



# The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**  
Volume 4 - Issue 12 - October 2004

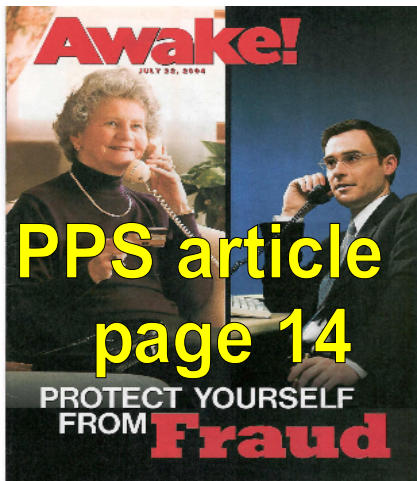
WebSite - <http://www.lincolnshirepostpolio.org.uk>

## MARY KINANE—CHAIR

Hello to our members and I would like to say that I am honoured to have been nominated and voted in as chairperson of the Lincolnshire Post-Polio Network. As many of you already know, I have been active with the Network for a number of years, helping with e-mail enquiries and taking on committee responsibilities.

In Lancaster, where I live, I am actively involved with local disability groups, in an on-going consultation process aimed at achieving improved services for those with disabilities in the Lancaster, Morecambe and Lune Valley District. I also do diversity training locally, assisting in

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**Rolling Right Along**  
By  
**Polio Survivor**  
**Dorothea**  
**Nudelman**  
Page 10  
Co-author of  
**Healing the Blues**



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.

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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### GRATEFUL THANKS FOR THE DONATIONS RECEIVED FROM

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**Lincolnshire Post-Polio Network,**  
**69 Woodvale Avenue, Lincoln, LN6 3RD, UK**  
**Tel: +44 01522 888601 Fax : +44 0870 1600840**  
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**Next LincPIN Newsletter - December 2004**  
**Articles for publication by 15.11.04 by post or** - newsletter@lincolnshirepostpolio.org.uk

**Chair - Mary Kinane**—mary.kinane@lincolnshirepostpolio.org.uk

**Founder and Secretary**—Hilary Hallam - hilary.hallam@lincolnshirepostpolio.org.uk

**Treasurer** - Denise Carlyle - denise.carlyle@lincolnshirepostpolio.org.uk

**Committee Member** - Diane Newman—diane.newman@lincolnshirepostpolio.org.uk

**Phone Team - Leader** Di Brennand - di.brennand@lincolnshirepostpolio.org.uk

**Phone Team** - Pat Hollingworth, Margaret Edmonds, Judy Barter

**Lincolnshire Post-Polio Network WebSite Administration**

Chris Salter - netadmin@lincolnshirepostpolio.org.uk

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contributing to a better understanding of disability issues in my area, in relation to the movement for Independent Living, civil rights and the move towards an understanding of the social model of disability. I am a service user representative with Leonard Cheshire Care Services, representing issues which service users bring up with regard to their care and the quality of the services provided, as well the policies and practices which guide the delivery of services.

We are an international organisation, with a good image and a good reputation, mainly perceived through the good quality of our website - thanks to the hard work of Chris Salter. Our outgoing chairperson and founder, Hilary Hallam, has spent the best part of nine years in developing the Charity and it is hoped that my moving into the role of chairperson will give the organisation a dimension of added strength, which we need at this time. We need not only to keep our work going, but to improve, and we have made a number of funding bids to the Department of Health (Section 64 funding) to enhance our presentation materials and skills so that we can bring awareness of PPS more readily to health professionals, as well as eventually to pay a part-time administrator.

The committee will continue to maintain the close working relationships that we have with members whose voluntary work in the following tasks is essential to our success: newsletter layout, newsletter distribution, telephone help and information, production of information leaflets about PPS for PPSers and health professionals, financial and clerical advice and support, web administration and ongoing web re-build, to name some of

the essential areas. All of the following people contribute their time freely and enthusiastically in these areas: Chris Salter, Robin & Pauline Butler, Jenni Paulger, Sheila Dunnett, Barry & Olivia Branston, Di Brennand, Pat Hollingworth, Judy Barter and Margaret Edmonds. Also of value are all the people who willingly network between LincsPPN and other organisations in the UK and beyond, with the British Polio Fellowship, the Post-Polio Support Group of the Republic of Ireland, Post-Polio Health International, The Neurological Alliance, the Long-Term Medical Conditions Alliance, Leonard Cheshire, and with various other groups worldwide. In a world which now appears smaller due to the advancement of internet technology and the exchange of information, polio survivors can communicate across continents and we can continue to promote important efforts to support polio survivors in the "developed" world, as well as fight to eradicate the possibilities of future polio epidemics in "developing" countries. If you or someone you know would like to be more centrally involved in the work we do, I would very much like to hear from you. You can contact me, or any of the committee, via our e-mail address, our snail mail address or telephoning us – all contact details are to be found on the opposite page of this edition.

Many thanks for your continued support and I look forward to your views. In future editions we will be continuing to invite members and non-members alike to contribute new material for the newsletter and to make suggestions about how best to improve the Network and the newsletter to represent your views and your interests.

Best wishes, Mary Kinane  
mary.kinane@lincolnshirepostpolio.org.uk

## Editorial by Hilary Hallam.

I would like to welcome Mary Kinane to the post of Chair. Nine months after finding PPS existed—I gave 'birth' to the organisation we now know as the Lincolnshire Post-Polio Network. 'She' is nine now and its time for Secondary School and a new 'headmistress'. As you will have seen from Mary's profile she also gives up much of her available time and energy to trying to make a difference for folks who are less-able.

PPS changes ones life, especially if you go undiagnosed and wrongly advised for many years. From working full time plus voluntary work to fighting for and managing on benefits is a hard knock to the system. The folks with PPS that work—and have worked—for the Lincolnshire Post-Polio Network over the years have all given up some of their available and very valuable time and energy to help promote the awareness of the condition. I would like to take this opportunity of thanking you all.

The LincPIN's contain a variety of articles. Some are sent to us, some we find ourselves, some we ask folks to write for us. This is issue 48—that's a lot of information.

Our main aim is to promote the awareness of PPS. One of our members sent us a copy of their AWAKE! Magazine which contained an article on PPS. I was amazed to learn that this magazine has an average printing of 22,530,000 copies in 87 languages. That is a massive number of people who will now be aware that the condition exists. This article states in grey shaded text box on page 17 'A confirmed diagnosis of paralytic poliomyelitis in the past'. Since 2000 we have used the criteria added in the adjacent box and information on the levels of nerve damage relating to the diagnostic name. I have also followed this article with details of publications on anaesthesia and reprinted Prof Selma Calmes info on page 20. Selma is a polio survivor.

I got a book from the library, and as a polio survivor age 5 who remembers nothing, found the information by polio survivors on their experiences an eye-opener. I compiled a review of this book *Out of Sight - The Experience of Disability 1900 - 1950*. Pages 5—9. We welcome your comments and experiences.

Dorothea Nudelman is the author of the article 'Rolling Along' on pages 10 to 13. Doro is a Professor of English and a Polio Survivor. When she learned about PPS she became depressed and courageously co-wrote the book 'Healing the Blues' *Drug-Free Psychotherapy for Depression* with David Willingham MSW. This is written in two personal voices, patient and therapist, this is the gripping story about the depression of a brave woman who faced her own despair and transformed it into a creative renewal of her life.

HEALING THE BLUES is also a guidebook to a drug-free approach to healing depression. Depression robs us of the enjoyment of life. Increasingly, drugs are seen as a quick solution. This book suggests an alternative approach: "Listening to the depression" for what it is telling us about our life. What's not working? What needs to be understood and changed? See page 13 for info.

We finish with another article by Alan Russell on their visit to Tunisia. We have just received an article from Alan and Margaret Lever about their 'wheelie' visit to Tunisia—next issue. Why not tell us your experiences of holidays.

Which reminds me—huge hugs to Lynn Hobday who is in hospital after breaking her leg. We all send our best wishes for a speedy recovery.

Ellen will be back next issue.

Christmassy items from around the world would be welcome for the next issue.

Please enter our Competition on page 21

A Review of the Book  
**Out of Sight**  
**The Experience of Disability 1900 – 1950**  
By Steve Humphries & Pamela Gordon  
A Channel Four Book.  
ISBN 0 – 7463-0642-3  
Compiled by Hilary Hallam

The experience of physical disability in Britain during the first half of the century is almost completely undocumented. We have little idea how it felt to be officially classified as blind, deaf, or crippled and be brought up in the harsh Dickensian institutions and special schools where so many children were sent. We know even less about how the great mass of disabled children who escaped an institutional upbringing coped at home, in hospital, at school and in the streets. During the Second World War however there was a dramatic but temporary change in the economic fortune of disabled people – an extraordinary story which has never been properly documented. More than a quarter of a million were recruited into full time employment – often into skilled and responsible positions – to do jobs vacated by those who had joined the armed forces.

The aim of this book – and the television series it accompanies – is to begin to fill this important gap in our social history, by providing the first ever account of the lives of men and women who are physically disabled. Till now there has been no serious attempt to allow disabled people who grew up in the first half of the century to speak about attitudes towards them, about their hopes and fears, their ambitions, their loves, their disappointments and their struggles.

This book looks at the lives of ‘ordinary’ disabled people.

Between the 1900’s and the 1950’s the great majority of physically disabled people in Britain were under fourteen years of age. More than half a million boys and girls had rickets, polio, tuberculosis, cerebral palsy,

seriously impaired vision, deafness or a host of other disabilities.

**The following excerpts all relate to polio survivors.**

Elise Cooper was brought up in Ponders End, North London, the youngest of thirteen children. She had polio when she was just over a year old. As she grew up the authorities wanted to put her into an institution. Her father was a foundry man at the local factory and he resisted.

*When I was nine the authorities where I lives wanted to send me away to a special institution. They told my dad that it was the only place I would be fit for. But my dad found out that this place was just for mentally handicapped kids. I would have to go there to live, goodness knows how long I would have been locked up there fore. But anyway my dad said ‘no’. He refused point blank, said I wouldn’t learn anything there and that I was brighter than some of my brothers who went to the local school. It was only thanks to him sticking his heels in tat I wasn’t packed off there for good.*

Olive Hall, born in 1923 in South Shields, contracted polio when she was only a few months old. Her father was a teamer at the local shipyard. He and Olive’s mother were determined to do the best they could for their daughter.

*After I got polio my mum and dad used to carry me to hospital every day for the hot baths treatment. I had them every day for three years. But I don’t think it was much good. Nothing happened. Mum and dad just tried to do anything that they could manage. There wasn’t any other help for me. The big strike was on at that time so it was tough for us all. Mum used to scrub floors in a laundry to buy me proper food and to be able to keep taking me to hospital for these baths. She even pawned her engagement ring in the end, the little bit of something she*

*(Continued on page 6)*

*(Continued from page 5)*

*had of her own. That was so I could be sent into hospital to get an operation they said would put my foot right. But it didn't work, just the opposite. I ended up with it worse. All deformed and the ankle bone all on top of the foot. My parents were trying to do their best by me but it was useless.*

Hilda Donnelly was born in 1914 in Hartlepool. Her father was fighting in the First World War and so when Hilda contracted polio at the age of one and a half her mother had to cope alone with only the help of her neighbours.

When I got polio I was really ill and my mum had to get the doctor out to me. He came and said what I had but then he never seemed to bother after that. Mum couldn't afford to send me into hospital and so the doctor left it up to her to care for me. I remember screaming whenever the bedclothes touched my legs at first. She was so worried about me. But all our neighbours were very kind. They all had remedies that they told mum to try on me. Anything that might make me even a little better, I got. She gave me Dr. Castle's tablets, they were a health tonic. I took them for years. I got Scotts Emulsion from one woman in the street. Another man used to bring two buckets of sea-water up from the shone every morning. Mum would heat it up and bath me in that. Then they massaged my legs and back with olive oil. She tried absolutely everything to make me walk again.

Muriel Faulkner was born in 1902, the daughter of a general labourer and she contacted polio in 1904. Her family lived in the village of Bronesberrow Heath near Ledbury.

*They kept you where people couldn't see you. They kept you out of sight. After I'd had my polio my parents didn't really let me out much at all. I was never allowed to walk out*

*with the rest of our family because of how I looked with my limp and all. Sometimes they used to take all the other children on the horse and cart to a show in another village. That was a real treat but I was never allowed to go. I was usually sent to my gran's whilst they all went off. It was as if they were ashamed of me and even as a child that made me feel awful.*

Kenneth Matthews, born in 1923, had suffered polio when only months old. He started elementary school along with the other children in the Welsh town of Seven Sisters.

*I was turned six when I went to school but I done very well at school. On my first day the headmaster called all the boys into the assembly hall. He explained to them all about me, what I'd got and what I'd been through. He sort of put them on their guard against banging me or bumping into me in the playground. I had to wear a black sling too so as they would all know which arm was the bad one. It was all skin and bones really because the muscles had been eaten away like. It was good that they all knew to take care of me. But I soon settle in and after a bit I made friends and got into scraps like all the other lads. I was a real good one-handed scrapper in the end.*

Olive Hall had contracted polio when she was twelve months old which left her unable to walk for many years. But at school she found that she was expected to do all the same sports as the other children with no consideration for her special needs. On one occasion this harsh and uncaring attitude almost lead to disastrous consequences.

*I just had to get on with it at school. Nobody would let you off anything just because of how you was. Every Tuesday we were all taken swimming. The cubicles were all along the side of the baths I remember. Well one particular day we had our swim, it was*

*(Continued on page 7)*

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*quite a long time to be in the water and some of the girls could swim very well. Of course I was weak because of the polio so I got tired easily when I did exercise. Then the teacher told us all to get out and change. She blew a whistle, I remember hearing that and I tried to get out of the deep end but then all my strength left me and I started to slide down, back into the water. All the water rushed inside me and I thought, this is it. But nobody noticed, none of the teachers even. After my friend Vera had got changed she went to tell the teacher I hadn't come to line up. Everybody thought that I must be larking on somewhere but the one of the girls spotted what looked like a dirty big rag on the bottom of the baths. It was me. One of the older girls jumped in and got me out. I was black and blue all over so they told me and the hospital told my mother I was lucky to be alive.*

There was little resistance to this harsh treatment of children with disabilities. The children themselves were usually too isolated and frightened to protest about any unfair treatment they felt they received. The only protests likely to happen were ones initiated by the parents, usually after a disabled son or daughter had been badly upset at school and had reported the incident at home.

Alice Maguire, born in 1909 in Croxton, Norfolk contracted polio when she was eight. Although she had severe difficulties in walking she recovered sufficiently to be able to attend the local school.

*One day one of my friends picked me to do monitor duty with her in our class. But the teacher said to us in front of all the other children, 'She's not being a monitor, I'd rather see a pin hopping around the room than see her.' She meant because of my bad legs and the way I walked. I went home very upset. Then that evening some of the other mothers and children came around to our*

*house. They'd all heard what the teacher had said to me. Well, next morning, there was a riot at the school! My mum and some of the others went down and complained to the teacher. They shouted at her and really told her what they thought. And she left the school that morning. I don't know where she went. She disappeared for a week and when she came back she completely ignored me, never spoke to me again.*

The feat engendered by surgery and medical experimentation was greatest in long stay hospital wards. Thousands of disabled boys and girls spent long periods of their childhood as hospital patients. Here the enforcement of strict institutional discipline and a mistaken belief in the complete immobilisation of some patients meant that occasionally children were not allowed to move at all in or from their beds.

Susan Miller contracted polio in 1921 when she was just a year old. She was sent straight into hospital from her home in Chiswick, West London. Susan was to remain in hospitals until she was twenty-one years old.

*From the age of five until I was thirteen I was encased in a plaster cast, rather like an Egyptian mummy in the children's ward of the Royal Sea Bathing Hospital in Margate. Whenever the little girl in the next bed to me wanted to play 'dollies' I undid the straps that were meant to keep my arms still and joined in with the game. But if the nurse ever saw us, and she mostly did, she thundered down the ward, yelled at me, put me back in my little coffin and tied my arms and hands down with bandages to the sides of the bed really tight. It was like being crucified flat. There were so many times when I wanted to play and talk and I would wriggle and accidentally break bits off the cast. And this would mean that I had to be re-plastered. The nurses got really furious and they would quite often wheel me, bed and all, into the cold, wet bathroom as a*

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*(Continued from page 7)*

*punishment. And I had to cry myself to sleep to the sound of a dripping tap.*

Unemployment brought absolute poverty for many disabled people. Dependent on parish relief for their survival, many gravitated to the poorest, cheapest slum streets in the big cities. Here there was often a concentration of disabled men and women living in rented tenement blocks or cheap lodging houses.

Len Tasker who had polio entered a similar world of poverty and deprivation in Coventry when he left hospital at the age of nineteen in 1934.

*When I first came out of hospital I thought it would be all rosy and that my life would get started then. But all I saw was poverty all around. Lots of disabled men begging in the streets, selling reels of cotton and matches and things like that. It was the thirties and there were no chances for the disabled then. I was totally dependent on my brother and his wife for money and food. There was nobody who would give me a job. I couldn't get any social benefits because I didn't have any insurance stamps because I had never worked with being in hospital. You had to be working, twelve months before you could get means tested for unemployment benefit so I was caught in a hole. If it hadn't have been for my brother working then I would have been on the streets. As it was there was never enough to go round the three of us. I felt so useless but I couldn't get a job. I'd never been trained for anything. I did a bit of handicrafts, making duchess sets for the neighbours and getting orders from them for a bit of pocket money. In the end I got a job peeling potatoes in the local fish and chip shop. I was so pleased to get a few pennies even though it was such long hours and boring work. I had to keep it a secret from my brother, what I was doing. He would have been angry if he'd have found out exactly what my job was. But I was so desperate for insurance stamps that I would*

*have done absolutely anything.*

The strong disapproval of disabled people having children which was reinforced by Eugenics ideas during the early part of the century continued, though in a diluted form, into the 1950's. The idea of disabled people coping and succeeding as parents was for example represented in fifties newsreels as something quite extraordinary. But some defied the prejudices of the time. For them parent hood was often especially fulfilling.

Betty Holland, who had polio, married a seaman in 1934.

*His mother was awful. She used to be really nasty to me and said that he shouldn't marry me because I wouldn't be able to manage a house or cook meals and keep him comfortable because of my disability. She really wanted him off me but luckily for me we were dead set on marriage and she couldn't stop us after all. And we managed perfectly. My husband used to help me with the things that I couldn't do and it all rolled along well for us. His mother was still horrible to me. She said that we would never be able to have children and that especially hurt me because I was hoping for a baby and I knew that my husband wanted to be a father. But I was determined to go as if nothing was wrong and just hope that a baby would come. I was over the moon when I got pregnant. And my little girl was all that we could have wished for.*

In the last ten years [1992] there has been a growing awareness amongst disabled people that they have been – and still are – denied basic human rights. At the heart of this transformation in the understanding of the nature of disability has been the rise of the disability movement. This movement has in turn been driven by the emergence of a number of organisations controlled and run by disabled people themselves. The central concern of this movement is the individual

*(Continued on page 9)*



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and collective empowerment of disabled people. It challenges the dominant perception of disability as medical illness or personal tragedy and focuses instead on how society systematically handicaps disabled people. This new perspective also challenges the conventional wisdom that the history of disabled people in our century is one of general progress and improvement in their social condition. Histories written from this viewpoint should provide many new insights into the recent history of disabled people. We suspect that research into the

experience of disability since the 1950's—about which remarkably little is known—may discover striking parallels with the experiences that we have documented earlier in the century. Certainly our conversations with younger disabled people suggest that they share much in common with those brought up before the last war. Patronising and hostile attitudes by the able-bodied and a refusal to recognise the rights of disabled people have shaped the experience of disability throughout the twentieth century.

Compiled by Hilary Hallam.

Two show stallions are arguing over who should take best of breed.

The first says, "I'll grant you are the closest I have ever seen to my equal, but my legs are just a bit straighter than yours, and, you know, the legs are of prime importance."

The second horse says, "I'll allow your legs are just a bit better than mine, but mine are the legs I was born with. I know for a fact you had thousands of dollars of corrective work. Your foals will inherit your natural legs, not your genius farrier!"

The first horse mulls this for a moment, then says, "You're right. I stand corrected."

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Now I have a "shoulder impingement" and getting physical therapy for that. The therapist gave me exercises, too.

"Have you been doing the exercises?" he asked me. "Yes. Religiously!"

The PT tried electrical stimulation of the shoulder. I think it's called a tens unit. So she puts the patches on, starts the machine and asks me to tell her when I feel a tingle. Just as that starts I say "OK. I can feel it," and "Say, is this going to interfere with my pacemaker?" [Note: I do not have a pacemaker!]

Well, its only fair. She stimulated blood flow to my shoulder, and I stimulated blood flow to her heart...

Doris' service dog Mesa was in a deep sleep and moving her feet because she could hear all kinds of animals talking in her head. Nothing really for concern. Doris and Mesa had spent 6 hours at the amusement park and Mesa was having Disney spells.

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A blind man walks into a store with his seeing eye dog. All of a sudden, he picks up the leash and begins swinging the dog over his head. The Manager runs up to the man and asks,

"What are you doing?!!" The blind man replies, "Just looking around."

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"I can't wait to go to Grandma's for Thanksgiving. My cousin's going to be there, and he has three feet!"

"Wow! How'd that happen?" "I don't know. My aunt wrote my parents and said, 'You won't recognize little Rubin, he's grown another foot!'"

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A man with a wooden leg wanted to buy fire insurance for his leg. The first actuary quoted an annual premium of \$500, estimating that the leg would burn once in 20 years and the value of the leg is \$10,000.

The second actuary quoted an annual premium of \$50. When the second actuary was asked how he arrived at such a small figure, he replied, "This situation is right here in the fire schedule rating table. The object is a wooden structure with an upper sprinkler, isn't it?"

## **ROLLING RIGHT ALONG** by **Dorothea Nudelman**

A friend of mine who is perfectly able-bodied has turned napping into a high art form. When she visits for an extended time, she often takes several naps in the course of a day. She laughs about it, but I find when she's here I nap more and enjoy myself more too! At such times, I never think of napping as a PPS issue—deep fatigue. It's just something I do that energizes me for hours afterwards. I'm beginning to learn that as more polio losses come I have to continue this massive exercise called "taking care of myself" in body, mind, and spirit.

The practical aspects of adjusting to the post-polio losses of strength and mobility are in themselves awesome. For some of us it means using a wheelchair for the first time or being fitted for a brace. For others it means substantial loss of endurance, increased pain, and chronic fatigue. Many experience a combination of the above. No matter how much we try to anticipate our own needs, I think it's natural to feel surprised and even discouraged when loss actually happens. From my perspective, having suffered depression, it is essential that we address the emotional aspects of these changes as we experience them. Moving beyond discouragement or depression frees us to fully enjoy the lives we have.

As many of you know from my book *Healing The Blues*, I was initially resistant to dealing with the onset of new polio losses in middle age. Now, in my mid-sixties, after yet another new home and new community, I have had to cope with more severe losses. After walking with crutches and braces since age ten, I have recently joined the ranks of the "vertically challenged." This has been a major and challenging change as many of you understand. But continuous work on my attitude and feelings has helped

me to "spit back" at anyone who looks at me as an object of pity. For me, pity is a death knell signalling the loss of hope, humor, and belief in myself.

Nevertheless, the world looks different from here. Always having to look up to make eye contact can feel diminishing; and for the person who is standing, it is often easier to dismiss, patronize, or ignore the person sitting. "If *she* needs to use a bathroom, there's an accessible one just outside Gallery 5." Hearing oneself addressed in the third person is very strange indeed!

For years I had wondered if I would ever have to use a wheelchair except for trips to the bathroom during the night. Further, I'd wondered how I'd make the decision to do so since a tiny part of me always hung onto the conviction that sitting down was "giving in." Hard to believe I still wanted to hang onto the hope that this would never happen, that I'd be spared "the chair." You'd think I were being sentenced to the "electric chair." So the practical aspects of confronting and evaluating whether I'd *have* to use a chair were deeply tied to my attitude towards doing so.

Twenty years ago when my husband and I built our first house, I didn't have a clue about how new physical losses would affect my mobility. When we moved recently to our present northern Sierra foothill location, I was still walking but had come to rely heavily on my electric scooter to get around outdoors and to manage the hilly terrain of the streets in town and on our country property. With growing awareness, we built our new home with all of the practicality needed to accommodate me in a wheelchair.

Building wide hallways and doorways in a single level living area were obvious. We installed grab bars in every bathroom and a "drive-in" shower with transfer seat in the master bath. We lowered the mirrors and

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built a wheelchair friendly cutout in the vanity counter as well. In the kitchen, we designed an island with clearance on all sides for my chair. There is also a lowered butcher-block tabletop at one end of the island that I use as a meal prep area. I installed a wall oven at a lower than traditional level so I could function independently while cooking. In the laundry room we raised the front-loading washer and dryer so they would be accessible whether standing or sitting. Almost everywhere in the house there are lower level built-ins instead of overhead cabinets so there is plenty of convenient access.

At the front door are a roof overhang and a front porch so that the gently sloped (stair free) entryway is navigable in a wheelchair, protected in inclement weather, and gives easy access to guests. Repeatedly, it strikes me how appropriate the phrase “universal access” is since so much of what is necessary for persons with disabilities is convenient and appealing to others.

When we finally moved in, last November, I was thoroughly exhausted. Walking the length of the house felt like hiking to the moon. Even though I’d tried to pace myself through the move, it took so much time to recover! I joked that this would be our last move, (the next one will be out the front door, feet first!). By January my legs still ached and my blood pressure soared. I’d had a couple of close calls when I nearly fell because my good knee, the one without the brace, buckled for no apparent reason. My common sense told me it was wake-up time.

Since we had laid hardwood or tile on all the floors, the surfaces were perfect for wheelchair cruising. My intelligence told me it was too risky to walk. My feelings balked. What was holding me back? I just didn’t want to sit down after a lifetime of walking. Then one day in late winter a newsletter arrived from the *RANCHO LOS AMIGOS*

*PPS SUPPORT GROUP* (March, 2004). It contained an article on “Understanding Muscle Strengths” with Dr. Sophia Chun. The article included many useful definitions of muscle strengths and a muscle test that one could self-administer. There was also a series of questions and answers about equipment available for those who might now need assistance walking. After I’d read the article thoroughly, and took the muscle test, I understood I truly didn’t have a “marketable muscle” in my good leg, not one strong enough to reliably support my walking. It was time for me to “ride.”

There were other, more mundane practicalities to face. In the months of slowing down before I made the decision to give up walking, I’d gained far too much weight to be healthy and move easily. While this is a common problem in PPS and aging, I knew I’d become less than vigilant about watching my weight and I’d also begun using food for entertainment and reward for hard work. I started the Atkins diet and have lost thirty pounds in the last ten months. It wasn’t easy, but doing so has made me aware that I had to change the way I ate if I were unable to raise my energy output. The weight loss and change in eating habits has renewed my confidence in my ability to make difficult changes.

Finally, this past summer I tried out the IBOT when it became available for evaluation in San Francisco. For those who haven’t heard, the IBOT is a robotic power wheelchair, equipped with three computers, capable of climbing stairs and curbs. I had watched its development by Dean Kamen for years and hoped that it would be the answer to my prayers. I’d imagined it as some kind of Bat-Mobile that would overcome rough terrain and other barriers! My new community is full of hills and steps making many friends’ homes off limits now.

Much to my disappointment, the IBOT

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*(Continued from page 11)*

proved to be too limited in the range of things it can do to merit either the cost or the risks. Can you imagine a health insurance company even cost-sharing a power chair that sells for \$29,000 + extra for training, with only a one year warranty on parts and labor? But IBOT technology is moving in the right direction. If we can send people to the moon, we can move closer to getting disabled people beyond earthly barriers. There is cause for hope, I think.

While it is impossible to change the world to meet our needs, we can all make small changes that make a difference in our daily lives. We can install grab bars to make ourselves safer; get rid of carpeting and lay vinyl for not much money; create more accessible food preparation areas and find easy one-dish recipes. If we can accept and expect change, we can maximize our assets. Small changes create ways to preserve our independence, vital to maintaining self-esteem.

Maybe accepting change is where the practical physical aspects of our dilemma come together with the mental and emotional ones. What will be important to us in ten years depends much more on how we feel about ourselves, our own image of self-worth, than whether we walk with crutches or sit in a wheelchair.

We can't control what happens to us; no one can do that. For me, letting go of the will to control my life has made a difference. When I let go of the need to do things the way I always have, to do everything I always have, I am relieved. I have learned to stop a task and take a nap when I listen to my body's signals. I have learned to say NO to another activity or commitment even if I think I might enjoy it. Consequently, I have discovered a richer relationship with my family, and I am better company for myself. In creating this newer, healthier balance, I have learned to cease worrying

about things. The practice of joyful surrender has made this possible. And it is worth more to me than losing thirty pounds!

This mental adjustment to change did not come easily. My bad feelings often got in the way. When I finally knew I had to give up walking and sit in a chair, I felt bummed, sad, defeated again by this old illness that makes unannounced comebacks. I wondered if everyone felt that way. But after allowing myself these feelings, I saw the benefits of having made a sound evaluation. I knew I could trust my own intuition without waiting for a doctor to prescribe a wheelchair for me. So much of this struggle is with feeling. As a dear friend said to me after I'd made the choice, "You know, you have courage and intelligence. To walk would be foolhardy now. You'd risk a terrible accident and confinement from which you might never recover. Riding means you're taking care of yourself. It takes guts to see it and do it!"

I started riding permanently almost ten months ago and the effects were noticeable immediately. No more pain in shoulders and hands from weight bearing; much reduced daily chronic fatigue; no more huge expense of energy from paying attention to each and every step I took! Confining as the chair looked and felt in some ways, sitting in it also provided a "get out of jail free" card. The anxiety that accompanies fear of falling, the tremendous focus and concentration, the endless challenge that walking everywhere had become disappeared. I felt released from a burden, no longer bound.

I still walk a little almost daily so my muscles don't forget how to do that, and my body gets stretched. It feels good. I also love getting out alone in my minivan with the electric scooter in the back, ready to travel. The world invites me with increasing "blue spots," ramps, and wide doors. I appreciate my good fortune in having a home that

*(Continued on page 13)*

works for me, a decent pension from my teaching years, and a husband who is willing to help carry the burden.

Years of depression cost me a great deal of pleasure and isolated me in paralyzing fear of what was to come. Now, I trust myself to see the way. I'm having a life full of laughter, honesty, and some sadness as well. The sadness that accompanies loss is real. If I fail to admit that, I spiral downward into fear and wear myself out. Then comes depression with its slow, dull ache. I never go to these negative places if I let myself snarl and cry every once in a while. Even wail. I heartily recommend it.

I can't predict what will happen in the future

any more than any able-bodied person. Yet, if I open my heart and allow myself to feel my opportunities and blessings, I can set out each day as boldly as Huck Finn. At my age, I can ask the right questions and make increasingly discerning judgments about what is good for me and what I need to leave by the wayside as I continue this journey.

Healing the Blues

By Dorothea Nudelman and

David Willingham MSW.

dnudelman@sbcglobal.net

ISBN: 0-940168-31-6

[Why not ask your local library  
to get you a copy]

**You know you're living in 2004 when...**

1. You accidentally enter your password on the microwave.
2. You haven't played solitaire with real cards in years.
3. You have a list of 15 phone numbers to reach your family of 3.
4. Your reason for not staying in touch with friends and family is that they don't have e-mail addresses.
5. Every commercial on television has a website at the bottom of the screen.
6. Leaving the house without your cell phone, which you didn't have the first 20 or 30 (or 60) years of your life, is now a cause for panic and you turn around to go and get it.
7. You get up in the morning and go online before getting your coffee.
8. You start tilting your head sideways to smile. :) ☺
10. You're reading this and nodding and laughing.
11. You are too busy to notice there was no #9 on this list.
12. You actually looked back up to check that there wasn't a number 9 on this list.

AND NOW YOU ARE  
LAUGHING AT YOURSELF.

Johnny was shuffling along, bent over at the waist, as his wife helped him into the doctor's waiting room. A woman in the office viewed the scene in sympathy. "Arthritis with complications?" she asked.

The wife shook her head, "Noooo. Do-it-yourselfism" she explained, "with concrete blocks."

o—o—o

Yesterday my husband came home from his training session with his occupational therapist and said, "I have good news and bad news."

I knew it was the day his OT was deciding if he needed to continue using the three wheeler they had lent him when he left the hospital or to go into an electric wheelchair.

"The good news is, using the electric wheelchair, I got 18 out of 20 on my driver's test."

I said, "Great! Now what's the bad news?"

He said, "They were pedestrians..."

**AWAKE!**  
**Distributed to approximately**  
**22,530,000**  
**people throughout the world**  
**in 87 languages**  
**published this PPS article**  
**July 22nd 2004**

**“Once Stricken,  
Twice Afflicted”**

**AS TOLD BY JACK MEINTSMA**

*As a result of effective vaccines and diligent immunization programs, science has made great progress in its effort to eradicate polio, a debilitating childhood disease. However, even decades after recovering from polio, some survivors find themselves afflicted again, facing what is called post-polio syndrome (PPS)*

You may never have heard of PPS. Neither had I until it became very much a part of my life. But in order to understand the syndrome's effects on me, let me go back to a day in 1941, when I was about a year old.

My mother noticed that I was slumped over in my high chair. She rushed me to the doctor. After examining me, the doctor told my mother, "Your son has infantile paralysis." I was soon paralyzed from the waist down.

After six months on a waiting list, I was admitted to the hospital. Years of recurring illness followed. Through intense physical therapy, I gradually regained the use of my legs. At the age of 14, I was walking again. But other problems, such as incontinence, remained. Over the years, I went

through several cycles of surgery, confinement to a wheelchair, and physical rehabilitation. Still, my left foot is three shoe sizes smaller than my right foot, and my left leg is about three centimetres shorter than my right leg. It was not until I was in my early 20's that I got the embarrassing problem of incontinence under control. Finally, I was completely over polio-or so I thought!

Then, at age 45, I began to experience pain in my legs, followed by fatigue. Also, my leg muscles moved involuntarily at night, making it very difficult for me to sleep. The symptoms did not let up; they only worsened. You can imagine my surprise when I was diagnosed with PPS-44 years after my mother recognized my initial illness.

### **What Is Polio?**

Polio is a highly infectious disease caused by a virus that enters the body through the mouth and multiplies in the intestines. After invading the nervous system, the virus can quickly cause total paralysis. As the virus passes along to the brain and then to the spinal cord, initial symptoms are fever, fatigue, headache, vomiting, stiffness in the neck, and pain in the limbs. Many of the nerves stop functioning, resulting in paralysis of some of the muscles in the arms, legs, and chest.

But the body's recuperative powers are amazing. Nerves that were not affected by the virus send out new "sprouts," as if running extra telephone lines, to reconnect the muscle cells that were orphaned when their previous nerves died. A single motor neuron in the spinal cord may also grow terminal axon sprouts, which may

*(Continued on page 16)*

**Text box in the Awake! article  
On page 20**

### **‘Might I Have Post-Polio Syndrome?’**

Most experts require some combination of the following criteria to make a diagnosis of post-polio syndrome.

- A confirmed diagnosis of paralytic poliomyelitis in the past
- A period of partial or complete functional recovery followed by an interval (of at least 15 years) of stable neurological function.
- Gradual or sudden onset of muscle weakness, fatigability, muscle atrophy, or muscle and joint pain
- Possible problems breathing or swallowing
- Persistent symptoms for at least a year
- Exclusion of other neurological, medical, and orthopedic problems.

Not all polio survivors develop PPS, though as they are, they may naturally develop premature tiring and aging of overextended neural-muscle units. Furthermore, over half of polio survivors who go to their doctor with new symptoms do not have PPS. Notes one expert: ‘Sixty percent of polio survivors with new symptoms have a medical or neurological problem that is unrelated to polio and that problem may be treatable. Half the remaining patients have increasing orthopedic issues related to their polio residua.’

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. ALWAYS consult your doctor before trying anything recommended in this or any other publication

### **EDITORS NOTE**

The following is the preferred criteria for a Diagnosis of PPS used by the Lincolnshire Post Polio Network since 2000.

### **CRITERIA FOR A DIAGNOSIS OF PPS FROM 2000**

1. A history of remote paralytic polio

*or*

*findings on history, physical examination results, and laboratory studies compatible with polio virus damage of the central nervous system in earlier life*

*Halstead L, MD - Silver J, MD  
Am. J. Phys. Med. & Rehab.  
Jan/Feb 2000*

2. A period where we recovered.
3. A stable period of functioning, from 10 to 50+ years.
4. New symptoms with no other explanation

Diagnoses were given at the time of polio on evidence of infection by Polio Virus I, II, or III and the level of clinically observed paralysis or weakness to any part of the body.

60%+ nerve damage  
clinical paralysis evident.  
Diagnosis Paralytic Polio.

45% - 59% nerve damage  
clinical weakness evident.  
Diagnosis Non Paralytic Polio.

Clinical weakness NOT observable  
below 44% nerve damage.  
Diagnosis Abortive Polio.

**Articles by Bodian D and Sharrard WJW**

**Text box in the Awake! article  
On page 21**

## **Is There a Cure ?**

Just as there is no confirmed etiology, or cause - and thus no definitive laboratory test – there is really no cure at the present time for post polio syndrome (PPS). There is, however, treatment revolving around three-pronged rehabilitation approach. Says one expert: “More than 80% of patients with PPS will demonstrate benefit with rehabilitation techniques.

The three approaches are:

### **1. Lifestyle Modifications**

- 1 energy conservation
- 2 assistive devices
- 3 non-fatiguing exercise
- 4 staying warm

### **2. Medications and supplements**

Though many medications, prescription as well as natural supplements, have been tried, none has been proved to help. There are many anecdotal reports of improvement, but further study is needed. Keep in mind that herbs can interact with prescription medicine, so always let your physician know what you are thinking of taking.

### **3. Quality of Life**

The strongest medicine that a practitioner can provide to a patient with PPS is education and encouragement. . . . Patients who were better able to make lifestyle modifications (those with better problem-solving skills, more accessible environments, more access to information and support, and a readiness to compensate with assistive devices) adapted better in their daily occupations.” - Dr. Susan Perlman.

*(Continued from page 14)*

connect to many more muscle cells than it did originally, thus greatly increasing the neuron's capacity. A motor neuron that previously stimulated 1,000 muscle cells might eventually reconnect to between 5,000 and 10,000 cells. This is evidently what happened in my case, so that I am able to walk again.

However, it is presently thought that over a period of 15 to 40 years, these neural-muscle units may begin to show signs of fatigue because of being overworked. PPS is a condition that causes symptoms to reappear in individuals who had recovered from polio decades earlier. Many victims experience muscle weakness, fatigue, joint and muscle pain, cold intolerance, and breathing problems. Though accurate figures are hard to obtain, the World Health Organization estimates that there are 20 million polio survivors worldwide. Current evidence indicates that 25 to 50 percent of them are affected by PPS.

## **What Can Be Done to Help?**

Researchers suggest that the old, overworked motor neuron becomes so exhausted that some of its nerve endings die, leaving many muscle fibres orphaned once again. To slow this process, a polio survivor needs to reduce the demand on the affected muscles. Some therapists recommend assistive devices, such as canes, braces, crutches, wheelchairs, and scooters. In my case, it became necessary for me to wear braces on both of my legs and feet. I also have specially made shoes that support my ankles and help to keep me from falling.

*(Continued on page 17)*



(Continued from page 16)

Moderate exercise and muscle stretching may also be required, depending on one's condition. Swimming or warm-water pool therapies are excellent means of improving cardiovascular function without straining the muscles. It is important for the patient to cooperate with the doctor or the therapist in any exercise program.

In polio survivors, repeated demands on the neurons ultimately result in the failure of some muscle fibres to work properly. Survivors may thus experience a decrease in stamina or even suffer debilitating fatigue. Loss of stamina may also result from the stress of constant pain or of dealing with a returning disability. I have found that periods of rest during the day help me recover from fatigue. Many doctors caution their patients to pace their day-to-day activities rather than push themselves to the point of exhaustion.

In my case, constant joint and muscle pain has been one of the hardest things to deal with. Some may experience muscle pain particularly in those muscles that they have strained during their usual daily activities. Others experience a flu like aching in all their muscles, along with exhaustion.

Pain may lessen with anti-inflammatory or other types of medication. But despite medications, many polio survivors suffer from disabling chronic pain. Physical therapy along with heat and stretching may help. A sufferer who gave up her practice as an anaesthesiologist told me, "I could get out of this wheelchair and struggle across the room, but the

(Continued on page 18)

### **Text box in the Awake! article On page 22**

#### **What About Exercise?**

Early on, recovering polio survivors were encouraged to exercise "until it hurts." Then In the 1980's, they were warned about the dangers of exercise, essentially about "using up" their viable muscle tissue.

Today experts recommend a path midway between those two extremes. Their message now is, 'Don't overdo it, but beware of inactivity.' The National Center on Physical Activity and Disability says: "New knowledge tells us that no matter what our level of disability is, we should be encouraged to value exercise, enterprising enough to come up with a highly customized plan and enduring enough to reap the rewards..

In summary, an individualized exercise plan should:

- 1 Be developed in conjunction with a knowledgeable physician or physical therapist
- 2 Start at a slow or moderate pace and progress gradually
- 3 Include warming up before and cooling down after
- 4 Focus on stretching and general aerobic exercises
- 5 Include warm-water pool exercise, if available

Says one expert in *The Johns Hopkins Medical Letter*: "Tiredness and pain persisting beyond an hour indicate that muscles have been over-used." So listen to your body and avoid pain, fatigue, and weakness.

(Continued from page 17)

pain is so great, it isn't worth it." Now, even with medication that helps, I must frequently resort to my wheelchair.

Some polio survivors have lost the ability to shunt blood away from the skin, which the body normally does to conserve heat in the muscle tissues. Without this ability, an affected limb will radiate more heat and cool down. When the muscles are cold, poor communication from the motor neuron to the muscles results, and muscles do not work properly. Thus, it is important to keep the affected muscles warm by wearing extra clothing. Some use an electric blanket or a hot-water bottle during cold nights. Avoiding exposure to cold weather helps. I found it necessary to move to a warmer climate.

Breathing problems are common, especially among those with a history of bulbar polio, a form of polio that affects the spinal cord in the upper neck and thereby weakens the breathing muscles. In times past, this type of polio landed many people in an iron lung. Today, a ventilator may be used to assist weakened lung muscles. In my case, it is very hard for me to breathe when I exert myself. Therefore, every day I use a small device to exercise my lung muscles.

Survivors need to be aware of another potential difficulty. It is not advisable for them to have surgery and then return home the same day. Dr. Richard L. Bruno, of the Kessler Institute for Rehabilitation, states: "NO POLIO SURVIVOR SHOULD HAVE SAME-DAY SURGERY FOR

(Continued on page 19)

## Text box in the Awake! article On page 23

### What are the Risk Factors?

Though every case is different, the following factors may increase the risk of a polio survivor developing post-polio syndrome:

- Severity of initial polio infection. Generally speaking, the more severe the initial polio, the higher the risk of PPS.
- Age at initial onset. Those who got polio at a younger age are actually less likely to face PPS.
- Recovery. Surprisingly, the greater and more complete the initial recovery, the greater the chance of eventually developing PPS.
- Physical activity. If a polio survivor has been in the habit of exercising to exhaustion over the years, this may increase the risk of PPS.

#### Editors Note:-

N.B. Facts in medical articles are based on published statistics, information and the personal details obtained from the people involved in the survey at the time the article is written.

The articles that these facts were taken from were written some years ago. Many more polio survivors are now coming to the fore with their experiences of new problems of unexpected functional decline. It is therefore possible that the bulleted facts above could be revised.

*(Continued from page 18)*

ANY REASON [see end of article] except for the most simple procedures that require only a local anaesthetic." He adds that polio survivors require twice as long to recover from the effects of any anaesthetic and may need additional pain medication. Their stay in the hospital will usually be longer than that of other patients. If I had known that, I might have been spared a bout of pneumonia following a recent minor surgery. It is wise to discuss these concerns with the surgeon and the anaesthesiologist before surgery.

### **My Life Today**

When I was able to walk at the age of 14, I thought my problems were, for the most part, behind me. However, after many years I find myself experiencing the same problems all over again. For polio survivors like me who develop PPS, the situation is, as one writer put it, "Once stricken, twice afflicted."

Of course, it is only normal to get discouraged at times. Nevertheless, I can still get around and take care of myself. I have found that the best medicine for me is to have a positive attitude, to adjust to changing circumstances as they develop, and to appreciate what I can still do.

For example, when I started in the full-time Christian ministry about ten years ago, it was easier for me to get around than it is now. I was able to walk for a considerable distance before tiring or experiencing much pain. Now, however, I can only walk a very short distance. To conserve energy, I try to avoid climbing stairs and walking up hills, I use my wheelchair whenever possible. By adapting my ministry in various ways, I find it very enjoyable and even

therapeutic.

Yes, PPS does affect my life. It is possible that my health will worsen. But I find great comfort in the Bible's promise of a new world in which all will be young again, with full health and mightiness. Over the years, I have often thought about the inspiring words of Isaiah 41: 10 "Do not be afraid, for I am with you. Do not gaze about, for I am your God I will fortify you. I will really help you." With God's help, I am determined to keep going until PPS is a thing of the past.

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**[Editors note:- Articles on anaesthesia can be found:-**

- **one on the next page**
- **on our Website as below [If you do not have internet access please send s.a.e]**

### **Bruno RL—**

- Title: Preventing Complications In Polio Survivors Undergoing Surgery
- Title: Be True To Your PPS And Your Teeth Won't Be False To You: Preventing Complications In Polio Survivors Undergoing Dental Procedures

### **Walker J**

- Title: Polio Survivors as Patients - Guide for Emergency Care & Surgical Health Workers LEAFLET
- Title: You are going to have surgery - A Guide for Polio Survivors LEAFLET

**SUMMARY OF ANESTHESIA ISSUES FOR POST-POLIO PATIENTS:**  
**SELMA H. CALMES, M.D. CHAIRMAN AND PROFESSOR**  
U.C.L.A, DEPARTMENT OF ANESTHESIOLOGY, OLIVE VIEW, UCLA MEDICAL  
CENTER, 14445 Olive View Drive, 3A-113, Sylmar, California 91342-1495  
Ph 818 364 4350 Fax 818 364 4775 - pager 818-529-0325,  
email scalmes@dhs.co.la.ca.us)

Polio results in wide-spread neural changes, not just destruction of the spinal cord anterior horn (motor nerve) cells, and these changes get worse as patients age. These anatomic changes affect many aspects of anesthesia care. No study of polio patients having anesthesia has been done. These recommendations are based on extensive review of the current literature and clinical experience with these patients.

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is due to central neuronal changes, especially in the Reticular Activating System, from the original disease.

2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the polio virus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intraop helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.

3. Succinylcholine often causes severe, generalized muscle pain postop. It's useful if this can be avoided, if possible. There is no experience with Raplon yet.

4. Pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multimodal postop pain control (local anesthesia at the incision plus PCA, etc) helps.

5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.

6. Patients who use ventilators often have worsening of ventilatory function postop, and some patients who have not needed ventilation preop have had to go on a ventilator (including long term use) postop. The marker for real difficulty is thought to be a VC < 1.0 liter. Such a patient needs good pulmonary preparation preop. Another ventilation risk relates to obstructive sleep apnea in the postop period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

7. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fracture during positioning. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

## COMPETITION

Since you travelled the path from full recovery to being less able have you had things said to you have made you wince. You know, 'Does she take sugar?'

As many polio survivors are:-

- going from the height of standing to the height of sitting on electric scooters and wheelchairs
- Visiting or being visited by a variety of health professionals and government officials whose knowledge of polio, pps and disability is a bit sparse
- visiting places, Museums, Malls, seaside resorts, hotels, motels, airports, etc
- in fact just becoming less able

we are having some really funny [although it did not feel like that at the time] things said to us.

At the AGM we thought it might be fun to get some stickers made up to express our thoughts. Have you got any phrases, one liners that you would share with us.

There will be two prizes of £10. One for the one that makes us laugh the most and the other for the one that reflects how we feel now PPS has altered the way we live our lives. Don't be shy, oh!, and not too rude. Come on folks this time lets hear from at least 50% of the membership.

To give you an idea. When Hilary and Richard visited a museum in Florida a couple of years ago. They unloaded two sets of wheels from their vehicle. Rode to the huge front door of the museum [about 24 foot high by eight foot wide]. Almost as if they had said 'Open Sesame' both doors opened wide. They thought 'That was helpful but one door would have been more than enough.' They wheeled up to the payment desk. There was no-one there. They turned to find the two people who had opened the doors still there looking around.

'Where is the rest of your party?' We are it.  
'Where are your carers?' We pointed to each other.  
'Oh! Do they let you out alone?'  
What we thought was definitely not printable.

What wording can you think of to put on a sticker for our wheels or to be made up into cartoons for the newsletter. Plus if anyone can make cartoons from the phrases sent to us we would be really grateful. Maybe you would just like to tell your story. Help make our readers laugh.

**Entries by email to [newsletter@lincolnshirepostpolio.org.uk](mailto:newsletter@lincolnshirepostpolio.org.uk)  
Or by post to LincsPPN address.**

**Entries by November 25th please.**

## TRAVELS WITH A WHEELCHAIR

Alan Russell visits Vienna  
May 2003

First published in issue 29 (Spring 2004) of "discover", the magazine for disabled people by disabled people in Cornwall.

I have a pen friend who lives in Vienna, who I have only met twice before when we have stayed in the Salzkammagut area of Austria, and when she invited us to stay with her in Vienna, we jumped at the chance, as we knew the eastern Tyrol area and the central Salzkammagut area, but the western part of Austria, where Vienna stands, was new country for us.

We managed to book return flights from Heathrow to Vienna with Air Austria for £100 each over the internet, which is cheaper than flying from Penzance to the Isles of Scilly, and I have to say, the service was superb. After checking in at Heathrow, we were offered to be accompanied to the gate, but as I was allowed to keep my power chair until boarding I declined. At the gate we were boarded first and I watched as my chair was loaded in the luggage bay under the aircraft. We were not allowed a bulkhead seat as on this aircraft, they are also exit seats and disabled, elderly and children are not allowed to sit there, as persons in that seat must be able to help other passengers escape in the case of a crash. Oh yes, the plane is sinking in the English Channel and all those kind people are going to stay on board helping others to get out. I think not. If it was me I'd be gone like a Gypsy's lurcher. I will say though that I had plenty of leg room and even though I wear callipers I was very comfortable.

Irene was waiting for us as we exited the arrival hall, and was most surprised how much help we received in collecting our bags. I still don't understand though why as EEC citizens we still have to go through customs and immigration. I thought we were members of one state. Nonetheless, we had a great flight with no complications.

We loaded our stuff in her car, and were instructed to use the toilet as we were not going home yet. How domineering these continentals are!! We obeyed and for the next few hours we were taken on a tour of the area west of Vienna, almost to the Hungarian border. It was so varied, consisting of a large wine growing area, huge lakes which to the Viennese are the equivalent of our seaside beaches, with sandy edges, bathing, boating and even wind surfing. The whole area abounds with numerous stately homes and monasteries, nearly all open to the public at no charge, and furnished in the most extravagant manner. In Austria, the church receives a lot of money raised in taxation from the state, and it shows. The gold altars are a sight to behold and are truly breathtaking. I never got bored with looking at them.

Irene's apartment was in the centre of the city, but the area was so quiet and clean you would never have guessed. The first morning, over breakfast, we were told that we were going to church, which came as quite a shock, as we are not Catholics. We are however great lovers of classical music, so it came as a very pleasant surprise to find that the service consisted of Schubert's Mass in B, sung by a 40 strong choir accompanied by a full orchestra. It was wonderful to hear it for the first time sung in its true context of a catholic church that Schubert himself attended. The church was situated next door to the Lipizzaner stables, but the Spanish riding School were away, so there was nothing to see, but just down the road was the famous Hotel Sacher, home of the famous sacher-torte. Well you can't go to Vienna without a taste of the most famous chocolate cake in Europe, so we didn't, and oh boy! Was it worthy of its fame? Hmmm

There is so much to this area than the City itself. A visit to the Vienna woods, showed that it is more than just a forest, with lots of open space and historical places, where

*(Continued on page 23)*

murder and intrigue involving the royal family, stand cheek to cheek with monasteries, and convents. We made a visit to a wine grower, and as I was not driving I was able to indulge my love of wine whilst taking a tour of the family concern, accompanied by the owner himself. In this area, a lot of the growers are vintners also, and instead of selling the wine to wholesalers, sell their wine in their own premises called "Heurigan". In these you buy the wine by the glass, and eat really good food usually made by the wife. Evidently, when these 'new wines' run out, the particular heuriga close until the next vintage is ready, but I believe they usually manage to last out. Sounds a good system to me.

The city of Vienna itself is truly spectacular. It is compact and easy to cover. We had a personal guide (not cheap at 100 euro for a day) to show us around, but felt it was money well spent. To get around the area they have a system of disabled transport where by pre-booking, a mini-bus will collect you and your family and take you where you want to go and then come and collect you when you say, all for the sum of 9 euro. It is subsidised by the government, and available to all disabled people. We used it again when we visited the Schonbrunn palace, which houses a great zoo, botanical gardens, a palace and immaculate grounds, together with a miniature train which traverses the grounds on a regular basis allowing visitors to get on and off at will. The whole of this area is wheel chair accessible.

The beautiful Blue Danube, Vienna's much acclaimed heart, actually doesn't flow through the city any more (an offshoot canal does though), neither is it blue, but the riverside area is truly breathtakingly beautiful. River trips run at regular times from outside the city and are well worth taking. On a trip you sail majestically past vineyards, castles, more monasteries and some of the most outstanding countryside imaginable. Another Viennese sight to visit

is the Prater, Vienna's answer to Battersea fun fair. It is a permanent fair and great fun, being full of all sorts of rides, including the oldest big wheel in the world, and the oldest horse drawn roundabout. Interestingly in the middle is the biggest outdoor restaurant I have ever seen. Here waiters rush round, serving about 250 customers, with trays held high crowded with litre glasses of beer (weighing up to 20 Kilos in all), but the strangest thing is the fare. It consists of 2 kilo roast legs of pork accompanied by sauerkraut, potato salad and pickles. All portions come in one size of 2 kilos, and if it is not enough you order more, if it is too much they supply doggy bags for you to take it home. You all sit at long tables and it is a very social event, a good chance to meet the Viennese on their own ground.

I fell in love with this beautiful part of Austria. It was clean, convenient, and very accessible. As a music lover there is so much choice, (a lot of which is free as it is in church), with the famous Opera House as well as the Volksoper, in which was being performed 'The Pirates of Penzance' in German! If you are not a music lover there is so much else to see. You don't have to be an intellectual to enjoy Vienna, but there are loads of museums and art galleries if you are. The buildings are incredibly interesting and even more so when accompanied by a guide. The shopping is to die for and many malls make life very easy for those with walking difficulties. I would recommend it to anyone, even if your difficulties are severe, as you will need to miss very little, and being a compact city, I found it not too tiring. I can't wait to go back. Many thanks to my friend Irene for being such a wonderful and knowledgeable hostess.

*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)*

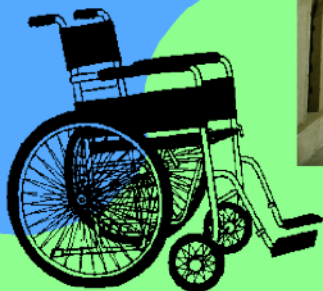
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**Vienna**



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Photographs by Alan Russell  
Wheelchair graphic by Patricia Clouse  
Layout design by Chris Salter