



The LincPIN

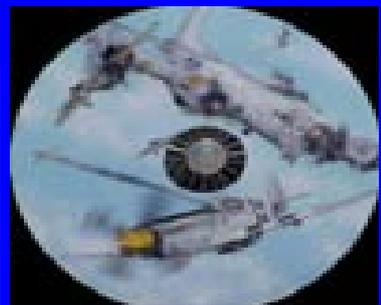
The **Lincolnshire Post-Polio Information Newsletter**
Volume 4 - Issue 8 - February 2004

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

How do you decorate yours?



Canes by Ellen Riddle
Our One Arm Bandit
Spokeguardart.com
"Greyhorse" - alias
Bruno Supercub 34



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ALWAYS consult your doctor before trying anything recommended in this or any other publication.
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WE WOULD LIKE TO THANK THE FOLLOWING FOR DONATIONS RECEIVED TOWARDS OUR WORK.

UK Account totalling £211.00 R. Watts - Carol Collins - Alan Standen
Anon donation of £50.00 - Anne Wood - Victor Gabriel - Diana Nash
Mrs B Bowles [wife of the late John Bowles] Yvonne Liggins
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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'

(UK £ post to Membership Sec, 78 Heron Road, Larkfield, Aylesford, Kent ME20 6JZ, UK
(US\$ checks post to Lincs PPN. c/o 4212 Blanding Blvd, Jacksonville FL 32210, USA)

UK Membership - Life Member (LM) £150 or £5 x 30 months S.O. - Member £10 a year.
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Overseas Newsletters by Airmail.

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 - April 2004

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

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Editorial - Another two months have passed by and we are now nearly into Spring of another year... time seems to go faster as we get older. I am told that is because we have more length of life to base this on.

Can I please ask - and I do this newsletter after newsletter - for items for the newsletter, for your stories, your hints and tips, questions, comments. It is extremely frustrating to learn that someone is not renewing their membership because the newsletter does not contain what they want to read... why not tell us during your membership?

Living with PPS is not easy; managing daily tasks is sometimes more than we can do; so many of us are doing less and less of what we want to do. Most of your committee have PPS and are giving up some of their energy to provide information for you. We can only print information that we find, items that are sent to us, and within the energy and financial level that we work under. We are all volunteers and do NOT receive full expenses for all we do. We need more help, but as with all medical support groups getting that help is not easy. Help us by telling us what you think is missing from the newsletter, by asking questions, by telling us about something that you have found works for you, etc.

It does not matter which country information comes from, PPS is PPS. The only difference is how health care is provided in the country that you live in. Post Polio Support Groups across the world share information and articles. Without the Internet and the ability to do this... where would we be? How many of us would know PPS existed? It took me 7 years of medically noted yet unexplained problems and unnecessary fast decline before I stumbled over PPS. I have talked with many UK folks on the phone who have gone years and years and seen health professional after health professional without anyone

mentioning their polio. This includes people wearing callipers/braces, atrophied limbs, in wheelchairs all their life since polio and folks who were in iron lungs.

This is the 44th newsletter and together they provide a huge insight into the Polio and PPS world. Every issue I hear from one or two people who tell me how their health professional found a recent article useful in helping diagnose or treat them.

This newsletter contains information about problems that polio survivors have experienced with surgery and emergency care. Personal stories were added to the main article and I have not been able to include them all in this issue but have added excerpts to give you some idea of their content. If anyone would like copies of any of these then please let us know. I would like to express my thanks to members Phyllis Hartke and Stella Cade from San Francisco Bay Area PPS Support Group for their constant contact and sharing of information. If the information in this newsletter prevents just one member from having the problems itemised then the inclusion of this item has been worth it.

I have also included information from some of the Neurological Alliances that our members are working with. Services in Lincolnshire have improved considerably since 'expert patients' have been allowed to take part in discussions and plans for the future of our health service. This is a slow process. It takes time to train new staff and find the finances to pay them. Working together we can no longer be dismissed as 'not enough of you'.

Carers, family members and friends reading this newsletter please start sharing with us how you feel about PPS and the changes its making in all our lives. See A Daughters Dream on page 7.

Mar-y-Mail

"Welcome to Mar-y-mail - items from our on-line e-mail enquiries to your newsletter, in the click of a mouse. Edited, filtered, spam-free and guaranteed Mi-doom-and-gloom-free (!). We hope you will enjoy the tit-bits on offer in this section.

I'm Mary Kinane and I've been dealing with on-line enquiries for the lincolnshirepostpolio.org.uk website since the beginning of January.

While most of our enquiries are confidential and not the stuff of newsletter fodder, we sometimes receive material which contributors are only too happy to share. With their permission, we have printed some contributions below.

Readers are welcome to send us short articles for publication in future editions of the newsletter - after all, this is YOUR newsletter and we want YOUR views, your stories about living with PPS, your humorous moments, your take on how the medical profession is responding to your needs (or not as the case may be), you name it, we want to know! Please send items by snail mail (post) or to mary.kinane@lincolnshirepostpolio.org.uk

Bungalow for Sale

For Sale Mobility Friendly 2 bedroom bungalow in purpose built complex with care on hand if needed.

Eastbourne East Sussex.
For details Tel. 01323 460369
E-mail M.A.Norfolk@btinternet.co.uk

Marie Norfolk

Aloha,

I am currently finishing a book that will be published in October of this year entitled, *The Christmas House*. It chronicles the story of his struggles with polio, which he contracted during the Depression in the 1934 epidemic.

This is an uplifting story about one man's dream that changed the way we celebrate Christmas. I wondered if your network might be interested in adding this book to your offerings for members, since it tells of the will to survive great obstacles set in a holiday theme.

Many thanks
Georja Skinner
author, *The Christmas House*
release date: October 2004

Greetings,

My name is Lisa Miljevic and I'm writing to let you know about a new business that my husband and I recently started for those of us that use a wheelchair for transportation. I have been in my chair ten years and after that long it has become a part of me, so what we have done is developed a new spoke guard made of a durable yet flexible plastic that you can literally bend right in half. Then we bevelled the guard for a snug fit on your spoke. To make the guard unique or custom we put art on the guard to create Spokeguard Art.

We offer our art, your art, logos or photos to personalize your chair to you. The guards are a blast to wear and are a good conversation starter with others to break the ice and the phobia of the wheelchair. We also have the ability to print (silk screen & iron on transfers) T-shirts whither they match your guards or not. Because I sit in a wheelchair understand how the writing or print gets

lost in the fold of your shirt or belly. We work with you to design the shirt so the front and back are legible. Please feel free to check out our web site (www.spokeguardart.com) for more information on SGA or call 1 877 ROLLART. Thank you for your time and I look forward to hearing from you.

**Sincerely,
Lisa Miljevic
member - UNITED WE ROLL**

Hi, my name is Doris Mullen, I live in Oceanside, California.

When I realized that I was developing postpolio I ran to the net for info... and probably would never have doctored for it at all, except that I happened to acquire a job with exceedingly good medical insurance. I believe that there are many polio people out there who are not bothering to doctor for this..... I have written my story and I think it is important for any of the polio people who never had the acute disease with paralysis or had it so young that they don't remember.

My polio story won't apply to most of you, but a few people might be helped a lot. It begins very typical-but ends very different: Polio as an infant, 2 childhood orthopedic surgeries on "polio foot", active and even a bit athletic in 20's and 30's, got lazy in 40's and out of shape (maybe noticed that polio leg was slightly weaker.

Stairs were slightly harder work in late 40's but I ignored it, planning to "get back into shape soon". Age 50, finally decided to get into shape, trying to bike and jog a very short distance at first. It kept getting more difficult until, I realized I couldn't raise my right leg sideways at all! And I had always assumed my polio had

affected only below my knee! I ran to the net and learned about post polio. I was careful to refrain from overuse. As was true with a lot of my "post polio friends" I realized that eventually if I kept getting weaker I might need to go onto Social Security Disability.

I started doctoring to get a diagnosis of post polio onto my medical records, as I was advised to do. I was tested to rule out other problems, negative, of course--until the MRI-lipomyelomeningocele!!!! A congenital neural tube defect related to Spina Bifida! Correctable with surgery! I ran to the net again and to my surprise discovered that it causes orthopedic deformity just like mine -- and just like polio.

It took a few minutes to really sink in that I never had polio at all, or post polio and according to my neurosurgeon, overuse is not an issue. What I need to avoid until I get the surgery is any jolting or bouncing moves, or stretching. I had been stretching a lot.

How could I have been so misdiagnosed? My mother was alone during a polio epidemic of the early 50's, My father away in the service and she had no transportation and was far from a hospital. I got very sick with a fever, she called the hospital and nurses told her to keep my legs in very hot water. The next day I broke out with the measles. A few years later at age five, the doctors, looking at my "polio foot" pronounced the diagnosis that it had indeed been polio.

This is not common, but there must be other people out there with this condition that so closely mimics polio and post polio. Try this link: www.lfsn.org/lipomyel.html or just put in lipomyelomeningocele and adult into a search engine or "tethered spinal cord".

(There also can be some visible signs at the base of the spine, which I have, and many doctors have seen. They just took my word for it that it was "just a birthmark".)

I've since had the surgery to repair the defect and stop the degeneration. My neurosurgeon says that indeed there are probably hundreds of other people out

there that have been misdiagnosed. I would like to reach everyone in the post polio world with this information. Anyone who can't remember an acute illness of polio should consider this a possibility. The great thing is - this degeneration can be stopped with surgery!

I welcome any feedback. Email me at medoris@yahoo.com (Please put polio feedback in the message line so I don't think it is spam.)

NEW DRUGS

DAMNITOL

Take 2 and the rest of the world can go to hell for up to 8 full hours.

ST. MOMMA'S WORT

Plant extract that treats mom's depression by rendering pre-schoolers unconscious for up to two days.

EMPTYNESTROGEN

Suppository that eliminates melancholy and loneliness by reminding you of how awful they were as teenagers and how you couldn't wait till they moved out.

PEPTOBIMBO

Liquid silicone drink for single women. Two full cups swallowed before an evening out increases breast size, decreases intelligence and prevents conception.

DUMBEROL

When taken with Peptobimbo, can cause dangerously low IQ, resulting in enjoyment of country music and trucks.

FLIPITOR

Increases life expectancy of commuters by controlling road rage and the urge to flip off other drivers.

MENICILLIN

Potent anti-boy-otic for older women.

BUYAGRA

Injectable stimulant taken prior to shopping. Increases potency, duration and credit limit of spending spree.

JACKASSPIRIN

Relieves headache caused by a man who can't remember your birthday, anniversary or phone number.

ANTI-TALKSIDENT

A spray carried in a purse or wallet to be used on anyone too eager to share their life stories with total strangers in elevators.

NAGAMENT

When administered to a husband, provides the same irritation level as nagging him all weekend, saving the wife the time and trouble of doing it herself

CAN YOU COME UP WITH SOME LIKE THIS. DRUGS, MEDICAL TREATMENT, DISABILITY ISSUES ETC?

TIT BITS

From the US Copyright Office, "The use of a copyright notice is no longer required under U. S. law" (since 1989). In other words, copyright automatically exists right from the moment of creation; no notice or symbol is required!

A trailer for a program came on last night.... dont put fresh produce in the seat part of a shopping trolley [cart] because germs can be left by little bottoms sitting there....

A Daughters' Dream

I have always had so much respect for my mother. She has always been so strong and independent, I could ask her anything and she would know the answer.

For years and years she has been my support system, teaching me how to cope with the things in life. Then suddenly she started to have problems that she could no longer shield me from. It was like a slap in the face!

" What do you mean you're struggling? You can do anything" My rock was starting to crumble and I hadn't even noticed the cracks. The person I wanted to be like could no longer cope, so how the hell was I going to cope?

I had been so sure I knew what my future held, but not anymore.

What sort of relationship was I going to have with my mum and she with her grandchildren.

Picture the scene.....

It's Christmas day and the whole family is sat together opening their presents. My mum is sat on the floor playing with the grandchildren and their new toys.

"Come on kids get dressed we're going outside to build a snowman! "

When they finally come back inside cold and tired mum gets on with cooking the dinner. After dinner we watch the Queens speech and then go for a walk round the park and feed the ducks.

We get back to a nice warm house and mum flops in the chair exhausted, but satisfied that everyone has had a great

day.

I know this might sound selfish but that's how I imagined things.

Not only is mum unsure of her future but so am I. My mind starts racing...

Will she get worse?

Who will help her?

What help does she need?

Why is this happening to me?

So as time goes on mum finds out what things she can do to help herself and comes to terms with her illness.

She hasn't really spoken to me about the future and what she thinks will happen, so I make my own mind up.

I don't want to accept what's happening, I'm angry and upset, but most of all I'm scared.

THE REAL QUESTION IS:-

Is she the only one living with her illness?

Alison Hallam

alison.hallam@ntlworld.com

Responses to this article are most welcome from Polio Survivors, their carers, family and friends.

We really need to learn more about how others view what is happening to us and how we cope with life, medical appointments, worries about our future and the arrival of brown enveloped benefits correspondence!!!!!!!

I so remember my daughter reading aloud from a Form.. Do you have an In-valid carriage? [not valid] "What on earth is an in-valid carriage?" Laughing I told her its invalid... I saw the frustration I experienced as she read this form.

BOOK REVIEW:

Title: POST POLIO SYNDROME
Authors: JULIE K SILVER and ANNE C GAWNE
ISBN 1 - 56053 - 606 - 3
306 Pages.
Price varies with Seller \$29.95 to \$37.00
Publisher: HANLEY AND BELFUS
PHILADELPHIA, USA
Date: 2003

This new encyclopaedic handbook, written by a wide range of authors, provides expert opinion in every aspect of treatment for the post polio syndrome. Its 18 chapters include more than 1000 references as well as 300 diagrams, photographs, tables and other graphic information. Each of the 18 chapters deals with a different axis of treatment ranging from diagnosis to the psychological well-being of survivors.

Beginning with DIAGNOSIS the modern approach to inclusion and exclusion criteria is explained, always remembering those in which a diagnosis of polio cannot be made because of the absence of special diagnostic tests. In the older age groups individuals may well need urgent treatments for confounding illness. A careful history must **always** be taken before the EVALUATION AND TREATMENT OF SYMPTOMATIC POLIO PATIENTS.

The chapter on INTER DISCIPLINARY TEAM ASSESSMENT, so necessary to streamline what may be a long and complicated course, is written by the co-editor (Anne Gawne) who unfortunately died before the entire book was completed. It is one of the best chapters in the book and clearly demarks the special roles of CLINIC CO-ORDINATOR (essential to spare time-wasting energy) and of the PHYSICIAN, REHABILITATION NURSE ORTHOTIST, OR SOCIAL WORKER, whoever the patient can trust or feel most comfortable with throughout a long course. (PRIMARY CARE is usually unreliable because of lack of specialist knowledge and availability).

Referrals to other team members can then be made including:-

The PHYSIOTHERAPIST (evaluation of muscle strength) and mobility of joints, posture, gait, and of scoliosis. Mobility issues, and the opportunity to try manual wheelchairs (which may damage arm muscles) as well as power operated vehicles, come under this heading.

The OCCUPATIONAL THERAPIST addresses the patients' independence in the home or at work and the necessity for careful management of energy. They may plan the daily and weekly schedule of tasks, prescribe power-saving devices, initiate upper extremity stretching, and provide splints and other devices to protect weak muscles.

THE ORTHOTIST evaluates gait and bracing needs, with special attention to the ankles, feet and appropriate shoes.

A CLINICAL SOCIAL WORKER OR PSYCHOLOGIST may be essential to aid coping strategies within the family and to help "Passers" using denial to hide their physical

impairment and "Minimisers" who attempt to deny the pain and physical challenge of Polio's late symptoms. "Identifiers", sufficiently disabled to have adopted the idea that high achievement is a requirement for survival, may also appear to be difficult and demanding and develop depression, which is significantly associated with a lack of treatment compliance. In these cases, mental health professionals may be able to assist in management.

Further essential and interesting chapters are devoted to the work of

- * RESPIRATORY THERAPISTS,
- * PODIATRISTS,
- * PHARMACOLOGISTS
- * SPEECH THERAPISTS.

There are valuable articles on

- * THE ELECTRO PHYSIOLOGY OF THE POST POLIO SYNDROME,
- * JOINT AND MUSCLE PAIN,
- * POST POLIO FATIGUE,
- * PULMONARY DYSFUNCTION,
- * SPEECH AND SWALLOWING PROBLEMS AND
- * EXERCISE (which still remains a controversial subject, requiring very careful application in relation to muscle weakness). The caveat appears still to be one of balance with appropriate rest.

The following 3 chapters are a lengthy and well documented study of Exercise and Aquatic therapy in chronic polio and the post-polio syndrome.

These are followed by articles on THE SCREENING AND TREATMENT OF FOOT AND ANKLE PROBLEMS, GAIT, ORTHOSES, FOOT WEAR AND ASSISTIVE DEVICES AND POWERED MOBILITY.

The book concludes with 4 chapters on OCCUPATIONAL THERAPY, ENERGY CONSERVATION AND PACING, AGING WITH POLIO AND THE PSYCHOLOGICAL WELL-BEING OF SURVIVORS FROM POLIO.

This is truly a "good buy" for patients, carers and professionals and I congratulate Julie Silver on completing it alone. However, this is not about a single "dream" clinic, but a fair account of a large number of individual clinics, departments or other establishments in Canada and the USA that have added their experience and wisdom to those of us able to profit from it - especially the patients!

Life Member - Dr. E.G. DOWSETT, JANUARY 2004

Dr. Julie K. Silver. The International Rehabilitation Center for Polio at Spaulding, Massachusetts, USA. Our non-profit center is dedicated to treatment, research, and innovation in the field of post polio treatments. We offer state of the art facilities with a world class staff well trained in the field. We are affiliated with the Harvard Medical School and Spaulding Rehabilitation Hospital. [www.polioclinic.com]

PURSUING POLIO CAUTIONS

Are you diligent in exploring and exercising caution when being treated for seemingly Non Polio Related Medical Treatments and Procedures or when getting Emergency Care?

No Polio Survivor can ever be too diligent in following these cautions...

**By: Phyllis Hartke, SFBAPS President
Life Member, LincsPPN.
phartke@aol.com (January 2004)**

Polio survivors learn about postpolio's cautions and risks in terms of proper management of polio's late effects. The cautions concern medications, anesthesia, surgery preparations and recovery, breathing and swallowing. SFBAPS newsletters, meetings, symposiums, and conferences repeatedly address these concerns. Likewise, these issues are frequently addressed in other postpolio support group newsletters, Internet resources, and recent books about PPS.

*Yet survivors sometimes fail to understand that this advice **must** be followed at all times, even when being treated for a medical condition seemingly unrelated to the polio and when symptoms on which a caution is based are not present and when in an emergency room situation. Failure to make this "connection" can cause serious medical complications that need not otherwise arise. It can even cause death.*

Even when polio survivors diligently explore and exercise the polio-related cautions and risks when undergoing

seemingly non-polio-related medical procedures or treatment, medical complications can arise. The medical provider may not heed the advice supplied even if it is another medical provider giving that advice. Also, family members with knowledge of your postpolio needs may not make the "connection" and may not exercise sufficient diligence about your postpolio condition and cautions.

Remember, only a small percentage of medical providers recognize or know about postpolio sequelae. Although the postpolio movement is gaining visibility among the medical profession, the percentage is not likely to increase rapidly any time soon. For a long time to come the polio survivor will carry the burden of educating medical providers treating them.

No one is as good an advocate for you than you. You likely will need to continue that advocacy when you are your sickest or experiencing a medical crisis that does not allow you to continue advocating for your needs and cautions. *I encourage every polio survivor to compile and diligently keep current a folder that contains:* 1) your medical history, 2) medical literature postpolio experts wrote advising medical providers about risks and cautions when treating polio survivors who have symptoms you experience, and 3) your living will and durable power of attorney for health care.

Identify the following:

- your insurance carrier and I.D.,
- your doctors' name/address/phone number and their medical speciality or practice area,
- all major illnesses and surgeries or medical procedures/tests and results,
- all disability equipment used,

including breathing apparatus,
all breathing and swallowing
difficulties you experience and
coping/management
techniques,
all medications and herbal remedies
you are taking and the dosages,
all allergic reactions and sensitivities
to medication, food, chemicals
any medicines contraindicated for
polios.

When armed with this information and literature you are more apt to get medical providers to heed the advice and exercise the precautions needed. And you have a better chance for your family and loved ones to acquire the knowledge needed for them to be discerning and vigilant advocates for your special needs and risks.

At SFBAPS meetings these last few years we shared stories about some of our members who suffered devastating health consequences when these cautions were not emphasized or followed. Several members died. Another occasion concerned a colonoscopy in which the attendants paid no attention to our member's cautions about sensitivities polio survivors typically have to sedatives. Although this member had no known sensitivity, she had an immediate reaction to the sedative used. An ambulance came to the medical office building, resuscitated her, did a tracheostomy, and transported her to a nearby hospital where she was placed on ventilator equipment and feeding tubes. Eventually the patient transferred to a nursing home. Our member had lost nearly all movement abilities. An intense physical therapy regime helped her regain some movement. Our member can once again feed herself and has advanced to using a power wheelchair for mobility. (Before the incident she

walked, using a scooter at times for distance.) Progress is slow, and prognosis for fuller recovery is unknown.

The need for polio survivors to be diligent in advocating about postpolio cautions when undergoing any medical procedure or treatment cannot be over-emphasized. Please educate yourself, your family or significant other, and your providers about the postpolio condition cautions.

[Editors note - This article contained six narratives of recent medical episodes demonstrating the "connection" and the cautions polio survivors or someone acting on their behalf must diligently exercise:

Surgery episodes by

- * polio survivor Phyllis Hartke
- * polio survivor Gladys Swensrud
- * family of polio survivor, printed in Nebraska Post-Polio Newsletter "Gleanings" Jan/Feb '04
- * polio survivor on BiPap at night
- * polio survivor Lawrence Becker, printed in *Ventilator-Assisted Living News*, Fall 2003

ER episode by polio survivor Stella Cade [see next page]

There is not room to print all these articles in this newsletter. Short excerpts are printed on page 17. If anyone wishes copies then please get in touch. It is imperative that you share with us the problems that you have had so that we can document these and provide this information to the Colleges of Medicine, Department of Health, etc. We look forward to hearing from you.]

I was with member Stella Cade a few weeks after she experienced the following and we discussed this at length.

*My Experience in the ER
or
"My Four Day Blackout"*

By LincsPPN Member Stella Cade
Poliogirl45@aol.com (January 2004)

I'm writing this article in the hope that it will prevent another polio from experiencing unnecessary medical complications in an emergency situation or when unable to advocate for their own care.

While on vacation I suffered a severe muscle spasm in my left hip and had to be taken to the emergency room. Because of the medical care received, I lost my memory of the next four days. I lost strength and mobility that I still have not recovered. And I behaved in an obnoxious, aggressive and threatening manner foreign to me.

Friday, August 8th, 2003: I had just spent a few days playing on the beach with my young grandchildren. I hadn't been wearing my shoes or my leg brace, and this undoubtedly triggered the hip spasm. The pain began in the motorhome on the trip back to San Antonio. Upon arrival back at our daughter's home, we left the grandkids with her and my husband took me to Southwest Medical Hospital Emergency Room. That's the last I remember, the kids jumping out of the motorhome to go for a swim in the backyard pool, to cool off. The motorhome air conditioning had quit working on the way to San Antonio and we were hot! And oh, how I wanted to go with them! But my hip hurt so bad, I just wanted to be still, to be left alone in the motorhome, to see if the spasm would stop and then I could go inside the house.

That is the last thing I remembered until the middle of the following week.

The medications taken in the ER erased my memory so that I do not remember the decision to go to the ER, or the trip there. Most of the details I pieced together later, from conversations with my husband and daughter, and from reading the medical receipts.

Upon arrival at the ER I was removed from our motorhome via a bodyboard, then placed on a gurney and taken inside. This was a Friday night and the ER was very busy. My husband said he counted 7 helicopters landing in the space of 2 hours. I was told the wait to see a doctor would be at least 4-5 hours. Meanwhile X-rays were taken (I remember none of this), and nothing found to be broken. Treating physician was a Dr. Wilson, who prescribed an injection of Demerol, followed by tablets of Valium, ViCodin, 800 mg tablets of Ibuprofen, Promethazine and one other drug I couldn't decipher from the bill. I was sent home with prescriptions for more Valium, Vicodin, and 800 mg tablets of Ibuprofen, which were filled by my husband at an all-night Walgreen's Pharmacy. We returned to our daughter's home at 3 a.m., and spent the rest of the night in the motorhome due to the lateness of the hour.

Saturday, August 9th, 2003: I was told it was 106 degrees in San Antonio that day, and I was still outside in the motorhome. My daughter was concerned about my condition and a possible heat stroke so she called 911. The police arrived, followed closely by the fire department and ambulance. What a show! Apparently I was really 'out of it', unaware of where I was and what was going on.

Again medical personnel removed me from the motorhome via a bodyboard to a gurney then transferred me to a waiting ambulance. I was taken back to

the same Emergency Room, although I don't remember why or what my condition was. I know the paramedics took down my medical history because I received a copy of the report, describing my medications and the drugs I was allergic to. The records indicate that I was alert, verbally responsive with blood pressure of 98/64, pulse of 63.

At the hospital the same physician as the previous night treated me. Same procedure was followed as the night before except no x-rays were taken. This I pieced together from the billing statement. The same injection of Demerol, the same medications were given except that the Valium dosage was doubled. Dr. Wilson again wrote more prescriptions for the same medications, even though this time there was a record from the paramedics showing what I was allergic to and that the Demerol, Valium and Ibuprofen were contraindicated. And once again my husband filled the prescriptions at the same Walgreens'.

Monday, August 11, 2003: Prescriptions for the same medications were again written by Dr. Wilson on Sunday. This is the third set of the three prescriptions for Valium, Vicodin and Ibuprofen he had written in three days. My husband filled them at Walgreens on Monday and we left for California in our motorhome that afternoon, arriving home on Friday, August 15th.

August 15th – August 29th: After our return to California, I felt mentally confused and my gait was so bad I was staggering like a drunk. I was very concerned about my mental and physical health and suspected it was the result of the incident at the ER, since I hadn't had any unusual problems prior to that. In an effort to regain my health, I booked many medical appointments in

the next two weeks, seeing my chiropractor on the 18th, 21st, and 28th, my physiatrist, on the 25th and 26th, and my primary care doctor, on the 22nd and 29th. My primary care doctor sent for and received my medical records from the ER in San Antonio.

Meanwhile I called my daughter in San Antonio to discuss what had happened that weekend. I was under the impression I just slept through the days. She was quite upset with me. She said I behaved very strangely, and that "Dad said you called him an SOB and told him you were going to divorce him". Also, that I roamed the guest bedroom, demanding more drugs and accusing them of hiding the drugs from me. She told me she gave me a bath after the second trip to the ER. I have no recollection of any of these events. When I told her I couldn't remember any of that, she told me I was lucid and not slurring my words so they were convinced I was in full control of my actions. She said I was even writing down when I took the medications. This was news to me.

I located the paper in my luggage that was used to write the meds down on, and saw that my daughter had initiated the schedule and had given me the first dose. After that my husband had given me the dosages, with the time and amount written down. Toward the end of the second day, I took over and started writing down the amounts and time the drugs were taken. Apparently I was ranting and raving, demanding more drugs, and they gave in to me and let me handle the medications. However, my handwriting was feathery, the henscratching of a very frail elderly woman, and getting worse with each dose. Not my usual bold script. And I was taking the meds too often, not as prescribed.

I had already seen the bills from the ER in San Antonio, and was amazed at the combination of drugs given each of those two nights. However, the fact that I had continued to take so many of these same meds and was medicating myself when I knew these drugs were contraindicated for my medical conditions came as a shock. What was I thinking? I knew better than to take these drugs!

Muscle spasms are a common occurrence among polio survivors, something I have lived with for years. In the past I have used a heating pad for muscle spasms. I keep one in my bed, and also in the guest bathroom linen closet at my daughter's home in San Antonio, where I am a frequent visitor. This was the worst muscle pain I had ever endured, but the medications still weren't killing the pain. And to treat a muscle spasm with this combination of drugs seemed dangerous to me.

Coulda, Shoulda, Woulda: What was my responsibility in all this? Why didn't I act in my own behalf, and stop taking the drugs? Why? Because I was completely under their influence and out of control! I needed help, someone who understood that my behavior was the result of the drugs and who would take action to see that I was taken off of them. From the first night in the ER, I was helpless to advocate for myself. This was a very scary episode for me, to take medications I know I cannot take, and behave so irresponsibly. And then not to be able to remember anything for days?! That still worries me.

My husband's no dummy. He has taken the time and trouble to learn about post-polio and my condition. He thought he understood and so did I, but he still 'didn't get it'. So I was shocked to see he had signed the paperwork at the

hospital, which named the drugs I was taking and the side effects, and apparently didn't make the connection between the drugs and my errant behavior. My behavior was radically different than normal, behavior he had never seen in over forty years of marriage. But he still thought I was 'in control, fully aware of what was going on and what I was doing' because I was not slurring my words. Duh!

KNOWLEDGE OF DRUG NAMES: My husband was well aware of the drugs I shouldn't take. However the drugs were listed under their generic names. Valium was Diazepam. Demerol was meperidine, which I have a family history of intolerance to. He knows that I shouldn't have Ibuprofen due to a liver condition, and this he overlooked. The doctor gave him the prescriptions; my husband signed the RX caution papers given by the hospital. He interfaced with the pharmacist three different times, filling far too many prescriptions for these medications in too short a time even though I was exhibiting signs of distress. He could and should have discussed these symptoms with the doctor and the pharmacist. The advice listed regarding the side effects on the hospital printout were to look for signs of aggressive behavior, confusion, agitation, anxiety, restlessness, hallucinations, etc and to call the doctor if these symptoms were to occur. Since I was clearly exhibiting these symptoms and signs of abhorrent behavior, some family member, doctor or pharmacist should have intervened on my behalf. The medication types, combinations, and the fact that the same doctor wrote prescriptions for these medications three times in three days should have been questioned. The medications I was already on should have been considered as well. Someone should have seen to it that the medication was discontinued or

changed to something less damaging.

The confusion and gait problems were diagnosed by my primary care doctor as vertigo, a condition resulting from the medications given in the ER. I was put on meclizine to clear up the vertigo. Both my primary care doctor and my physiatrist said the amount of drugs was overkill and the combination of drugs given was an error. My primary care doctor said they could have caused me to have a seizure. The doctor explained how the drugs given in ER and later prescribed for home use, along with my other medications (Zoloft) and health conditions (post-polio and impaired liver function) could cause a blackout, where I would appear lucid but behave bizarrely, with no recollection of events.

Six months later I still haven't regained all of my strength, but at least my head is clear. I continue seeing my doctors regularly and have a deep muscle tissue massage each week. I am still weak. I am having to lock my left knee to walk, causing it to hyperextend. However I have initiated procedures that hopefully will prevent an event like this from happening to me again.

THINGS I LEARNED:

1. Avoid emergency rooms whenever possible, especially one in a strange town. When you are home, call or see your regular physician first, if at all possible. Don't wait until you are so sick that a visit to an ER is necessary. But don't put off going if your health demands it, I'm just suggesting you exercise caution first.

There were so many accidents, knifing and gun shot victims coming into the San Antonio ER that night, that my muscle spasm was too minor an incident to warrant much attention. The staff was

greatly overtaxed. Often doctors moonlighting from the local military bases or visiting, rotating ER doctors staff Emergency Rooms. Your cardiologist, pulmonologist, etc., doctors may come when called, but they are not the initial treating doctor in emergency rooms. You are going to see a stranger. Also, the latest policy being instituted is to have the hospital administrator rule on whether the ER is at capacity and whether to send patients to other hospitals. The doctor may no longer make this decision, the hospital administrator will and he must be contacted before any patients are turned away. This puts a heavier burden on the ER staff, and creates a profit incentive for the hospital. This is not in the best interest of the patients.

2. Make a list of all the medications you are taking, and also list their generic names. [Editors note - Remember if you go abroad that other countries can have two more names and also in some cases a different method of dosage - ask your pharmacist before you leave] List the number of mg and the dosage frequency. Make a list of all your medical conditions. Also make a list of drugs you are allergic to, and include in this the drugs you have been advised not to take because they interfere with a medical condition or interact with other drugs you are taking. Sometimes we forget to name these because we are not actually 'allergic' to them in the true sense. Do not depend on the hospital staff, the pharmacist or your family to figure this out. Put this list in your wallet, next to your insurance card.

Some pharmacies, such as Walgreen's have a system where you fill out an application specifying your detailed medical history, what meds you take and which ones you shouldn't take, your primary care doctor's name and phone

number, your emergency contact names and telephone numbers, etc. An abbreviated medical history and the rest of the information are put on a laminated card that fits in your wallet. It includes a telephone number at Walgreen's available 24 hours a day, where any treating medical personnel anywhere can get the more complete, updated history of your medical needs. The cost is \$14.95 for the first year, then \$9.95 a year after that. You can review and update your health profile any time something changes, and you get an updated laminated card each year. This can be done in the pharmacy or over the Internet. Put the card in the same place you keep your Medicare or HMO/PPO insurance card. That way, you are reminded to pull it out when you visit the doctor. Have the staff copy it at the same time they copy your insurance card. Insist, as they will try to refuse. If you are taken in on an emergency by your family or by ambulance, they will first look for your insurance card, and find the Health History with it, so that your information will be 'right in their face', hard to ignore.

3. Educate your family. I thought mine was! It came as a nasty surprise that they trusted the doctor and his treatment completely and were lulled into a false sense of security. Even though I was well 'looked after', physically, I do not think my family was involved enough in my care. They ignored the obvious side effects of the drugs; didn't bother to read the paperwork sent home with me, which would have educated them on these side effects. And common sense should have told them that the abnormal behavior I was exhibiting was not only unusual for me but was not present before I took the medications. **If the behavioral changes came about after the medication was administered, not before, then take a look at these**

medications' side effects! If the medication could have been changed within the initial 24 hours, the results of my ER experience would have been dramatically different.

4. Accountability: This part is simple, but so often overlooked. Friends or family taking you to the hospital, if they are acting on your behalf and accepting or signing for paperwork, then they **MUST READ** that paperwork. It is given for a reason and signing for it is not just a formality, it's a responsibility!

SIDE EFFECTS I EXPERIENCED:

Polio is a disease of the Central Nervous System. Medications that impact the CNS should be considered carefully because they may have a greater effect on polios. The following is a list of the side effects of the drugs given:

1. Demerol (Meperidine) is an opioid analgesic, morphine. Demerol is a substance that is added to many surgical anesthetics to block out memory of the surgery undergone. Known to cause **blackouts** as well as seizures, it is **frequently associated with central nervous system irritability and myoclonic seizures.** In my case it caused hallucinations, spasms, confusion, restlessness, drowsiness, dizziness, etc. My primary care doctor informed me that Demerol is no longer used on the frail or elderly at Mt. Diablo Hospital because of the adverse side effects.

2. ViCodin (Hydrocodeine) affects the central nervous system causing dysphoria (a mood of general dissatisfaction, restlessness, anxiety, discomfort and unhappiness), agitation, and bradycardia (slow heartbeat).

3. Valium (Diazepam) also affects the central nervous system causing confusion, aggressive behavior, and

staggering or jerky movements. Can cause permanent muscle wasting in polio survivors.

4. Promethazine causes agitation, nervousness, excitability, dizziness, drowsiness, etc.

5. Ibuprofen (Motrin, Advil) is contraindicated in my case due a poorly functioning liver. Ibuprofen in mega doses such as those at prescription levels will cause permanent liver damage. It can cause dizziness, drowsiness, blurred vision, seizures, muscle cramping, and slow breathing.

MEDICATIONS AND THEIR SIDE EFFECTS ON POLIOS:

Caveat: All polios are unique from one another in their medical characteristics. The reactions I had to these medications may not happen to you. However, if you have taken drugs in the past and they worked for you, that doesn't mean they work for each and every one of us. Or that if you took them five years ago, that they are right for you now, because we all experience a decline each year in our muscle mass and that has an impact on the drugs taken.

I'm suggesting you exercise caution, educate your family, and get your paperwork together. If this could happen to me, then it could happen to any of you.

Excerpts from the other articles.

Phyllis Hartke - Gynae operation 2003. This is a long article detailing all the effort she went to to provide information and all the problems that occurred despite this.

"I had polio in 1952, complete paralysis below the waist. After recovery there was little obvious residual - right leg one

half inch shorter than the left leg and its muscles a bit atrophied.....

Although I never had any respiratory distress during or since the polio episode (except for the medication reaction last April) and never needed an iron lung, I still worried about respiratory impairment. Often early symptoms are overlooked for at least three reasons: 1) the progression of motor neuron impairment in PPS is very slow, 2) limb muscle weakness prevents patients from exceeding their ventilatory capacity, and 3) few physicians know proper respiratory examination and treatment methods for patients with neuromuscular disease.....

When lying flat on my back breathing is a little difficult. For many years I simply paid no attention to any possibility of a problem, opting instead to sleep on my stomach or side almost exclusively and using pillows to elevate my head and upper torso when lying on my back. Swallowing clear liquids and clearing saliva from the throat are now problematic, requiring a conscious effort on my part to tell myself "OK, now swallow." This effort is not needed when I cough or use a straw. Coughing also occurs when speaking or taking a deep breath.....

The pulmonologist smiled broadly and told me: "The symptoms are classic bulbar polio." Another case example of polio afflicting the *entire body* regardless of the type of polio diagnosed so many years ago [spinal vs bulbar vs bulbar spinal vs encephalitic]. Diagnosis did not take into account subclinical polio effects. Medical studies done by WJW Sharrard and David Bodian, estimate 44% nerve damage can occur without clinical weakness.....

Gladys Swensrud - Knee surgery 2003

Little did I know that having an advocate after surgery would be equally as important as the advance preparation I had done prior to surgery. After surgery, I was delivered to a corner room, far from the nurses' station, without the proper technology where my breathing could not be monitored. My husband had already left for the night when I realized the dilemma.

A DAUGHTER, A POLIO MOTHER, AND A TALE OF SURGERY

Reprinted with permission from the Nebraska Post-Polio Newsletter, the Jan/Feb 2004 Ed. of Gleanings

"My mom is very intelligent," says Denise Brenforder. "She had polio when she was 19; she raised five children, she held responsible jobs. In fact, all of us kids are intelligent. Still, none of us knew enough to know what questions to ask to give her a better chance when she had surgery."

Denise is talking about her mom, Dorothy Burreight, and the surgery she had last July that left her a quadriplegic.

Dorothy had been experiencing numbness in her legs. Her family doctor sent her to a neurologist for help, and then just to be sure, she got a second opinion. The result was that Dorothy had a laminectomy to relieve the pressure on the compressed spinal cord in her neck.

Dorothy expected to have five vertebrae fused, spend maybe six weeks in rehab, and then slowly resume the active, vital, life she was used to living.

Unfortunately, that's not the way things turned out. After the surgery, Dorothy

seemed in good shape. She needed help getting her circulation back to normal, but everyone was encouraged by her condition. Before long however, a blood clot developed at the surgery site. Doctors thought she was having a heart attack. A second surgery was required to relieve the pressure caused by the blood clot.

This time, Dorothy came out of the surgery paralyzed from the shoulders down. Two days later she went into respiratory arrest. Now she breathes through a trach with the help of a ventilator.

After over three months in various Omaha hospitals, Dorothy is now in Madonna Rehab in Lincoln, receiving physical and speech therapy and being fitted for a new chair.

"There's no doubt in my mind that if we had taken more precautions, some of this could have been avoided," says Denise. "At least, it certainly wouldn't have hurt to check it out ahead of time."

Denise talks about going on the Internet after the second surgery to read about what polio survivors should do to prepare for surgery.

"I couldn't believe what I was seeing! Although my mom mentioned to the doctors that she was a polio survivor, they paid no attention to that fact. Her history of polio didn't seem significant enough to anyone even to give her a pulmonary test or let her talk with the anesthesiologist before the surgery. We would have discussed a number of things with her doctors if we had known then what we know now.

"All the symptoms were there on the Internet, exactly what she went through. I have every belief that we might have a

different outcome here if we had known that having polio makes a difference in the way surgeries are handled. Even if we had the same result, at least we would have the peace of mind of knowing that we had done everything we could, informed ourselves the best way possible."

Denise believes they have found a good place for her mom to be right now. "Madonna is a nice facility," she says. "But I sure wish she didn't have to be here at all. I just hope others who had polio will learn what to do before they schedule surgery. If it helps anyone at all to read about what happened to my mom, then I'm glad to tell this story. I'd hate for anyone else to have to go through this."

One of the online articles Denise found most helpful: <http://www.ott.zynet.com.uk/polio/lincolnshire/> "You Are Going to Have Surgery: A guide for Polio Survivors" by J.M. Walker, PhD, PT

Polio survivor on BiPap at night

From: Richarddaggett@comcast.net
To: Polio@maelstrom.stjohns.edu

Just about all polio survivors who use a vent know that talking is not a problem. I wish all medical "professionals" knew this. My best friend went into the hospital on November 10th for **routine gall bladder surgery**. He had moderately impaired pulmonary function, using a BiPAP at night. *Before the surgery he took a packet of information to the surgeon and the anesthetist. Both of them indicated that they were familiar with PPS, and how to handle someone with reduced pulmonary capacity.*

It is now almost three months later.

My friend is still in the hospital and has post-operation ileus (paralyzed intestinal tract). He is hooked up to IVs, with tubes going into his body and tubes going out. He was intubated for about two weeks,

then they decided to give him a trach.

The trach doesn't bother me, or him. I have had a trach for almost 20 years. He and I talked about the possibility that someday he might need one. What does bother me is that they gave him a "cuffed" trach. A cuffed trach prevents the user from speaking. For almost three months he has been unable to speak.

When I talk to the hospital staff about deflating the cuff they look at me as if I'm an alien being. They always say something to the effect that, "Oh, he's not ready to come off the vent yet." They apparently think that a trach and a vent equals a cuffed trach, and no ability to speak. I point to my trach and my vent, explaining that I have a trach and a vent, have no need of a cuff, and can speak quite well, thank you.

I've written to several MDs with excellent knowledge of polio and PPS. They all agree that the cuff should be deflated. I've forwarded their responses to the staff treating my friend. It has had no impact!

Polio survivor Lawrence Becker, printed in Ventilator-Assisted Living News, Fall 2003

There are still some special precautions ventilator users and perhaps polio survivors in general need to take when considering surgery. (See "Before Surgery") But in my recent experience, medical professionals are now ready to hear and to accommodate our insistence on noninvasive ventilation whenever appropriate. My physicians have also been willing to add (again on request) the extra layers of protection I might need during surgery and other procedures performed under sedation, such as endoscopic examinations or colonoscopy. My cardiac ablation surgery illustrates all those points.

Neurological Alliance Updates....

10 million of the UK's 56 million population have a neurological condition and a vast percentage of the symptoms and problems that we have overlap. As single condition groups for far too long we have been told... "there are not enough of you to warrant a clinic". As the National Neurological Alliance says....

Let's see what we can achieve together.

Lincolnshire Neurological Alliance
Registered Charity No. 1101774

Next meeting dates are
Wednesday 31st March 2004
Wednesday 9th June 2004
10.30 a.m. to 12.30 a.m.

St Barnabas Hospice Day and
Education Centre
Hawthorne Road, Lincoln

Lincolnshire Neurological Alliance
Leadenhall Manor
Leadenhall Road
Holbeach St. Marks, PE12 8HA
Tel: 01406 701090

Further Information about the Alliance
info@lincolnshire-neurological-alliance.org.uk

West Berkshire Neurological Alliance.
Member Pat Galvin
patgalvin@waitrose.com

Lancashire and South Cumbria Neurological Alliance.

"On December 6th an exploratory meeting to discuss the possibility of setting up a Regional Neurological Alliance in the North West was held with the assistance of Wendy Langtree of the Patient and Public Involvement (PPI) Nursing Directorate at Lancashire

Teaching Hospitals' NHS Trust in Preston. Attending were myself, representing the Post Polio Network (as it has become known in these parts!), plus sixteen other groups representing people with neurological conditions, from those that are well known about, like Parkinson's and MS, to lesser understood conditions such as Epilepsy and Guillain Barré Syndrome.

First to speak at the 6th December meeting was Gwam Rajiah, Directorate Manager of Specialist Services at Preston. Gwam acknowledged that the Trust had not always been very proactive in involving patient groups within service development, but that this situation was changing and he personally had had very positive experiences of working with patient groups in the other specialist services he managed, like renal services. He thought the formation of an Alliance would benefit patients, patients support groups, commissioners, and service providing organisations. Afterwards those attending got the chance to ask questions and to provide information from their specific groups as to the 5 improvements in service delivery they would most like to see.

Members of the Greater Manchester N.A. and the West Berkshire N.A. both gave talks about their experiences of forming and running an Alliance, of raising money and of running groups. Each gave excellent reasons why smaller groups have a bigger voice if they join together under an umbrella organisation. Both speakers offered encouragement and pointers as to how such an alliance in the North West could become a reality.

As a result of this meeting, a further meeting was arranged for 24th January, again with the assistance of Wendy Langtree PPI, without whom we would

not have had the venue nor the resources supplied on the day - tea, coffee, handouts, OHP's, etc. At this meeting, which was very well attended, we mulled over the content of the previous meeting and finally agreed in principle to undertake to forming a working committee over the next six months, with the assistance of the local CVS (Council for Voluntary Service), who will undertake to provide some training of volunteers in how to run committees.

These two meetings have brought us to a point where we have in principle decided to join the forces to get a North West/Morecambe Bay Neurological Alliance off the ground. Although some fears were expressed about how such an Alliance would manage financially when so many charities are looking for money, at the same time the meeting felt that we could not afford to waste any time thinking about whether to form an Alliance in this area with no starting budget. As our Manchester speaker had said, patient views were of increasing importance to NHS Trusts, and new methods of involving patients and the public in health planning were constantly being developed. Also the National Neurological Alliance was stronger and more able to support regional groups. This was as good as any time to grasp the nettle and seek affiliation with the main body of the Neurological Alliance. We look forward to the same level of enthusiasm at our next coming together on 3rd April 2004 at the same venue - Preston Royal Hospital. Meanwhile, a voluntary core group of 13 people will meet at Preston CVS on 21st February for a training day.

The written submissions which formed part of the consultation on 6th December will be included in a future action plan of the Specialist Services at Preston and

we expect the feedback will come to us at our April meeting (see below). It was agreed that this feedback would be valuable as a potential starting point for future work for any alliance - those in attendance needed to know what other groups had put in their five points, and the meeting as a whole needs to see explicitly what points are shared among groups.

If any reader would like further information on setting up Regional Neurological Alliances, you can e-mail: info@neurologicalalliance.org.uk or go the website at

www.neurologicalalliance.org.uk
The Neurological Alliance,
PO Box 36731,
London,
SW9 6WY.
Telephone: 020 7793 5907
Fax 020 7793 5939

**Mary Kinane, Secretary
Lancashire and South Cumbria NA.**

Diane Newman reports as Secretary of the LincsPPN, Chair of the Cambridgeshire Neurological Alliance and Regional alliance representative of the Neurological Alliance.

Hello Everyone, Although not a Polio Survivor – I still “survived” the “scenic-route” most neurologically-challenged patients take round hospital departments, when diagnosed 80% disabled with M.E. 10 yrs ago, but with much improvement now – thankfully.

I would like to make a contribution to LincsPIN of some UK based articles that, I hope, will be of interest.

The first, part of a copy of an original presentation by Professor Chris Kennard, President of Association of British Neurologists (ABN) is called “UK

Neurology – The next ten years *Putting the patient first,*” taken from notes of the Neurological Alliance AGM, 5 November 2003. You will see there was a Q & A session as well (I raised an M.E. issue and, GP tutors and specialist training for GPs).

Professor Kennard set out the current problems in neurological services and then presented the ABN’s newly published document “UK Neurology, the next ten years. Putting the patient first”. We have the Full Report if anyone would like this or go to The Association of British Neurologists (www.theabn.org)

He set out new proposals for training neuroscience clinicians (including neurologists, neuro surgeons, neurophysiologists), which would bring down the present training time to 7 years (following qualification as doctor), rather than the present 9 years.

Professor Kennard also introduced the vision of a “Brain Centre”. A project to develop a neurological centre in London to bring together a range of organisations (e.g. ABN, SBNS and voluntary organisations) and services (e.g. information, helpline, meeting space). He asked for support from Neurological Alliance member organisations for this project.

Professor Kennard then answered a number of questions as follows.

1 Q. How many neurologists are currently in training?

A. At present there are about 70 trainees. There is a need to double the numbers of neurologists and so there is a need to increase the numbers of trainees. An extra 20 have been gained since 2001, but the ABN is still asking for more.

There is a possibility of getting a pilot for

the new training scheme that they are proposing. They could double numbers of neurologists in 8 – 10 years if the new proposals for training were agreed. There is also a need to get other health professionals to take some of the work that doctors currently do so that neurologists are only used for the jobs that only they can do.

2 Q. There are many more neurologists in Italy – what can we learn from neurological services in Italy?

A. In other parts of Europe access to medicine as a career is much more open. In the UK it is tightly controlled by the Department of Health and based on workforce planning. This can often lead to fewer doctors being trained than are required (whereas in places like Italy they often have more than they need and some can be out of work or not practising full time as neurologists). Also neurological services are much more comprehensive than in the UK – there are more general neurologists working at a less specialised level. A good model of neurological services is in Holland where there the ratio of neurologists to population is **1: 24,000**

[Editors note - UK population is approximately 56 million - UK neurologists full time posts at 2003 was 370. Quick maths makes that **1:151,351**. Lincolnshire has 634,300 population and until January 2003 did not have a resident neurologist, till Dr. John Bowen started work. Other neurologists did and do still come into the county to take some clinic sessions, totalling less than two other posts. As you can see we are still nowhere near the national average, let alone the figure mentioned above but back in 1998 when we helped instigate the then named Lincolnshire Neuroscience Forum one neurologist visited Lincoln Hospital one day a month!

In-patients are coded to condition, Out-patients are coded to clinic. Therefore the NHS do not know how many people have

each neurological condition. Five years ago we found that Lincolnshire Health Authorities figures came from extrapolating the population from National figures and national figures came from adding up local health authority figures. How can the Department of Health plan a workforce if they do not have accurate statistics?]

3 Q. GPs awareness of neurological conditions is often very poor. For example, recognising the symptoms and existence of the late effects of polio. What is being done about this?

A. There is a GP distance learning project (produced by the Brain and Spine Foundation) which some GPs have undertaken. Also there is a need for consultants to support GPs e.g. through email advice to GPs. There is very little dedicated training time for neurology for doctors in their basic training. At Charing Cross where he champions it, they only have two weeks out of 6 years of basic training. The ABN has just surveyed medical schools to ask them how much training they do on neurology – it is generally appallingly low.

4 Q. The specialisation of neurologists into e.g. epilepsy and Parkinson's disease means that there are less neurologists who know about conditions such as Charcot Marie Tooth and other rare conditions. What can be done about this?

A. The development of neurological networks could help with this. This should result in general neurologists and specialist neurologists working together across an area in a network and they could cross refer. This has worked well in cancer.

5 Q. People with ME (CFS) find it almost impossible to see a neurologist. What can be done?

A. People with ME do often get a rare deal. Probably what is needed are NICE

guidelines on ME.

6 Q. Should GP tutors at a local level be encouraging doctors to become GPs with a specialist interest.

A. Yes that would be very helpful?

7 Q. You mentioned access to MRI and CT scans being very difficult – these are needed both for emergency and routine diagnostic work. What is being done about the deficiency in numbers of scanning machines in the UK?

A. Part of the problem is actually that machines lie idle for large periods of time. They are generally only operated from 9-5 on five days a week. Also there are large shortages of radiographers. So we could do with more machines, but more importantly we need to use what we have more productively and to recruit and train staff to operate them.

8 Q. Does the ABN publish the numbers of neurologists annually? This would be useful.

A. No we don't do this, but we could in future. At present the number is 370 full time equivalents (420 actual neurologists).

9 Q. The idea of a network sounds good, but we are often not clear what should be provided at a specialist level and what should be local as part of a basic service. Might there be some clarity about that?

A. A proportion of people should be treated at district level. People with acute neuro problems should be seen by a neurologist within 3 hours of having a stroke. It should be like the service now provided for people with heart attacks. People with "brain attacks" should receive the same level of care.

Cambridge Neurological Alliance AGM

Wednesday 10th March 2004 - 10.00 to 4.00

Papworth Conference Suite,

Upper Pendrill Court, Papworth Everard

CAMBRIDGE CB3 8RG

**An Upside down View:
Questions For Vent Users
by the one-armed bandit**

As most of you know I'm an upside down polio. In the back of my mind has been the fear of developing more breathing problems. I prefer to say 'just' breathing problems, leaving out the more but as I become more honest with myself I realize that I've always had some problems; just have been able to keep them within 'normal' range.

Eleven plus years ago when I went to a pps clinic for the first time I was warned about developing severe problems and that if I didn't take care I'd be on a vent within five years. This hasn't happened and I am still (happily) vent free. But during the past year I've been noting little tell-tale things that point to my breathing becoming more of a problem.

Almost two years ago when I was evaluated for my chair I went back for three sessions with the OT to learn how to relax. It was then that I discovered that I was having more problems with deep breathing than I thought. At that time I could get one or two good deep breaths and then after no matter how hard I tried I simply didn't succeed. Taking honest rest breaks and trying to relax has helped... or has it? I'm not really sure.

Anyway my question for those of you on vents here are my questions:

1. What symptoms led you to go get your respiratory problems checked out?
2. Did your doctor feel you should have gone in sooner? If so, when the doctor say you should have gone it to see him and what would the

benefits of going sooner have been?

3. Did you first just need a Bi or C-pap at night?
4. Did the above help for awhile and then gradually not? and was there any therapy suggested or tried along with the added use of a vent?
5. Does using the vent give you more actual energy?
6. What are the pluses that outweigh the negatives of using a vent?
7. If therapy was given did it help or make matters worse in your case?
8. What, if anything, do you wish you had done differently and when?

Thanks ahead of time. I know that reading your stories, your experiences will help me see myself and where I am with this problem. I kind of already know I should probably go and get this checked out but wish to do my homework first to have an idea of what may be ahead for me; what (if any) options there may be; and what (if any) dangers there might be with exercise; physical therapy as a treatment.

Please take a moment to send me your answers. I promise to not only use this information for myself but to build future articles around them as I can't help but feel that this fear is one silently shared by many of us.

Perhaps, as you already there help me to face my own fears with your knowledge and exeperience I too, can help others as I share my journey towards both accepting yet another facet of this Post Polio we all deal with and the paths I take to solve it while continuing to live a full and rich life.

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Continued from page 23
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Donations can be made to Lincolnshire Post Polio Network
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already a CAF Charity Card holder, go to www.CAFonline.org

