two hours of testing and questioning factory reps, the wheelchair was still not working right. Sara asked, "I thought you said you could fix this thing in FIFTEEN MINUTES!"

"I can and I will," he replied. "Humm, just as soon as I figure out what's wrong with it."

**I sat there waiting** for my new doctor to make his way through the file that contained my very extensive medical history. After he finished all seventeen pages, he looked at me and said,

"Bill. You look better in person than you do on paper."

**Oxymoron:** One who does not know how to use pimple medication.

**Technical Books** - "Sleeping pills you read!"

**The pharmacist** told me to take these pills as often as I can get the cap off.

<http://www.topica.com/lists/CripHumor>  
Polio Survivor Marsha in Texas  
<marsha1945@sbcglobal.net>

## *Polio Particles, No. 19*

### *from Polio Survivor, Dr. Mary Westbrook, Australia.*

#### **Queensland research into polio survivors**

An article, *The late effects of poliomyelitis in Queensland*, by physiotherapists Mary Lynch and Nancy Low Choy was published in the June 2004 issue of *Australasian Epidemiologist*. It reported a questionnaire survey of 126 survivors who were recruited from the waiting list of a Brisbane Post Polio Clinic (no longer operating). The most common new symptoms experienced by polio survivors were new muscle weakness (87%), unusual tiredness (79%), joint pain (79%), cramps (71%), walking changes (69%), muscle pain (61%), and increased falls (60%). The main activities of daily living which survivors needed increased assistance with were heavy household tasks (46%), climbing stairs (42%), and using public transport (37%). Changes to their employment (eg working fewer hours) had been made by 67% of respondents who were still working. Almost all survivors (83%) reported having made lifestyle changes as a result of their symptoms.

#### **Expert patients and doctors**

As very few health practitioners are well informed about the late effects of polio, most polio survivors have had experiences of having more knowledge about some aspects of their condition than do the practitioners they consult. Some practitioners value their patients' knowledge and are keen to learn more about PPS. Other practitioners ignore or angrily dismiss our knowledge. The editorial in a recent issue of the *British Medical Journal* (27/3/04) carried the headline, 'Expert patient—dream or nightmare?' It said that when *doctors come across the term 'expert patient' they hear different things*, ranging from doctors who regard expert patients as *people who have the confidence, skills information and knowledge to play a central role in the management of life with chronic diseases* to those whose *expert patient of the imagination is one clutching a sheaf of printouts from the internet, demanding a particular treatment that is unproved, manifestly unsuitable, astronomically expensive, or all three. Or possibly worst of all, a treatment the doctor has never heard of.* The BMJ comments: *If one asks lawyers, architects, social workers, or management consultants whether they prefer clients who take an interest in the issues they face and are motivated to work in partnership to achieve successful results, the answer seems obvious. So why does the idea of expert patients provoke such antipathy within the medical profession?* The Chief Medical Officer for England is currently promoting the idea of the person with chronic illness becoming an expert or knowledgeable patient. Surveys show that most British doctors dislike this promotion; 63% saying expert patients will take up more of their time. In fact, says the BMJ editorial, research studies show that expert patients make less visits and better use of visits to doctors and manage their symptoms better. In any case, says the editorial, all patients with chronic conditions and their carers *are experts regardless of how much medical knowledge they may have....As highly educated professionals in well paid employment, doctors are not necessarily best placed to*

*understand the realities of life for many of their patients, particularly those living with debilitating medical conditions, who are disproportionately unemployed, old and poor.. The editorial concludes: Long live expert patients—but in the interests of doctor-patient relations, let us find something else to call them. What we need is a simple, understandable phrase that is less prone to evoke hostility. For our money the best term is 'involved'...involvement clearly requires at least two parties, rather than implying that the health professional role is somehow redundant ...Neither intimidating or patronising, involvement is a broad church in which many if not most of us would be happy to find a home.*

### **'End of polio' exhibition**

The Griffin Museum of Photography near Boston recently presented this exhibition by Brazilian photojournalist Sebastiao Salgado. One reviewer (Milford Daily News 29/8/04) wrote that Salgado *documents the suffering and hopes of humans ravaged by polio with unforgiving realism. An 11-year-old polio-stricken child, wearing sandals on his knees for protection, crawls into a soccer game in Somalia. A father pours a vial of vaccine into his son's mouth in a railroad car in India where they've been confined to prevent the disease's spread...[the museum director says] Salgado's photos 'go far beyond promoting public awareness of a cause. They grab you and force you to face the pain of others with the hope that you will be motivated to fight for change'*. Many of the photographs can be viewed on [www.endofpolio.org/home.html](http://www.endofpolio.org/home.html). Large posters of some of Salgado's photos will soon be on display at Westmead Hospital. His photographs will also be shown at a Rotary exhibition on polio to be held at the Australian National Museum in Canberra from December to February, 2005. The Managing Director of Aventis Pasteur, which will be a major sponsor of the Rotary exhibition has presented the Network has a book of Salgado's photographs.

### **Rhonda Galbally and polio**

Rhonda Galbally AO has recently written her autobiography, *Just Passions*, published this year by Pluto Press. Rhonda was CEO of VicHealth and has started a company, *Our Community*, to support and advocate for community groups. Rhonda contracted polio when she was 13 months old and spent much of her childhood in hospital having surgery. Her family *all hated my disability. We saw it as the worst thing that could happen to a family...I would have given any thing, promised anything, for the miracle of complete recovery..* Her parents resisted health practitioners' pressure to place her in a school for crippled children. Some children, she writes, *were not so fortunate. Their parents would choose full-time medicine over full-time education...By focusing on physical gains, these children would end up as adults with little education, often having to take jobs in sheltered workshops (some of which are sweatshops) or having no job at all.* As an adult Rhonda confesses to *an awful secret -- I shared other people's loathing of disability. Until I joined the disability rights movement I didn't recognise my own hatred of disability—it had been repressed...I was leading a split life. I demonstrated in front of the Miss Australia Quest, a beauty contest run by the Spastic Society on behalf of disabled inmates who were never going to win...At the same time I would still*

*have done anything to avoid being thought of as really disabled. So I refused to use a wheelchair at airports, even though I'd nearly pass out from pain and exhaustion as I struggled down the concourse. The late effects of polio led to Rhonda in turn adopting walking stick(s), crutches, scooter and wheelchair. Paradoxically, the more I use equipment the more disabled I look to others, but the more mobile I am. I tried to explain this to my mum, who took months to agree to go walking with me in my chair. It's not a failure, I told her...it's a symbol of flexibility and success in finally coming to terms with my disability. Rhonda says her first childhood experience of technology was as a sadistic tool of mainstream medicine. One evening with a friend, who has cerebral palsy, The grog loosened up our memories and took the edge off them, making them bearable to recall and even tell one another. It also loosened our sense of humour. We shrieked with laughter (with a strong edge of hysteria), as we tried to imagine the mentality of the person who made up instruments of torture to stretch little babies; he must be called Thomas, because the main weapon was the double-Thomas splint, a rack where little children were spread-eagled on a crucifix with parted legs and tied in with bandages so they could move only their hands. Your feet were bandaged into plaster boots, and a strap drew out your knees...Your hands were set into beautiful beaten stainless steel, to prevent them going out of shape. And you just lay on a bed and looked at a ceiling. After spending two years in one of those things all my muscles had atrophied. It was gross and excruciatingly painful. And in hospital I missed my mum and dad and big brother and lay in a state of terror and despair like a torture victim. As an adult the much travelled Rhonda still found leaving home extremely anxiety provoking, even for domestic flights (even for car trips). I had a dread of never returning, or of getting back and discovering that home had disappeared. I was still stuck in the feelings I had as a baby of thirteen months, when my home disappeared completely...For years after I came home from hospital, if things weren't directly in my sight, I'd think they'd gone. I even hated playing hide and seek—I might never be found. There is much else of interest in this fascinating book. Look for it in your local library.*

## **Post-polio and menopause**

Post-Polio Health International (formerly GINI) has funded research at the University of Michigan, to investigate whether women with late effects of polio experience menopause differently—physically and emotionally—than do their non-disabled peers. A group of male polio survivors was also included in the study to examine whether their well-being differed from age-matched polio women both pre- and post-menopause. The complete report is online at [www.post-polio.org](http://www.post-polio.org) (click on research). These are some of the findings: Polio women who had a natural menopause (eg not caused by hysterectomy) did so at the same age, on average, as did non-disabled women. Polio survivors were more likely to have had a hysterectomy (almost 35%) than the US average of 21%. More polio women (39%) used hormone replacement therapy than did their non-disabled peers (23%). It would be interesting to know why these differences occurred and whether they exist in Australia. Overall there were no differences in post-polio symptom severity, activities of daily living or emotional well-being between polio women who took, or did not take, HRT. Polio women using HRT did not report an improvement in post-

polio symptoms. On average polio women approaching menopause were more satisfied with their lives and less unhappy than were post-polio men their age, but women who were at least five years into menopause were more stressed than their male counterparts. They also reported more severe post-polio symptoms. The authors say that the findings *suggest an acceleration of decline for women compared to men in later years; this will require further investigation*. In general, polio women in this study had an overall positive (45%) or neutral (35%) experience of menopause. Fewer had a negative experience (18%). Both female and male polio survivors reported somewhat more stress than the national US ratings for their age groups. The differences in stress levels was only substantial in the case of middle aged (45-55 years) polio women who reported much greater stress than their non-disabled peers.

### **Elimination of vaccine related polio in USA**

The October 13<sup>th</sup> 2004 issue of JAMA (Journal of the American Medical Association) reported that the changes in US polio vaccination policy have resulted in the elimination of vaccine-associated paralytic poliomyelitis (VAPP) in the US. Prior to 1997 vaccination in the US was from the Sabin oral live vaccine (OPV). Then a policy of using IVP (Salk inactivated vaccine, IPV) for the initial vaccination followed by OVP for subsequent inoculations was introduced. In 2000 an exclusive IVP schedule was adopted. Between 1961 and 1989 an average of 9 cases of VAPP were confirmed each year in the US. Between 1990 and 1999 59 cases of VAPP occurred. No cases occurred among people who had the IPV-OVP schedule nor among those who had only IPV. The last case of VAPP in the US occurred in 1999.

In Australia IVP is recommended as the preferred form of vaccination but IVP is not as yet funded by the government, which does fund OVP. An article, titled *Polio cases slipping through the net*, appeared in the Sydney Morning Herald on October 16<sup>th</sup>. It said that *According to international guidelines, one case of VAPP can be expected from every 2.4 million doses of Sabin vaccine ...in Australia this equates to one case every three years but there have been only two probable cases since 1986*. Concern was expressed that some cases of VAPP are going unrecognised here.

### **Polio virus escapes from laboratories twice**

*The polio eradication exercise is beginning to acquire shades of a science thriller*, according to *The Times of India*, October 6<sup>th</sup>, 2004. Polio virus has escaped twice from Indian laboratories and caused 10 cases of paralytic polio. Laboratory strains of the virus were identified in three polio cases in 2000 and in seven recent cases. A task force has been set up to investigate which laboratory(s) the viruses came from. Initially however it has to come up with a list of laboratories that store polio virus, a formidable task that may take two years as there are many private laboratories in India and there is no requirement that they be registered.

## *Physician sees ways to reverse failure of US health-care system.*

When I sit at the bedside of an ailing patient, I try to reconstruct the series of pathological events causing that body to fail. Applying a method of reasoning originating over 2,500 years ago with Hippocrates. I hope to make a proper diagnosis, prescribe a suitable program of treatment and predict an outcome.

Each time physicians trace the development of an illness, we are propagating the science of methodology of medicine's ancient roots. In most circumstances, disease is not the inevitable outcome of a single event or point in time, but rather a probalistic result of many events, each impinging on the individual, producing the sum total of his illness.

The ultimate reaction and implementation of treatment should be the result of a reverent pact between the patient and doctor. In theory, the practice of medicine should evolve from the foundation of our history and continue to provide education, advice and ultimately, decision-making for proper treatment. Such lofty goals require time, interest, and a partnership between the patient's life and the doctors judgement.

However, America is where the dream ends. We have awakened instead a health-care nightmare—a system like an amalgam between a fast-food restaurant and a discount department store: 'Patient: Drive thru and heal thyself.'

Do we want a health-care system in which market forces and profit motives of Fortune 500 corporations and their clerical representatives make decisions for us?

American health care has become sort of a lottery. If you work for an employer that provides generous benefits, you win. If you work for a small company or are independent, you may in fact lose. Insurance companies—publicly held corporations that answer to stockholders—may decide which doctor you can see, how much and what type of medications you can take, whether or not you qualify for a test, and how long you can stay in hospital. Protests by patients and doctors are almost irrelevant. Medical conditions can be evaluated by insurance clerks who have no medical education and have never met the patient.

Politicians love to say that the United States has the best health-care system in the world. It does not even come close. We certainly have a nation of highly trained, talented professionals who work with the latest equipment and are capable of delivering first-class care. However, time and financial constraint often invoke limitations. Politicians, economists and corporate executives fail to mention that the system is rigged with incongruity in a way that would not be tolerated in the sale of any other consumer product.

The United States spends more on health care than any other nation. Yet, it is no

surprise that its health-care system is in a crisis. Insurers pay for medications to improve a man's erectile function, yet deny coverage for a woman's mammogram. Taxpayers subsidize pharmaceutical research costs, yet pay more than anyone else in the world for medicines produced through such research. Our government imposes cumbersome regulations on health-care providers and facilities, yet withholds resources and funding that would enable compliance.

The system is complex and unwieldy, but it does not have to be this way! This health-care crisis needs to be treated like any other national challenge with seriousness and focus. But as long as Washington maintains the illusion that market-based medicine will heal our health-care system woes, billions of dollars will continue to be wasted, and companies will continue making money by denying care and services.

A plan should be created to redirect resources into taking care of actual health care needs and delivery while minimizing the overwhelming labyrinth of administrative and liability overhead. Ultimately, the patient needs to be empowered with valuable information on how to be a smart consumer of health-care services. When all else fails, be a good patient: Focus on prevention, wellness and self-education. Form alliances with health-care professionals whom you trust and can serve you as advisers and mentors. Your care is in your hands as much as it is in the physician's. It is certainly a far cry from ancient Greece, but the reality is, you must be your own best advocate.

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Why not send Dr. Petrella a copy of your newsletter.

Dr. J Terry Petrella, 2800 Bahia Vista Street, #200, Sarasota, Florida 34239, U.S.A.

 **01522 888601** 

Di Brennand—Phone Team Leader  
Would like to remind members not on the Internet  
that a call to the above number  
will tell you which of the Phone Team  
Di, Pat, Margaret or Judy is on duty that week.  
They will be only too pleased to help with your query.

Pat—It is great to have you back again.

## **Yellow Card Reporting and, Monitoring the Safety and Quality of Medicines: New Drugs Under Intensive Surveillance (Black Triangle Drugs)**

***by Di Newman, Committee member and,  
Co-ordinator Cambridgeshire Neurological Alliance***

This information was gleaned from the website of the Medicines and Healthcare Products Regulatory Agency (MHRA), which is part of the Department of Health and monitors the safety of medicines in the UK. It collects information about suspected reactions to medicines including prescription medicines, herbal remedies and other medicines you can buy without a prescription. To find out more about the MHRA, visit their website or call 020 7084 2000.

If you think you or someone else has had an unwanted or harmful reaction after taking a medicine (a suspected adverse drug reaction - ADR), the MHRA would like to know. Reports are made of ADRs, by GPs, medical and health professionals, dentists, etc, on a 'Yellow Card' system, OR, report the ADR yourself, by phoning the above, or completing a "yellow card" form, or online (website access to updates, reports, monthly listings of current drugs under "intensive surveillance" and, various related information). If you think the reaction is serious, contact your doctor or phone NHS Direct on 0845 4647.

What are Black Triangle Drugs? The Committee on Safety of Medicines (CSM) / MHRA (Medicines) encourages the reporting of all suspected reactions to newer drugs and vaccines (those products that are indicated by the inverted black triangle symbol).

If you see the Black Triangle Symbol against a product entry in the British National Formulary (BNF), Nurse Prescribers' Formulary (NPF), MIMMS, the ABPI (Association of British Pharmaceutical Industry) Compendium of Datasheet and Summaries of Products Characteristics and advertising material, this indicates that the CSM / MHRA are intensively monitoring that product.

A black triangle will be assigned to a drug if the drug is a new active substance. However, a product containing previously licensed active substances may also be monitored if it meets one or more of the following criteria:

- A new combination of active substances;
- Administration via a novel route or drug delivery system;
- A significant new indication which may alter the established risk / benefit profile of that drug

The CSM / MHRA wish to receive all suspected ADRs associated with these products in order to confirm risk / benefit profile established during the pre-marketing phase. The black triangle drugs are monitored closely for two years and the black triangle symbol is not removed until the safety of the drug is well established.

Other information available on the MHRA website: Investigations into misleading advertising, pharmaceutical mis-representation by representatives, suspensions of drugs, tissue engineering, SSRIs, vaccine safety, clinical trials, devices information etc.

Related websites:

- \* Medicines, Healthcare and Products Regulatory Agency: [www.mhra.gov.uk](http://www.mhra.gov.uk)
- \* British National Formulary (information on all drugs - e.g. policies, uses / side effects, registrations, etc): [www.bnf.org](http://www.bnf.org)
- \* Yellow Card [www.yellowcard.gov.uk](http://www.yellowcard.gov.uk)
- \* The Association of British Pharmaceutical Industry (Latest news "Response to Health Select Committee Report 'The Influence of the Pharmaceutical Industry' and 'NICE's draft recommendations on Alzheimer's medicines are blow to patients and to future research'): [www.abpi.org.uk](http://www.abpi.org.uk)

***PSYCHOLOGICAL ISSUES  
AND FAMILY RELATIONS IN POSTPOLIO SURVIVORS  
Volume 2 - Issue 8, December 1999***

by Drs. Susan and David O'Grady, Ph.D.

How does post polio syndrome affect survivors and their families emotionally and interpersonally?.....

The late effects of polio are threatening and upsetting because they change the things people can do and how they do them..... These changes are emotionally upsetting, affect self-image, challenge a person's idea of who he or she is, and push a person into new roles in relation to others roles not necessarily wanted or sought.

Most importantly, you can't do what you used to do, what used to be easy, you now have to work hard to do what you used to do independently. You now have to have help to do what you used to do or use an adaptive device. What used to be comfortable to do, you now do only with significant pain. What you used to accomplish in two hours now takes half a day and then you're too tired to do anything else.....

And there's anger at being forced to drastically and unexpectedly alter one's lifestyle. People ask, "Why me, or why us?" There is a feeling of being cheated, having already faced the effects of polio and have managed to live with it, now the polio has tricked you, robbing you again, forcing more changes. The old coping strategies of minimizing, overachieving and overcompensating cannot be used in the same way as in the past..... It is natural to feel a deep sense of loss of one's identity and of abilities. ...

A common aspect of post-polio is chronic pain which affects us in many ways. It affects our thoughts, our mood and our relationships. People become more internally focused..... Some may feel depressed and discouraged because they can't do the things they used to do.... Pain creates internal stress. Stress in turn affects our perception of pain..... You need to learn ways to relax, to regenerate emotionally and physically.....

Why do people (spouses/family members\*) hold back from expressing their feelings? Sometimes they are afraid to talk about the current changes as they don't want to draw attention to the fact that the partner is changing..... Many also feel protective of their partner..... Some don't feel they have the right to complain, or resent having to make sacrifices, work harder, do more than the spouse, and give up activities, but they may feel too guilty to express any of these feelings..... Many partners feel frustration at not being able to do more to help, or are frustrated at seeing the polio survivor make mistakes in pushing too hard and not pacing themselves and being unable to stop them.

Loss of control is at the heart of all disabling conditions, and often this loss of control is felt almost as strongly, although differently by the families and friends of

the disabled.

### **At the Workshop: What polio survivors had to say, what families had to say.**

"What part of the experience of the post-polio syndrome is most difficult to communicate to your spouse/family?"

Paraphrased, here are some of the areas of concern:

#### **Polio Survivor.**

- We are afraid of what the future holds.....
- We are afraid that our physical needs will place such demands on our families that they will grow weary and resentful and withdraw support.....
- We want family and friends to not judge us by our appearance. Appearances can be deceiving.....
- When we are tired, we mean it. In fact, it usually means we're exhausted
- Sometimes we need to put ourselves first, which is difficult for most of us to do, as this is a major shift for us.....

#### **Partner and family.**

- \* It is difficult to see our partners in pain. We feel helpless...
- \* It is hard to see our partners reject changes that would help them cope better.....
- \* The lack of predictability of the illness is frustrating and frightening
- \* Sometimes our partner's anger is hard to deal with.....
- \* Over time, our role in household responsibilities is getting larger. We accept this. Still, your comment of appreciation is very welcome.
- \* Some of us feel concern about our own physical ability to provide care for our partners as we, ourselves, age and contend with our own aches and pains.....
- \* It is difficult to know when to be the cheerleader, when to be comforting and soothing, and when to confront anger or passivity. We'd like to feel we have permission from our partners to express our feelings about this

In conclusion, there was broad agreement that life is all about challenge and response, that amidst all the hardship, post-polio presents an opportunity for personal growth for both survivors and family if the challenge can be faced with flexibility, acceptance and openness.

[It is good to share experiences not only polio survivor to polio survivor but also family member to family member in a similar position. "Does your mum do that too?, gosh I thought it was only my mum. I love her so much but she is so stubborn, she repeatedly says no she does not want any help and then the next day moans at me because I never help her. Are all polio survivors that stubborn?" We often suggest getting a pen or phone pal, meet up with other members near to you but rarely does this take place. If anyone would like to do this then please let us know and we will help. Those who have attended Annual Meetings will tell you, that sharing stories and experiences often changes stress and anger to laughter.. "I asked for a full base line assessment and he put his hand on one knee and said push, then the other knee and said push. That was it!" "I was denied night time care because at question 99 I lightheartedly replied that I can roll over in bed in my silken underwear"]

## **TRAVELS WITH A WHEELCHAIR**

### **Alan Russell visits China**

*First published in issue 24 (Autumn/Winter 2002) of "discover", the magazine for disabled people by disabled people in Cornwall.*

If ever I attended journalist college, (which is highly unlikely), I am sure that one of the main things they will teach me is "try not to lose your reader in the first paragraph". Well, I am sorry, but if you are 100% reliant on a wheelchair, and are unwilling to be carried for most of the time, then China is not for you. The places that we visited (and they were the main sightseeing places) are totally wheelchair unfriendly, and I would go so far as to say that even if you had severe walking difficulties you would find it very hard.

We set off from Heathrow and flew with Air China to Beijing. A comfortable enough journey, but total chaos at the airport on landing. Luckily Travelsphere Holidays provided a tour manager to assist us through all the red tape, and immigration formalities. Then the fun started. There was no way out of the airport to the coach park without going over 12" high kerbs or down steps. The coach drivers in each place were very helpful, but the coaches had very low underneath storage, so the chair had to be completely dismantled every time it was loaded. We stayed in four different hotels and on board a ship, all of which had steps and stairs everywhere, and no ramps. With the exception of the ship they all had lifts, but to reach the lifts you had to climb steps. None of the rooms were accessible to a wheelchair user, and the toilet pan was so low that fit people had to be cranked up to get off it.

That said, it sounds as though we had a rough time. Well that would be very wrong. The China we saw is one of the most fascinating, friendly and safe places we have ever visited. On our first full day we visited Tian-an Men Square and The Forbidden City. Both of these have very rough paving, and walking over them is dodgy, but there are plenty of places to park your bottom as you flow through the numerous temples, palaces and gardens. Something that you will notice on your first day is that the Chinese are noticeable for two things. One is deep throated hawking and spitting (we found the women held their own with the men). The other is their 'interest' in all things unusual. This is apparent by their staring very hard and long at you if you are blonde, tall, hairy or have a physical disability. After a while you realise that they are not being rude, and if you smile and converse in sign language, you have a friend for life.

Daily life in Beijing is truly spellbinding. It is a city of three million bicycles, bustling street markets and food stalls, but above all a warm and friendly people, eager to welcome and please their visitors. You will be approached by street vendors, but after the second polite 'No' they will leave you alone. However try haggling, it is great fun and you can pick up some tremendous bargains. Haggling is a way of life in China, start off at about 20% of what they ask, and settle at about 40%. The sellers enjoy it as much as you, and take no notice of the hurt look on their faces when you make a silly offer. Remember though; do not start to haggle unless you really are interested in buying. Watch out for fake Rolex watches at around £3, but post cards and guide books can be bought for next to nothing. Do not buy fruit unless you can wash, boil or peel it, and make sure that the water you buy has an

unbroken seal. (Whatever you do, do not drink, or even clean your teeth with, the local water) Unscrupulous vendors sometimes re-fill used bottles from the main. Hotels supply boiled water for teeth cleaning, and bottled drinking water is cheap (approx.25p)

After Beijing we flew to Wushan (approx. 1hour) and then a coach ride, past rice paddy fields ploughed by water buffaloes, to Shashi, where we embarked on our ship for a 4 night cruise up the Yangste River. The ship was superbly fitted, and the food and service was second to none, but it had 5 decks, and no lift. So your day must be well planned if you don't want to wear yourself out. All through the trip, breakfast was a buffet of continental, English or Chinese (do you fancy quails breast and curried chicken wings for breakfast?) Lunch and dinner was always Chinese and banquet style, where you helped yourself from the 20 or so dishes on a roundabout in the middle of the table, and ate with chopsticks. Forks were available for those with manual dexterity problems. You could tell the ones who didn't use chopsticks...they had clean tee shirts after the meals.

It was interesting and a little frightening to see the new dam on the Yangste, which will cause the river above to rise 175 metres and will affect people living near the river for 500 miles upstream. Millions of people are being relocated above the new water line, and the scenes of devastation as they demolish the old cities along the banks appear heartbreaking.

Chongqing was our disembarkation point. This was the headquarters of the Nationalist Chinese before the communist take over. It is a beautiful city built on very high hills, at the confluence of two rivers. It is famous in China for its love of very hot food, but luckily for some they do tone it down for the visitors. Here we met local people in their environment. I noticed that although they lived in what perhaps we might call a 'slum' area, the people and particularly the children, were so happy and spotlessly clean. I was put off a bit by the live ducks, chicken, frogs, fish and water snakes for sale in the market, especially when they were 'dispatched' for the purchasers there and then.

Next day we flew to Xian and a visit to the Terracotta Army. We met the farmer who discovered these full sized models, while drilling for water in 1974. They had lain undiscovered since 247BC, when they were made to guard the tomb of a Qin Dynasty emperor. Wisely, only a small portion of the site has been excavated, as the authorities feel that they have more than enough to get on with, and that time well provide a means of preserving them better. At this site, a wheelchair pusher is provided on request, and he is properly trained in wheelchair handling. The cost? £3 for a day!!

After Xian, a short flight to Shanghai, a modern bustling city with modern skyscrapers on the one hand, and tiny shacks for some of the residents on the other. A gentle stroll along the riverside Bund area prepares you for the mad rush around the Nanjing Road shopping area and tiny markets where 'Yves St Lauren silk' shirts (oh yeah?) are sold for £3 and 'Gucci' hand bags are sold for the same amount. A night time visit to Shanghai is a must. All the buildings are lit at night, and everybody promenades as the weather is cooler then. If you don't fancy promenading, you can always join the throng for communal line dancing in the

public squares, or Tai Chi in the parks. At no time did I ever feel threatened whether in the dark or in backstreets.

Our return to Beijing after a flight from Shanghai was to highlight our trip with a visit to a part of the Great Wall at Badaling. The Wall is 3,800 miles long, so this visit only scratches the surface. It is one hang of a climb... but... well.. I burst into tears when I reached the top. It was a lifelong ambition of mine to go there, and here I was, probably for the last time, and I soaked in every bit of the atmosphere while I was there. The feeling of being on the only manmade structure visible from space, parts of which are 2,600 years old, was just so emotional. Some rang their families from the wall only to be reminded that it was 4 am at home!! Oops!! I bought a 'I climbed the Great Wall' tee shirt and had my photo taken, (I told you I was emotional).

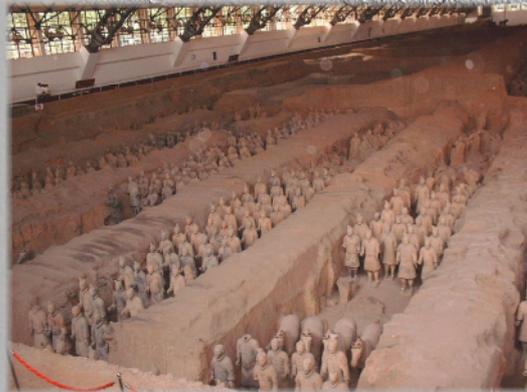
The flight home was fine, but again chaos ruled in Beijing airport and all I can remember is sitting in my chair for hours on end queuing for different red tape departments.

Oh by the way... Disabled access in the airports and visitor sites is referred to as 'The Gate of Love'. Oh Yes. I think that Beijing was the gate to a country and people that I fell in love with. Would I go again? Hmm.... Not unless a miracle occurred and I was 100% fit; there were just too many steps, uneven pavements and high kerbs and not enough opportunities to use my wheelchair. I think that some people would miss out on a lot if they were susceptible to fatigue, as we were on the go for all the day, with not a lot of opportunities to rest. However, I wouldn't have missed it for the world.

*About the Author – Alan Russell is a founder member of the Cornwall Post-Polio Support Network and a regular travel columnist for "discover". He can be contacted at [alan.russell@originalthinktank.org.uk](mailto:alan.russell@originalthinktank.org.uk)*

<p><b>Going To Europe? Important Changes to E111 Forms Get Medical Care in the European Union with an E111 Form</b></p> <p>PLEASE NOTE: Old E111 forms expired on 31<sup>st</sup> December 2004.</p> <p>Your new E111 form will be valid until 31<sup>st</sup> December 2005. New forms issued on an individual, not family basis.</p> <p>The free E111 form entitles you to free or reduced-cost state healthcare if you fall ill or have an accident while travelling in a European Union (EU) country.</p> <p>Important changes to E111s If you're planning to travel in Europe during 2005 and are a UK resident, you should apply for a new E111 form. Those issued before 19 August 2004 are only valid until</p>	<p>31 December 2004.</p> <p>Each individual traveller now needs their own E111 form, including children. However, if you're a family you only need to complete one application form for you, your partner and your children.</p> <p>Later in 2005 the UK will be adopting the European Health Insurance Card (EHIC), which will be issued to those who have applied for the new E111 form and tick the box to receive the new card.</p> <p>You can get your free E111 form and 'Health for Travellers' booklet at any Post Office branch.</p> <p>PLEASE NOTE: that an E111 form is not a substitute for comprehensive insurance</p> <p>For further information visit: <a href="http://www.dh.gov.uk/travellers">www.dh.gov.uk/travellers</a>, <a href="http://www.postoffice.co.uk">www.postoffice.co.uk</a> or call 08457 22 33 44.</p>
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# TRAVELS WITH A WHEELCHAIR



Top Left - Sampan (Daning River)  
Top Right - Terracotta Army (Xian)  
Bottom - Great Wall of China  
(Alan and Tricia Russell from right)

Photographs - Alan Russell  
Wheelchair graphic - Patricia Clouse  
Original background photograph - David Bowers  
Layout Design - Chris Salter