



The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 4 - Issue 3 - April 2003

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



Yash and
Greg Airth 2002
Page 12



Jean Knight Hill
Lincoln 1951
Page 8



Jann Hartmann 2002
Page 10



Laurie Mitchell 2002
Page 14

**ANNUAL GENERAL MEETING,
SPEAKERS & WORKSHOP
SATURDAY 11TH OCTOBER 2003**

See pages 3 & 21

"Neither Lazy Nor Crazy"—Conference—See Back Page

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.

CONTENTS

Page 2 -	Contact Information.
Page 3 -	Editorial
Page 4 -	Treasurer's Thoughts.
Page 5 -	Meet Di Newman.
Page 6 -	A Shot in the Dark
Page 7 -	Hints, Tips and Bits from Polio Survivors & The Lantern
Page 8, 9 -	What a Co-incidence!
Page 9 -	Paget's Disease.
Page 10 -	What Type are You? by Jann Hartman
Page 11 -	Letter to a Friend & Flatulence Isn't Funny by LaVonne Schoneman
Page 12 -	Disabled Housing Appeal, newspaper article
Page 13 -	Information from the Disabled Driving Association
Page 14, 15 -	Polio's Prison by Laurie Mitchell,
Page 16 -	How Surgical Relaxation of My Upper Esophageal Sphincter Benefited Me
Page 17	Part of report on West Berkshire Neurological Alliance Conference - cont 22.
Page 18, 19 -	Adaptive Dancing
Page 20 -	Laughter the Best Medicine.
Page 21 -	AGM info [full info next newsletter] and Return Slip
Page 22 -	continued from page 17.
Page 23 -	'Letter to the Bank'
Page 24 -	Poster on Conference Not Lazy Nor Crazy.

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

Lincolnshire Post-Polio Network,
69 Woodvale Avenue, Lincoln, LN6 3RD, UK
Tel: +44 01522 888601 Fax : +44 0870 1600840
[Do not dial first 0 if ringing from outside the UK]

Membership Information

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

Please make cheques payable to 'Lincolnshire Post-Polio Network'
post to Membership Sec, 78 Heron Road, Larkfield, Aylesford, Kent ME20 6JZ, UK
(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.
All UK Memberships payable by Standing Order - Forms from Membership Secretary.
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 - June 2003

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

Founder & Chair - Hilary Hallam - hilary.hallam@lincolnshirepostpolio.org.uk

Vice Chair - Denise Carlyle - denise.carlyle@lincolnshirepostpolio.org.uk

Secretary - Di Newman - di.newman@lincolnshirepostpolio.org.uk

Treasurer - Jenni Paulger - jenni.paulger@lincolnshirepostpolio.org.uk

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

Committee Members - phil.bilton@lincolnshirepostpolio.org.uk

Lincolnshire Post-Polio Network WebSite Administration

Chris Salter - webadmin@lincolnshirepostpolio.org.uk

Editorial by Hilary Hallam

Advance Notification - Annual General Meeting will be held on Saturday 11th October 2003 at Ancaster Day Centre, Boundary Street, Lincoln. The day will consist of the Annual General Meeting starting at 10.30 a.m. There will be a buffet lunch. The remainder of the day there will be Speakers and a Workshop. The Workshop. A separate room has been booked for Partners/Family Members and Friends. A time for all to speak freely about what it is like living as or with a polio survivor. A time to share your problems and how you have managed situations.

Aaron Mattes has confirmed as a speaker and will be staying the whole weekend. He will demonstrate Assisted Active Isolated Stretching and then show us range of movement exercises that we can do ourselves/with help from another. All can join in. Three other health professionals have intimated their interest in speaking - neurologist/rehab doctor/physiotherapist but as yet have not confirmed if they are free. Now its up to you. What subjects would you like discussing? To help us plan this day please return the slip on page 21 - or email us the information.

Conference - Neither Lazy or Crazy. The Truth about the Cause and Treatment of Myalgic Encephalomyelitis and Post Polio Sequelae. July 12th, Telford, Shropshire. SEE POSTER ON BACK PAGE. Hilary and other members already have tickets.

Meeting Lincolnshire's New Neurologist.

Dr. John Bowen met with members of the Lincolnshire Neurological Alliance on the evening of 24th May 2003. Using Powerpoint he gave us an overview of Neurology, as it was, as it is, how he would like to see it for the future.

What do neurologists do? They see patients with headaches and face pain, blackouts and epilepsy, peripheral nerve and root problems, Stroke, Multiple sclerosis, Parkinsons Disease and other movement disorders, Dementia, Giddyness and vertigo, medically unexplained symptoms. Plus there is all the paperwork, meetings, training, speeches, conferences etc to fit in to the week.

What should neurologists do? Depends who you ask. Patients want to see me quickly. GP wants me to see

their patient today. The department manager wants me to see patients within 21 weeks. Physicians and Surgeons want me to see any patient they cannot diagnose. All want me to see this patient who has 'nothing wrong'.

THIS neurologist would like to see anyone where a neuro diagnosis is suspected in a time frame that is both effective and humane.

Management would like neurologists to see anyone with a significant neuro disorder, anyone who would benefit from neuro input, people who would receive no better care by other means and anyone who wants to see a neuro. Where symptoms are unchanged for 3 years a delay of some weeks in seeing the neurologist should not be a problem. Rarely is anything best done in isolation. There are also multiple needs and it is important to ensure that both doctor and patient discuss the needs to ensure there are no misunderstandings.

What has been done so far.

- Consultant neurophysiologist. appointed 2002
- MS Nurse specialist appointed January 2003
- Consultant neurologist appointed January 2003
- Work commenced on the new Neuro Rehab facility at Lincoln County Hospital
- Neuro clinic started in Grantham March 2003.
- Botox clinics expected to start in June 2003.

What he would like to see in the future.

Expansion of specialist clinics

Acquisition of specialist nurses and community liaison volunteer

Real estate - a Lincoln Neurology Centre with beds, clinics, offices , Multi disciplinary staffed. Neurophysiology, OT, Telemetry, hydrotherapy, social workers, rehab., psychology, and a stroke unit.

This is the vision for the next two years!

We will keep our fingers crossed.

More news next newsletter.

Exeter ME/PPS Day - Report next newsletter.

Items for the newsletter from members would be gratefully received. By post or email. It would be great to have the Newsletter File bulging with items to use in future issues.

DONATIONS RECEIVED

**Val Scrivener - Yvonne Webb - Mrs K F Preece - Diana Nash
Ervin Melchiori - Dr & Mrs Shaw - Colin Thomson - Sylvia Fortune
Apologies to Michael Hessian for calling him Malcom in the last newsletter.**

Treasurer's Thoughts

Life Membership

You will all be aware that this organisation runs on its membership fees and donations, and for seven years has run on money in, money out, with little in reserve.

If we assume our members typically join at 50 and have the normal life span (until about 80) their £100 one off payment costs them £3.33 a year, this is a very good deal when you consider the £10 annual membership fee barely covers the cost of the newsletter. Approximately 25% of our membership are Life Members (i.e. they have paid their fees forever) and finances being what they are we've spent it, so the cost of sending their newsletters etc is met from current fund raising.

It is with reluctance we have increased the cost of Life Membership by 50% to £150 (still a very good deal). For those in the UK it is still possible to pay by monthly Standing Orders of £5, it's just that they will now run for 30 months instead of 20 months.

Annual Membership

Those of you who pay Annual Membership will be pleased to hear there have been no changes. We are aware that postage rates are on the increase, but our membership is very important to us and we want as many of you to stay for as long as possible, so we are hoping to absorb the extra costs ourselves.

Web Site and Back Copies of the Newsletter

It is very seldom that we are asked for back copies of the newsletter (only once since I have been treasurer), but we have reluctantly increased the price to reflect the actual cost of production and postage.

Those of you who access the web site will be aware that past editions of the newsletter from Volume 1 No. 1 to Volume 2 No. 12 (August 2000) are available from the site.

Prior to a major refurbishment of the site, certain critical sections will be brought up to date and amongst those the addition of the last few years newsletter editions from Volume 3 No. 1 onwards will be given top priority.

Wendy Grimmitt

Many of you will know Wendy Grimmitt, the previous Secretary to the organisation, who recently moved to the West Midlands. In March Wendy was featured in The Birmingham Evening Mail in an article entitled "Misery returns for polio victims". This was part of a drive by the British Polio Fellowship who ran a series of 6 road shows in the Midlands in a bid to identify more of the 80% of polio survivors whom they believe are now suffering from some form of PPS. We wish them much success and hope that many of their new members will access our information as well.

Your comments

As always I would be grateful to hear any comments or ideas you have.

jenni.paulger@lincolnshirepostpolio.org.uk

Meet Di Newman

Hello, I would like to introduce myself. I'm Diane Newman, Secretary to the Lincolnshire Post Polio Network and although not someone affected with PPS - I have M.E. - my interests are to see better services, such as rehabilitation, for all neurological conditions, diseases and injuries. We ALL have common grounds and needs and require similar services. Certainly, as with PPS. we share the same "scenic-route" journey round hospital departments, often to no avail, trying to access an appropriate diagnosis - in terms of level of (dis)ability - treatment, rehabilitation, or meaningful dialogue on the way!

I too, am affected by profound exhaustion, "brain fog", balance problems, nausea, cognitive and short-term memory impairment, muscle and weakness and pain referred to as "neurogenic" pain - in that the muscle pain and weakness is radiating from the brain similar to that experienced by many other neurological conditions, one being Myalgic Encephalomyelitis (M.E.), It is also known as Chronic Fatigue Syndrome (CFS).

I have to say, the term "fatigue" is like saying someone who suffers with migraine has only a "headache". As someone affected by M.E. for nearly 10 years, I was diagnosed as 80% disabled and confined to bed and home for most of 6 years. M.E. is not about being "fatigued". It's about being "pole-axed", barely able to brush your hair, clean teeth or walk. Thankfully, with good "pacing" skills for rehabilitation, excellent diet (nutrition) and access to the knowledge and expertise of leading M.E./CFS Specialists, such as Dr. Derek Parkin who was at the Pilgrim Hospital in Lincolnshire. I learnt to manage the disease well. (and funds in order to see them!).

My interest in neurological conditions and their long-term specialist tailor-made rehabilitation requirements, stem from when I worked with severe Alzheimer Disease patients (up until I was struck down with severe M.E.). In fact working with these wise, elderly people taught me much of what I know in terms of whatever the ravishes that many diseases leave in their wake. Deep inside us - albeit often out of duress, with no other option and sheer survival - our "former" selves remain enclosed - trapped. Those - often very confused and misunderstood Alzheimer people taught me that despite all - once given the opportunity and equipment they

could read, walk, talk, laugh or play the piano and do simple gardening, when given the time, staff and space to re-develop/re-capture/re-skill. They showed us, that with patience we could "access" their "former" characters, personalities, skills and interests. It was at that point in my life I started raising the awareness for extra staffing needs, time for quality of life and less medication.

10 years on, I see the same needs apply to most long-term medical conditions, particularly with neurological conditions. Our aim is for patient rehabilitation groups to work together on common grounds of needs e.g. for Neuro-physiotherapists, Occupational Therapists, Nutritionists, Counsellors, Specialist Nurses, Incontinence Services etc.

A few years ago I attended a regional neurological alliance meeting in Lincoln - where I met Hilary Hallam. We talked together after the meeting and almost everything we each said about our own condition, and our support groups, was virtually identical. I found her incredibly informative and inspirational. Following her lead, as I live in Peterborough, I instigated proceedings in Cambridgeshire and we now have the Cambridgeshire Neurological Alliance.

Previously I founded an M.E and CFS Self Help Group, and we endeavour to help people access management and coping skills in order to manage their life on the daily basis. At present we are campaigning for better access to services, Specialists and a more appropriate health policy. We hope shortly to announce an Education Development day, where leading M.E. Specialists will be giving talks to medical and health professionals. The ultimate aim is to gain a Specialist M.E. Nurse for the region. Especially for those severally affected, confined to bed/house. Like Lincolnshire we have also found that coming together with other neurological support groups - who are in fact all seeking the same change in services - is beneficial. We now represent a huge percentage of the population, instead of just our own condition. Together we are MUCH STRONGER.

I look forward to working with the rest of The Lincolnshire Post Polio Committee and find the newsletters a great source of interest and information.

With kindest regards Diane Newman
diane.newman@lincolnshirepostpolio.org.uk

A Shot in the Dark

April 15th 2003

Dear Sir/Madam,

This is merely a 'Shot in the Dark' BUT - ON YET ANOTHER VISIT TO THE DOCTORS, I was helping an old lady who was having difficulty getting into the surgery with her wheelchair. We got chatting, and discovered, we both suffered polio as children. She then gave me some astonishing information about your organisation. I gave her my phone number and a few days later she rang and gave me your address. She told me to write down a life and medical history and how the polio affected me. I hope this is right, as I really would like more information. I have never heard of Post Polio Syndrome.

So here goes:- I am 58 (born in 1944), divorced, live alone in a small council flat and unemployed, and I now employ the aid of a stick. I had polio in 1952 when I was eight years old. I have vivid memories of my dear mm carrying me to the M.O. (Medical Officer, my Dad was in the Army) because, I couldn't move my legs, my back hurt, and I couldn't see. The MO bundled mum and myself into his car and sped off to the hospital. I was put in an Isolation Ward, and remember mm and everyone having to wear gowns, masks and gloves. After a while I was given a lumbar puncture, then I can remember heavy weights hanging over the bed, at the bottom, and other mechanisms were attached to my legs and ankles pulling on both legs. My condition deteriorated, I had trouble breathing, I was then put into an iron lung and this is where I stayed for I believe 18 months. As I recovered I was sent away to a convalescent home where I learned to walk with the aid of callipers. I continued to recover, got rid of the callipers and eventually around 1956 was declared fit and healthy.

Mum was told my cousin and I had caught the disease by eating apples we had picked up by the side of a stagnant pond that contained the polio germ. My cousin and two other children were also affected.

Since then I have led a very full and active life. I eventually married and had two very healthy children. In 1976 I got a full blown dose of I think it was called Russian or Red Flu. I got over it but weeks later suffered an asthma

attack. Doctor says it was a result of the flu. The asthma was well controlled with the help of inhalers and I carried on with my very full and busy life.

Then in 1989 my joints started to stiffen and become painful, so I exercised more by cycling and walking more often. It still hurt like hell. I was then diagnosed with having arthritis. I was given anti-inflammatories. These worked well. I then went through a divorce, moved into a small flat, and carried on with my busy life that now included three grandchildren all living close by.

January 1999 I suffered a back injury and this is where my world seems to start crumbling. I am not a moaner, nor a hypochondriac, I am a very positive person. I feel this back injury or rather the aftermath of it has really affected my well being, and my overall health has suffered dramatically. Since this happened I have gone from an active, energetic person who always walked fast, rode my bike for miles, to someone who is now frequently feeling 'unwell' for no reason or course. I am experiencing sore throats, chest infections, pains in my chest, a terrible lack of energy, unexplained tiredness most of the day, can't wait for bedtime and then have difficulty sleeping. I have more noticeable pain in my joints and muscles from head to foot, and less strength in them. Even my hands that used to break an apple in half - to the children's delight - are weaker. I have trouble with indigestion because my food doesn't want to go down properly. I am now getting discomfort on short walks or any spell of exercise as I have difficulty with my breath or lack of it. So I have to use my inhalers more often. I also get headaches, cramps in my legs, toes and hands. Feet swell and heels are tender and my shoulders are hurting, so I am trying very hard to exercise as much as I can, before I seize up altogether. I have been tested for diabetes, thyroid and anaemia all normal.

Well at last the end, after all this please dont think I'm looking for some miracle cure to all ills, I'm not. I know a lot of it must be down the ageing process and I must get on and help myself. BUT if you have any suggestions and information I would be very grateful.

I thank you for your time and patience and eagerly await your reply.

With kind regards.... Lelsey in Berkshire.

Hints, Tips and Bits from Polio Survivors.

From 3 emails to the St. John's Polio List - with permission from the senders. Similar stories from all over the world.

1. I have been seeing a doctor in X, USA knowledgeable in Post Polio. Her recommendation is for me to apply for disability which I have been fighting for several reasons.

I am 47 years old and my life wasn't supposed to take this turn. I have two kids in college and I don't think we can live on only my husbands salary.

Recently I saw my regular doctor and blood tests were taken. My muscle enzyme is still high, potassium is low. I also took a Pulmonary test and the results from that were not good and I am being scheduled for more tests. Also I am supposed to get a Scooter in a few days, which I am not happy about although it has been approximately 10 years since I have been able to walk the Malls.

My question is, has anyone else experienced what I am going through, because so many days I feel like the Lone Ranger with no-one understanding what I am going through, or having someone to talk to about this. I think my husband is losing patience with me, and the Kids have their own lives. I work all week and on the weekend I rest to repeat the same process next week.

2. Do go to your Primary Care Physician first. Neurology may not be the right place to go (I sometimes wonder if "good neurologist" isn't an oxymoron, especially after the one who informed me that since they didn't teach about PPS at Harvard Medical School, it most certainly did not exist.

3. I am learning to view each adaptation I make as a victory for the quality of the rest of my life, rather than a loss and defeat. It helps to make each day a joy--whether riding my scooter, using my companion chair in the minivan, using my up-life cushion, my shower chair, and any other help I can get to make me feel better, get around easier, and do more things that I enjoy.

Hoping that all of you will be able to have peace and joy with your changes.

The Lantern Hotel

"The Lantern Hotel in Worthing is a fully adapted facility offering 18 en-suite residential rooms and a similar number of en-suite hotel rooms. It is currently owned and run by the British Polio Fellowship, primarily for polio-disabled people. Because of funding difficulties, a decision has been taken to close the Lantern by the end of this year, resulting in the 13 long-term residents having to find alternative care places. I am frantically searching for suggestions of people or organisations who might be able to help in an effort to keep the Lantern open and wonder whether you may be able to offer any advice. More information about the Lantern is available on the BPF WebSite - www.britishpolio.org

Any suggestions you may be able to make will be gratefully received."

Pat Galvin. patgalvin@waitrose.com

Hello Friends

Contacting you to check whether you have heard that the BPF voted last month to close the Lantern Home & Hotel in Worthing at Christmas. In case you are not aware of the Lantern is in part residential home and part hotel. There are 18 bedsit rooms for permanent polio residents and the hotel can cater to 22 persons all year. It is owned by the BPF and they have voted to close it due to financial problems and Government rules and regulations.

There are about 10,000 BPF members and it has come as some surprise for us to hear that the BPF have been subsidising the Lantern and are not running out of money. Many members believe that the BPF should have informed the membership of the problems and attempts raised to launch an appeal for money, etc.

It is imperative that we do not lose this unique and necessary home and hotel. Is there anything that you can do to help? I would like very much to hear from you.

Best regards. Clare

[Many of our UK members are also members of the BPF. If you have any ideas then please email Pat, discuss this on our members list, and/or write to Clare c/o the LincsPPN and we will pass the information on. More than once members have expressed concern that nursing homes will not understand the special needs of polio survivors. To lose this would be a shame.]

What a Co-incidence!

How often do you hear that phrase but it seems to happen time and time again. My co-incidence has to do with Hilary - but let me start at the beginning.

I had polio in 1943 when I was 9 years old, right in the middle of the war when doctors were in very short supply and those that were around were ancient - at least I thought mine was and unfortunately he didn't know anything about polio. Consequently I was not diagnosed as having had polio until two years later when my mother took me to an orthopedist because my feet were deformed. This all happened in North Hykeham, right next to Lincoln.

Years pass and I eventually end up in California where just a few years ago I was diagnosed as having PPS. Living in a rural area of Northern California my only access to information on this condition has been through the Internet. The first thing I found when searching for information was the link to the Lincolnshire Post Polio Network. I immediately fired off an email to ask questions about the years back then. I knew there were others in North Hykeham that had polio at the same time I did, and I was curious as to whether any of them were still around. When I heard back it was from a lady by the name of Hilary Hallam. She asked me for some more information about myself and eventually we had a long conversation on the phone. She told me that she lived just down the road from the border with North Hykeham. In fact her children had gone to the North Kesteven Secondary School - which had been a farm where I used to go every morning for our daily jug of milk. [Incidentally my mother taught at the Robert Pattinson school in the fifties].

One of the things about having to slow down is that I have time to reminisce. Hilary asked me to think about writing a piece for the LincPIN. Thinking about this brought back so many of those childhood memories. My love of reading developed during the months that I was in bed. My father built me a wooden backrest and a cradle for my legs so that I could read, write and do puzzles, etc. I was also blessed to have a mother who was a nurse and my eventual recovery was due to her excellent care. At the same time she was working at the ARP first aid post, filling in for the district nurse and various other and sundry medical needs of the village

during those long war years. (Yes it was a village in those days, now I hear it's just an extension of Lincoln.

Now to the present and the different needs of PPS. One of the hardest things for me has been to learn to say 'No'. The first time was the hardest but cutting back to doing only things that give me the greatest sense of fulfilment was a good thing to do. I never have liked to cook so I am an 'extreme' fan of the crockpot - easy to put together a meal in the morning when I feel at my best and then enjoy the wonderful aromas while dinner is cooking. Other energy-saving tips are to share the chores with your spouse and if it's not important - "Let it go!" I would highly recommend doing the things you enjoy and leave the others (also the advice given me by the doctor who diagnosed my PPS). I struggled with the "I've just got to do this" and "I really ought to do that", but if it's not important to your life and well-being, it really isn't important at all.

I have a wonderful husband who for several years was not able to help very much because of the pain of disintegrating hips. Last year he became the proud recipient of two new hips and now he is my 'legs'. It was a rough year but because I was able to help him I don't have a problem with asking for his help when I need it. The big word here is 'sharing'. He loves to go shopping (I don't), so between us we have worked out a system that enables me to function and to enjoy life. When dealing with family and friends about the disabilities of PPS it's best to be honest. Be willing to say, "I can do this BUT that is too energy draining". I lie down or nap every afternoon and have asked people not to call me during that time. Polio survivors tend to be very independent (or so I have read) and the fear of giving up some of that independence makes one reluctant to ask for help. As long as you do the asking and make it quite clear that help is welcome and appreciated, you are still in control of your own life.

I direct a church choir which gives me a great deal of joy and when I told them that I might have to retire, they were all willing to step forward and help so that I can continue.

I have two very dear friends who have been going through the rigors of cancer and it has helped me to see how inconsequential my disabilities are compared to the many rounds of chemotherapy and its after effects.

My husband says, 'It's a good day - I woke up this morning!' He is almost 80. I try to treat each day as a blessing - a gift. I got up this morning.

My maiden name was Knight and my father was a chief inspector for the AA. Back then, a lot of people knew both my mother and my father. When we moved to North Hykeham in 1933 the population was about 700! The Roe family - father Sid and sons Peter and Harold lived in the farm opposite our house (29 Moor Lane). I know Sid was on the county council and I think Peter was also. I attended South Park High School from 1944 to 1951 when we left Hykeham.

My name is Jean Knight Hill. I would love to hear from folks.

My email address is evh@pacific.net or write to me via the LincsPPN.

Paget's Disease

From Jennie Bedford, Canadian Member
jenniebedford@telus.net

A very good friend of mine passed the following on to me. I checked it out on the Web and there's more information there if you want it.

Here is a UK website.
<http://www.cancerbacup.org.uk/info/paget.htm>

Paget's Disease:

This is a rare form of breast cancer, and is on the outside of the breast, on the nipple and areola.

It appeared as a rash, which later became a lesion with a crusty outer edge. I would not have ever suspected it to be breast cancer but it was. My nipple never seemed any different to me, but the rash bothered me, so I went to the doctor for that. Sometimes, it itched and was sore, but other than that it didn't bother me. It was just ugly and a nuisance, and could not be cleared up with all the creams prescribed by my doctor and dermatologist for the dermatitis on my eyes just prior to this outbreak.

They seemed a little concerned but did not

warn me it could be cancerous.

Now, I suspect there are not many women out there who know a lesion or rash on the nipple or areola can be breast cancer. Mine started out as a single red pimple on the areola. One of the biggest problems with Paget's Disease of the nipple is that the symptoms appear to be harmless. It is frequently thought to be a skin inflammation or infection, leading to unfortunate delays in detection and care.

What are the symptoms?

The symptoms include:

1. A persistent redness, oozing, and crusting of your nipple causing it to itch and burn. (As I stated, mine did not itch or burn much, and had no oozing I was aware of, but it did have a crust along the outer edge on one side.
2. A sore on your nipple that will not heal. (Mine was on the areola area with a whitish thick looking area in center of nipple).
3. Usually only one nipple is affected.

How is it diagnosed?

Your doctor will do a physical exam and should suggest having a mammogram of both breasts, done immediately. Even though the redness, oozing and crusting closely resemble dermatitis (inflammation of the skin), your doctor should suspect cancer if the sore is only on one breast.

Your doctor should order a biopsy of your sore to confirm what is going on.

This message should be taken seriously and passed on to as many of your relatives and friends as possible; it could save someone's life.

My breast cancer has spread and metastasized to my bones after receiving mega doses of chemotherapy, 28 treatments of radiation and taking Tamoxifen.

If this had been diagnosed as breast cancer in the beginning, perhaps it would not have spread...

What Type Are You? by Jann Hartman

Ages ago when I was still working, I filled out a short Myers-Briggs questionnaire. Today, I've retained few details, but I do remember that Type A's outnumbered Type B's by 2 to 1. Then, this was proven to me at a meeting where we were separated into two groups. There were 2 tables of very loud type A's and 1 table of rather quiet type B's. Each group was given a simple task to do. The "laid back" type B's were done with the assigned task before the "driven" Type A's even started. Many Type A's think Type B's don't "have a life." And, Type B's admit that Type A's "drive them crazy." But, there is no need to be just one or the other. Most people are a good mixture of both. Still, there are a few "flaming" type A's.

"So what are people with the Type A habit trying to accomplish exactly? Why everything, of course, and quickly, and better than anyone else ever has, and perfectly! And why? Because they can, and it's important, and they need to before someone else does, and because it will finally prove to their parents that they are worthwhile..." [Transforming Type A Personality by Carol H. Lankton, M.A., LMFT]

It's exhausting. If this is you, you need to give yourself a break...today! Typical Type A behavior results in a lot of unnecessary stresses: mental and physical, and even financial. As Dr. Phil would say: How's that working for you?

Some simple changes may be useful:

- ◆ Learn to do Yoga Breathing for relaxation.
- ◆ Eat some nutritious tasty snacks (like dry roasted soynuts).
- ◆ Make lists: then delegate all that you can.
- ◆ Be very flexible about getting things done (deadlines are stressful).
- ◆ Rest is very important whether done in a recliner or out on the patio lounger.
- ◆ Find a Type B who you admire or a reformed Type A and follow their example.
- ◆ Identify changes to be made, and start making them...slowly.
- ◆ Give up trying to be all things to all people.
- ◆ Surround yourself with positive people, and stay away from those who are negative.
- ◆ Give yourself permission to take care of your needs and your body.
- ◆ Don't forget to take some time to stop and smell the roses each and every day!

Many people are realizing that Type A behaviors

which worked well during Polio recovery have now become liabilities as we now deal with Post Polio Syndrome. There is much wisdom in that realization. And, now is the time to make changes!

Short questionnaire I placed on the Internet.

What is your definition of a Type A?

What is your definition of a Type B?

Then tell me:

Are you a Type A? Or, a Type B?

(Most people are a mix of both types, but please pick just one for the purpose of this study.)

How do you know? (for instance, someone told you, you just know, or you have taken a personality test, etc.)

Is your husband/wife the same type as you are? (yes, no, n/a)

Complete the following sentences (or thoughts):

"Wheelchair races are....."

"My idea of a good time is....."

"I love to....."

"When I want to relax, I....."

Do only one of these:

If you are a Type A, complete this: "Type Bs...."

If you are a Type B, complete this: "Type As...."

Statistics:-

31 people took the survey.

23 Type A - several consider themselves 'reformed'.

7 Type B

1 Can't decide.

10 of the 20 couples said Partner is the same.

7 couples both Type A.

3 couples both Type B.

Many thanks to all - including the LincsPPN members - who had the time to participate. And, for anyone interested, I am a Type B (with a little Type A thrown in, I guess) married for over 30 years to a wonderful Type B guy. We still travel but now do less stressful vacations. Life can be very good even with PPS as long as we have support from others.

Jann Hartmann,
Life Member, Baltimore, Maryland, USA.

From LaVonne Schoneman

LETTER TO A FRIEND (missing Mom on Mother's Day)

I lost my mother a few years ago too. I try to find a mother to surprise with an unexpected gift - usually a different one each year. A huge can of Watkins cinnamon for one who bakes, some pretty, floral smelling soap for another, just a little thing that helps me honor Mom's memory by honoring them. A piece of costume jewellery, a book, flowers (a yard bouquet or house plant), a hanky, just something little but nice. It really helps ME cope. Also I have found wearing a piece of jewellery of Mother's helps on the holidays, like Christmas, or her birthday (which is near mine and we always celebrated together). I have a favorite pin I wear at Christmas. February is my hard month as our birthdays and Valentine's Day and her death date are all then. Now, I try to remember a grandson born in Feb. and even buy myself a little gift, a magazine or new lipstick, whatever. It all helps ease the pain of loss... I also remember friends and, of course!, my daughters.

by LaVonne Schoneman - Vonnejo@aol.com
Copyright (c) 2003
(originally appeared on Sheri McGregor's website www.motherswhodream.com
Have a look at this site, some good articles)

FLATULENCE ISN'T FUNNY.

Among the many euphemisms for flatulence are:- breaking wind, spider's barking, popped a bean ... you get the idea.

Now why would I want to bring up such a stinky subject? The reason is simple. We have plenty of problems in this world without this one. For years we have been alternatively annoyed, embarrassed, shocked, outraged and amused when confronted with this subject. If it is a baby we understand. Otherwise we are likely to lose our sweet dispositions fast.

"He is nothing but an old f**t," we say. But consider the problem of the person who truly has not way of controlling this condition. Never mind the reasons: "I ate beans or cabbage, My system is upset, We just got over the flu". The simple truth is that this is too humiliating for words. Especially when it happens to me. Most especially in the presence of other people.

How can we control it? I learned this simple

solution when I was at my wits end. Acidophilus works. The good stuff that comes in yoghurt is the secret. You probably know that eating yoghurt or drinking buttermilk will help offset yeast infections when you take certain antibiotics, but did you know this ingredient - lactobacillus - is available in capsule form. It also comes in tablets. The types range from cow to goat's milk lactobacillus. I have learned through trial and error (Oh the errors!) that the most effective method for me is goat milk Acidophilus capsules. They come in bottles of 50,100 or 250 capsules. These are available under many brand names including store brand names. The truth is that Schiff's Goat Milk Acidophilus is the brand that works best for me. In capsule, not tablet, form. At the risk of sounding like a spokesman for the company, let me assure you I am not.

For my entire life I have had this problem. It was complicated by medication taken to control ulcers. When I discovered Acidophilus I realised that a huge problem could be controlled by a simple solution. In the beginning I took a capsule every time I ate anything - especially anything sugar. This amounted to up to six capsules a day, or the equivalent of several cartons of yogurt. This may be the only thing handy when travelling. However after many, many years I have gotten the problem under control with only one or two capsules a day. Seems like a miracle doesn't it.

So many times wives tell me this problem is ruining their happy homes. But it isn't only a man's problem. I know. Therefore, I suggest you give it a try is this is one of the annoying or humiliating predicaments you deal with. We can't cure all our problems, but we can certainly inroads on this one.

My husband, who served in the tropics in W.W. II, still has a fungus infestation known to some as "Jungle Rot". It got into every orifice of the body and just stayed there. If you were one of those veterans who got it then, chances are that a few of you still have it to some degree now. If it infects the intestinal tract you may get relief with a daily glass of buttermilk and an acidophilus capsule like he does.

Remember I'm not a doctor and I don't offer medical advice - this is a coping tip, just like all the other coping tips you see here. But personally speaking it works for me. Maybe it will work for you too!

© LaVonne Schoneman
-HOW TO COPE series 1992.

Members featured in Newspaper Articles.
With permission from
The Advertiser, Maidenhead, March 28th 2003.

Disabled housing appeal.

Couple to launch campaign for adapted properties.

By Val Bootle.

A woman crippled by polio is asking disabled people and their carers to campaign for housing which is properly adapted for them.

"People with disabilities are being treated abysmally," said Yash Airth, who lives with her husband Greg in a Maidenhead & District Housing Association property in Deansfield Court, Furze Platt.

Mr. Airth, 41 has multiple sclerosis and Mrs. Airth 44, who contracted polio when she was a baby, are both becoming increasingly disabled.

Between them they need four wheelchairs, two for folding and putting in the car and two electrically powered ones to manoeuvre around in, but there is not room in their one-bedroomed home for them.

The couple also said their bathroom was too small to get a wheelchair into, putting the WC out of reach, so the couple have had to make room for a commode in their bedroom.

"Why should we have to sleep in a smelly room? Surely human rights are involved," said Mrs. Airth.

The couple have both stressed they are genuinely grateful to have been found accommodation.

"We moved into this ground floor flat two years ago. It was brand new and we were told the place was going to be wheelchair-friendly. But it is not."

"Surely it would be cheaper for the housing association to get things right in the first place?" said Mrs Airth.

She said they could [not] be the only disabled people in the borough, who kept asking for more suitable accommodation, or for badly needed improvements to their homes.

If everyone banded together and launched a campaign, they could make their voices heard, she said.

Mrs. Airth is willing to run the campaign and hopes people across the borough will get in touch with

them.

She used to work for a City of London bank and at present serves on a social services trust and a housing association tenants panel.

Although she has been through the process of establishing they need to move on medical grounds, the housing association has said there was no suitable property available.

"The doctor has written to them. The neurologist has written to them. The occupational therapist has written to them. But they take no notice of anybody. It seems these things are swept under the carpet," she said.

The couple are puzzled why the housing association is building new developments of homes, none of which are designed for disabled people.

Housing Association spokeswoman, Diane Hane confirmed they were not building properties specifically for the disabled.

Instead all new homes the association puts up are built to 'lifetime' standard, she said.

This meant homes should still be suitable if tenants become disabled or elderly and frail.

"We do hundreds of adaptations every year and have built extensions," she said.

She added that Mr. and Mrs. Airth had been on a transfer list since the summer, but their names could not be added sooner because the association had to conduct an assessment of the couple's needs.

Yash Airth airths@yahoo.com

[Editors note- again and again we get reports that people who are supplying or providing equipment for the disabled show very little actual knowledge and experience of actually using what they provide. There should be more Disabled awareness days prior to taking on employment in any field where disability is involved. They should try spending a full day in a wheelchair and finding out where wheelchairs can and cannot go, including doing dog leg entries to toilets, toilets with no room to transfer sideways for a wheelchair user, others half full of other equipment, etc. Wearing distorted vision glasses, putting small knobby items in shoes so that walking is impaired, wearing headphones with white noise playing. The one I love best - wearing a huge incontinence pad for 24 hours!

Someone just read this over my shoulder and said, "Yes and all at the same time!!!!]"

Disabled Drivers Association.
Registered Office and National Headquarters.
Ashwellthorpe,
Norwich, NR16 1EX.
Tel:- 0870 770 3333
www.DDA.org.uk

February to April 2003 leaflet.

Being a member of the Disabled Drivers' Association ensures that you are involved in our campaigning and have access to free and effective advice through our information service. Go on join us or renew your membership now. You know it makes sense.

Membership is £10 a year.

Did you know?

We produce a series of leaflets. Although normally priced at up to £5.00 they are free to members. Subject currently covered are parking, choosing a vehicle and adaptations and VAT relief. We also stock a range of leaflets from other organisations on many relevant subjects. Just ask for details.

[Editors note:- e.g. information on VAT relief on new vehicles that are adapted for the use of a wheelchair user prior to delivery. No VAT on the car or adaptations.]

New Discount from Eurotunnel.

Latest news from the Office Manager is that she has just agreed a 20% discount with Eurotunnel. This is great news for those disabled travellers who prefer to stay in their car rather than clamber in and out for the short crossing. Unlike the ferries, you stay with your vehicle on the Eurotunnel trains.

Members can contact us for a free copy of our leaflets that not only gives details of this concession, but of many others on a vast range of Cross Channel, North Sea and Irish ferry routes.

[Editors note:- I have used this concession scheme in the past from Hull to Rotterdam for the PPS Conference in Jena Germany and from Holyhead to Dublin for the PPS Conference in Dublin. Considerable reduction in price and vehicle parked directly by the access to the lifts]

Decision on Review of the Blue Badge Scheme.

At last the Government has reached a conclusion on the recommendations contained in the review of the blue badge scheme. Many of the points that we have made have been accepted:- For example -

- ◆ Tightening up on the issue of badges to ensure only those people with genuine need get one. This includes not only wheelchair users, but also all those people who can only walk very short distances.
- ◆ Transfer of the task of assessing some badge applications from GP's to other health professionals with greater experience of disability.

We have already started to press government for early implementation of the review. This will hopefully prevent the delays we have suffered in the past.

Even blue badge holders risk clamping.

On private land in England and Wales there is little to stop the landowner, or someone acting on his behalf, from clamping a disabled motorist's vehicle. DDA has campaigned for the law to change so that this cannot happen. This has now happened and we are pressing the Home Secretary to bring these laws into force without further delay.

Baywatch Campaign Moves Up a Gear.

The Baywatch Campaign is a joint venture between DDA and three other disability groups and has the object of reducing the misuse of our parking bays at Supermarkets. With the support of ASDA, Safeway, Sainsbury's and Tesco we have been able to obtain a grant of £15,000 from the Department to further develop this work. Look out for news very soon in the Magic Carpet (DDA magazine).

Have you seen the DDA On-Line Shop.

If you have access to the Internet do have a look at www.Buy.At/DDA where you will find an increasing number of well known shops. Simply access these on-line shops from our website and DDA will receive commission. Just think you can have all the convenience of on-line shopping delivered to your door, pay the normal internet prices and help raise funds for the DDA.

POLIO'S PRISON

by Laurie Mitchell

Apprehensive, a young mother clutches her sweater around her with one hand; the other holds the hand of a small boy. She leads him up some steps, through automatic double doors into a lobby.

As they enter the large, attractive room, she glances around and notices murals, potted plants and indoor trees. She feels relief. As she and her son approach the receptionist's desk, they are greeted with a warm, welcoming smile.

Almost immediately, a social worker greets the mother and leans over to shake the 4-year old's hand to ask if he'd like to take a tour of the hospital. He looks at his mother, who nods.

The social worker presents him with a brown teddy bear, dressed in a little doctor's white coat. The bear wears a tiny stethoscope around its neck. A wide smile replaces the boy's look of apprehension as he asks, "Is it mine? Can I keep it?" The bear is his to keep.

Hugging his teddy bear, the little boy peeks inside a typical hospital room and sees what his room will look like.

He meets the nurses, and learns what to expect during his hospitalization. He is not afraid.

Another time, another place, another child.

Her mother carries a 4-year-old girl into the hospital waiting room. The mother sits on a wooden chair, and glances around at white plastered walls. There is no decoration. The dark brown linoleum floor needs refinishing. Nurses wear white starched uniforms, white shoes, white hose and white caps. Each cap is pinned with the insignia that designates her school of nursing.

The child, who has polio, sits on her mother's lap. She has not been told why she is here.

After an exchange of words between mother and a nurse, she is torn from her mother's arms without so much as a goodbye, placed on a small wheelchair and pushed down the hall to an elevator.

When the elevator stops, the chair is wheeled down a long hallway into a ward - a long wing at right angle to the hall. The child is undressed and put into a short, open backed hospital gown. She is placed in bed; side rails pulled up, a captive in a strange setting.

I was that child, I was afraid.

Ten beds lined each side of the room, headboards against the windows. A white cotton curtain separated each bed.

I watched the other children. They were various ages, some sitting, some lying down, and some with immobile arms or legs in traction. Some chattered, but others sat mute, wide eyes frozen in faces, too fearful even to cry.

Visitors were allowed Wednesday and Sunday afternoons from 2 to 4. Children whose parents lacked transportation received no visitors, and watched with sorrow-filled eyes as other children greeted their parents. Children would cling tearfully to their parents when visiting hours ended.

Each morning, ward 'rounds' were made by doctors, nurses and interns. As this entourage approached, the doctor lifted the patient's chart from its rack at the foot of the bed. The patient's progress was discussed, questions were asked, and suggestions were made. Any change in treatment was then given to the head nurse for follow-up.

I was filled with dread as I watched this group move ever closer. I felt doomed - as an accused person awaits conviction and sentence. I knew something must happen - otherwise why was I here? What would they conspire to do to me?

I learned early on that when the supper cart came around, if there was a piece of stick candy on the tray, it signalled a dire consequence. As a condemned prisoner awaits his doom, I also fearfully awaited mine.

The second clue came early the next morning

when everyone in the ward received breakfast except me. Not long after, a gurney rolled to the side of my bed. I was lifted aboard and wheeled out.

I could not imagine my fate. The answer came only too soon.

I learned many years later that during the 1920's and 30's when most of my surgeries occurred, the medical establishment had not yet discovered sodium pentathol. I was born too soon... the anesthetic administered to my young body was ether, right out of the can. A metal sieve with cotton wadding soaked with raw ether was placed over my nose and mouth.

I do not recall any pre surgery sedative given, as is the practice today. The vivid memories I shall carry to my grave are how hard I fought for my very survival.

I must have fought with strength far beyond my young years, because it took three people on each side to hold me down, while the seventh administered the ether. Imprinted on my memory are sounds of thousands of buzzing bees in my head, my body whirling around a centrifugal force greater than I, and then finally blackout.

This scenario repeated itself many times during my 10 years of intermittent corrective surgeries. Between hospitalizations I was an outpatient.

After sessions of physiotherapy I had to return for evaluation. I attended a 'tribunal' where I stood before doctors, naked with the exception of a loincloth that covered my privacy. How humiliating it was.

As doctors discussed whatever problems they found, no-one asked, or even cared, what I felt. Invariably, after these sessions I was separated from my mother and admitted once again to the ward for yet another surgery.

This scene happened many times from age 4 to 14, when doctors finally agreed they could do no more. By this time I'd had tendon transplant, bone grafts and various modifications of legs and feet, including the shortening of one leg so it would match the atrophied limb. One foot is two shoe sizes smaller than the other, which results in double

cost for shoes. During this 10-year period, after each surgery, I attended schools for the handicapped.

What a difference a few decades make in the approach to children's medical care. When I review what I experienced as a small child, psychologically traumatized by medical staffs who apparently felt no empathy for a terrorized child. I'm pleased at the progress that has been made. The scars on my legs are minor compared to my psychological scars.

If parents and medical personnel could have crawled inside the skin of that 4-year-old girl and imagine the terror in her little heart, they would have freed that child from psychic scars - scars that still haunt her and affect her life today.

Small children are now acknowledged as having the same emotions adults do - fear, anger, anxiety, pain, sorry and joy. Children are no longer viewed as objects unable to think or feel.

Although too many years have passed for me to benefit from these changes, I am happy for the children of today who will not have to endure experiences such as mine.

This article was printed in the Albuquerque Journal, New Mexico, December 1993.

Under the sub-heading

No Teddy Bear
Greeted Little Girl
During Hospitalization
For Polio in 1930's.

Thanks again to Laurie for an insight into her life. If you would like to contact Laurie then email her directly or send her a letter via our office.

© Laurie Mitchell
lmitchell@acrnnet.com

HOW SURGICAL RELAXATION OF MY UPPER ESOPHAGEAL SPHINCTER BENEFITED ME

**By Peter C Ellis,
Nepean, Ontario, Canada**

As determined by a post operative videofluoroscopy of a modified barium swallow study assessed by a Radiologist and Speech Language Pathologist.

PROBLEMS SINCE YEAR 1997

Moderate to severe swallowing difficulty in the throat, a constricted upper esophageal sphincter (UES) and a small diverticulum (pouch) in the front just above the UES.

RECOMMENDATIONS MADE IN DEC, 2001

After having a second modified barium swallow video x-ray study in 2001, I was asked to explore the possibilities in having my UES surgical relaxed by an Ear Nose Throat (ENT) specialist in the short term and also to explore the possibility in having a feeding tube installed in my stomach in the long run by a gastroenterologist. The feeding tube did not appear a very attractive solution, so I decided to go for the UES relaxation surgery.

COMPLAINTS & SYMPTOMS BEFORE THE OPERATION

1. Food and secretions pooled in my throat at the entrance to the UES. Food also collected in my pouch.
2. Had great difficulty to pass food from my throat into my esophagus.
3. Had to use up to ten multiple swallows to get food down with sips of water
4. Sometimes food that entered the upper sphincter came back up into my throat.
5. Had great difficulty to speak with a clear voice through my secretions
6. Was always coughing up mucus and secretions.
7. Had walking pneumonia in year 2001.

SURGERY Jan 28, 2003

My ENT doctor surgically cut my UES muscle to relax it but used caution so as not to relax the muscle completely for fear of giving me reflex problems. My pouch was not repaired because it was too small.

POST SURGERY BENEFITS

The post operative modified barium swallow video x-ray study revealed the following

1. Pooling of food and secretions has now disappeared
2. My swallowing is less effortful and takes less time.
3. There was no evidence of aspiration
4. I use up to five multiple swallows as compared to ten with sips of water.
5. Food still collects in my pouch. In time, My ENT doctor said my pouch will gradually disappear, thus eliminating this problem.
6. My speech is much clearer.
7. I still cough up lots of mucus during the day. Am going to be referred to a respirologist again.

SUMMARY

After six weeks, I can say that I am very happy and satisfied with the results. It took me some time to find a willing and experienced doctor to do the operation as I could not find an ENT specialist who has carried out this procedure on a bulbar polio survivor. My ENT doctor was young, full of confidence and had lots of experience in carrying out this operation on cancer patients. I was the first bulbar polio patient that he had ever operated on. I would recommend this procedure to anyone who has a constricted upper esophageal sphincter and who has a very weak throat.

March 18, 2003

ellispc@sympatico.ca

West Berks Neurological Alliance Conference.
Newbury, Berkshire, March 28th 2003.
Part of full report - more next newsletter.

John Holt from WBNA welcomed 90 delegates to the Conference. The majority in attendance were health professionals, mostly from West Berkshire. There were also representatives of a variety of medical condition organisations. The talks were aimed at health professionals.

The opening speaker was Baroness Susan Greenfield, Director of the Royal Institution of Great Britain, and Professor of Pharmacology, Oxford, University. Her talk was on the Plasticity of the Brain and how it changes our lives. Despite the excitement generated by the mapping of the human genome, genes come at the end of a long list of items when it comes to their contribution to brain function. To explain this she showed an amusing slide of a self-opening umbrella that was initially triggered by rain on a leaf which triggered animals to do certain functions so that at the end the umbrella opened. She explained how a constant dialogue with the environment would determine not only activation of the genes but, more significantly, the final configuration of connections between brain cells.

She told us about a variety of researches that showed that environmental influences could change the way our brain works. About two groups of mice that were given the gene for Huntingtons Chorea. The group that was given toys to play with deteriorated at a far slower degree. A child that had a stroke at birth yet the brain was able to rewire itself over two years. London Taxi drivers who have to learn the Knowledge - the entire A to Z of London Streets - have a far larger area of the brain working than the norm for this function.

The plasticity of neuronal connectivity continues from childhood throughout the rest of our lives, it is effectively the personalisation of the brain. People can lose their mind temporarily as with ecstasy. When the brains of people with Alzheimer's are looked at they are losing brain connections the opposite of when they were babies growing up. They are retracing their early development.

The next speaker was Professor Alan Thompson, Department of Clinical Neurology and NeuroRehabilitation, Institute of Neurology, London.

His talk was on Multiple Sclerosis: Role of Rehabilitation. 'The impact of a condition like Multiple Sclerosis, which can affect every part of the central nervous systems in a variable, unpredictable and at times devastating fashion, on the individual affected and all those around them, is immense. The

management of such an impact requires a comprehensive, accessible and flexible service, which centres on the needs of the person with MS. Such an approach is well incorporated within the philosophy of rehabilitation but this must be expert and equitable.' MS is the major cause of disability in young adults. Symptoms were very similar to PPS [and in fact many other neurological conditions]. The pathology of MS probably relates to inflammation and axonal damage.

He told of four levels to MS. The Diagnosis, Minimal, Moderate and Severe Disability. That there should be standard provisions of service. That the patient's view must be taken into consideration, especially when there is severe disability. Patients should be given the options, with full explanations, so that they can decide what treatment they want and when. That patients should be encouraged to tell how they are, how they feel, how they are coping and not reply in the vein. 'The physio says I am doing well'

He told us that multi disciplinary care is less costly. That some physiotherapy is better than none, and apart from the wilds of Wales it is cheaper to have therapy at home or in the local community. He told us of a variety of articles where the rehabilitation process has been evaluated but it is important to check how many subjects there were, what level they were at, and what controls were used. An UK report shows that there is little difference in the percentage of people receiving care between 1986 and now.

There are many new organisations looking at healthcare and service development. Once all this has been produced then there is the problem of how to translate what should be happening into the systems available. There is a great need for service to be provided at an earlier stage than now with more local services. Seamless care is the aim. How is the question?

The next speaker - again excellent - was Penny Lilley, The Lilley Clinic, Hungerford and her subject Maintaining the Body in Chronic Illness. She is a member of ACPIN, Physiotherapists interested in Neurology.

She advocates and practices a holistic multi-disciplinary approach to rehabilitation providing not only physical improvement but having a positive impact on the mental component of our perceived quality of life. Most often chronic complaints do not get ongoing therapy and patients feel abandoned when this happens. She informed us about a variety of case studies. Study in 96 - 97 less than 50% are referred for therapy.

Factors that add to the Chronic Illness are the ageing

Adaptive Dancing

Adaptive Dancing is a new concept in dancing that has now become a reality for couples where one uses a wheelchair, complete with all the style and grace anticipated with dance.

Judy Kimmons has been a long time student of dance and has trained in all areas of social dance for the purpose of teaching and competition. As a result of problems with joints, her ambitions of competition were cut short. However, Judy still enjoys dancing socially and continues to advance her skills with private and group lessons.

Dale Watts has been in a wheelchair since 1986 and his hopes of ever dancing disappeared with his ability to walk. That is, up until February of 2000.

Dale Watts and Judy Kimmons work together for a major corporation. Dale as a Project Manager and Judy as a Programmer/Analyst. As their personal friendship grew, Dale learned of Judy's love and talent as a dancer. Judy learned of Dale's desire to dance in spite of his being in a wheelchair. The challenge was made. In February of 2000 out of curiosity that had turned into a challenge that neither could pass up, they began a long and time-consuming quest to dance together. With Dale's never-yielding desire and the tireless energy of the two of them, they accomplished what they set out to accomplish, beyond their expectations, and Adaptive Dancing was born.

As a result, Judy and Dale decided to share their break-through and years of hard work. Instruction is available not only for those using wheelchairs and their partners, but also for dancers, dance instructors and therapists. It is their goal to equip others with the desire and skills needed to each others.

[See their website for details of tapes, CD's and manuals. Adaptive Dancing have

kindly provided us with two CD's, Welcome to Adaptive Dancing and Adaptive Dancing Two-Step and Walz Demo. If anyone is interested in this form of dancing and would like to look at these then please contact us.]

Like all good things, Adaptive Dancing had humble beginnings. It first began in a small exercise room at a clubhouse of a townhouse complex. Dale put Judy in a wheelchair to educate her on the mechanics of the wheelchair. Judy also spent a couple of afternoons going to lunch and shopping to get some experience of the wheelchair and the obstacles that had to be overcome in everyday life. Adaptive Dancing moved to the gymnasium at Craig Hospital in Denver Colorado. Today, Judy and Dale practice their craft at the Stampede Dance Emporia as well as Craig Hospital and can also be found at Lewts Dance Denver dance studio located in Aurora, Colorado.

Dancing is an excellent way to improve well being both physically and socially. Adaptive Dancing is dedicated to the idea that social dancing should not exclude people who use wheelchairs. They have developed an innovative practical approach to promote dancing for couples where one partner uses a wheelchair.

Mission Statement.

- ◆ To improve the quality of life physically, mentally and socially through dance for people using wheelchairs!
- ◆ To teach those using wheelchairs, their partners, dancers, instructors and therapists the techniques of Adaptive Dancing and to equip them with the desire and skills needed to teach others. This is done through workshops, classes and video taped instruction.
- ◆ To increase public awareness that people who use wheelchairs, with the same wants, desires and capabilities as those who do not. Adaptive Dancing does this by demonstrating that although using a wheelchair, a person

can still enjoy the pleasures of social dancing.

Why Dance?

- ◆ Exercise - improve upper body strength, eye/hand co-ordination, arm extension, hand and finger extension and balance.
- ◆ Because you can and it's fun.
- ◆ Social Interaction - something you and a partner can do for fun together in addition to building a better understanding of each other's roles in the relationship. It also brings people together, improves interpersonal skills and is a barrier breaker. Being handicapped physically is nothing to be frightened of. When you find a person in a wheelchair in a dance environment, instead of a glance and a smile, ask them to dance! You may be surprised
- ◆ Builds Self Confidence - improve your self-confidence by learning a skill no one thought you could do.

Editors Comments

At the Atlanta PPS Conference in 1997 I was persuaded to take part in a dance session in the evening. "It is for wheelchairs but scooters can join in too." The problem was that scooters do not turn on their axis! It was very frustrating trying to emulate the wheelchair dancers. My partner was a male nurse who was all smiles and 'don't worry' until I stood up and suggested we change places. However, he found it as hard as I had, but between us we gave the audience a few laughs. Those in wheelchairs really did have a good time, from memory I think it was mostly country dancing.

Going back another ten years I used to go to 'Club 87' for the young disabled in Lincoln. I learned to 'jive' with electric and manual wheelchair users. This has caused me to smile, as I remember the bruises I got from catching my legs on footplates, they were almost alive. In fact now an occasional wheelchair user myself I think they are alive, they seem to leap out forward to embrace every door frame I go through! I prefer my

scooter for everyday use but there are times in shops with cluttered aisles and narrow toilets with dog leg entry corridors when a wheelchair would be more useful. I cannot push a manual chair more than a few yards and hate being pushed.

The NHS do supply electric wheelchairs but getting one is almost like climbing Mount Everest! You cannot get an electric scooter and as most of us cannot afford to buy them on benefits we have to approach charities who have funds available.

Polio Survivors are advised to pace and rest and use aids and equipment to manage their energy and prevent unnecessary early damage to their depleting nerves. If only the powers that be could see the long term position - the earlier we are given electric wheels the sooner we can start to manage our energy and do MORE for ourselves and the longer we will be able to manage without assistance, and the cheaper it will be in the long term.

Are you still on a waiting list for an electric chair?

Have you been refused 'wheels', or told you do not need one yet? If this is the case how much impact has that had on your quality of life?

Have you been told that you should get yourself some wheels to better manage your energy, but cannot afford it?

How much more could you do if you had some electric wheels - scooter or wheelchair - and some way to transport it?

Have you been assessed for a manual chair and then found that you cannot push it yourself/cannot operate the footplates/other?

If you have purchased or been given electric wheels that are really good for you, then why not tell us. Remember to include how you transport them and who does the lifting.

LAUGHTER THE BEST MEDICINE.

1. Coffee (n.), a person who is coughed upon.
2. Flabbergasted (adj.), appalled over how much weight you have gained.
3. Abdicate (v.), to give up all hope of ever having a flat stomach.
4. Esplanade (v.), to attempt an explanation while drunk.
5. Willy-nilly (adj.), impotent.
6. Negligent (adj.), describes a condition in which you absentmindedly answer the door in your nightie.
7. Lymph (v.), to walk with a lisp.
8. Gargoyle (n) garlic-flavored mouthwash.
9. Flatulence (n.) the emergency vehicle that picks you up after you are run over by a steamroller.
10. Balderdash (n.), a rapidly receding hairline.
11. Testicle (n.), a humorous question on an exam.
12. Rectitude (n.), the formal, dignified demeanor assumed by a proctologist immediately before he examines you.
13. Oyster (n.), a person who sprinkles his conversation with Yiddish expressions.
14. Circumvent (n.), the opening in the front of boxer shorts.
15. Frisbeetarianism (n.), The belief that, when you die, your soul goes up the roof and gets stuck there.
16. Pokemon (n), A Jamaican proctologist.

NEW WORDS FOR "FAVORITE THINGS"

Maalox and nose drops and needles for knitting,
Walkers and handrails and new dental fittings,
Bundles of magazines tied up in string,
These are a few of my favorite things.

Cadillacs and cataracts and hearing aids and glasses,
Polident and Fixodent and false teeth in glasses,
Pacemakers, golf carts and porches with swings,
These are a few of my favorite things

When the pipes leak,
When the bones creak,
When the knees go bad,
I simply remember my favorite things,
And then I don't feel so bad.

Hot tea and crumpets, and corn pads for bunions,
No spicy hot food or food cooked with onions,
Bathrobes and heat pads and hot meals they bring,
These are a few of my favorite things.

Back pains, confused brains, and no fear of sinnin,
Thin bones and fractures and hair that is thinin,
And we won't mention our short shrunken frames,
When we remember our favorite things.

When the joints ache, when the hips break,
When the eyes grow dim,
Then I remember the great life I've had,
And then I don't feel so bad.

Authors Unknown.

LINCOLNSHIRE POST POLIO NETWORK
ANNUAL GENERAL MEETING
Buffet Lunch - SPEAKERS & WORKSHOP
10.30 a.m. - 5.00 p.m.

SATURDAY 11TH OCTOBER 2003
ANCASTER DAY CENTRE, BOUNDARY STREET, LINCOLN
[Boundary Street is on the A1434 - South Lincoln]

WORKSHOP - Separate meeting room for Family/Friends
"What it is like living as or with a polio survivor."

SPEAKERS CONFIRMED - Aaron Mattes, MS RKT LMT

3 Other health professionals interested in speaking

Let us know what subjects you want covering.

AGM FREE - The rest of the day as follows

Tickets £10.00 inc. Buffet Lunch -/- £7.00 with no lunch.

HOTEL - IBIS just off A46 bypass next to the Pride of Lincoln.

Tel:- 01522 698333 Mentioning Lincs PPN when booking.

All rooms are £29.95 - continental breakfast extra

Lounge/Bar - few snacks or get a Take Away sent in.

Full meal service at the Pride of Lincoln next door.

Get together in the Bar both Friday and Saturday evenings.

To help us plan this event will all members please
complete & return/email information as soon as possible.

Full information will be sent to all hoping to attend or definitely attending.

NAME

Email address - None /

Am unable to attend.

Would like to attend but unsure at this time No. of tickets.

Will be attending accompanied by Family/Friends

Will be staying at the IBIS Hotel YES/NO

Would like information on local B&B's. YES/NO

Would like to see talk on

continued from page 17.

Factors that add to the Chronic Illness are the ageing process – body adaption to immobility – realisation of disability. The implications of neuro problems are far reaching, not only physical, but also emotional and social.

Her aims are maximum function, optimal potential, boost morale – trouble shoot problems being experienced as needs may change, e.g. orthosis, aids, passing people on to other disciplines. She encourages continued mobility using appropriate aids adding that every patient is different, there are no set patterns to work from.

A 1994 study Pound et al on Stroke showed that Physiotherapy does have an impact, especially as the patient is actually getting some hands on treatment. Another study in 1981 showed that early advice is important. Another study showed that spinal injury patients have very little follow up.

She told us of one case where a man was found to walk better when put on a treadmill and the speed increased. [I forget the condition]

Another of her patient's – a polio survivor - when assessed was found to have a huge bursitis to the shoulder that needed treating, she needed better support for her scoliosis, breathing exercises. Showing the need for a holistic and multi disciplinary approach.

Following speaker was Dr. Christine Collin, Senior Consultant in NeuroRehabilitation, Royal Berks and Battle Hospital, Reading, speaking on Motor Neurone Disease and Post Polio Syndrome.

Both polio and motor neurone disease (MND) also known as Amyotrophic Lateral Sclerosis (ALS) are disease of the anterior horn cell, a nerve cell which controls muscle movement. Polio is a viral infection which is largely prevented in the western world by successful immunisation of babies but in parts of the developing world there are still frequent outbreaks. Because the two conditions affect the same nerve cells there have been studies looking for any association but here has been no convincing evidence to link either polio the illness or the polio vaccine to MND.

Post Polio Syndrome (PPS) is an elusive concept and can best be described as the long term sequelae of poliomyelitis with symptoms that include progressive weakness, fatigue and pain. Management of people with increasing weakness and disability in midlife or later with a past history of polio requires careful assessment to define what is going on. The patient may have a great fear that the original illness is returning or is reactivated but this is not so. There is also often anxiety that they may not be believed. Investigations will often include scans of the brain and spinal cord, electrical nerve conduction tests, x-rays of joints and breathing tests. Suggested treatments may include operations to release trapped nerves, the use of orthoses to support weakened parts,

LETTER TO THE BANK

Dear Sirs,

I am writing to thank you for bouncing the cheque with which I endeavored to pay my plumber last month. By my calculations, some three nanoseconds must have elapsed between his presenting the check, and the arrival in my account of the funds needed to honor it. I refer, of course, to the automatic monthly deposit of my entire salary, an arrangement which, I admit, has only been in place seven or eight years. You are to be commended for seizing that brief window of opportunity, and also for debiting my account with \$50 by way of penalty for the inconvenience I caused to your bank. My thankfulness springs from the manner in which this incident has caused me to re-think my errant financial ways. You have set me on the path of fiscal righteousness. No more will our relationship be blighted by these unpleasant incidents, for I am restructuring my affairs in 2001, taking as my model the procedures, attitudes and conduct of your very bank. I can think of no greater compliment, and I know you will be excited and proud to hear it. To this end, please be advised about the following changes.

First, I have noticed that whereas I personally attend to your telephone calls and letters, when I try to contact you I am confronted by the impersonal, ever-changing, pre-recorded, faceless entity which our bank has become. From now on I, like you, choose to deal only with a flesh and blood person. My mortgage and loan repayments will, therefore and hereafter, no longer be automatic, but will arrive at your bank, by check, addressed personally and confidentially to an employee of your branch, whom you must nominate. You will be aware that it is an offence under the Postal Act for any other person to open such an envelope.

Please find attached an Application Contact Status, which I require your chosen employee to complete. I am sorry it runs to eight pages, but in order that I know as much about him or her as your bank knows about me, there is no alternative. Please note that all copies of his or her medical history must be countersigned by a Justice of the Peace, and that the mandatory details of his/her financial situation (income, debts, assets and liabilities) must be accompanied by documented proof. In due course I will issue your employee with a PIN number which he/she must quote in all dealings with me. I regret that it cannot be shorter than 28 digits but, again, I have modelled it on the number of button presses required to access my account balance on your phone bank service. As they say, imitation is the sincerest form of flattery. Let me level the playing field even further by introducing you to my new telephone system, which you will notice, is very much like

yours. My Authorized Contact at your bank, the only person with whom I will have any dealings, may call me at any time and will be answered by an automated voice. By pressing Buttons on the one, he/she will be guided through an extensive set of menus:

1. To make an appointment to see me
2. To query a missing repayment
3. To make a general complaint or inquiry
4. To transfer the call to my living room in case I am there;
5. To transfer the call to my bedroom in case I am sleeping.
6. To transfer the call to my toilet in case I am attending to nature.
7. To transfer the call to my mobile phone in case I am not at home.
8. To leave a message on my computer. To leave a message, a password to access my computer is required. Password will be communicated at a later date to the contact.
9. To return to the main menu and listen carefully to options 1 through 9.

The contact will then be put on hold, pending the attention of my automated answering service.

While this may on occasion involve a lengthy wait, uplifting music will play for the duration. This month I've chosen a refrain from The Best Of Woody Guthrie: "Oh, the banks are made of marble with a guard at every door, And the vaults are filled with silver that the miners sweated for". After twenty minutes of that, our mutual contact will probably know it by heart, so the lyrics will cease, although the accompanying music will continue.

On a more serious note, we come to the matter of cost. As your bank has often pointed out, the ongoing drive for greater efficiency comes at a cost - a cost which you have always been quick to pass on to me. Let me repay your kindness by passing some costs back. First, there is the matter of advertising material you send me. This I will read for a fee of \$20 per page. Inquiries from your nominated contact will be billed at \$5 per minute of my time spent in response. Any debits to my account, as, for example, in the matter of the penalty for the dishonored check, will be passed back to you. My new phone service runs at 75 cents a minute (even Woody Guthrie doesn't come for free), so you would be well advised to keep your inquiries brief and to the point. Regrettably, but again following your example, I must also levy an establishment fee to cover the setting up of this new arrangement.

May I wish you a happy, if ever-so-slightly less prosperous... Good Day.

Author Unknown

FIRST BRITISH CONFERENCE
“Neither Lazy Nor Crazy”
THE TRUTH ABOUT THE CAUSE & TREATMENT
OF
MYALGIC ENCEPHALOMYELITIS
AND POST-POLIO SEQUELAE

SATURDAY 12th JULY 2003
12.00 p.m. UNTIL 5.30p.m.

AT THE OAKENGATES THEATRE
TELFORD, SHROPSHIRE

SPEAKERS

Prof. Richard L Bruno, HD PhD.

Chairperson, International Post-Polio Task Force.
Director, The Post-Polio Institute and Fatigue Management Programs.
Englewood (New Jersey) Hospital and Medical Center USA.

This will be Prof. Bruno's only British lecture in conjunction with the official launch of the updated paperback version of his book The Polio Paradox.

Dr. Elizabeth G Dowsett, MBChB Dip.Bact.

One of the UK's foremost experts on ME who has carried out research in this field for over four decades!

CONFERENCE CHAIRPERSON

Liz Lynne M.E.P. (W. Midlands)

Rapporteur for European Year of Disabled People 2003

Booking forms can be obtained by sending
SAE (along with 2 loose 2nd class stamps) to:-

ME/PPS CONFERENCE,
25% ME GROUP, 4 DOUGLAS COURT,
TROON, AYRSHIRE. KA10 6SQ

Or download booking form from www.25megroup.org

Conference Sponsored by:

25% ME Group
& Shropshire & Wrekin ME Support