



# The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**  
Volume 3 - Issue 3 - February 2001

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Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. Although it does not provide an endorsement, it is provided as a service to those seeking such information. ALWAYS consult your doctor before trying anything recommended in this or any other publication. **Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177**

EDITORIAL by Hilary Hallam

It's now just over five years since I found out that there were late effects to polio. Since then I have attended six PPS Conferences that have given me a broad base of information from many different health professionals. There is NO doubt in my mind that the problems being experienced by Polio Survivors who do not live where there is a recognised Post Polio Clinic are the same right across the world - mainly caused by lack of knowledge and awareness of the condition by the medical profession. Colleges of Medicine have not taught their students enough about polio putting it on a 'need to know' level with leprosy. The fact that a late stage of polio was first medically described in 1875 and 20 years of Post Polio Conferences has not been enough to convince the decision makers at the top to change this or provide continuing education. The fact that a huge number - possibly as high as 80% - of polio survivors recovered so well that externally you can see little evidence of their internal damage until they start to have new problems means polio survivors are still a 'hidden population'. Show your current professionals photos of you during your years of best recovery and they are likely to be amazed.

Lectures on the mechanics of polio recovery and new problems being experienced must be increased. Polio survivors have muscles that have evolved to do or assist in movements that they were not designed for. You cannot do any movement unless muscles somewhere are working - 'we don't know how he is walking' is not a statement that we should hear, rather 'he is using his x y and z muscles to achieve this action'. Manual Muscle Testing tests single muscle action not pattern of movement and does not observe grip, lift and bring to mouth in combination. It does not allow for substitution or assistance of other muscles to achieve an action. Resting muscles store energy ready for action. Most often some grades recorded do not match the reported weakness. Grading a polio survivors muscles incorrectly can have implications right across the medical and benefit field. e.g. anaesthesia in operations and medical procedures, drug prescription, joint replacements and other orthopaedic surgery, refusal of electric wheelchairs or other aids that would reduce damage, incorrect medical reports that deny benefits, unnecessary stress to the patient whose reported weaknesses are not believed, etc. The only way to ensure that other polio survivors still out there and people with other neurological conditions with similar problems do not struggle as we are doing is to get together and ensure that changes are made and now. Share your experiences and help us make the changes necessary.

This newsletter contains articles, reports, and excerpts that I hope you will find informative and confirmation of the above. Our Information Packs continue to be

updated. Anyone who has been a member for some years may not have a copy that contains charts to assist you in assessing yourself. If you would like a copy of the charts please get in touch with Wendy - contact details on the back page.

Ending on a personal note that I hope will help ensure that you will be able to deal with a similar situation without the same problems. In January 2000, Social Services and a City Council representative agreed in principle that alterations could be made to enlarge my bedroom, install central heating in this and the bathroom extension, and make the drive near the house accessible. In October the agency who do all the work for disabled and elderly people assured me the work could be completed by the end of January. In mid November I was told the name of the builder, that the foundation slab would be done prior to Xmas and the remainder of the work in January. Having experienced problems and stress with work being done on my house in mid 1997 plus the lack of any heating in my bedroom and bathroom getting out of the way was the only thing to do. I decided to go to the Daytona Beach PPS Conference [report pages 8 - 13] to visit the University of Miami PPS Clinic and other Florida PPS specialists and groups returning on the 31st January. For the first few weeks my daughter - knowing I would give her plenty of hassle - kept telling me that all was in hand and leave it to her. In fact she was continually ringing round the organisations involved trying to find out what was going on. Eventually in early January she rang and said 'You are not going to believe this but I have just had a call from someone in the City Council asking to visit the house prior to the meeting to discuss if the work could go ahead!' My comments were unprintable! As the stress to both myself and my daughter would be intolerable I am remaining here for a few more weeks. When I return I will be contacting other disability organisations to discuss this situation. The length of time this has taken and the way it has been handled has put my daughter and I under unnecessary stress, inconvenience and additional financial cost that we could have done without. Whilst we appreciate that there is a system to go through the way this has been dealt with is unbelievable.

Computers and the internet have allowed me to continue working, deal with the [linpolio@legend.co.uk](mailto:linpolio@legend.co.uk) email, compile this newsletter, update and improve my presentations, speak at one PPS meeting and am already booked for another two. Janice and Wendy have been taking the phone calls and report the story is almost always the same. Donations, sponsorships and grants are needed to continue our work. If you have any suggestions please contact any of the committee members. Happy Valentines Day - the 4th Anniversary of our WebSite.

**California is experiencing rolling blackouts. The following excerpt is excellent advice and taken from the State Independent Living Council Press Release.**

**ADVICE FOR PERSONS WITH DISABILITIES  
CONCERNING THE CURRENT POWER  
SHORTAGE AND POTENTIAL BLACKOUTS**

In response to such concerns, the State Independent Living Council suggests that the following steps be taken by persons with disabilities or those who are in poor health or sensitive to extreme temperatures:

1) Contact the local electrical utility company in advance about any specific needs regarding breathing machines or other life-sustaining devices that depend on electricity. If lack of electricity would create an immediate threat to life or safety, local public safety agencies should also be given advance notification. To expedite emergency response, house numbers should be readily visible from the street.

2) Establish a support network of friends and neighbors who can check in periodically if the power is out, to assure that assistance is available if needed.

3) Keep a flashlight or lantern equipped with fresh batteries within easy reach, so that there is some light immediately available if the power does go out. For people with limited reach or grasping ability, inexpensive battery-operated touch lamps are a good option. Such lights can be installed in areas of greatest use, and are small enough to be carried in an emergency.

4) Do not use candles for light or heat in an emergency, as they can be fire hazards.

5) Extra blankets or warm clothing should be stored within easy reach. Most homes will retain some heat for several hours during electrical outages; do not use barbecues, gas powered appliances or propane heaters as heat sources, as the result can be carbon monoxide poisoning.

6) For people using battery-powered mobility or breathing equipment, assure that batteries are fully charged each day.

7) Store supplies of medicine and drinking water so they will be readily accessible in the event that there is a power outage; some household water supplies can be disrupted during blackouts. Assemble a 10 day supply of prescription medications and durable medical goods and store

them in a convenient location, in the event that a prolonged electrical outage or other emergency should require evacuation. A copy of emergency contact numbers and current prescriptions should be stored in the same location.

8) Cordless telephones may not work during a power outage, so consider keeping a standard phone plugged into a second phone jack in case it is ever needed. A cellular telephone is also a good backup option, but be aware that in a widespread emergency any communication network may quickly become overloaded with calls.

9) Monitoring radio stations during emergency situations can help in determining the extent and probable duration of any electrical outages. Assure that a battery-operated radio is available for this purpose, with at least one set of extra batteries.

10) During Stage Three Alerts, monitor local television or radio news stations to determine if and where blackouts will occur. Check monthly electric utility bills to determine the applicable Power Block number, as that is usually how the blackout areas will be identified. If the Power Block number is not shown on the monthly bill, contact the local electric utility company to learn where that information is available. (Remember this is for the USA)

11) When an electrical outage does occur, turn off all appliances, computers and lights--except for one that will indicate when power has been restored.

"Of course, one of the most important things people can do today is to help reduce demand for electricity by using energy more efficiently," said Collins"

Little pill, here in my hand  
I wonder how you understand  
Just what to do or where to go  
To stop the aches that hurt me so/  
Within your covering lies relief  
You work alone in unbelief  
You sink in regions there below  
As down my throat you quickly go!  
But what, I wonder, little pill  
How do you know where I am ill  
And just how do you really know  
Just where you are supposed to go?

Author Unknown - sent by  
bb\_dutchess@YAHOO.COM Beverly Bucellato

**SO WHAT SHOULD WE CALL IT? HOW SHOULD WE DEFINE IT?**  
**by Hilary Hallam.**

POLIO - POLIOMYELITIS  
ABORTIVE POLIO - UNSTABLE POLIO  
PARALYTIC POLIO - IMMUNE TO POLIO  
SUB CLINICAL POLIO - INFANTILE PARALYSIS  
NON PARALYTIC POLIO - POST POLIO SEQUELAE  
POST POLIO SYNDROME - LATE EFFECTS OF POLIO  
POST POLIO MUSCULAR ATROPHY -LATE FUNCTIONAL DETERIORATION FROM POLIO

These are just some of the terms being used to describe events following ingestion of one of the three polio enteroviruses. To complicate matters these terms appear to be interpreted in different ways by different health professionals, government departments and countries. There are some excellent medical articles, included in this and previous newsletters and in our Library but often we hear the phrase 'but they are not British articles'.

Post Polio Support Groups around the world are contacted almost daily by people telling the same story. They had polio, recovered well and until a certain stage in their life was living it to the full. In the last few years something has happened and they are now no longer able to function as they did and its not just age related. Repeated visits to health professionals have left them inadequately diagnosed and treated. Many report being treated as if they are exaggerating the symptoms, and some are told that 'its all in your mind'. They have just learned from a newspaper article or searching on the Internet that there is a latter stage to polio, their symptoms fit those they are reading, and they are looking for doctors that will be able to help them. The tragedy is that the huge sigh of relief they get on learning that they are not mad, its not all in their mind, that there is a possible reason for what is happening, gets dashed when they find that there are few specialists in the condition. Few places in the world to get the necessary holistic multi-disciplinary assessment needed. For the majority of Polio Survivors there are many more hurdles to get over.

Why is this happening? The first reason is the fact that the vaccine first used in the mid 50's reduced the numbers affected. Therefore there was no need to continue researching a condition that was dying out. Therefore most Colleges of Medicine, in epidemic free countries, do more than mention the condition as they do leprosy. The fact that late effects of polio was first medically noted in 1875 has been forgotten.

In the latter decades of the 1900's most health professionals when asked about polio think 'polio vaccine' and when prompted recall their early lectures about paralysis and iron lungs. If you do not have a thin limb, a short foot, callipers then you often get asked 'Are you sure you had polio?' Most health professionals will tell you that they have never seen a case of polio in the first instance, and if they have a patient on their books who had polio will often happily tell you how fit that person is, highlighting another reason why we have difficulty. There is no set pattern, different damage, recovery, lifestyles and new symptoms.

The majority of polio survivors recovered way beyond what was expected of them, most showing little external sign of the internal nerve damage. Polio survivors had to struggle to recover and determination to succeed in whatever they could was the norm. If you told a Polio Survivor that they could not do something then they went out of their way to prove you wrong. Even those who visibly lived with their polio in calipers (braces) and wheelchairs have made huge successes of their lives. What has not been realised is the level of recovery and the many and varied professions and qualifications that polio survivors have achieved. The Armed Services, Police, Doctors and allied health professionals, Professors, teachers, lawyers, accountants, others worked in professions where they were climbing ladders, standing all day using heavy machinery. Some played professional sport and many achieved highly in sports like football, judo, karate, rugby, athletics, climbing, and all manner of water sports. POLIO was part of their past, over and done with, end of story, and no-one told them otherwise.

Another reason is this difference of opinion of how we should define each level of polio depending on the amount of damage that your body received. Following the ingestion of one of the three polio viruses

there is a line from below becoming immune, through immunity, mild flu like illness, clinically evident weakness, clinically evident paralysis to death. Bodian and others in the 40's and 50's from post mortems of those that had identifiable polio revealed that the virus affected 90% of our body. Prof. Sharrard showed that clinically evident weakness did not show till over 40% damage. Therefore we can have different levels of damage and name in different areas of our body. What we do know is that you cannot have late effects of nerve damage from one of the three polioviruses if you did not have that nerve damage in the first place. EMG's and muscle biopsies can show evidence of changes in the muscle but if they are taken from an area of the body that did not experience any polio damage then a negative test might not be conclusive. There is only one way to find out exactly how much nerve damage you had if you took in a polio virus and that is a post mortem - not an acceptable diagnostic tool!

Despite the fact that these new symptoms first described in 1875 and have been part of research since the mid 70's and conferences since 1982, and many medical articles, many health professionals working today have not heard of the condition, and many of those that have are still sceptical of its existence. Taking the phrase Post Polio Syndrome (PPS) as the most commonly used one another reason is that there are NO tests for PPS. It is a clinical diagnosis of exclusion. Where there is a holistic multi-disciplinary approach where the polio survivor is seen to perform the tasks that they are reporting difficulty with, assessment, diagnosis, advice and treatment are given. However, there are very few health professionals who are specialists in polio and its late effects for primary care physicians to refer their patients to. The majority are being seen by health professionals without specialist knowledge and experience who do not realise that using manual muscle testing believing it to be a reliable diagnostic tool of finding weakness means they are most often not finding evidence to back up the reported weakness and functional decline.

Manual Muscle Testing used as an assessment of muscle ability in a single one off action on a Polio Survivor will get different results depending on size of the tester, amount of pressure used, time of day, and what the person has been doing prior to this test. Manual Muscle Testing does not test a pattern of movement only a single muscle action. It does not allow for the fact that to do an action polio survivors can and do substitute other muscles, and/or use additional muscles to achieve patterns of movement. It does not allow for the fact that as soon as a muscle rests it starts storing energy for the next time its needed. Polio affected muscles can repeat or sustain an action for a short time but then once symptoms have started this declines far earlier than would normally be expected. It does not allow for the fact that a Polio Muscle functions at a much lower level than a normal muscle, i.e. 5 at 53 to 59%, 4 at 40%, 3 at 20%, 2 at 10% and 1 at 1% (Beasley and Perry). Dr. Perry explains why this happens in an article on the next page.

In late 1997 Professor Sharrard, an eminent UK Professor of Polio working at the time of the epidemics replied to me, 'What you are describing is Polio fullstop. It does not go away, you did not HAD it, you have it. Polio has the most remarkable recovery system and that is what you have lived with and without which you would have remained at your worst. You are just describing what we knew could happen to you at some stage in your latter years. It's just Polio.'

So what should we call it, how should we define it, how should we be assessed (see page 10) and treated. There are many medical articles that give us this information but in the U.K. we are told there are not enough of us to fund this. If we are not examined and assessed correctly then conditions can be missed, operations don't have the expected result, and we can and are deteriorating at an unnecessary rate. I put this to Joan L. Headley, Executive Director of GINI (Gazette International Networking Institute) International Polio Network after the Daytona Beach Conference and asked would it be possible for a definitive statement that prevents as much misinterpretation as possible to be produced and signed by as many eminent polio and post polio specialists and PPS groups across the world as possible. There are estimated to be over 12 million polio survivors in the world whose lives could benefit from this. We continue to correspond on this.

Other chronic neurological conditions have similar problems, add our numbers together and we become a large % of the population. We are working with the Neurological Alliance and Long-Term Medical Conditions Alliance in the hope of getting holistic multi-disciplinary assessment for all.  
Hilary Hallam, Founder and Chair - Lincolnshire Post Polio Network <linpolio@legend.co.uk>

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**General Information Letter  
for Polio Survivors:  
Why are "old polios" who were  
stable for years now losing function?  
What should they do about it?**

by  
*Jacquelin Perry, MD, DSc (Hon),  
Rancho Los Amigos National Rehabilitation  
Center, Downey, California*

Jacquelin Perry, MD, DSc (Hon), was certified by the American Board of Orthopedic Surgery – one of the first women to be certified – in 1958. Immediately after her residency in orthopedic surgery, she was invited by Dr. Vernon Nichol (Chief of Surgical Services) to join his staff at Rancho Los Amigos in the Los Angeles area. She has been involved in the management of the problems of polio survivors since that time. She is Professor Emeritus Orthopaedics, University of Southern California.

The basic problem is that polio destroyed some of the nerve cells that activate the muscles. To the extent possible, the neurological system responded by having the remaining nerves adopt the muscle fibers that had lost their original nerve supply. This meant that nerve cells now had a demand much greater than normal. While this was an effective solution initially, the passage of time (30+ years, usually) has taught us that overuse can be destructive. As a result, these secondary nerves are wearing out with resulting muscle loss, i.e., post-polio syndrome.

Post-polio muscle strength is commonly over estimated as the usual test depends on manual resistance by the examiner. In addition, polio survivors mask their disability by clever use of their normal control and normal position sense to substitute for missing musculature. The post-polio muscle graded "normal" (5) averages 25% less than "true" normal (only 50% normal for the quadriceps). Similarly, the muscle graded "good" (4) is only 40% of normal strength. These strengths are adequate for a person to carry on customary activities in a typical manner, but at a demand that is 2 - 2-1/2 times the usual intensity; hence, the muscle nerves have been experiencing strain for years.

The apparent abrupt loss in function relates to two functions. One is the buffer zone present in all of our physiological systems which enables them to accept strain for a considerable time, but once the buffer limits

are exceeded, the loss is very prominent. Secondly, activities such as walking or lifting objects present fixed mechanical demands. As long as the person's muscle strength exceeds that demand, he/she can continue to perform as usual but with earlier fatigue. When the strength goes below the essential limit, suddenly that function is lost.

The answer is redesigning your lifestyle to avoid those activities that cause muscle strain, cramping, persistent fatigue, and, consequently, weakening. This means to very carefully look at how you are using your arms, legs, and back, and to avoid those tasks that cause the symptoms of persistent fatigue, muscle soreness, and/or a sense of weakness after use. At times, this requires the employment of special devices to take the load off of the arms. If the changes are made early, strength can be recovered. It will not be sufficient to prepare the muscles for excessive strain again, but it does bring the muscles up to a more useful level. Other ways of reducing strain is by using self-care devices, walking aids, braces, and corrective surgery to lessen the stress.

Once the strain has been reduced, then cautious exercise may be of value. We have been using short duration (5 repetitions) or moderate intensity (50-70% of one's maximum capability). Let me caution you not to take on the exercises, however, until you have worked out a lifestyle that avoids the strain. Also, if the exercises cause any pain, persistent fatigue, or increased weakness, STOP! This means just the mechanics/activities of daily living (ADL) are sufficient exercise for your muscles.

Recent research on the course of muscle strength over time in persons over age 50 years showed a normal average decline of 1% per year, but for post-polio survivors the rate was 2% per year. The rate of change is so subtle that a four-year study was needed for a measurable change. Also, the weaker "polios" experienced greater functional loss. This latter fact appeared to indicate strength training by exercise would deter the process. However, retesting this group of polio survivors at eight years and adding muscle analysis told a different story. The muscle fibers were hypertrophied, twice normal size, not atrophic. The person with the greatest strength loss also had the greatest hypertrophy.\* MRI recordings showed areas of muscle loss and fatty replacement. The source of the visible muscle atrophy is muscle fiber loss secondary to nerve fiber overuse failure. These findings confirm the need for a saving program rather than challenging exercise.

The advantage of having had polio rather than another disability is that it allowed one to resume a very active and profit-able life for many years. Now it is necessary to recognize that excessive strain was being experienced and that lifestyles must be changed to

accommodate this situation.

Be an "Intelligent Hypochondriac" -- Listen to your body and adopt a program that avoids the strain.

\* "Several histologic studies have shown that the myofibers of polio survivors can be twice the size of those found in other persons. A few studies have provided indirect evidence for a possible transformation of some of the surviving type II (fast-twitch fibers) to type I (slow-twitch fibers). The few studies performed have shown a preponderance of type I muscle fibers in very weak muscles that were constantly being used in daily activities. It has been postulated that a person would have to utilize all motor units in these very weak muscles to perform all daily activities and that, over time, the type II fibers are transformed to type I fibers."

Source: Agre, J.C., Sliwa, J.A. (2000). Neuromuscular rehabilitation and electrodiagnosis. *Archives of Physical Medicine & Rehabilitation* 81(3), Suppl S27-31.

Starting New Study - Sophia Chun, MD, works with Dr. Perry at the Post-Polio Service, Rancho Los Amigos National Rehabilitation Center, Downey, California ([www.rancho.org](http://www.rancho.org)), and reports that they will be studying the effects of creatine monohydrate on strength, endurance, and fatigue level in symptomatic post-polio patients (in Southern California) starting in late October or November 2000.

### Seasonal Affective Disorder by Vivien Holland

Although we have a large part of the winter ahead of us, I always feel heartened once we're into the new year and the days start to get longer. After the prolonged wet weather last year, it's been most welcome to have some bright days, even though it's been quite cold. Maybe like me you sometimes feel like hibernating. I like to make the home as cosy as possible, drawing the curtains as soon as the light begins to fade, putting on table lamps and even lighting a scented candle.

The winter can be a depressing time, especially for those who are housebound, or living alone, so anything that helps us get through to the Spring is welcome. Some are affected very badly by the long dark days and might be diagnosed as having Seasonal Affective Disorder (SAD), which is related to the short hours of daylight. Symptoms can include depression, irritability, insomnia and weight gain. In serious cases, sometimes light therapy is recommended which involves sitting in front of a light box for up to an hour each day, which gives off the full spectrum of light we get from daylight. Light boxes can be quite expensive though.

This full spectrum light benefits us in many ways. It

causes the skin to form Vitamin D which strengthens bones. Blood cholesterol levels are reduced and high blood pressure is lowered. It improves the function of the immune system and has a beneficial effect on our emotional and mental well being. It's no wonder most of us feel better for spending some time outdoors.

Knowing how good daylight is for us and how we'd all benefit from a bit extra, I was very pleased recently to come across some light bulbs that do the same job as a light box. At £23.90 each, these "Biolights" are a lot cheaper than a light box, they fit an ordinary bayonet socket and will last a long time. (If used for 3 hours a day they will last up to 8 years and if used for 8 hours, 3-4 years.) I'm told that running costs are cheaper than ordinary light bulbs. I like the idea of having the home lit by "daylight" over a longer period rather than having an intensive amount of light for one hour, as with a light box. Also everyone in the family can benefit, even pets and plants apparently. To be effective, the light needs to reach the eyes without the barrier of eye glasses or contact lenses. Also an open type of lampshade is needed rather than one that encloses the bulb. They are perfectly safe to use for extended periods, but in case you're wondering, I'm afraid they won't give you a tan!

Biolights are available mail order from Higher Nature, Tel: 01435 882880. The company also sell a wide range of food supplements which you may be interested in. (n.b. Cod liver oil gives us Vitamins A and D, making it a very useful winter supplement.) I am not connected with the company.

### N.B. ERROR IN LAST NEWSLETTER.

On page 21 of the last newsletter in the sixth paragraph second sentence of Virginia Holland's article on Relaxation I inadvertently typed the word "breathing" instead of "good". Please alter your copy to read..... but I have purposely used the word "good" instead of "deep".

Patient on phone to Doctor.

'Doctor my wife is pregnant and her contractions are two minutes apart'

'Is this her first child?' the doctor asked..

'NO!' the man shouted, 'This is her husband'

**Florida East Coast Post-Polio Support Group  
Late Effects of Polio - Overview 2000  
December 8th - 10th 2000  
Daytona Beach, Florida.**

Barbara Goldstein <bgold@iag.net> and her committee and members are to be congratulated on an excellent conference. I will cover most of the speakers in this newsletter and the remainder in the next.

**Paul E. Peach, M.D. Medical Director,  
Palmyra Post Polio Clinic, Georgia.  
Post Polio Theories and Management - report.**

Dr. Peach talked about the fact that the new problems polio survivors are experiencing were first medically recorded in 1875 and that since the early 80's there has been a resurgence of research. He went through the criteria and symptoms and then explained some of the theories as to why this is happening. There is no definitive theory at present, suggestions are premature aging of motor units due to polio nerve damage [Dr. Lønnberg from Denmark at the Dublin PPS Conference explained a very basic average graph of functional ability. The left hand side is functional ability and the bottom line is age in years. Start from birth and the line goes up to adulthood and then down again in a much longer shallower line. When you had your polio your line dipped down again and up with recovery, but it is unlikely to reach the level it would have done had you not had polio] chronic viral infection [quite a few polio survivors talk about feeling flu-like when symptoms are bad], immune response, central fatigue, chronic and acute overuse of nerves and muscles, and motor unit dysfunction. Is there just one reason or are there many? It is important to have an evaluation by medical specialists who are knowledgeable and experienced in diagnosing and managing Post polio symptoms and functional problems. There are no tests for PPS but tests are done to eliminate other possible causes. [Remember we can have all other conditions as well as or instead of - showing the importance of accurate holistic assessment. 'You had polio you have PPS' can be just as problematical as not being diagnosed. Continue to report your new symptoms as the can fit so many conditions, do not assume it must be PPS or related to polio.]

What can you do about the symptoms? Eliminate or reduce overuse patterns. Try using aids such as bracing, scooters, wheelchairs. Make changes in your lifestyle by altering your work and home environment to save wasting energy where it is not necessary. Change your job or give up working. Pace and rest activities. The sooner you start making changes the sooner the level of decline that you are experiencing will lessen.

**Augusta S. Alba, MD, DPM&R, DNP-N  
Director Rehabilitation Medicine,**

**Coler Goldwater Memorial Hospital and  
Clinical Associate Professor  
Rusk Institute of Rehabilitation Medicine,  
New York University Medical Center.  
Swallowing, Breathing,  
Artificial Ventilation - report.**

Dr. Alba's presentation was excellent, her handout very comprehensive, but very medical in content and difficult to report on without diagrams. We will therefore include a more comprehensive article on this in a future newsletter. Please let us know what questions you would like answered. I have included the subject headings and one excerpt to give you an idea of the topics covered. If you wish a full copy of the text for your health professionals then please get in touch.

Swallowing - covers examination and stages of swallow and recommendations for feeding procedures and further assessment and treatment programs. It mentions GERD (gastroesophageal reflux disease) and OSA (Obstructive Sleep Apnea)

**Excerpt from Breathing.**

**Causes of decline in breathing reserve.** The vital capacity (VC or deepest breath possible) and maximum voluntary ventilation (MVV) decrease with aging. This natural aging process which is somewhat accelerated in post-polio, leads to a decrease in breathing reserve. During rest or activity the breathing reserve index for that particular state is defined as the MV/MVV. The MV is the minute ventilation or amount of air required by the person during one minute. The MVV is the greatest amount of air the person can exchange during one minute with maximal effort.

**Most post polio individuals have a decrease in breathing reserve** but do not require artificial ventilation for respiratory insufficiency. [end of excerpt] [This fact is important if you are to undergo any kind of anaesthetic]. It goes on to describe late onset of respiratory insufficiency and breathing exercises.

Artificial Ventilation - covers, Cough, CPAP/BiPAP, Positive Pressure Ventilation. Home Mechanical Ventilation, patient education, bronchial hygiene regimens, relaxation techniques, diaphragmatic retraining, support and coaching, Arterial blood gases - invasive and non-invasive, pulmonary function tests, sputum cultures and sensitivities, mobile electrocardiograms, ventilator management and tracheotomy care.

**Frederick M Maynard, MD  
U.P. Rehab Medicine Assoc., PC  
Marquette, MI  
Life Course Perspective**



The Life-course perspective for studying disability emphasises the importance of developmental stages and tasks within an historical and medical context. It finds that decisions about current disability-related issues are influenced by broader concerns about identity and the fulfilment of personal and cultural expectations (Scheer J, & Luborksy, ML (1991) The cultural context of polio biographies. *Orthopedics* 14(11), 1173-1181.) Early life experiences with disability are often found to still be important in later life.

The life-course perspective on the late effects of polio considers it a secondary condition for which most polio survivors are 'at risk' as they grow older. The new problems with mobility, including fatigue, pain, increased weakness, and falling, are considered to be triggered by the onset of the other medical conditions (see CO-MORBIDITIES) such as obesity, arthritis, depression, heart disease, diabetes, injuries (see TRAUMA) stress, etc. How polio survivors respond, psychologically, behaviourally, and medically, to the onset of these other conditions will determine the course of possible functional decline during the rest of their lives.

Approaching the new medical problems of polio survivors using the traditional medical disease/illness perspective promotes fear due to unknown etiology and course, expectations of cure, anger, hopelessness, dependency, and multiple expensive evaluations. A life-course perspective promotes self-awareness, emotional growth, and information seeking. It advocates lifestyle change and health promotion to forestall or prevent future problems.

From Maynard, Frederick (1999) Life-Course Perspective. In F.M. Maynard & J. L. Headley (Eds), *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, Revised Edition. St. Louis: Gazette International. If you would like a copy please contact us for details.

**Frederick M Maynard, MD**  
**Managing the late effects of polio from**  
**a life-course perspective.**

**Excerpt - Clinical Evaluation and Management**

What then should a physician's approach be in treating patients with post polio syndrome? It should begin comprehensive and detailed history that allows them to gain a life-course perspective on the person's functional abilities and activity patterns and on the severity of any residual polio impairments and functional limitations. This will enable a practitioner to consider all current symptoms in the appropriate context and to evaluate them in relation to current muscle strength, joint deformities, functional abilities, and other general health indicators. On the basis of the initial comprehensive assessment a further in-depth review of systems may be needed to consider the impact of all

other health issues on musculoskeletal functioning and PPS symptomatology. The practitioner must adopt a primary-care-physician approach to the health of the person with post polio and must decide if a diagnostic workup is needed to identify other conditions that may be treatable and that may impact on the general health issues that must be considered, include cardiopulmonary diseases that affect vitality and endurance; endocrine diseases such as hypothyroidism and diabetes; immunological abnormalities including allergic disorders and states of chronic stress; nocturnal hyperventilation and sleep apnea; dysphagia; neuromusculoskeletal problems including spinal disorders associated with spinal cord or nerve root impingement; peripheral nerve compression syndromes; myofascial pain syndromes; arthritis; and psychoemotional disorders such as depression and posttraumatic stress syndromes.

After all secondary conditions have been fully evaluated and optimally treated or managed, persons with post-polio must build a partnership with their physician based on effective communication and trust. Patients should receive all rehabilitative therapies that can assist them to improve functional limitations, re-establish mental and physical equilibrium in their lives and adopt an attitude of negotiation, with any residual new (secondary) disability. They should be informed about and offered adjunctive treatment options, such as exercise drugs for fatigue or new assistive devices. Consultations with occupational therapists, social workers or psychologists, as well as participation in support groups, can be of additional assistance in considering beneficial changes in life-style.

Lastly, the physician needs to facilitate the patient's adoption of a health promotion and risk prevention attitude toward their health and life-style. After reviewing their vulnerability to progressive functional loss over the life course, patients should be encouraged to participate in wellness programs that can provide them with information and guide them in taking behavioural changes that focus on nutrition, exercise, functional activity, posture, stress reduction, and coping. In summary, new scientific knowledge and advances about the late effects of polio will be used optimally in the lives of person with post-polio only if applied with advanced skill in the art of medicine. end of excerpt.

[Full copy available on request - see Chart page 23]

**Gudni Thorsteinsson, M.D.**

**Department of Physical Medicine & Rehabilitation**  
**Mayo Clinic Jacksonville, Florida.**  
**Management of Post Polio Syndrome - report.**

Excerpt on Pain, the third most common symptom in postpolio syndrome, has been noted in the muscles in 39 to 86% of persons and in the joints in 51 to 79%. The peripheral or muscle pain (myalgic pain) is perceived as a deep ache and may be a symptom of

muscle disuse or overuse (as previously explained) or muscle dysfunction manifested by cramps. Possibly, post polio syndrome pain is a part of myofascial pain syndrome or fibromyalgia. Recent studies have found that Fibromyalgia is extremely prevalent in patients with post polio syndrome. end

He explained how it is important to have posture and body mechanics evaluated so that changes can be made during activities of daily living, household tasks and work to reduce or avoid the actions that are causing the pain. Bracing and use of other aids can help. Anti-depressants or similar medication for myofascial pain should be considered. Gentle stretching exercises, range of movement and relaxation can be helpful. For joint pain heat and nonsteroidal anti-inflammatory drugs and Acetaminophen (pain killer) can be of substantial help. Narcotic medications should be avoided but may be necessary if extensive trials of other medicines fail.

**Mary Ann Keenan, M.D.**  
**Neuro Orthopaedic Program,**  
**Einstein Medical Centre, Philadelphia.**  
**Polio Surgery for the new Millennium - report.**

Dr. Keenan explained that our symptoms must be assessed with an interdisciplinary approach, it must be holistic, and that surgery is last on the list. The goals of late surgery are the relief of pain, correction of deformities, move muscle forces checking that moving it it does not lose strength, stabilise unstable joints and make bracing more effective. It is not for eliminating bracing or improving muscle strength. She then went through various parts of the body and of particular note are Rotator Cuff Surgery and Joint Replacement.

Shoulders and Rotator Cuff Surgery - there are four muscles, the supraspinatus, infraspinatus, teres major and sub scapula. The supraspinatus takes the peak pressure. Normally only one is torn, but in polio we see both the supraspinatus and infraspinatus torn. This occurs with using the arms to push up from and lower into seated position, not from using crutches. Avoid the need for surgery if at all possible. If there is damage, you have to ask 'Is it worth repairing?' Evaluate what the outcome will be. We checked on non polios of same sex, age and the results of relief were the same, but there is one difference the underlying strength is different. This is a big operation, people who need their arms now have them taken out of action whilst they recover, they become really disabled immediately following the operation. Major and minor surgery is the same for the doctor but for a polio survivor even minor surgery can be major. There is nothing that can be done for weakness at the shoulder, it is therefore imperative that you SAVE YOUR SHOULDERS. Use aids that save you overstraining or overusing these joints. such as electric rise leg raise chairs.

Joint replacements. It is imperative that all muscles are

graded correctly. Hip replacement - Grade 4 strength hip adductor and extensor strength is needed, plus adequate bone stock. Correct other leg deformities and an orthotic may be necessary. Knee replacement - Need adequate bone stock, correct other bone deformities, use an unconstrained prosthesis, and protect the leg with a KAFO forever. [KAFO, knee ankle foot orthosis, long leg brace]. It is imperative that all polio survivors who are told that they need orthopaedic surgery are evaluated by specialists who have adequate knowledge and experience of treating polio survivors.

**Mary Ann Keenan, M.D. Alberto Esquenazi, M.D.**  
**The Einstein-Moss Rehab Post-Polio Program,**  
**Institute for Mobility Evaluation and Treatment,**  
**Albert Einstein Medical Center,**  
**5501 Old York Road, Philadelphia, PA 19141.**  
**Polio 2001 - An overview - full article.**

#### **Acute Poliomyelitis.**

Because of effective immunization programs, acute poliomyelitis has become a rare occurrence in most of the world. The last major epidemics in the developed world occurred during the early 1950's.

Poliomyelitis is the result of a viral infection, which attacks the anterior horn cells of the spinal cord. The anterior horn cells control the skeletal muscle cells of the trunk and limbs. All of the anterior horn cells are affected with the acute infection. This accounts for the diffuse severe paralysis seen with the initial infection. A variable number of anterior horn cells survive the initial infection.

Acute polio is characterised by the sudden onset of paralysis accompanied by fever, acute muscle pain and often a stiff neck. Paralysis of the respiratory muscles is life threatening in the acute stage. When the shoulder muscles are involved, respiratory compromise should be suspected because of the close proximity of the anterior horn cells controlling each in the spinal cord. Mechanical support of ventilation may be required.

The treatment in the acute stage of the disease consists of providing the needed respiratory support, decreasing muscle pain, and performing regular range of motion exercises to prevent the formation of joint contractures.

#### **Subacute Poliomyelitis.**

The subacute stage of polio is characterized by the recovery of a variable amount of muscle function. Mechanisms of regaining strength include 1) anterior horn cell survival, 2) axon sprouting, 3) muscle hypertrophy. Although all of the anterior horn cells in the spinal cord were affected by the initial infection, some will survive. The average number of anterior horn cells to survive is 47% (Range 12 to 94%) as seen from post mortem studies. The pattern of anterior horn cell

survival in the spinal cord is random and does not follow anatomically continuous areas. The distribution of the paralysis is variable depending on which anterior horn cells were destroyed.

Additional muscle function is gained during the recovery phase by axon sprouting. One anterior horn cell innervates a group of muscle cells. When muscle cells are 'orphaned' by the death of their anterior horn cell, a nearby nerve cell can sprout additional connections (axons) and 'adopt' some of the muscle cells. A motor unit is defined as a nerve cell and all of the muscle cells it controls. The axon sprouting which occurs after polio can result in very large motor units.

The other mechanism by which people regain strength after polio is by muscle hypertrophy. The surviving muscle cells enlarge in an effort to provide additional needed power. During the subacute stage of the disease, which may last from 16 to 24 months following onset, the emphasis is on preventing deformities and preserving function. Splinting and braces are often helpful to maintain joint position and supplement function.

### **Residual poliomyelitis.**

It was during the residual stage that the orthopaedic surgeon traditionally became active utilising surgical procedures to restore lost function and provide structural stability. If the person was still growing, it was important to prevent the formation of skeletal deformities resulting from the muscle imbalance.

The person with compromised function of the diaphragm was taught glossopharyngeal breathing in which air is swallowed into the lungs. This provides sufficient air exchange for light activities performed while sitting. The person often still required mechanical support of ventilation while sleeping.

### **Post Polio Syndrome.**

With the last major polio epidemics in the United States occurring in the early 1950's, it has become common to see individuals who had polio as a child now returning complaining of increasing weakness. Many are concerned about loss of function. Polio has always been considered to be a static disease in that the paralysis is not progressive. The increasing weakness has been attributed to the overuse of muscles already weakened by the polio. Often muscles, which were thought unaffected, exhibit weakness at a later date. Studies have shown that a muscle must lose 30 to 40% of its strength for weakness to be detected using manual muscle testing. Gait laboratory studies have also demonstrated that activities of daily living require more muscle strength and stamina than were previously appreciated. Polio survivors have traditionally been encouraged to work harder to regain strength. The concepts of 'no pain, no gain' has proven detrimental to

the polio survivor because it has encouraged chronic overuse of their muscles and resulted in further deterioration of function.

Most polio survivors begin to notice the deterioration approximately 30 years after the onset of the disease. The combination of symptoms varies slightly between people. The diagnosis of post-polio syndrome is made on the following clinical criteria:-

- A history of poliomyelitis.
- A pattern of muscle weakness which is random and does not follow any nerve root or peripheral nerve distribution.
- A constellation of symptoms indicating decreasing strength and function. (Table 1).

There are no tests that are diagnostic of post polio syndrome. Electromyography can demonstrate the presence of large motor units resulting from the previous axon sprouting. These findings are supportive but not diagnostic of polio.

Table 1.

Increasing Muscle Weakness.	Sleep Apnea
Joint pain or Instability	Intolerance of Cold
Severe Fatigue	Depression
Muscle Pain	Intolerance of Cold
Muscle Fasciculations.	Muscle Cramp.

### **Treatment of Post-Polio Syndrome.**

The treatment of post-polio syndrome is directed at preserving current muscle strength and preventing further weakness from occurring. Generally, it is not possible to strengthen a muscle that has been weakened by polio. Some gain in strength can be seen when chronic overuse is corrected. The basic principles of treatment of post-polio syndrome are:

- Lifestyle modifications to prevent chronic overuse of weak muscles.
- A limited exercise program incorporating frequent rest periods to prevent disuse atrophy and weakness.
- Lightweight orthotic support of limbs to protect joints and substitute for muscle function.
- Orthopaedic surgery to correct limb or trunk deformities.

### **Spine**

A common complaint is back pain that usually results from postural strain. Excessive lumbar (low back) extension is used to substitute for weak or paralyzed hip extensors. Neck pain is frequently seen also. This, too, is from slowly increasing weakness. At times the neck muscles become tight from the strain and can actually

press on the brachial plexus nerves of the arms causing numbness. This is called 'Thoracic Outlet Syndrome' It is treated with gentle stretching exercises of the neck. Both complaints can be treated by the use of external supports. It is important to relieve the excess workload from the muscles to prevent further deterioration. For neck pain tilting the seat of a chair backward 10 degrees is often sufficient to relieve the fatigue of the posterior cervical muscles from supporting the head. Patient education is essential since most individuals are reluctant to use braces that they long ago discarded.

Paralysis of the cervical (neck) spine musculature can result in the inability to maintain the head erect. This interferes with performing all other functions including walking. Fusion of the cervical spine can correct the problem.

Scoliosis (spinal curvature) is common secondary to paralysis and the resulting muscle imbalance. It can be further enhanced if a leg length discrepancy exists. External supports can be used to support the spine but these often interfere with breathing. Spinal fusion may be needed to control the spine adequately. If fusion is needed, prolonged immobilisation post-operatively is to be avoided. Prior to any surgery requiring general anesthesia or significant sedation, the vital capacity of the lungs should be assessed to determine the individual's need for respiratory support.

### **Upper Extremity.**

**Shoulder.** - The Shoulder is important for placing the hand in the desired position for use. The shoulder is totally dependant on muscle strength for active mobility. Weak muscles about the shoulder can be made more functional with the use of mobile arm supports for the wheelchair user. This allows a greater arc of motion with less muscle strength. In the ambulatory person who requires upper extremity aids, shoulder stability is more important and a shoulder fusion may be helpful if there is sufficient strength of the chest wall muscles. Motion between the shoulder blade and the chest wall is maintained allowing use of the extremity for tabletop activities. Shoulder fusion does restrict the ability of the person to position the hand for bathroom hygiene so it is undesirable to fuse both shoulders.

Preservation of shoulder strength should be a priority of treatment since bracing and surgery of the paretic shoulder offer limited improvement. Shoulder weakness is found in 95% of individuals with post polio syndrome and correlates closely with the amount of lower extremity weakness present. Rotator cuff tears are also common. Individuals with weak legs will use their arms to push up from a chair and pull themselves upstairs. They also lean heavily on upper extremity aids while walking. It is therefore important to remove as

many unnecessary strains from the shoulders as possible. This can be done using elevated seats, motorized lift chairs, elevators or motorised stair chair glides [stair lifts] and optimal lower extremity bracing. In minimally or non ambulatory individuals, an electric wheelchair or motorized scooter should be prescribed to prevent excessive strain on the shoulder muscles caused by propelling a manual wheelchair.

**Elbow** - The elbow requires sufficient flexor strength to lift an object against gravity for function. A mobile arm support can maximise the effectiveness of the muscle strength for the person. Tendon transfers, such as deltoid to the biceps, may also be useful in restoring muscle function.

**Hand** - Opponens paralysis is common in the hand and results in a 50% loss of hand function. A splint used during the acute and recovery phase is useful to prevent an adduction contracture. Tendon transfers can restore Opponens function. The most common muscle transferred is the superficial flexor of the ring finger.

Paralysis of the small intrinsic muscles of the hand interferes with function. A lumbrical bar orthosis will prevent hyperextension of the metacarpophalangeal joints and allow the long extensors to extend the fingers and open the hand. Surgical capsulodesis (tightening of the joint capsule) to limit metacarpophalangeal joint extension will accomplish the same result.

Paralysis of the finger flexors and extensors can be overcome with the use of a flexor hinge brace if the wrist extensor function is present. Tendon transfers can provide the same result allowing the tenodesis effect to provide grasp and pinch functions.

### **Lower extremities.**

Full range of motion of the hip and knee joints is needed for function. Contractures should be corrected when possible to permit more effective bracing. Iliotibial band contractures of the outer thigh are common. This causes the hip to assume a position of flexion, external rotation and abduction. The knee assumes a valgus (knock-knee) alignment and the tibia is externally rotated on the femur. Release or lengthening of the iliotibial band will correct the deformity.

An individual with flail lower extremities can stand using crutches and a knee-ankle-foot orthosis (KAFO) with the knees locked in extension and the ankles in slight dorsiflexion by hyperextending the hips and utilising the strong anterior hip capsule for support. Flexion contractures of the hips or knees prevents this alignment. If trunk support and upper extremity strength is adequate, the person could ambulate with a swing-through gait for short distances. This gait has

high energy demands. With time the posterior knee joint capsule becomes stretched and the knee develops a recurvatum (back knee) deformity which is painful and can lead to arthritic degeneration of the knee. A knee ankle foot orthosis (KAFO) will protect the knee and provide improved stability for walking. If there is Grade 3 (FAIR) strength in the hip flexor muscles and passive full knee extension, then the knee joints can be left unlocked for walking. In this case a posteriorly offset knee joint is used to stabilize the knee and ankle dorsiflexion is limited to minus 3 degrees of neutral dorsiflexion to provide a hyperextension moment to the knee for stability.

Quadriceps (front thigh muscles) strength is not essential for ambulation. A strong gluteus maximus (buttocks) and good calf strength can substitute by keeping the knee locked in extension. If the calf strength is inadequate to control the forward motion of the tibia in mid to late stance, an ankle foot orthosis (AFO - brace) is needed. This could result in a back knee deformity from the hyperextension push on the knee joint. An equinus (toe down) position of the foot inhibits forward momentum and limits step length by preventing body weight from rolling over the forefoot prior to contact of the opposite leg with the ground. When good hamstring (back of thigh muscles) function is present, two of these muscles can be transferred to the quadriceps tendon to provide dynamic knee stability.

Muscle imbalances in the foot can lead to deformity. When muscle imbalances exist, tendon releases or transfers should be considered prior to the development of fixed deformities. Equinus (toe down) contractures of the ankle is very common. This results in genu recurvatum (back knee). The equinus should be corrected by Achilles tendon (heel cord) lengthening. Accommodating the toe down posture by using an elevated heel on the shoe is not a good solution since this places excessive stress on the calf muscles to control the leg.

An Achilles tendon lengthening is frequently needed to correct an equinus (toe down) contracture of the ankle to permit adequate bracing. When a cavus foot (very high arch) deformity is present, this causes forefoot equinus, which also limits bracing. If no fixed bony abnormalities are present, then release of the plantar fascia ligament will be sufficient to correct the deformity. If the cavus deformity is caused by bony deformity, then a closing wedge osteotomy (cutting the bone) is needed to correct the deformity. A triple arthrodesis (fusion) of the heel can be used to correct deformities and provide a stable base of support.

The longstanding muscle imbalances, patterns of muscle substitution, and resulting joint and ligament strains often lead to degenerative arthritis. Total joint replacement can be performed but several special

considerations are needed. Osteoporosis is common in the polio survivor because of the prolonged lack of muscle action on the bone. Joint contractures must be corrected at the time of surgery to prevent excessive forces on the artificial joint, which might lead to loosening. Weak muscles must be supported with the appropriate braces after surgery. The rehabilitation program will be longer than usual to regain joint motion and muscle function. Continuous passive motion devices and frequent joint range of motion must be used to gain joint mobility after surgery. Since the hip joint is difficult to brace, there must be at least grade 3 after surgery. Surgery can be expected to weaken the surrounding muscles. This must be taken into account before proceeding with total hip arthroplasty to prevent chronic dislocation. End of article.

More information from this Conference in the next newsletter. I hope that you have found the selection chosen informative. Please do help us by asking questions and giving us ideas for future issues.

Remember the story of your polio and how you manage your life can give others ideas how to make changes in theirs. It's far easier to maybe try what someone else has found successful than accept being told that you must do this or that. Trying a store or tourist attraction scooter will give you an idea how much you can do using one.

**Diagnosis PPS plus, plus.  
by Hilary Hallam**

Just because we are Polio Survivors it does not mean that all our symptoms are PPS. It is important that you and those health professionals you see consider and test for other conditions.

Richard had been reporting increasing symptoms of pain, weakness and tremors for the last few years. He had fallen in the spring of 1999 and broken a bone in his hand requiring surgery. He had then to make the decision to return to wearing a full leg brace. Since then his symptoms had increased and medically the right things were not happening. I had met Ass. Professor Carol Vandenakker, Director of the University of Miami Department of Rehabilitation at the Atlanta PPS Conference in 1997 and the GINI Conference last June. We contacted her and asked if she would do a full Rehab Assessment at her Post Polio Clinic. She agreed and a date was fixed following the PPS Conference to give me an opportunity to see another PPS clinic working.

We arrived in Miami at 3p.m., breaking down on a flyover exit at junction 6 of the I95. Three lanes, hardshoulder with concrete wall and fast moving traffic. It felt like being in a nightmare. We rang the AAA. 'It will be an hour minimum to reach you ma'am, can you please get out and lift the trucks hood'. I explained that we were within inches of the wall on

### **Email to Support Group in Six Weeks!**

Carol Vincent from Indiana in the Summer and Florida in the Winter emailed the Lincolnshire Post Polio Network on December 13th 2000 asking about the relationship between neuropathy and post polio syndrome. I replied and as we were only about 20 miles apart we soon met and chatted about PPS. In the meantime Carol went into full swing looking for other polio survivors in the area and finding eight very quickly and was soon looking for premises for meetings.

Carol fixed the first meeting of the Southern Hillsborough PPS Group for the fourth Thursday in January with myself as guest speaker and publicised this on local radio and in the newspapers. She was soon inundated with callers. [56 Polio Survivors by the end of January 2001] The meeting was well attended in fact the room was full to bursting. She provided two packs of information, the Lincolnshire Post Polio Information Pack and an Orientation Pack with details of the next few meetings and speakers, lists of local specialists and other PPS leaflets, and information on who had contacted her. Meetings will be monthly on the fourth Thursday and the next meeting will focus on getting to know one another and talking about polio and how one feels about what is happening.

She provided the Tampa Tribune reporter with her story and both this and the report in the paper follow.

### **The Pronouncement by Carol Norris Vincent.**

The doctor made her pronouncement. I had Post Polio Syndrome.

The diagnosis did not surprise me. I had been having pain and weakness for 10 years. But my recent physical accomplishment was bittersweet because of it. With my husband and six friends I had made the gruelling hike into and out of the Grand Canyon - something my siblings who knew me as a totally unathletic, could not fathom!

I reflected on the 52 years since I had awakened on my eighth birthday unable to move. As were so many others during the mid 1940's, I was rushed to the hospital and placed in a huge ward full of children in crib-like iron beds. Bits and pieces of memory flashed through my

mind: The view of the lighted top of the KPL building out the hospital window, the harried nurses who flitted from one crisis to another. Mother and Daddy peering at me through the barred window from the outside, and that unforgettable moment when I could not breathe. I remember trying to holler for a nurse but no sound came out.

The panic that not breathing caused haunts me to this day. The nurses rushed in and took me to a room with children in iron lungs in it. I was placed in one of these dreadful tomb-like machines that incessantly wheezed and clicked, using its bellows as lungs for the paralyzed patient. I was one of the fortunate ones who once again began breathing on my own so my stay in the lung was short.

A month later, when I was free from paralysis, I went home where Mother massaged me daily with Sister Kenny's new but still controversial treatments. Mother - a very strong willed woman - diligently massaged my back and legs until they returned to normal strength. I can still see the determination in her face and smell the warm, wet wool cloths that were applied to my body after the massaging was done.

I hated the uncomfortable back brace I had to wear, it hurt and rubbed my skin raw. It was made of canvas and reinforced with rigid metal stays. To this day, I can see the face of one young doctor who was the antithesis of what I thought a doctor should be. While examining me, he bent over with a cigarette in his mouth and burned my eyebrow! Adding insult to injury he quipped to a colleague, 'She looks like she's wearing her Mother's girdle.' What a jerk! He was so incredibly insensitive, showed no compassion, and certainly was not behaving professionally.

Mother's vigorous massaging and the back brace soon helped me return to a normal life with no visible limp. Still, there were lingering signs that only I knew were a result of polio. I was awkward, uncoordinated, fell a lot, and could never do sit-ups. And then there was the claustrophobia - it came and went, but I functioned normally.

So I adjusted to myself: this was the person I was - and I forgot about polio. When I turned 40, I decided it was time to get fit - I took up aerobic dancing, jogged regularly, and later took up 4 mile daily walking.

But after a decade of this fitness effort, I found myself weaker than ever, no more co-ordinated, and with quirky aches and pains that could not be attributed to arthritis or just aging.

Still it took 10 years and numerous tests for the grim and painful truth to be revealed: the remnants of the disease that I thought I had left behind more than 50 years ago had permeated my body and would be with me the rest of my life. In reality, my fitness efforts and the Grand Canyon hike had taken a toll that I had not counted on - I had used up some of the remaining muscle that I had left.

Once the spectre of polio has been eradicated from the entire world, Post Polio Syndrome (PPS) eventually will no longer be around. Because of the discovery of the polio vaccine, polio was almost totally eradicated in America in the late 1950's. America's polio victims - more than 50% of whom now have some symptoms of PPS - are in their 50's, 60's and 70's. When we are all gone, there won't be a need for PPS specialists anymore. And no one will hear the pronouncement: you have Post Polio Syndrome.

**The Tampa Tribune  
Community Focus Brandon  
serving all of  
Southern and Eastern Hillsborough.  
Saturday January 20th 2001.**

[Photograph] Carol Norris Vincent works on a computer from her Sun City Center Home to find others with Post Polio Syndrome and to organise a support group. [The Lincolnshire Post Polio Network WebSite is on the screen.]

**Polio sufferer fights old foe,  
seeks to share.**

**Sun City Center** - A woman struggling with Post Polio Syndrome hopes a support group will help others who find the childhood disease rearing its head again.

**by Liz Bleau of the Tampa Tribune.**

Carol Norris Vincent, now 62, recovered quickly from polio that paralyzed her when she was 8.

After only a day or two in an iron lung, she was breathing again on her own. Struck down with polio in the summer, she was back in school that fall, wearing a back brace.

She thought her recovery was complete. When she turned 40 she decided to get fit and took up aerobic dancing, jogged regularly and later walked four miles daily.

Ten years after she started her fitness routine, she found herself weak and with quirky aches and pains that could not be attributed to arthritis or aging. After numerous tests, she found out she has Post Polio Syndrome.

'I learned the remnants of the disease that I thought I had left behind more than 50 years ago had permeated my body and would be with me the rest of my life' she said.

The syndrome covers a wide range of new symptoms that affect polio patients later in life including pain, weakness, breathing and/or swallowing difficulties, sleep disorders, muscle twitching and fatigue. Research shows that those who were most affected by the polio virus at initial onset and who made the best recovery seem to have the worst Post Polio Syndrome symptoms.

Vincent belongs to a Post Polio Syndrome support group in Indiana. It meets only once a year and its main communication with members is through a newsletter.

She is trying to establish a Post Polio syndrome support group for Hillsborough County. The group's first meeting will be from 10 to 11.30 a.m. Thursday at the United Methodist Church, 1210 Del Webb Blvd, W, Sun City Center.

Guest speaker for the meeting will be Hilary Hallam, founder and chairwoman of a Post Polio Support Group in England. That group has 300 members and about 700 people who subscribe to the updates of its WebSite ([www.ott.zynet.co.uk/polio/lincolnshire/](http://www.ott.zynet.co.uk/polio/lincolnshire/))

Hallam, who is spending part of the winter in Palmetto, had polio when she was 5 and like Vincent thought she had made a full recovery.

'I thought my polio was past tense,' she said, until she slipped on a wet floor in 1988 and began to have a variety of medical problems. Until then she had been an active adult who taught swimming and was a lifeguard.

Now, she wears a full leg brace and travels in an electric scooter.

It took Hallam seven years to have her symptoms diagnosed as Post Polio Syndrome, and that was

done only after she did much of the research herself after hearing about it on a radio program.

'A big part of the what we do in our support group and through the WebSite is help people assess themselves, Hallam said, 'Sometimes they need to let their doctors know how to help in their medical assessment'. [see further information at the end of this piece directly opposite in the next column]

She gives the example of a recent seminar in Daytona Beach where she showed health professionals how she is able to respond well to simple motor tasks doctors often give their patients.

'But when I am asked to pick up a cup with a pint of liquid in it, I can't do it because its a pattern of movement that we PPS victims often have the most difficulty with,' Hallam said.

Vincent learned too late that the fitness routine she as doing was not in her best interests. She hopes through the support group that other polio victims can avoid making the same mistake.

Research has shown that most polio survivors cannot replenish their muscle strength by increased exercise. Instead, they continue to lose what muscle strength they have. Any physical activity routine should be done with the help of a therapist.

Vincent suffers from cold feet, weakness, and an inability to stand for long periods of time.

'I can't stand long enough to cook a whole meal.' Vincent said.

When she goes to a museum or a place where there will be a lot of walking, she uses a wheelchair.

Hallam will distribute information packets at the Sun City Center meeting that will tell people how to assess their condition and better manage their lives.

For more information about the meeting, contact Vincent at (813) 634 7670 or at wavncv@yahoo.com  
Vincent says those planning to attend the meeting should let her know in advance so sufficient information packets can be prepared.

Liz Bleau covers south Hillsborough County and can be reached at (813) 633 4323 or ebleau@tampatrib.com

**The Lincolnshire Post Polio Network Information Pack** (which is continually updated) and talks that I give explain that we have to assess what we do in our daily lives. How do you do each action of daily living and has that changed from last year, five years ago, ten years ago. The change/s that have taken place are the important facts to tell those assessing you.

Manual Muscle Testing has continued to overgrade my ability. It has not picked up the following weaknesses that have occurred since 1988.

Left arm - I can lift a pint glass of liquid from a table but not bring it to my mouth without using a second hand, carry a bag with only a few light items in it for more than a few yards, type with that hand for more than half a minute unless I am palm resting on an ergonomic keyboard and even then I have to type and rest repeatedly, hold a fork in the normal way to keep a piece of meat still to cut it, hold a vegetable for peeling, etc.

Right arm, which is stronger but the wrist is now weak. I cannot peel vegetables towards me, I have to use a peeler than can peel away from me, and I cannot beat scrambled eggs with wrist action and now use elbow rotation.

Taking all these actions I can only do them in the way I have modified the action for a few repeats then the muscles fatigue. I have to pace and rest each action. Working in the kitchen I have to stand and lean against the work surface so that I can use both hands and at a level lower than the worktop usually in the sink area. I cannot work sitting on a perching stool as this is uncomfortable for my lower back and the angle of my arms is too high. I can only stand for a few minutes before resting. It is very frustrating not being able to cook a meal, bake a cake, etc like I used to. Now its having to purchase more expensive already prepared vegetables and salad, pre-cooked meats, etc. From Gourmet Cooking (ok well being honest reasonably cooked food) to 'Ding' food. Take it out of the freezer and pop it into the microwave and wait for the 'Ding'.

All this use of energy has to be taken from the 10 energy tokens a day that we have available. It takes some working out but the pacing and resting allowing the polio muscles with limited functional ability to work, recover, and work again means that we can manage our lives better. What is hard for many of us is not being able to dust, Hoover, decorate, garden, etc. like we used to do just a few years ago. Something we did not think would



happen to us for at least another thirty years.

Dr. Whiteley, neurologist, in mid 97 said 'Tell me what post polio is in two minutes'. I replied, 'It's like being a torch with rechargeable batteries that are 45 years old. If I want light out of me during the day then I have to work out when and how much and decide when and how often to switch myself on and off. If I need light in the evening then I stay switched off as much as possible during the day. If I drain the batteries one day then they take two or three to regain their charge.' It means a lot of planning but it works. I do overdo at times but I know that I will have to payback over the next few days to recoup. However, now its an informed decision and I know the consequences.

Appointments with health professionals have limited time and the fastest way to get over information is visual. Remember there is little time for lengthy reading of medical articles. Those of us on the internet will like me probably have printed off everything they found in the first few weeks - enough to wallpaper a house twice over! As I have said before in previous newsletters, walking in with a huge bundle of medical articles and a toilet roll length of symptoms is not a good way of approaching a health professional, especially one who may have only had a short lecture on polio and know little or nothing about its late effects.

It is a good idea to put yourself in their position, how would you like the information to be presented to you and in the time allotted?

The difference in what I used to do before the fall in 1988 - 5 part time jobs to 60+ hours a week, voluntary work, bringing up two kids, housework, gardening, decorating, lifeguarding, walking miles, and now is considerable. Photographs of me as a policewoman, doing judo, lifeguarding, etc. show how able I used to be.

If you have not already, why not fill out A Polio Time Line - see page 23 for a condensed sample of our charts - normally two pages with a chart table underneath each body so that you can list operations, symptoms, achievements at best recovery. This shows quickly and visually that something is happening and its more than age related.

### **Meeting with other polio survivors is fun.**

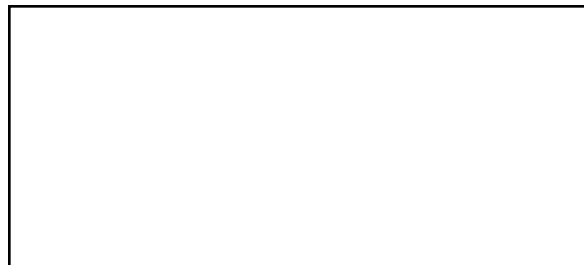
I have attended six post polio conferences now and a few post polio group meetings and met with many polio survivors. I can assure you - and I know those who have attended the evening after

our Annual General Meetings will agree - most of the time its fun, lots of laughter, lots of time to let off steam and tell people who do understand what you are talking about. A chance to share information, tips that have worked for you, a chance for carers to talk to each other. We will be doing the same this year in late September - information next newsletter. Why not think about joining us for the weekend. Those of you who have been before why not write and tell us what you thought of your visit. Mr. Hill at the last meeting said 'Its great being part of the main group instead of the couple with a disability in the corner.'

I would be happy to visit areas of the country (UK) and do a talk during the summer months. To start the ball rolling I will be visiting with my parents in North Devon late April travelling from Lincoln via the M42 and M5. If you would like to host a meeting - and it could be in your house, or a nearby room/hall accessible to wheelchairs - then please contact me by email. Allow 2 hours for the presentation (Overhead Projector needed) question time and a chance to meet with others. A short break for a drink and a loo visit is also a good idea. If you wish we will provide you with a Poster and Press Release, and will have Information Packs, leaflets and handouts available for the meeting. A donation or raffle towards the cost of the handouts and travel expenses would be greatly appreciated.

Hilary Hallam, Founder and Chair,  
Lincolnshire Post Polio Network  
linpolio@legend.co.uk

Members this is your newsletter and we would love to receive more input from you. Stories, appropriate jokes, hints and tips, etc. Suggestions for items for future newsletter themes would be appreciated. We look forward to hearing from you.



the passenger side and there was no way I was going to attempt opening my door. Thankfully once the truck had cooled down it restarted and we got out of there as soon as there was a break in the traffic, drove down the other side of this flyover through a set of lights and there on the left was our hotel and the right the hospital. Relief! We pulled in, rang the AAA back, got a room next to where we had parked and the luggage unloaded for us. We crashed out and it was over three hours before we found the energy to eat some of the food in our cooler box. A very very stressful and very energy sapping experience!

Using our scooters and in short hops due to Richards arm weakness we went across the road to the Hospital and I had my first insight into a different health system. He signed in and had medical insurance cards photostatted and filled in what seemed like never ending forms. We then went through for a multi-disciplinary appointment with Prof Vandenakker, her Physical Therapist, Occupational Therapist and Orthotist. She took down some basic facts - he had been diagnosed with PPS in 1991 - and then commenced examination discussing this with the rest of the team. The whole team were very impressed with the Polio Time Line and photographs which gave a far fuller picture. Looking at Richard at that moment in time with paralyzed left leg in full brace, heavy steel toe capped boots, very weak contracted left arm with tremors, weakening right arm with massive shoulder pain etc. and then seeing photos of him only a few years back working on a truck engine, attending pre 1840 rendezvous camps, blacksmithing, etc., learning that his trade was a bench jeweller and that he had only been wearing the brace again for eighteen months, gave them a totally different picture from their initial assessment. Mention polio and its assumed you have always been like you are now.

Prof. Vandenakker said that some of Richards reported symptoms were obviously not PPS and was surprised to hear that he had been reporting these symptoms for some years without result. She arranged an MRI of the brain that evening and came over to the clinic from her office the next day to give us her teams report on the previous day and the results of the MRI. Thankfully there was no tumour, no stroke, but as we suspected and had discussed with her the tremors were Parkinson like. It would take at least five more days to have the full tests necessary and knowing that we did not have the money to remain in the hotel she had researched and found us a top Parkinsons Neurologist, only 20 miles from where he lives. She explained that he would have to have a full neurological workup and diagnoses before anyone could finalise an assessment and provide a rehabilitation plan.

V. Daniel Kasscieh, D.O. is a board certified neurologist practising in Sarasota-Venice area with

Neurological Associates. He is president of the Florida West Coast Parkinson Association and medical director of Neurological Associates which is designated a World Class Center of Excellence by the National Parkinson Foundation. Visit their WebSite <[www.neuro-fl.com](http://www.neuro-fl.com)>. Taken from his article on Parkinson's Disease. The Disorder and Current Therapy.

**Historical background.** Parkinsons Disease has been referred to in history as far back as the ancient Egyptians. Hieroglyphic writings make reference to the symptoms of the disease. [Editors note - also at least one drawing of a person with a thin shorter leg showing polio] There are references to Parkinson's disease throughout historical literature including the Bible, writings of Galen-the-Great, a Greek physician of the second century, and in Shakespeare's works.

In 1817 a British surgeon, James Parkinson, wrote an essay on The Shaking Palsy. In this paper he described the primary clinical symptoms of six patients affected with the disease. In the later 1800's, this clinical syndrome of tremor, rigidity, and slowness of movements (bradykinesia) came to bear Dr. Parkinson's name.

**Cause** - The underlying disease process for Parkinson's disease was discovered in the 1950's. It was found that a specific area of the brain known as the substantia nigra was affected. The substantia nigra is a dark pigmented area located in the brainstem. It contains specialized nerve cells (neurons) that produce a neurotransmitter, dopamine. Dopamine is responsible for allowing the brain to generate signals for smooth, well regulated motor (muscle) function. In patients with Parkinson's disease, the dopamine producing neurons slowly die off. This results in a dopamine shortage in the brain. Patients who develop symptoms of Parkinson's disease have already lost 80 percent of the dopamine producing neurons. Despite extensive clinical research, the cause for the loss of these dopamine-containing neurons in the substantia nigra remains a medical mystery.

Clinical signs and symptoms - The primary clinical features of Parkinson's Disease include, rigidity, bradykinesia (slowness of movement), postural instability (loss of balance) and tremor. [end excerpt] Note the fact that the substantia nigra is also affected by the polio virus.

Dr. Kasscieh prescribed the Parkinsons drug Sinemet (Carbidopa-Levodopa) and Artane (trihexyphenidyl) with some improvement. There are no tests to see if you have Parkinsons, it is a clinical diagnosis and trying the drugs to see if they work.

With reference to the Polio Time Line and assessment we had tabulated he ordered an MRI of the shoulder and referral to a shoulder specialist orthopaedic

surgeon.

On 31st January Dr. Schofield told him the MRI showed tears in the Rotator Cuff and scheduled arthroscopic repair on 20th February. We were surprised to learn that for six weeks he cannot use that arm at all - although it can be passively moved by others. For another four and a half months he can use his arm lifting no more than a mug of coffee and no weight bearing with cane or pushing up from chair till after that. We are aware from information we have that for a polio survivor full recovery can take up to a year. As his left arm has little function it is going to be very tough and disabling for some time. Speaking with Dr. Zilioli, an Orthopaedic Surgeon and Polio Survivor from Florida on the phone last night he said that the one good aspect was that no-one would have to spend time explaining to us all the ins and outs of the surgery, anaesthetic and recovery. He was pleased to hear that we were already putting changes into place in the home to make life easier and going to practice not using the right arm before the operation. Dr. Zilioli explained that the operation would provide relief of pain and provided he was careful not to injure his shoulder during recovery and work with a therapist to ensure that he kept all his working parts still working then the operation would be a success. Frustration he said would be the biggest issue.

Dr. Kassacieh also referred him to an Orthotist. Richard has arthrodesed ankles and floppy toes and combining that with his weak arms getting dressed is a long drawn out procedure taking about 70 minutes. To put his boot on his foot, sitting, he lifts his left leg up and turns it round so that his foot is sole uppermost and facing left! (his left leg is totally paralysed and he can therefore turn his leg at the hip like this). With the boot upside down as well it is a slow, delicate and exhausting procedure to get the foot in the shoe without the toes curling under and it cannot be done by anyone else. This is not going to be possible after the operation. Boots that open right to the toes were the answer, but we were horrified to find out that his medical insurance Medicare only allows \$48 and pays 80% of that for the one boot that fits the calliper. No allowance at all for the other boot regardless of the fact that this foot is also arthrodesed and the boot contains a special shaped insert. The boots were \$172. Alan Ross of Suncoast Prosthetics and Orthotics explained that all Insurance's are different and some things are covered and some are not and some allowances are less than the cost of the materials with no amount for labour. However, Alan said if we had an old built up shoe he make the front open to the toes, and put a calliper plate in the sole to tide him over till he is well into recovery and able to put his own shoes on again.

We often complain about the NHS, the long delays in getting appointments, tests, treatment, operations, etc. When we are ill we do not have to stop first and think can I afford the percentage of the bill to see my GP

and other consultants, have the tests, operations, get aids, pay for therapy, buy the drugs prescribed. There is no prescription set amount like in the U.K. you have to pay the cost of the drugs. Living on benefits, especially if you live alone with no other salary coming in, means do I visit the doctor or eat?

This has been an insight for me. There appears to be a doctor for each part of your anatomy and you have to ring round to see who will see you and will they take your insurance. If you can't afford the co-pay (20%) are they prepared to waive that. Every time I heard the phrase 'Oh don't worry we can arrange a payment plan for you of say \$10 a month.' You cannot afford to see many health professionals before you would be on bread and water for life. There is no mobility allowance. If you are prescribed an electric wheelchair or scooter for use in your house there is nothing towards transporting this. There is also nothing for dental treatment or glasses and your benefits are assessed on your previous salary.

Whichever country you live in it is still very frustrating, depressing, and very very stressful.

**IT IS NOT EASY BEING A CARER  
TO A POLIO SURVIVOR  
AND ITS NOT EASY HAVING  
TO ACCEPT A CARERS HELP.**

Many of you might think it strange for a Polio Survivor to be writing this article but as you read on you will see how this came about.

A few months back I spent over 24 hours with Sylvia Dymond in Hampshire and saw first hand what it is like to have a professional carer come into your life at different times in the day. This change from doing it yourself to having to have and watch someone do for you in your home things that a few years ago you were doing for yourself is not easy to come to terms with. It was something you realised might have to happen when you were really old, thirty years time perhaps, but not now! Sylvia and I discussed this after they had gone and we agreed that we needed to share this in a newsletter and ask you for your thoughts.

I got home and I talked with my daughter and others about what its like to be a carer. 'You are a nightmare at times to live with,' said my daughter, 'you are not consistent, you know you should not overdo but you still do sometimes and then complain you are tired, but what is worse is that you keep trying to tell me how to do things step by step'. What did I answer, 'I need to talk, I might not be able to do it myself now but I need to keep control'. 'Yes,' said my daughter, 'but we have got to compromise on this, after all I am nearly 25 and perfectly capable of doing what you ask without you telling me in fine detail'. I still felt threatened by this and felt that it virtually meant that I could not even speak about what needed to be done. At this time I was unable to see it from her point of view.

Let me go back a bit. Many of us are in our 40's and 50's expecting to be working till retirement, and then doing all those wonderful things that retired folks do. Not only do we have to cope with our new symptoms but with changing jobs, or going part time, or giving up work altogether. Some of what we had planned for the rest of our working and retired lives is not now going to be possible. We are not prepared for it mentally and for many not financially either and no way of ever making money again.

Every loss that we experience we go through the stages of grief. Every little problem can open the whole box of PPS and what its doing to our lives. Whilst we struggle to cope with symptoms and are

not getting the correct medical support that we need we are often told that we are being lazy, we could do more if we tried harder, etc. We know we are not being lazy, because we have always pushed ourselves to the limit and beyond for years so why are we finding tasks that were easy before much more difficult. It really is a worry and we can react in all sorts of different ways. We try to ignore it, we push ourselves harder and then collapse exhausted in a chair, we get depressed by it, we get angry and annoyed at even silly things, burst into tears, lose confidence, all sorts of reactions whilst we are in this state of limbo not knowing or understanding what is happening. What must it be like living with someone who is like this?

Then we find PPS exists and at last we have a possible reason for some of this and now we will get medical help. The relief is short lived as most of us have found that far from being easy this is an uphill struggle with many setbacks which impact on the rest of our daily life. We get quizzically looked at down noses over half glasses, we see a look of 'oh its her again', we get told we are imagining all this, or they are sure its not as bad as we make out, some get told that they have checked and there is no such thing as PPS, or maybe you didn't have polio, a new one is that you deteriorate for eight years and then you plateau and just age. We had different damage, different recovery, live different lives, there are so many variables that there can be no set pattern.

Its very depressing when you know something is happening, that you are declining in daily functioning like being 30 to 40 years older than your actual age. Unless there is a multi disciplinary PPS clinic that you can get to, your symptoms seem to get shared out between many different health professionals with no-one case managing you. No-one but you is seeing and feeling the whole picture.

We know we can have every other condition instead of or as well as late effects of polio or PPS or whatever we call it, but if we do not get assessed properly by specialists who really do understand polio and its late effects other conditions could easily get missed. Its just as bad to not get diagnosed with PPS as it is to be told 'oh you had polio then its PPS when it might not be.

Often a diagnosis is given and then test results show its not that and you move on to another department, another diagnosis. In the UK with our Free Health Service this often means waiting again for an appointment sometimes for many

months, even a year or more. If we have had to go on benefits then this waiting and lack of a definitive medical report impacts on benefit applications, and many are having to fight appeals and tribunals where our situation is not understood. In the States its a totally different system and although you can get to see specialists within a couple of weeks you have to ring round and find who will see you. Although there are good PPS Clinics in some parts of the States its a huge country and many do not have the insurance or funds to travel and pay for this.

So to those of you who care for us, or live with us, friends and family, it is not an easy time. We don't like what is happening, we don't want it to happen, but it is and the one thing we feel we must do is keep control. The stress of all this gets us down and we probably don't stop to think how our carers and family are feeling about what is happening, after all **they** are not going through this. But we now realise you are. One day you offer to help and we brush you off quite brusquely, and the next day we are doing some more of the same task and what do we do, we say well don't just stand there, can't you give me a hand. Nightmare... I think maybe my daughter was right.

Meeting with Richard last May, who also has PPS - having corresponded via the Internet for two and a half years - and driving to St.Louis for the GINI conference meant that when I was driving I was in control and whilst I was happy and grateful for the directions and which lane etc, I did not like things like seeing him look at the speedo to ensure I was not speeding. Looking at it from his point of view it was his truck and he really wanted to be driving but as we both have PPS we had to change drivers - pacing and resting. This has happened in lots of other aspects of our daily life and we keep changing roles. Together we still do not make one whole working person able to do all that is necessary.

The funny part about this is about six weeks ago when I was helping him do something and it was not easy and he was instructing me and I said exactly what my daughter had said to me, 'I don't need you to tell me how to do this step by step, I am not stupid' and he said 'but I want to do it and can't but for goodness sake let me be in control'. We both stopped and laughed and were able to tell each other how we really felt about all this. Now if we get frustrated by something that's been said we think not just about that particular point but the whole day and what else is part of this reaction. If the other person is having a bad day then we can let it go then but if we need to talk

about it later we can. Its certainly given us both a much greater understanding of the situation and ability to compromise with far less stress. Telling my daughter over the phone what happened allowed her to explain other things that were bugging her and we were able to talk easily about this instead of getting angry.

When we are caring we can't second guess what your needs are, you have to plan ahead and realise that we cannot just stop what we are doing immediately. We don't mind helping, we want to help but we need as much warning as possible so we can leave what we are doing at an appropriate point.

If possible each of us should try and put ourselves in the others role and think how we would like this situation to occur to us.

Another problem that came to light at Sylvia's and many times afterwards was that when we have been alone for some time and someone comes home we are ready to talk, we have stored up lots to say and we don't want interrupting in case we forget something. We forget that the person coming in is working as our carer and is probably limited by time, or is a family member who has returned from work and who needs to rest themselves. Carers we need to talk and you need to say something like 'let me get the dinner started', or 'lets get you into the bath, and then we can have a chat'. Family you need to say something like 'let me get changed and we can chat in half an hour.' Likewise for the Polio Survivor if there is something important that needs to be said immediately they arrive then you need to say, so and so happened and we really need to talk about it as soon as you have a moment. Write down what you want to say so that when the time comes you don't forget anything.

Plan ahead. Maybe you can pick a day each week to add to a calendar the have to do's and the want to do's. E.g. if he wants to play golf on Thursday you know that shopping that day is out, and likewise if you have a doctors appointment he knows he will have to fit golf in another day. Seems easy but we found it took some time to get used to this change in lifestyle but its working well now.

Hilary Hallam <linpolio@legend.co.uk>

I received this email just after finishing this article. Margaret E. Davies from Arkansas, USA wrote...

When all these changes first started, I had a ruff

time and I would have days when I would be watching TV and see a woman wearing high heel shoes (of all things!) and I would get so angry! I would cry, scream and curse at anyone who got in front of me. Now I have never wanted to hurt my family, so I learned to tell them, "you have done nothing wrong, I am just having a bad day."

At that time, I was sure this would "come to pass". One day I realized, This is here to stay!!!! I started working my way thru it. I wish I could say, and it just vanished. But it did not. It has really improved and now I have finally reached the point that I can look back on my pre PPS life and smile at the good memories. I used to try and block them out. I would tell my family "that life is dead and gone!"

I give my family a huge gold star for coping with me. I think that kind of coping is called "love".

<mardavis@CSWNET.COM>

Letters to the LincPIN from polio survivors, family members, friends, carers, **and medical professionals**, that tell your side of the story will be gratefully received. We need to make informed decisions about the rest of our lives and the more information we have to make that decision on the easier it is.

Nearly every polio survivor that contacts us says that its so good to talk to someone who has polio and who understands what we are talking about. One way that those of us who are on the Internet can do this is by joining a discussion list. We have our own members list and if you are not subscribed and want to be then please email us. I will explain for those without computers or the internet how this works. You can subscribe to many lists on many different subjects. You get mail from this service either one a day with all mail on it or singly from each person who has written that day. If you want to reply to a message then you can reply directly to the person who sent it and/or to the list so everyone can read your reply. In this way many subjects get discussed. You find new friends and correspond privately, sharing photographs and much much more than just polio. Come home from a disastrous medical appointment and tell the list what happened, you get it off your chest, you get replies often the first can be within minutes, and it really does help relieve the stress. Some years back Dr. Bruno offered me his help - see Letter to a Polio Survivor in our Library - and told me to let him know how I got on. I got home very distressed from the disastrous appointment where despite prior knowledge of what we were going to discuss and the offer of the consultant to come and do this, I was turned down again and again and even my having had polio was questioned. I typed out what had happened and sent it. I sat back relieved that I had got

this off my chest but was still very angry. Just before logging off in only nine minutes there was a reply. Dr. Bruno does not mince words and his reply made me laugh so much and there could have been no better medicine for me at that time.

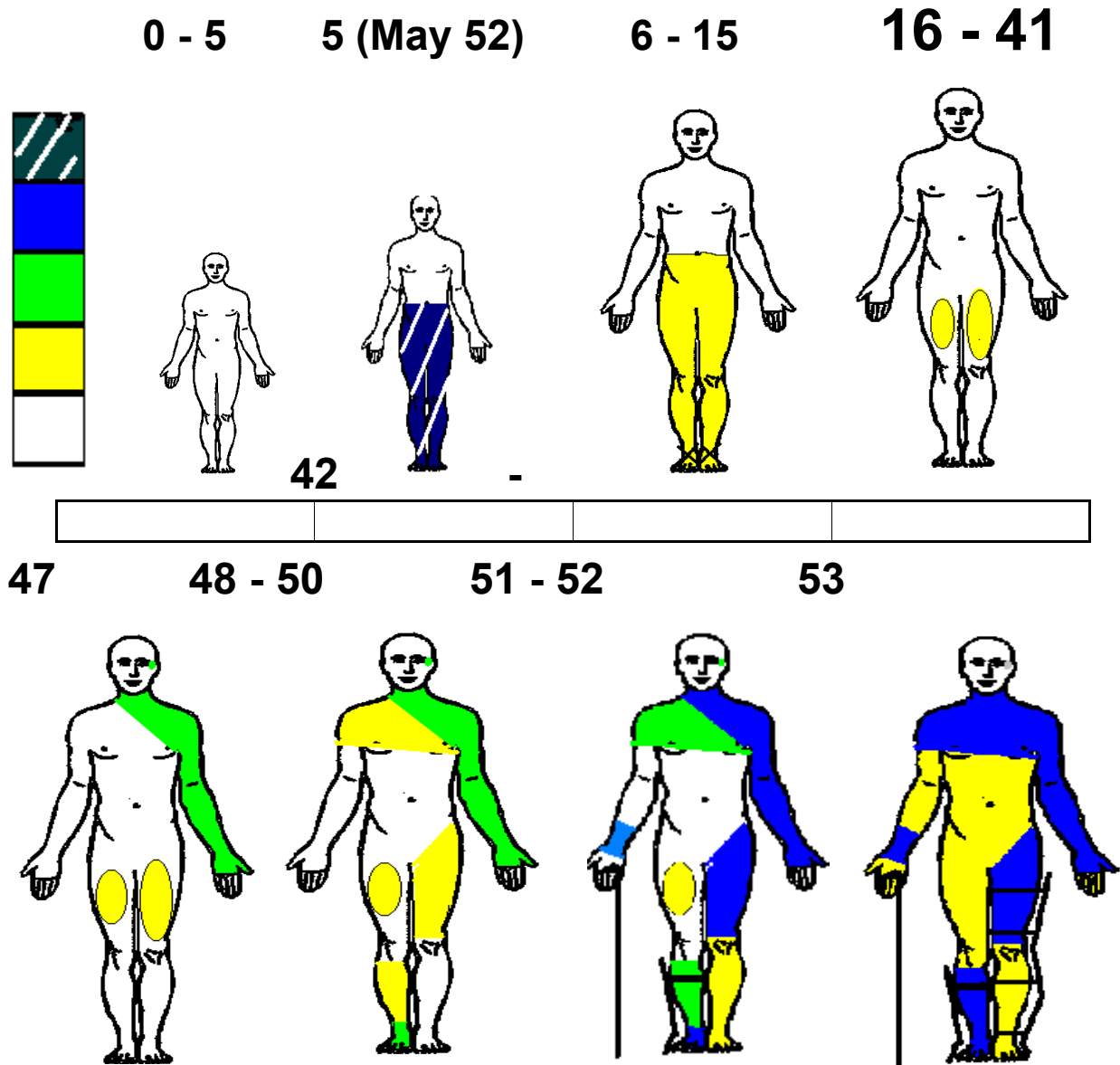
I have now been to other PPS group meetings and met with many polio survivors and meeting up really does help. Yesterday we visited with Paul and Alison Elrod in Brandon, Florida. We learned much from each other and had many laughs. Paul has made lightweight aluminium poles with attachments to lift the shower head up and down; screw into the tap controls so he can turn the water on and off. A railroad tool for packing bearings - looks like a poker with a right angled crook on it and a round loop on the other for holding - tucks down inside the footrest backstrap of his wheelchair and is handy for lifting footrests up and down and many other unexpected uses!. His toilet is built on a tiled brick area and then he put wooden blocks under the toilet seat and shim for the hinge for exact height adjustment. He told us about his life and being lifted up and down stairs to school and college and much much more. We have asked him to write his story as there is so much we can learn from reading it, and have some great laughs on the way.

Even if you have a computer how about asking us which other members are near to you and meeting with them over coffee, or ringing each other now and then, or even writing to someone if they are too far away for a phone call. A few are already doing this. It really does help to talk. Why not ask me to do a talk in your area so that you can meet with others?

An Internet list - the first I joined - the St. Johns Polio List has been going for quite a few years and there are many polio survivors subscribed to this from around the world. That is how I learned about PPS in the first place, and met many who are now my friends. Chris Salter and I met on this list and that meeting has proved invaluable with the great WebSite that he provides for us.

It is also with much sadness that I tell you that Tony Miles - a Life Member - has died. I met Tony on a few occasions over the last few years and talked with him on the phone, the last time only a couple of months back. Tony I hope that you meet up with Barbara Casson - a Polio Survivor subscriber to the St. Johns Polio list who 'left this life to soar among her beloved stars on January 28th 2001'. The back page contains a poem she wrote. To both families our condolences in your loss.

**Example of a Polio Time Line - Basic Information.  
Condensed from two pages - Charts in Information Packs or Separately.**



Input information under each body. Operations, symptoms etc. Under best recovery record achievements.			

At the age of 5 I caught polio and had waist down paralysis. At ages 12/13 I had multiple tendon transplants. From then to 36 years post polio I was fit, active and working 60+ hours a week, Coastal Lifeguard voluntarily May

to September weekends, bringing up two children, gardening, decorating, driving a manual car, etc. Employed as a Secretary, Policewoman, Lifeguard, Swimming Teacher, had completed a 39 mile walk, passed to Orange Belt in Judo, Distinction in Life-saving, Advanced Swimming and Lifeguard Teacher. From a fall in October 1988, slid on wet patch on floor in school I had increasing symptoms starting in left arm, then left eye, started falling for no reason but was carrying items, gait got worse, left leg lifted for clutch, etc.

The main symptom are weakness and functional decline and despite being prescribed exercise and working hard at this I continued to decline. Found PPS existed Nov 95. Diagnosed PPS December 1997.

**Add photographs, pre polio, with polio, a couple at best recovery, and a couple now.**

**Remembering Barbara Casson, Polio Survivor, Star Gazer and  
Good Friend to all she met in real life and on the Internet.**

Barbara was a member of the St. Johns Polio List and many others. She also spent many hours Star Gazing and wrote the following poem in 1999. She sent this to Linda in California at that time and remembering it Linda has posted this on her WebSite in her memory. Taking this theme her internet friends have got together and Ellen has organised the naming of a Star in her memory and the framed certificate has been sent to her family. The certificate states... Let it be known to all that the Star herein designated in the Smithsonian Astrophysical Star Catalogue as '7499 Draco' and residing within the boundaries of the constellation Draco 'The Dragon' is hereby named in memory of 'Moondoggy Barb'. The stars astrophysical verified position is Right Ascension 12h05m12.2s - Declination 75°27'16 Type. G9111 Magnitude 7.5. Distance unknown.

*My deepest desire is to be out in deepest, darkest space floating effortlessly,  
Watching the glittering of the stars  
Being sucked into a black hole,  
And then being aware of the speck of light at the end of the blackness.  
As I emerge through the opening of light,  
I am now in a whole new dimension of life which I find so very curious,  
I'm not physical anymore and yet I see myself and others.  
How is that possible?  
So many things to learn and wonder about.  
I feel such incredible joy in being. How else can I describe it?  
I am amazed at others who surround me  
And reach out to me in total peace and love.  
~ Barbara Casson 1999 ~*

Barbara left this life to soar among her beloved stars on January 28, 2001

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

**Membership - Requests for Information Packs, Leaflets, copies of articles**

**Hon. Sec. Wendy Grimmitt** <CWGrimmitt@aol.com>

12 Larch Ave, Allington Gardens, Allington, Grantham, NG32 2DR

**UK Membership** - Life Member (LM) £100 or £5 x 20 months S.O. - Member £10 a year.

(All UK Memberships payable by Standing Order - Form on request)

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

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**Lincolnshire Post-Polio Network, 69 Woodvale Avenue, Lincoln, LN6 3RD, UK**  
Tel: +44(0)1522 888601 Fax +44(0)870 1600840

**Next LincPIN Newsletter - April 2001**

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**Founder & Chair** - Hilary Hallam <linpolio@legend.co.uk>

**Vice Chair** - Janice Eary <janice.eary@hotmail.com>

**Vice Chairman/WebSite Administration**, Chris Salter - <linpolioweb@loncps.demon.co.uk>

**Honorary Secretary** - Wendy Grimmitt - <CWGrimmitt@aol.com>

**Honorary Treasurer**, Frank Grimmitt - <CWGrimmitt@aol.com>

**Committee Members** - Phil Bilton, John Eary, Ted Hutchinson, Jennifer McGowan.