

The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 4 - Issue 6 - October 2003

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



Seasons Greetings
to all our members and their families

WINTER POSTCARD

The Mountain Robins perch
amongst the leafless
branches
of the Mountain Ash
tree
their
berry-coloured bellies
glowing orange-red
amidst the berry
blusters
they pose
for a group photo
to send their relatives
down south
before resuming
their holiday feast.



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

Lynn Hobday, Patricia Bamford, W I Hyam, P R Waddington, Sandara Lawrence, J Sims, Vivien Holland, Jennifer McGowan, John Finley, Diane Newman, Elizabeth Doublet, Miss J.I. Thompson, Ann Wood, Jenni Paulger, Sylvia Fortune, J Raynor, Hilary Hallam, Olive Mowatt, The Thompson Family, Marcia Falconer, Susan O'Kelly, Linda Van Aken, Judy Baxley, Yash Airth, Yvonne Webb, Denise Carlyle, Joy Witheridge, Irene Meade

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

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Membership Information

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

Please make cheques payable to 'Lincolnshire Post-Polio Network'

(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)

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Next LincPIN Newsletter - December 2003

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

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**The Annual General Meeting was held on
Saturday October 11th 2003**

Chair - Hilary Hallam, Lincolnshire.
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Margaret Edmonds, London.

Thankyou to all who joined us on the day which included Helene MacLean, Mary Guild and Jim Forret from the Scottish Post Polio Network and Ros Sinclair who is also a Trustee of the British Polio Fellowship. Like Ros, many of our members are also members of the British Polio Fellowship. Working together with other polio groups for the benefit of all polio survivors is very important and the meeting confirmed that we should seek even closer co-operation so that we can all look forward to a brighter future together. We are also members of Post Polio Health International and liaise with many PPS Support Groups around the world.

The Lincolnshire Post Polio Network are members of the Neurological Alliance and Long Term Medical Conditions Alliance in the UK. Some of our members are also working with the following local neurological alliances. Lincolnshire, Cambridgeshire, West Berkshire, Merseyside, and being formed Essex, Devon and Lancashire. Statistically together - over 10 million in the UK - it brings an end to the response 'there are not enough of you to warrant a clinic.'

A big thankyou to all of you who work hard to continue the work of the Lincolnshire Post Polio Network. Special thanks to ex committee member Phil Bilton for his 'hands on' help on the day; to Bob Price who oversees our USA account and to Jenni Paulger now spending some months in the sun each year for offering to remain as our financial advisor.

Huge thanks to Aaron Mattes for coming all the way from Florida; for demonstrating Active Isolated Stretching and for stretching many of our members with good results. Robin was stunned to find that the stretching had increased his height and he had to alter his rear view mirror. See photos front and back pages.

We were sorry that Dr. Ali Arshad was unable to be with us on the day - his car broke down. He was disappointed as he was looking forward to meeting more polio survivors. He is a Consultant in Rehabilitation with a fully staffed multi disciplinary clinic at the Haywood Hospital, Burslem, Stoke on Trent. We will ask him to speak next year.

Most of us have PPS - Di has ME - and that means that we do not have the oomph to do all that we would like to do. Giving up energy to work for the LincsPPN means less time for personal lives. We are all getting older - and as with nearly all pps groups worldwide - we need more members to share the tasks that need doing. If you can spare us an hour or two each week/month then why not ring and have a chat and see if there is something that you can do to help spread the workload.

Newsletter - I am pleased to report that this newsletter contains more from our members. Other members do want to hear your hints, tips and ideas, and the stories of your search for a diagnosis and treatment. So why not drop us a line, or an email. The more items that I can put in the 'To be used in newsletters' file the easier my job and the greater sharing of ideas. If by chance your item does not appear please contact us so that we can ensure we include it next newsletter. I look forward to receiving more contributions from members, jokes, stories, poems, etc.

PHONE LINE - more help wanted.

It is now just over a year since the jolly band of three (Di, Pat and Margaret) took the running of the phone line off Hilary's worn-out hands and ears. It has not been an onerous task split between the three of us - one week on, two weeks off. However it would be really great if there were more volunteers so that the workload could be split up even more. Being on 'duty' does not mean that you can't go out for a week!!!! Life carries on per normal. Some weeks there are no calls, other weeks a few. Usually the callers are asking for more information about PPS - their names and addresses are taken and passed on to Robin who will send them an information pack. Often it is giving someone the reassurance that there is such a thing as PPS.

If you feel that you would like to help out please give Di a ring on 0151 924 4680 or email her on d.brennan@btopenworld.com and she would be pleased to chat to you about what is entailed. In order for us ALL to have the benefits of the Lincolnshire Postpolio network we MUST all help in some small way. Helping with the phone line could be your answer. Giving up a small amount of time once every few weeks will guarantee that the organisation is here for you in the future.

Editorial by Hilary Hallam - As I start this newsletter, at my fathers in Devon, the rain is going sideways up the valley, the sea is crashing on the rocks and flying high in the air. A day to stay inside and do the newsletter or rest or both.

Pace and Rest - a phrase that I tell others to do but am often asked 'How do you manage to do all you do?' Well the answer is that normally I plan most weeks fairly well. However, sometimes the level of work needing to be done means that I have to choose, between LincsPPN stuff, personal life or rest. Yes, I am admitting that I have been doing too much, for too long, with too little rest and this has meant more brain fog. I have forgotten to do things; used the wrong words; written items later in the day that just did not make sense when reread next morning; and worst of all certain that conversations have taken place that I am assured have not. To carers and friends reading this please find some way of telling your PPSer if you see this is happening. The sooner you do, the sooner they can think seriously about the amount of work they are trying to fit into the days. I am therefore not pushing myself over this newsletter and apologise for the delay.

Our trip across the southern USA States to speak at the San Francisco/Kaiser Permanente PPS Conference went very well - although we now have a great deal of experience of travelling on public transport and what can go wrong. I will write that up for the next issue.

We travelled by Amtrak and a two hour stop over in New Orleans gave us the chance to meet members Peggy and Terry Hibbard again. In Texas we did not see an oil well or a steer - we went through most of the 1,000 miles of Texas in the dark!! Patty and Steve Gutting and Ellen and Lon Riddle pulled out all the stops and gave us four great days in San Antonio. We got to see the Alamo and its story on Imax, the Market, a wonderful

Art Gallery with huge displays of glass, and rode along the riverwalk. Quick change pins allowed Lon to lift many different sets of wheels into their van on their hoist.

San Diego. First we met Coy Deer at the railway station - he only lives five blocks away. We were joined at the hotel by Phyllis, Stella and Sue from the San Francisco Bay Area PPS Group and the next day we all went for a tour round the Salk Institute - 2005 is the 50th anniversary of the Salk Polio Vaccine - arranged by Mary Schlesinger from the San Diego PPS Group. We were joined by member John Finlay from Mablethorpe who coincidentally had arrived in San Diego two days earlier. Sadly Kathleen Murray, Dr. Salk's assistant was in hospital and unable to be with us. We were shown a very interesting video that she presented about Dr. Salk's work. This was Mary's first day out for some months so I would like to say a special thankyou.

We Greyhounded it to Palm Desert where Linda Dempster was our host in her bungalow on a golf course. Amazingly to us the golf course runs between the back gardens of the streets houses. Sitting out the back under her roofed patio looking across the golf green to the mountains beyond in temperatures over 100. Not quite as hot as you might think thanks to the hose pipe that runs along the edge of the roof of the patio - its got tiny holes in it and the water sprays out in a fine mist and lowers the temperature on the patio. Charlie - a visiting hummingbird - made us laugh when he saw her new cat for the first time. He flew down and hovered in front of the cat, did the same thing behind and both sides and then flew off. Our visit co-incided with their local PPS meeting where I did a presentation on self assessment, and met LincsPPN member Joyce Sutton and her husband Joe. Linda thanks for a great visit.

Member Susan Conley drove down from Big Bear Lake and took us along the desert

road and then up 8,000 feet into the mountains. We had to get up very early the next day so that I could thank the Rotarians of Big Bear Lake - at their breakfast meeting - in person for their generous donation of \$1,000 last year. Now I know why they are called the Dawnbusters! Susan had also arranged for us to meet with her local PPS group and we had a very interesting time sharing information. Big Bear Lake is an amazing place - there is a sun observatory, a toilet in the middle of the lake for boat users, ski runs, amazing rock formations and the house used in the film Frankenstein. We also visited Susan and Fran's shop, Colbys Gourmet Specialities.

Next we stayed at Rancho Los Amigos Medical Centre invited by Richard Daggett and Mary Atwood of the Rancho PPS Group and joined many local pps group leaders at a meeting with Dr. Jacquelin Perry. One group - living in a retirement village - have Co-posts, two people for every job and all groups agreed that it would make our lives much easier if we all had this level of help. I brought up the problem of single manual muscle testing and its failings as a form of assessment - Dr. Perry confirmed this and said it was essential that we had a full multi disciplinary assessment by pps knowledgeable staff. Thanks to all at Rancho

We then travelled by the Starlight Express from LA to San Francisco, wonderful scenery along the coast and in a couple of places we could almost touch the sea. We took a full days rest and then next afternoon in reception I chatted with PPSers as they arrived - most of whom I have known via the Internet for some years. It is really good meeting in real life, so many laughs, so much understanding of problems, and all of us trying to speak at once! Most amusing was when another scooter wheeled in and came up to the seven wheelies already chatting. As soon as she announced she was 'Grace' we all stood from our wheels to give her a hug - the able bodied in reception

stunned by this apparent miracle cure! Grace Young, an OT known throughout the PPS world.

The Conference was the next day and attended by over 250 people. It was very well organised and I thank the SFBAPS and KP for giving me the chance to present the problems and ways of lessening these being experienced by polio survivors worldwide. Of note is that the PPS professionals were telling all to 'educate your health professionals' - I said that 'All health professionals should contact their Colleges of Medicine and say we need to be given more information on polio and PPS, it is embarrassing seeing patients who are more informed than we are.' All agreed and I think we should all suggest this to health professionals we meet. Stella Cade has collected polio memorabilia and presented this in the foyer. The doll wearing callipers was a powerful reminder of the past. Gladys Swensrud from San Diego has written very comprehensive notes on the conference and shared them with many groups. I am indebted to her and have included the morning session with this newsletter. Afternoon session next newsletter. Of particular note and now added to my presentation was KP Physio Anne von Reiche comment 'I start my appointments by stating my expectations of the appointment.' The next day I gave a similar presentation to the members of the SFBAPS who were unable to attend the conference.

Thanks to Stella & Bill Cade for their hospitality, many laughs, and the drive up and down the famous SF hills, trip across the Golden Gate bridge and tour of the SS Jeremiah a restored Liberty Ship. Richards father was a gunner on one of these during the war and despite the struggle to get up there the chance to sit at a gun was a chance not to be missed. Thanks to all who helped make this trip enjoyable and educational.

Letters to the Editor

Essex Neurological Alliance - First meeting on November 26th, will all members in Essex please get in touch with Sue Joscelyne if you are interested in inputting to the group the problems of polio survivors. Life Member Dr. Betty Dowsett will be there and has helped get this off the ground. Please ring Sue in Leigh on Sea on 01702 711119. [Due to the late issue of this newsletter Robin has written to all Essex members - why not take this chance of attending this first meeting and meeting each other]

Dear PPS Members,

Having just become a member of the Lincolnshire Post Polio Network, I would like to say Hello. I've never been one for writing letters so I will do my best. I must say it's been nice reading the newsletters from yourself. **Sometimes its hard to explain how you feel and reading the newsletters I know others understand what's going on.**

I also was told by my Mom and Dad they were only allowed to look at me through a glass screen. I might not be as bad as others but I think that is down to my mom when I was a baby. I never cried but this one day I was bad, so my mom rushed me to the doctor. I was six months old then. The doctor rushed me down to the hospital. I've had problems all my life. I am 42 years old now and experiencing a lot more problems with fatigue and am in a lot more pain. It is in my muscles and joints as well.

Back in 1999 after seeing the doctor they sent me to the Royal Orthopaedic Hospital. After lots of appointments and x-rays, MRI scans they found changes to my right femur (thigh bone) a condition called fibrous dysplasia. After a few weeks I was still in pain and went

back to the doctors who got me an appointment at City Hospital with a neurologist Dr. S. G. Sturman. He told me it was PPS and to ring the PPS Network. Going back to what I have said the problems I have been experiencing I am forcing myself to work or even doing around the house and so on. Sometimes if I'm having a bad day I just sit down and stay there because I cannot walk without being in pain. I am finding it hard because I've always been on the go. I take things a lot slower at work now and pace myself. I try not to walk too far now because of the pain and not if I have to, to be honest all I want to do is rest.

D. Johnson, West Midlands.

Dear LincPIN

I emailed you on 1st July 2003 and rang you. We talked a lot and I went back to your website and, amazingly, found a neurologist who is interested in PPS who was in my local NHS.

I finally got to see Dr. Jackson on Monday and he does suspect I had polio and have PPS - my clawed toes probably gave it away.

Firstly, I must thank you personally for your help in pushing me along to this satisfactory starting point. I say that because, for years, no one thought I had a problem, and worse, the last consultant I saw actually asked me what did I want him to do - what an *****!

Anyway, it is a strange feeling of relief to find someone who does not think you are daft, does know what you are talking about, and is organising tests etc. There is probably nothing he can do about it, apart from trying to find out the progression, extent, etc.

Anyway, thanks for everything. I owe the Lincolnshire PPS Network a lot, the least for being there for me to be a member and support all your and everyone's pursuance of getting information about this condition (if there is anyone else apart from you, that is)

chris-howell@btconnect.com

Dear Members of the Lincolnshire Post-Polio Network,

This is just a note from two of your 'distant' fellow LPPN members, Marcia Falconer and Eddie Bollenbach. We want to take this opportunity to thank 'YOU' for supporting 'US'.

The 'You' in this case is all of you sitting here at your Annual General Meeting; the polio survivors of England who have given so much of their own free time, energy (and money) to help other polio survivors. You may be relatively small in numbers but the impression you have made upon the whole world is enormous.

The 'US' who send thanks are: firstly, Eddie and me, and secondly those LPPN members who live too far away to come to the AGM. But most importantly, those of 'US' who send our thanks to you are the many, many people who have been touched - and helped - in one way or another by the LPPN - and by your generosity. The LPPN WebSite, the LincPIN Newsletter and the 'personal touch' are so very, very important in supplying help and information about PPS across the world.

Take time to feel good about yourselves for starting this organisation, supporting it and working for it. Please reach around and give your neighbour a good 'pat on the back' for a job well done from all of 'US'. Sincerely,

Marcia Falconer and Eddie Bollenbach.
marcia.falconer@sympatico.ca
edward.bollenbach@snet.net

For new members - both are polio survivors. Marcia is a virologist in Ontario Canada and Eddie a biologist in Connecticut USA and since meeting online through PPS and our organisation have written

1999 - 'Non Paralytic Polio and PPS' for our WebSite Library

2000 - 'Late Functional Loss in Non Paralytic Polio' American Journal of Phys. Med. & Rehab. Special supplement on PPS Jan/Feb 2000.

2003 - new article submitted.

Dear LincPIN,

APPROACHING POSSIBLE SURGERY

It was suggested to me that my experience might be of interest to others. Basically it involved finding and supplying information and also going to consultations with a list of questions and concerns written down as it is all too easy to forget everything in the heat of the moment. It also saves time!

Just over two years ago having used sticks or crutches since the age of fourteen and having lead an active life I began to experience problems with my shoulders, especially the left one. My GP referred me to an orthopaedic surgeon specialising in upper limb problems. He was very helpful and informative, listened to my areas of concern but admitted not having a great deal of experience with post polio people.

With help from my sister who lives some distance away the Lincolnshire site was found on the net. Not being on the net at home I visited the site at the local library

and discovered the article 'A Knife is not so Rough if... (Preventing Complications in Polio Survivors Undergoing Surgery) by Richard L. Bruno.

A copy was sent to the consultant with a covering letter in which I said that I realised that many health professionals had little experience in treating people who have had polio. I asked if it might be of interest to any members of his team. A positive note was received in return with a promise to put a copy in my case notes. At the pre-admission clinic I was impressed to find that members of staff had read the article and appeared interested. The guidelines were discussed and followed which I am sure contributed to my speedy recovery from surgery.

Two years later surgery was undertaken on my other shoulder by the same consultant and although the anaesthetist was different he immediately referred to the previous occasion and stated willingness to observe the procedures which had obviously been successful

Lesley Forsyth, Scotland..

Dear LincPIN,

This is written in a whimsical style as for me it is a way of finding a fresh vantage point.

*Meercats represent humans,
Mintomyelitis is Poliomyelitis.
and Post Minto Syndrome(PMS)
is the Post Polio Syndrome(PPS).
A Meercat season is
ten years human time.*

MINTOMYELITIS

This is an open letter to all Meercats who have suffered from Mintomyelitis.

As you know if Meercats survive the initial attack, it affects them in different ways. Most lose power in their tail and paws. Minto struck me in early adult life whilst away on National Meercat Service. It was in the least common form and affected whiskers, eyes, swallowing and squeak box.

Recovery was good, leaving a tendency to choke from time to time and difficulty in swallowing even the tastiest scorpion if it was too crunchy or dusty. I know that I was very fortunate compared to others following Minto, as these residues of illness did not stop me from leading a fulfilling and interesting life.

In retrospect, however, there remained some doubt – was recovery quite as complete as I had thought (apart from the throat and squeak box)? It was noticeable that I had to push myself energy-wise compared to other animals and there was a marked loss of vitality in the fifth season* at an age when most Meercats are still in full swing.

Was this my bloodline –an inherited trait-or were these the early signs of 'Post Minto Syndrome' (PMS)**.

Then things went really pear-shaped late in the sixth season. It started with a painless pleural rub and a period of more frequent choking. There were strange changes in my lungs, sometimes overwhelming fatigue and other weird symptoms. Resistance to cold was lost. And my stomach would cling onto a meal for hours and needed drugs to kick start it. Concentration and attention span decreased and I became clumsy in speech and movement when particularly fatigued...and so on. The whole mixture seemed inexplicable

From initial X-rays the Meerdocs

predicted an imminent reunion with my ancestors. However they were mystified when urgent surgery for a lung abscess revealed no underlying cause. The spectrum of symptoms puzzled them too.

We were ignorant then. Surfing the Internet brought the possibility of PMS, and then we found that few in the medical establishment accepted its existence. After five years we have come to think that my condition is PMS, although still this is not recognised as valid by my Meerdocs.

HAVING PMS.

Particularly for Meercats who have had the paralytic form of Minto, the initial illness is quite enough. Life is unfair - it is sufficient to go through the first illness and its after effects and the suffering it entailed. Then the old condition returns, worsens and to add insult to injury, new problems appear.

My own reaction to the possibility of PMS was one of denial – all this would pass, some magical reason for it and a cure would appear and bingo - all would be well. It soon became apparent that this was not going to happen and there followed the usual responses of Meercats to any kind of loss - anger, querulousness, frustration, despair and finally the beginnings of sad acceptance. But all this is a bit superfluous for you – you have been there and even my mentioning it is a bit of a presumption.

HAVING PMS BUT NO DIAGNOSIS.

You may ask whether it is necessary to have a diagnosis. Assuredly it is – without a diagnosis firstly you will have a whole succession of consultations and endless often repeated tests. Without a

diagnosis you have a barrier to gaining help, benefits etc, without a diagnosis you are in a kind of limbo and you are faced with understandable doubt and mistrust.

I have the impression that that some Meerdocs are most comfortable with acute medical or surgical situations. The diagnoses, treatments and outcomes are so clear and satisfying to all. Is it that by contrast chronic illness is more problematic and therefore may cause more anxiety?

From the patient's side nobody wants to be a trouble or a burden, and that is how I felt.

The buzz word in Meerdoc circles is 'evidence based' by which is meant that things are only acceptable if looked at and confirmed by lots of them. This is an excellent principle and is one which might be introduced into other walks of life.

The question is what happens with those conditions that have not yet been subject to such close scrutiny?

HOW DO YOU FEEL?

Naturally, your relatives and friends are going to ask you how you are. Has this proved as difficult for you as it has for me? PMS is a kaleidoscope of experiences and at any one time one of them may be in the ascendant. If you describe just one, your present symptom, it may give a very strange impression.

Amongst the symptoms, tiredness is a constant and we would need a new dictionary of tiredness terms to covers its nuances in PMS. So we do our best to explain the inexplicable and see them glaze over or turn away with

sympathetic incomprehension in their eyes. In attempts to relate to their lives we resort to simile – 'It's a bit like the first day after a bad attack of 'flu' – not quite accurate but it will do. I've thought of saying, 'Its like walking around in an old fashioned diving suit' - totally over the top but it has a grain of truth in it. Eventually you give up – it's just not possible and it becomes repetitive.

HOW ARE YOU REGARDED?

Speaking for myself, firstly you have to come to terms with the fact that you are living under a cloud of disbelief, your own and others. There is not a lot that can be said to help you if you have to walk through this dark tunnel, except to remind you that others have been there too and emerged from it.

Also we tend to put high value on what we do as work, how much we earn or over how many others we have power, and we also make judgements on surface appearance and presentation.

What a disadvantage these attitudes put on those who have had Minto or PMS. Not only may our presentation be altered by paralysed limbs, but our occupation may have suffered, and certainly we are not going to be powerful creatures as the world sees it. Are we now irrelevant?

How sad and what a travesty. We Meercats must remind ourselves that we all share a wonderful gift of life and joy of consciousness. How can one 'awareness' be more valuable than any other?

Similarly, how can we think that one task, one occupation is more or less important than another?

WHY DON'T YOU

Out of love and concern, your friends and family will suggest, nay insist, that you undertake some amusing and diverting hobby or pastime to keep you happy and occupied. Even though now I am well into PMS, when I look back to earlier stages, there probably never was a time when this was remotely feasible for me – almost immediately the effort of living from day to day was all that I could manage. This continues, so that I am lying flat or sitting most of the time with short walks when possible. Hobbies etc were and are way beyond my energy span. Maybe this is a particular feature of the bulbar form of PMS.

When we do not have much in the energy banks we become acutely aware of how we use it. It becomes as gold dust, a really precious commodity. How are we spending it – are we frittering it away in worry, anxiety, dither, conflict, daydreaming, etc? And we look out at the world and see profligate waste of this precious gift.

Energy-time becomes important, conserve to preserve works sometimes, at others it is a case of taking advantage of whatever brief window appears.

To return to the 'Why don't you...' theme. One of the favourites in my family was of the alternative therapy variety. So if someone rings up and says that fossilized maggots from the Kalahari desert are excellent for immunity, lack of energy etc, etc of course muggins has to have a go. Heigh-ho!

Please do not contact with any suggestions about elephant dung either seriously or in jest.

It is curious to observe the tangle that Meerdocs have got themselves into

over the Complementary Medicine business. Do so many of us seek alternative remedies because it gives us a sense of control? Do others feel that something has been lost in the rush to reap the undoubted benefits of technology in traditional medicine, or is there some other explanation?

MY MEERDOC ROUND & ROUND

a) **The Primary Meerdoc** - Choose him or her with care. I have been most fortunate in having a truly golden whiskered one. He is not a PMS believer but has been very thoughtful in management and has been a point of sanity

b) **The Home Consultant** - He is kind, was willing to refer on, but has become increasingly miffed by my failure to fit into any acceptable pattern. There are difficult feelings around about this, which neither of us seem able to take hold of during our meetings.

c) **Early Consultant** - One of the first consultants was an expert on lungs. Although a CAT scan had just been done at the local hospital it was repeated 'so that it can be done on our machine'. At the outpatient appointment, the individual seen just before me was clearly on his last legs and it was a traumatic situation for everyone present. Funny lungs and fatigue did not rate after that for quite understandable reasons. I was given the label of 'liverish', to which label we gave a rueful smile.

d) **The Minto Expert** - Of all the consultations this was the most personally disappointing. The opinion was that this was not Post Minto Syndrome (using the criterion that there was no subjective deterioration at the primary site of Mintomyelitis). Perhaps having had the more rare form of Minto

meant that the signs and symptoms did not easily fit into any usual pattern. Anyway, clearly it did not fit into evidence-based views.

This lack of the PMS label was the beginning of what seemed like an endless search, numerous 'opinions' and truly countless tests. With increasing deterioration we were also very driven to find answers.

e) **The 4th or 5th Consultant** who I experienced as a very open person, said at the final consultation 'There's something wrong with you but I don't know what it is'. He had set out alongside us with high hopes of a solution, and it felt that we all shared in the disappointment.

f) **He sent me on to a** quiet and thorough Meerdoc who added at the end of the investigations 'I believe you' - Very helpful. I must be a rather slow thinking Meercat because it took me a few seconds to begin to wonder what had been reported back from previous examinations.

There followed an 'Oops moment'. Had we contributed in any way to a previously held negative view of me as a person? - A sobering thought. We began to think of events or statements we might have made which could have crystallized this view. Had I allowed this experience to skew my thinking? More troubling still, in the perception of others did I have a fictitious illness?

g) **This last Meerdoc** is doing some really sterling work in the area of Chronic Fatigue Syndrome. Think his scheme will be very helpful in that condition in a year or so when it comes to be recognised, but sadly it did not quite fit the bill for me.

h) A recent (private) foray to 'a centre of excellence' in many ways was a microcosm of the best and worst of these Post Minto Syndrome/Meerdoc experiences. In some ways it was helpful – in others it was perhaps the most bruising of all the encounters and felt quite dismissive.

This latest Meerdoc was a tall rather austere individual with a highly polished analytical mind and an approach based on honing in on the essentials. As had happened before, a GP referral letter had arrived but not other bits despite our best efforts. We had had to overcome our natural diffidence, and the wish not to cause waves in our attempts to get everything there in time, and it had not worked. We were reluctant also to go outside the Health Service.

He made some new, good, valuable and accurate points.

Despite this, unfortunately there was a sting in the tail as his slogan was; 'No diagnosis- no illness!'

This was combined with a small but significant addition in the letter to the Primary Meerdoc that there was a problem with aspiration of secretions into the lungs but people react differently to these situations. It made me feel that I had had a poor reaction to a minor inconvenience, presumably I must be neurotic, depressed, a malingerer, inadequate or just a poor fish who cannot put up with much. Our earlier fears were confirmed!

I cannot be sure but I was of the view he had never heard of PMS

As Granny Meerdoc used to say (and we all would duck if we guessed the phrase was coming)-' Its like getting a slap in the snout from the trunk of a testy

tusker'

i) The last attempt to clarify the situation was in the form of two e-mails, one to Dr.Henry in the USA and one to the 'original Minto Expert'. Both kindly replied. Dr Henry looked at the list of symptoms and said that PMS was the likely diagnosis plus ageing. The Minto Expert said yes, it could be PMS. One theory is that nerve fibres whose damage went unnoticed during the acute illness can die back prematurely later in life, which would account for many of the features I have. He added that this is a difficult theory to either prove or disprove. Hurrah at last for a glimmer of light.

Conclusions

These are some of the lessons we have learned from this journey.

- * Firstly let you and your family be lights to themselves.
- * Remember that you are an expert on yourself. Also that Minto is only one aspect of your existence as a whole being.
- * Accept the kindness care and skills offered by the Meerdocs, -do not be thrown if their diagnostic efforts come to nothing and be kind to those who find the uncertainty distressing, as you know what that feels like.
- * Stick to your last - be immune to any suggestion that you are not telling the truth, or that it is your fault or a deficiency in you.
- * Remember that others have been in the same situation.
- * Try not to get into anticipatory anxiety about the future, take each day as it comes.
- * If upset, disappear back into the family of Meerdocs in the home savannah as fast as possible, recover and come back to enter the fray another day.

An Upside Down View **By Ellen the One Armed Bandit**

Some of you may remember me from my early days on SJU [St. Johns Polio List] a few years back as Ellen by the Sea tree. It was during my sea tree years that I first met Hilary. She and others on the SJU list helped me to start using wheels by encouraging me to just try the store scooters. A few years later I got a used scooter of my own; along with a lift and started to enjoy new freedom.

Until I found that my one armed-ness got in the way. I discovered that the scooter was more tiring for my good hand and arm. It began to sit in my garage more than not.

It took a few more years to find a doctor willing to help me acquire a powerchair. In my case it was my primary care doctor who read and studied PPS who saved the day. He not only read everything I brought to him, but spent time online looking for more information. When I finally had my Mother in Law push me into his office in a manual chair he smiled, "at last you are ready to take this step."

I had polio at the age of four in 1950. I was hospitalized from one to three months. By the time I realized I might want the records they had all been destroyed. However I do know for sure I was never in an iron lung, but may have been on a respirator. There were weeks I didn't move at all, but my mom wasn't told if I was totally paralyzed at first or not. The one thing that is certain is that by time I left the hospital I was walking with a tiny limp that was ignored as it was my left arm, shoulder and neck that were weakened and drew the doctor's attention.

I know that my mother was very pleased with this, as I remember being told just how lucky I was from the time I first went to school and met up with the other kids teasing. I was known as the "polio kid" or the one-armed jump rope turner, catcher,

runner, etc.

It seems I have always thought of myself as the one-armed whatever I was doing. Even though I developed my left hand muscles by first squeezing a rubber ball continuously and later in high school by learning how to type and play the piano. I still called myself the one armed pianist/typist.

As an adult I saw myself as the one-armed driver, waitress, teacher, lover and friend. Of all the childhood nicknames which carried a load of hurt this one I came to see as describing part of who I am.

Recently I was talking with Hilary and heard the term "upside down polio". Honestly, it's a term I had managed not to hear before. I started to laugh as it definitely explains me. Even my PPS is taking more of its toll on my upper body than my legs. I was first diagnosed with PPS in 1989, but it flew right over my head and I didn't accept it until I hit the wall hard in 1992 and went to a pps clinic to be evaluated. I was sure they would dub me "lazy" and tell me to go back to work. They didn't and I was awarded SSD [Benefits] in Jan of 1993. In my upside down view of things I see 1992 as when PPS changed my life.

Along with my one armed-ness, upside down explains a lot about me. My perception of the world and life in general is usually not the same as others around me. Perhaps, being an upside down polio explains some of this. I like to think so anyway.

Hence the name of this column and my signature for it "An Upside Down View" by Ellen the One Armed Bandit. Ah, yes, you ask about where Bandit enters in. Well, since I now live in Texas I am enthralled by the old west image the word evokes. It also describes another aspect of my approach to life. I have stolen here and there all along as I doggedly did things that everyone said would be impossible for me; the one-handed

woman; to do. Even, with PPS I still see myself as the one armed bandit.

conserving my legs is as important as conserving my good arm.

In the next issue I will start sharing some of my upside down views. I will start with how a powerchair is helping this upside-down-one-armed-bandit. I will also share why

See y'all next issue! Gentle hugs
Ellen.Riddle@sbcglobal.net

CHRISTMAS CHARISMA

Icicles tinkle
snow drifts abound
frozen pine needles
stab at the ground

A bird eats a berry
left on a branch bare
it's lone and red
only he'd dare

Drooping conifers
an outline
against a brilliant
blue sky

Fir boughs
quiver
heavy laden
with snow

Sheltering
raccoon tracks
where
do they go?

HUSH... Hush...
it's
Christmas Charisma
... hush...

LaVonne Schoneman
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History of a Christmas Carol - There is one Christmas Carol that has always baffled me. What in the world do leaping lords, French hens, swimming swans, and especially the partridge who won't come out of the pear tree have to do with Christmas?

From 1558 until 1829, Roman Catholics in England were not permitted to practice their faith openly. Someone during that era wrote this carol as a catechism song for young Catholics. It has two levels of leaning: the surface meaning plus a hidden meaning known only to members of their church. Each element in the carol has a code word for a religious reality, which the children could remember.

- *The partridge in a pear tree was Jesus Christ.
- *Two turtledoves were the Old and New Testaments.
- *Three French hens stood for faith, hope and love.
- *The four calling birds were the four gospels of Matthew, Mark, Luke & John.
- *The five golden rings recalled the Torah or Law, the first five books of the Old Testament.
- *The six geese a-laying stood for the six days of creation.
- *Seven swans a-swimming represented the sevenfold gifts of the Holy Spirit: Prophecy, Serving, Teaching, Exhortation, Contribution, Leadership, and Mercy.
- *The eight maids a-milking were the eight beatitudes.
- *Nine ladies dancing were the nine fruits of the Holy Spirit: Love, Joy, Peace, Patience, Kindness, Goodness, Faithfulness, Gentleness, and Self Control.
- *The ten lords a-leaping were the Ten Commandments.
- *The eleven pipers piping stood for the eleven faithful disciples.
- *The twelve drummers drumming symbolized the twelve points of belief in the Apostles' Creed.

Caring from a Caregiver by Birde R

Caregiving will teach you many lessons. One of the most important lessons you learn, is to live your own life more fully. Caregivers face special problems and issues. Caring for another individual is an intimate and personal experience. People who find themselves in the role of caregiver must understand one important reality: You simply can't do it alone! You cannot possibly do this job 24 hours a day, 7 days a week! You cannot be a good caregiver if you can't take care of yourself. You need to know that you can be happy in your role as a caregiver, but not if you always let the illness or disability of others overshadow your own needs.

What does it mean to be a happy person when you are a family caregiver? How can you gain a feeling of confidence in your abilities and have a sense of pride in your achievements? How do you stand up for yourself, take care of yourself and find a balance between your own needs and those of your loved ones?

Our inner strength is the gift we have been given. It is the "pay back" for the pain, and although many of us would gladly trade it in for an easier life and our loved one's health and well being, we nevertheless ought to recognize its extraordinary value.

The problem is I don't think most caregivers do recognize it. I think most caregivers are so caught up in the act of caregiving that they don't step back and look at the extraordinary things they do. I think a great many caregivers don't even identify themselves as caregivers.

Sometimes we expect too much of ourselves, and we get into a state of constant worry or anxiety because we

think we are not doing enough. Know that there is no RIGHT or WRONG way to caregive. It is okay if you do not have all the answers, no one does. I wish caregivers themselves would recognize their value, acknowledge their individual achievements. For the most part, caregivers use their inner strength to help their loved ones and to get through difficult caregiving days. Caregivers need to begin to use it to take better care of themselves, to feel proud, to experience the beauty of self love.

What is caregiving? How do you define a family caregiver? You define family caregivers by their emotions and their spirit, by the sadness in their eyes, but also by the determination in their hearts. Caregivers are very special people!

10 TIPS FOR FAMILY CAREGIVING

1. Choose to take charge of your life. Don't let your loved one's illness or disability always take center stage. We fall into caregiving often because of an unexpected event, but somewhere along the line you need to step back and consciously say, "I choose to take on this caregiving role." It goes a long way toward eliminating the feeling of being a victim.

2. Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you. Self care isn't a luxury. It's a necessity. It is your right as a human being. Step back and recognize just how extraordinary you are! Take time for yourself. All too often, caregivers place their own needs last. Being a caregiver should not mean giving up all activities and relationships with other people. Studies show that sacrificing oneself in the care of another and denying oneself pleasurable activities can lead to emotional exhaustion, depression and physical

illness. Taking breaks from caregiving is essential for both full-time and part-time caregivers. You have a right--and even a responsibility--to take time away from caregiving.

3. Seek, accept, and at times demand help. Don't ever be ashamed to ask for help. You need to realize that asking for help is important. When people offer assistance, accept it and suggest specific things that they can do. Accept what people can give. Resistance to accepting help is a common cause of stress and depression among caregivers. In our culture, with its emphasis on independence and self-reliance, it's not easy to request help. Some caregivers see asking for help as a sign of helplessness, inadequacy or failure. Actually, asking for needed help is just the opposite.

Reaching out for assistance before you are beyond your limits is an important characteristic of a strong individual. It also helps ensure quality care for your family member. People can best help if they know exactly what your needs are and how they can participate. Be specific and positive. Friends may feel uncomfortable helping with the bathing and dressing needs. (The loved one might feel awkward as well.) But they could help with running errands, shopping for groceries, preparing a meal or providing companionship. When family or friends ask how they can help, make a specific suggestion. Say, for example, "Could you visit with ___ for an hour so I can go to the store?" or, "When you go to the store could you pick up a few things I need?" If family members or friends live too far away to provide physical support, encourage them to call the loved one regularly. That takes some of the pressure off the caregiver to be the primary social outlet. Tasks unrelated to caregiving may be easier for some people. If you can be

flexible, ask what would be the best time and task for them. Accommodating others, when you can, helps prevent their feeling stress and increases the chances that they will help out again. Your pastor or a Counselor can provide valuable help, emotional and prayerful support from these people is a good source of strength. Delegate as much as you can. We each have strengths. If you've been designated as the primary caregiver, that doesn't sentence you to doing everything by yourself. Recognize that others may want to help. Find a way to spread the load to other family members, friends, or professionals. Compensate for your weaknesses so you can emphasize your strengths. Quality support for someone needing care can come from many directions. That's something every caregiver needs to know. Don't hesitate to ask. Nobody wants to see you become run down due to the caregiving role. If you need something, feel free to ask. Trying to do it all will only create another caregiving situation - your own. You won't be helping anyone if you wear out or get sick. One way or another, help is there. Be sure to ask.

Caregiving, especially at its most intense levels, is definitely more than a one person job. Asking for help is a sign of your strength and an acknowledgement of your abilities and your limitations. It's also important to show appreciation for any help received. Let people know how much their support means to you.

4. Seek support from other caregivers. There is great strength in knowing you are not alone. Many caregivers have found it helpful to share their experiences with other caregivers. Caregivers often mention that other family members who are not the primary caregiver simply do not understand the stress of daily care giving. Other

stress of daily care giving. Other caregivers understand how an off-hand comment given by the patient or other family members can be deeply painful, how draining care giving can be. It is important for caregivers to get respite and the support they need from a network of other caregivers who can empathize and share in experiences. Sharing, even on-line with other caregivers helps caregivers cope with the stressful demands on them, enables caregivers to learn alternative care strategies, provides a sense of sharing the burden by expressing their feelings in an open non-judgmental environment with others who can relate to the experience, provides a new perspective, and can provide a vital support system. Community caregivers are also a source of emotional and caregiver support. It is critically important that caregivers seek out and get the support and respite they need.

5. Stand up and be counted. Stand up for your rights as a caregiver and a citizen. Recognize that caregiving comes on top of being a parent, a child, a spouse. Honor your caregiving role and speak up for your well-deserved recognition and rights. Become your own advocate, both within your own immediate caregiving sphere and beyond.

6. Trust your instincts. Most of the time they'll lead you in the right direction.

7. Grieve for your losses, allow yourself to feel the way you feel, and then allow yourself to dream new dreams. Almost every caregiver experiences a wide range of emotions, some of which are conflicting, confusing and ambivalent. You may feel love, sadness, frustration, dislike, repugnance, guilt, grief, fear, resentment, helplessness or despair (and that's all in one day). You may feel angry about the increased dependency

of your family member and the many demands on your time, energy and money. You may grieve for the loss of that person as he or she used to be. Feeling unappreciated is sometimes a problem for the caregiver, particularly if the ill or injured person expresses only dissatisfaction or is unable to show appreciation. These feelings are normal. These feelings are neither "good" nor "bad," nor do they reflect the degree of your caring. Feeling angry does not mean you love that person less. Being a caregiver is the fortitude to go on despite the pain. It is the wellspring of hope we always dip into. It is the power to make a difference. It is the clever way we solve a difficult problem. It is the knowledge that we have been tested by fire, and we have survived. Caregivers are allowed to dream! It's true! Don't deprive yourself of your dreams. Dare to dream...it's normal I assure you!

8. Educate yourself about your loved one's condition. Information is empowering. Take the time to educate yourself about the medical condition of your loved one. If you understand the nature of the problem you may be better able to deal and assist with it. Read not only publications from a physicians point of view, but nursing journals, articles written by other caregivers, and books relating to the injury or illness.

9. Watch out for signs of depression and or illness, and don't delay in getting professional help when you need it. If you cannot get a grip on yourself, you must seek out professional help. **TRUST ME ON THIS!** A doctor, social worker, or a therapist can help you to recognize what you can do to change your situation and help you to adjust to your role so that you can meet the challenges with a clear mind, with strength, confidence and an open heart. It is SO important to promptly get professional help when you need it,

**I was recently diagnosed with AAADD
Age Activated Attention Deficit Disorder
(PPS in another guise!)**

This is how it manifests:

I decide to wash my car. As I start towards the garage I notice that there is some post on the hall table. I decide to go through the post before I wash my car, noticing that there are bills to pay amongst it. I lay my car keys down on the hall table, put the junk mail in the rubbish bin under the hall table and notice that the bin is full. So I decide to put the bills back on the table and take out the full bin as the dustbin men will be coming that morning. As the postbox is near my gate I think it would be a good idea to pay the bills and put them in the postbox at the same time as I take the rubbish out. I take out my cheque book and notice that there is only one cheque left. My new cheque book is in my desk in the study, so I go into the study. I notice that there is a half full can of coke on the desk, which I had forgotten to finish off earlier in the day. I don't want to knock this over and as it has got warm I decide I should put it back in the fridge to get cold again. As I head towards the kitchen with the coke a vase of flowers in the study catches my eye – they obviously need more water. I put the coke down on the top of the desk and head back through

the hall noticing my reading glasses that I'd been searching for all morning on the hall chair. I decide I had better put them back on my desk in the study, before I lose them again, but first I am going to fill up the water in the vase of flowers. I head for the kitchen worktop and suddenly spot the TV remote control. Someone – not me – has left it on the kitchen worktop. I realise that when tonight comes and we want to watch the TV we won't be able to find the remote control so I decide to put it back in the sitting room. First however I put some water in the vase and somehow spill most of it on the kitchen floor. I put the remote control back on the worktop, mop the floor with the paper towels and then head back into the hall trying to remember what it was I was planning to do.

At the end of the day, the car hasn't been washed, the bills haven't been paid. There is a warm tin of coke sitting on the desk top, the flowers haven't been watered, there is still only one cheque in my cheque book and I can't find the remote control. I can't find my reading glasses and I don't remember what I did with my car keys. Then when I try to figure out why nothing got done today I am really baffled because I know I was busy all day long and I'm REALLY tired!
Anon.

including assistance with your own physical and mental health. Experience teaches us that the ability to manage care giving over a sustained period of time is much more emotionally, psychologically, as well as physically draining than sporadic, short term care giving. Providing care at the expense of your mental and physical health or relationships with other family members does not benefit anyone. Remember your own good health is the very best present you can give your loved one.

10. There's a difference between caring and doing. Establish Your Limits. You have the right to set limits on what you will or can do.

It's all right to say no. Doing so, however, can be difficult, especially if you must make painful choices. Consider, and be open to technologies and opportunities to promote your loved one's independence. Find out about programs, services, and new technologies which may help your loved one regain their independence, or improve the quality of their life. Encourage your loved one to do for themselves the things they are able to do. You are not helping or caring for them if you always do these things for them that they are able to do for themselves.

**OAKLAND KAISER CONFERENCE
POST POLIO SYNDROME
AGING WITH A DISABILITY
September 19, 2003**

**Notes by Gladys Swensrud, San Diego
Morning Session.**

The conference on September 19, 2003, was held at the City Center Marriott in Oakland, California. The purpose was to bring health professionals together with Polio survivors for a day of information sharing and learning about the disorder of Post Polio Syndrome.

Dr. Sandel, Medical Director of the Kaiser Foundation Rehabilitation Center opened the gathering by introducing to the audience that the conference was sponsored by the Kaiser CME program and San Francisco Bay Area Polio Survivors group. She thanked everyone involved with helping this conference come to fruition. She began her presentation with a few statistics, noting, among other facts that twenty percent of all citizens are to some extent disabled in the U. S., and it is believed that 1.8 million people had polio in North America. The Kaiser Permanente Rehabilitation Center in Northern CA has been involved in polio rehab since the 30's and 40's. Its focus has been a physiology-based program with an emphasis on Neurology and Neurophysiology. She noted that polio was a life-changing event for patients and their families. Dr. Sandel explained that aging with a disability, specifically in our case - polio, represents a new aging challenge to the medical profession. Doctors, who in most cases have not seen a case of polio, are at risk for not being aware of this condition and managing it correctly.

Next, **Phyllis Hartke**, a polio survivor and President of the SFBAPS group welcomed everyone to the conference, and she recognized those who had helped to make this event happen. She particularly thanked Dr. Sandel, Kaiser Permanente and the planning team for making this conference

come together. In her opening remarks, Phyllis noted that most health care providers know little about Post Polio Syndrome, but she hoped that those in attendance on this day would know much more by the end of the conference day. Among the facts most important to her, she reminded everyone that a "team approach" to patient care is the best way to handle old Polio. Polio patients have certain requirements that they need for professionals who will be servicing them to know, and hopefully physicians will learn today the most needed requests of their Polio patients. She also urged doctors in attendance to return to work and share the information they would be learning with their peers.

Speaker - Dr. Fernando Torres-Gil holds a dual role as a doctor and a Polio survivor. Dr. Torres-Gil explained that although he has a disability, he also wants to learn to grow old gracefully with it. He would like to bring us (himself included) to the next stages of aging with a disability; he hopes to inform the larger society in general about long term care, health care reform, and how health care will approach an aging society with many disabilities, as well as how the needs of the masses can be met within the health profession. His extensive credentials began as a grad student in his passions of gerontology/geriatrics. Much of his career revolved around the health policies of those groups. He explained that he is now fifty-five, and he began to feel that he was aging prematurely. He realized that his level of fatigue and discomfort could be related to his disability and not just a regular part of the aging process. He recalled his Polio history of being quarantined and sent from his home to Shiners' hospital for treatment. Like most polio survivors of our era, he put that part of his life behind him and went on to be a super achiever. Now at 55, he realizes that his specific aging problems are related to Post Polio, and he is dedicating his life to being a "poster adult" to aging with a disability. Dr. Torres-Gil made the point that as our generation is aging (we are

all getting older), we are reaching a crisis as life expectancy is growing. We see older people now growing into their 60s, 70s and 80s as a normal situation. The world as a whole is an aging society. That comes equipped with it's own set of problems involving Social Security and Medicare.

As far as disability is concerned, that *world* is a much more difficult one to bring together for health systems. Each group of handicapped people, Post Polio patients, people with MS or ALS etc, has its own group of advocates. Their needs are diverse, but at the same time, their needs are similar. One of the challenges of the medical profession is that the aging world and the disability world don't communicate with one another. Together they will be a stronger voice to be listened to. Dr. Torres-Gil feels that the bridge between those two systems needs to bring them together.

Long Term Care (LTC) will be one bridging factor. LTC is about giving options and choices to having that patient, whether elderly, disabled or both, live at home and have assistance available for them to live at home and within their communities. It will need to become part of the lexicon of the medical profession.

Dr. Torres-Gil has learned that on the policy side, more changes are afoot, but funding is a problem to help support this cause. Prices in health care are escalating, and getting funding for PPS, which is a pre-existing condition, is not likely. The big debates are on prescription drugs and the things connected to programs like Social Security and Medicare. Old polio is almost a problem of the past generation, so finding monetary sources to help our cause is difficult.

From his personal experience, he is astounded by his own healthcare plan's ignorance. His personal physicians mean well, but they aren't incorporating needed information into their protocols. He has learned that he has to be his own advocate.

He gathers information and brings it together in a presentable format to help himself. PPS is a multi-disciplinary and inter-disciplinary integrated health and service problem. These terms mean that they also bring in the rehab and non-health issues like housing, transportation, income supports and all those supportive issues that will help us to age gracefully.

As an aside, Dr. Torres-Gil announced that he is also interested in alternative medicines like water programs, yoga, etc. He believes there is a role involving those types of programs to bring together a truly multifaceted program. Physicians are now at the cutting edge of the aging with PPS and other disability issues, and how they advocate for these people will have important benefits well beyond the realm of Post Polio Syndrome alone.

Discussant - Dr. Della Penna, a geriatrician, is Director of the Kaiser Permanente Aging Network. He is working with Kaiser Permanente to bring about change for those who are aging with a disability. Dr. Della Penna told the group that he feels that Kaiser's challenge is to work *with* an aging population. The KP network has set up four disciplines as structures and accountability - quality measurements to know how well Kaiser is performing. They will be asking question of the patient to monitor their success, such as how does the patient feel a specific program meets their needs; Kaiser will be working to find out if there is some way to know if good programs can be replicated to help many people in need. As a method to teach those in attendance about this issue, Dr. Della Penna asked Dr. Torres-Gil how he would suggest advocating health issues for oneself. Dr. Torres-Gil responded that gathering together with several groups works better to benefit the needs of many people. As he had suggested earlier, combining patients with similar problems needing similar solutions works to bring strength to their issues. He felt to advocate

within a single group (i.e. just PPS, just ALS or just MS, etc.) does not attract political influence and support. We, as patients, need to be sophisticated as advocates so as not to polarize those whose help we are requesting. [As we are trying to do in the UK as part of Neurological Alliances]

Speaker - Dr. Perlman is Director of the Post Polio Center at UCLA. She explained that Dr. Torres-Gil works with the top area of health issues...he looks to the future to find funding for programs in need of financial support. She, on the other hand, works directly with patients on a day-to-day basis. She told the audience that she works in the "here and now" with her patients, and funding is often a problem. Her job has very practical limitations. The March of Dimes noted that we need to improve education to all levels...professionals, policy makers, etc.

Dr. Perlman began her presentation by addressing the fact that our zeal to rehab patients with polio could have probably created the consequences with which PPS patients now live. She added her own set of statistics stating that polio survivors run a 40% risk of developing new problems. She noted that other groups also develop similar syndrome problems...like post strike syndrome as an example. In each group, approximately half will have future problems and half will not. Most people feel that time and overuse will be risk factors for developing Post Polio problems later in life. Her experience gave less credence to time. She feels a deeper issue is the severity of the residual deficit (while years go it wasn't thought to be an issue) coupled with overuse. Gender is not thought to be an issue. She then ran a history of statistics that are thought to take their toll on this process, such as wear and tear on the body, longevity genes, genes that turn off as we age, genes that turn on which steal resources from other places, bad genes that show up later in life, oxidative stress, increased free radicals, decrease in energy production, hormones in

aging related changes, approaches to living longer, the immune system with aging and the older adult and a low grade inflammation in the spinal fluid, brain and blood that cause increased problems just as in MS.

She reviewed the history of polio and the statistics of the vast numbers of those affected. She reminded all that just because you have PPS it doesn't exclude one from other health problems as well.

Dr. Perlman interjected here that there may be two or more types of PPS: some people experiencing fatigue and pain may be in one group, and those with progressive atrophy may be in another. Many studies could be done with funding, if available. Within her suggestions addressing polio survivors, she noted: do not use drugs that weaken nerve muscle communication, don't work muscles to the point of exhaustion, and use assistive devices, like bracing. Dr. Perlman said that improving part of the problems would help others, like breathing help using night ventilation will assist with fatigue. Neurologists should meet with patients annually and do normal strength testing, but not necessarily invasive testing such as EMGs. Use resources for funding where available. In question and answers, she was asked about drugs and some study designs available in the coming years. She discussed the factors of weight and new designs in bracing as examples.

Discussant - Dr. Bakshi is also a neurologist. She has been able to observe many patients with polio in her native India. Her question to Dr. Perlman was: Could menopause be a factor in women and their development in Post Polio Syndrome? Dr. Perlman says no, but on the issue of PPS and menopause replacement, the data is not there yet, so caution should be taken.

As far as old polio patients with no PPS symptoms yet, she suggested to Dr. Bakshi and the group that a careful evaluation of

health be taken. Then the patient needs to be reminded that there could be ten (or more) years of clinical sub-problems that the patient is not aware of, and some destruction may already have been done. The patient should be warned of the signs to watch for like undo fatigue or weakness that could be the first symptoms that they were experiencing problems. Statin type drugs were also discussed with a note to be cautious in their use.

On the funding issue, Dr. Torres-Gill remarked that more money is now being poured into the NIH than they can spend, but the problem is that there is no cure for PPS, so no money goes into research for it. Contacting members of congress could be one avenue to approaching this issue.

Speaker - Hilary Hallam, from the U.K., began with some introductory quips that she has encountered from doctors. She recounted her history as a survivor from a normal, "over productive, type A" person to the point where a fall set the stage for what was to come. It was a steady downhill from the fall to the point of assessments; doctor to doctor and seven years later, her PP situation was realized by a question she asked of a doctor: "Could my problems be related to an old bout with polio?" Two years following that fateful question, she was finally in a place that her condition was accepted.

Hilary's objective in her lecture was to address doctors and make suggestions to them how polio facts can be resurfaced so that doctors are aware of the old condition. She warned the doctors in attendance that you can't tell if a person had polio necessarily by looking at them. She talked about the fact that doctors need to realize that polio was systemic, so consider all problems and not just tunnel vision about the part that the patient manifests as a clear problem. In people that are not sure of the why, perhaps the professional needs to ask a few questions about family history. Hilary

told survivors to be sure to tell the health professional about your whole life using a Polio Time Line Chart, then address the issues that are giving you trouble in a systematic fashion. Both sides need to consider the phrasing of questions and answers to ensure that the pictures in the mind of health professional and patient match. She talked about the way we, as PPS patients, have learned to compensate for our limitations. She also addressed manual muscle testing and how inadequate it is for our purposes. *Repetitive* muscle testing techniques will show deterioration not seen on single testing.

Discussant - Dr. Shannon O'Brien was present to discuss the psychological aspects of having had polio. With time waning in the morning presentations. She actually asked the question of Hilary about how she handled the psychological aspects of being limited again in her life after having been saddled with the problem the first time.

Speakers next, on the research panel were **Dr. Tessa Gordon, from the University of Alberta (Canada) Neurosciences Center** and **Dr. Spencer Wang, Director of Diagnostic Medicine, Kaiser Vallejo** - a neuroscientist perspective - Progressive activity related regression of the sprouting capacity of surviving motoneurons.

Dr. Gordon explained sprouting, denervation and reinnervation of muscle fibers. Her discussion paralleled that of Dr. Sam Pfaff, Salk Institute researcher, for those of us who have been fortunate enough to hear his presentations. In her report she suggested that "... age-related loss of functional motor units appears to be associated with impaired sprouting, which, in turn, may be directly related to the progressively higher daily activity that the remaining motor units experience." One of the most notable sentences in her brief report in the syllabus was the following: "Indications that relatively low levels of daily neuromuscular activity may increase

muscle endurance suggest that conservative approaches to exercise may be taken with caution."

Dr. Wang said that the muscle information given to us by Dr. Gordon helps explain the *why* of what he learns on EMG's and what is happening to nerves. He told us that tests cannot always determine all the answers we want. He explained the EMG process/muscle probe by needle. A typical EMG tests seven to ten muscle fibers. He can see the condition of the muscle. He can tell if cells have been orphaned and if other cells have come to cover for them. He discussed conventional EMG to Macro EMGs. Macro EMG gives a more global perspective of the muscles. It lends itself to missing less data because it covers more territory. He mentioned that there is no "gold standard" to follow pathologically to measure muscle size. Basically you need to follow trends in determining readings. He told the group that if Post Polio survivors over tax muscles, things likely *will* get worse and deterioration is the end result. But the reverse to that is if survivors do activities to relax muscles, such as water therapy or specifically testing physical therapy with assistance from a professional, things can get better...perhaps not on muscle strength itself, but daily functioning and pain can be improved.

Afternoon session in next newsletter.

Stress Management

Just in case you've had a rough day, here is a stress management technique recommended in all the latest psychological texts. The funny thing is that it really works.

- 1 *Picture yourself near a stream.*
- 2 *Birds are softly chirping in the cool mountain air.*
- 3 *No one but you knows your secret place.*
- 4 *You are in total seclusion from the hectic place called "the world."*
- 5 *The soothing sound of a gentle waterfall fills the air with a cascade of serenity.*
- 6 *The water is crystal clear.*
- 7 *You can easily make out the face of the person you're holding underwater.*

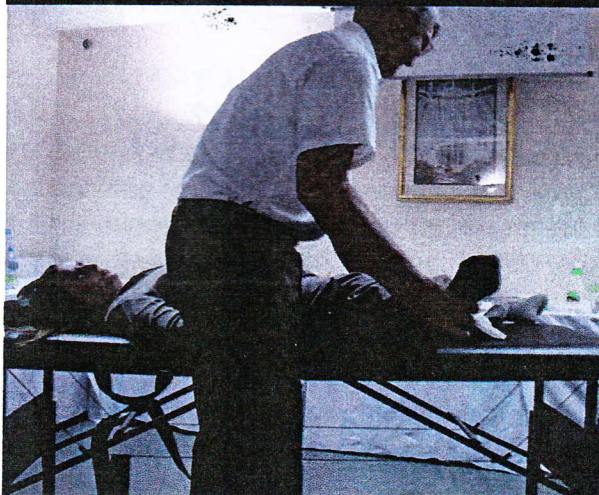
sent to us by Robert S. Rose, Palm Springs, California rsr@DC.RR.COM

CAN YOU READ THIS?

Acocdrnig to an elgnsih unviesitry sutdy the oredr of letetrs in a wrod dosen't mtttaer, the olny thnig thta's iopmrrantt is that the frsit and lsat ltteer of eevery word is in the crrecot ptoision. The rset can be jmbueld and one is stlil albe to raed the txet wiohtut dclftfuiiy.



- * My wife really likes to make pottery, but to me it's just kiln time.
- * Dijon vu - the same mustard as before.
- * Without geometry life is pointless
- * When you dream in colour its a pigment of your imagination.
- * Energiser Bunny arrested - charged with battery.
- * A hangover is the wrath of grapes.
- * Corduroy pillows are making headlines.



PHOTOS - Hamish after treatment.
Dr. Dowsett and Mary Kinane being treated by
Aaron Mattes, MS RKT, LMT.

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