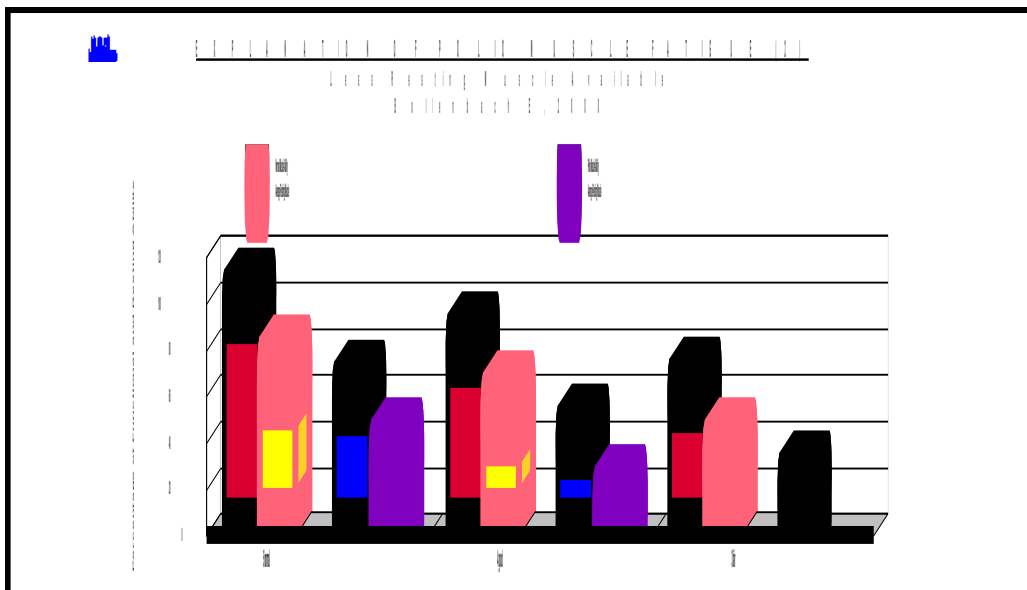
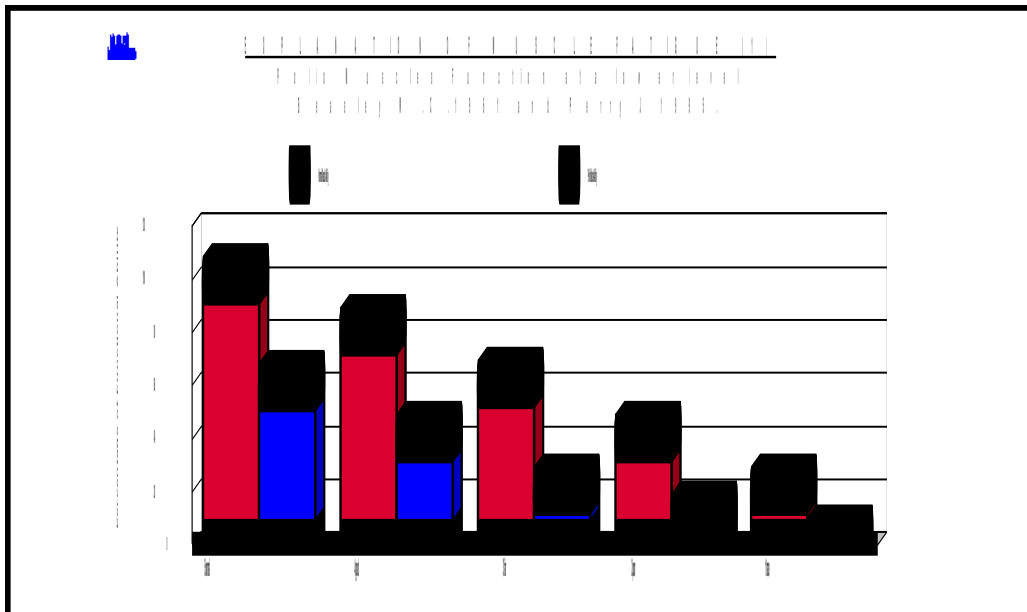


# The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**  
Volume 3 - Issue 10 - April 2002

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

TWO SLIDES FROM PRESENTATION REFERRED TO ON PAGE NINE



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## Editorial by Hilary Hallam

By the time you receive this Richard and I will have returned to Lincoln. As I start the newsletter, Richard and I have just returned from an 1100 mile round trip to north east Georgia. Sue Karnes - a Life Member - invited us to come and visit. (read Sue's story page 18) Tommy and Judy Conrad (the instigators of the Branson Internet Reunion, June 6th to 10th 2002 in Branson Missouri - email Ann Post <POST@TARLETON.EDU>), Lily and Tim Guerry from the other side of Atlanta, and Jo Caywood from Macon Georgia joined in. (All of us subscribe to the St.Johns Polio Email List). On the way back we stopped for a few days with Art and Nancy Coburn near Gainesville, Florida. It was good to talk with Art and his Massage Therapist again. Randy has agreed to write us an article about massage and PPS. With grateful thanks to our hosts we were able to take plenty of rests en route and during our visits. We were back to 'our normal' on the fourth day home.

During the time over in the USA we have been to quite a few PPS meetings and met with other Polio Survivors. Read and replied to thousands of emails and talked with others on the phone. Sharing information helps spread it further.

**A Thousand Plus Thankyou's.** Our back page which we started with a few adverts to generate some more funds will now include donations received. Hot off the Press we are delighted to tell you to turn to the back page where we give a Thousand Plus Thankyou's. In future we would like to acknowledge the donations received towards our work in a block on the back page. We would like to put your name and town and/or county/country where you live. It is not our intention, as a general rule, to mention amounts unless you request this or the donation is large and we have received your permission to print the amount.

The **LincPIN - Lincolnshire's Post-Polio Information Newsletter** - contains a huge variety of articles about problems that Polio Survivors might come up against. This is number 34, over 800 pages! Together they give you plenty of medical information to share with any health professional you are seeing.

The newsletters contain many articles that have been written by well renowned Post Polio Specialists. They have been working with Polio Survivors for many years in their PPS clinics. They have amassed a lot of information on polio and its late effects. The assessments they provide for their patients are comprehensive and multi-disciplinary. You are seen by a doctor, a physiotherapist, an occupational therapist, a social worker or counsellor, and if necessary an orthotist, respiratory therapist etc. Reported actions of weakness are observed. Testing can take up to 2 days.

An excellent article in this newsletter that we hope

will help you - To Reap the Rewards of Post-Polio Exercise by Sunny Roller M.A. and Frederick M. Maynard, M.D. - has also given us a marvellous example to highlight a problem that is occurring in the UK, and possibly in other places as well.

Not every word of an article can be remembered, often there is a particular paragraph or phrase that stands out to the reader. If this phrase is then passed on to other health professionals who have not read the full article it can then be taken out of context with damaging results to the patient.

The following explains this - [Excerpt from To Reap the Benefits of PPS Exercise

As a general rule,

- muscles that have a grade of 3 or less (using the muscle examination scale: 0 = no contraction and 5 = normal strength) should be protected and not exercised;
- grade 3+ muscles can be exercised with caution;
- grade 4 and 4+ muscles can be exercised moderately;
- and grade 5 muscles can be exercised vigorously]

The phrase **grade 5 muscles can be exercised vigorously, grade 4 and 4+ muscles can be exercised moderately** are of particular note. If a muscle is incorrectly overgraded then the prescribed exercise can be too high. It is imperative that the whole article is read and single phrases are not taken out of context. As reported in our newsletters since June 1999 when I realised why recorded gradings on my medical records had to be incorrect - Manual Muscle Testing alone will in most cases not accurately grade our muscles endurance. If you believe this has happened to you then please write and tell us.

During the last few weeks email communication has been flying backwards and forwards across the Pond in response to the content of the draft editorial that I sent to Dr. Maynard and Sunny Roller for their comments. I have included highlights of the exchange so that you can have some idea of the work that goes on behind the scenes.

I am grateful to the Health Professionals involved who so graciously give up their valuable time to answer our emails so quickly. Read the article and further comment and then Ask Dr. Perry that follows.

Upper Cervical Article postponed to next newsletter.

# *To Reap the Rewards of Post Polio Exercise*

by  
**Sunny Roller, M.A.**  
**Polio Survivor, Program Manager**  
**University of Michigan Health System**  
and  
**Frederick M. Maynard, M.D.**  
**U.P. Rehabilitation Medicine Associates, PC**  
**Marquette, Michigan**

In this year, 2002, we know more about exercise for persons who had polio than we did fifteen years ago. There have been a variety of studies conducted by superb and caring scientists, along with numerous personal accounts from polio survivors, themselves, which warrant a new way of thinking about exercise.

Exercise is different than physical activity. For the purposes of this article on exercise, it may be helpful to define these two terms. Exercise is generally defined as planned, structured and repetitive bodily movement, whereas physical activity is the movement you do throughout the day. Physical activity does increase the amount of calories you burn, but unlike exercise, is not necessarily planned, structured or repetitive motion. One benefit of exercise can be an improved ability to take part in ongoing daily physical activity.

Whether you have a planned exercise program or simply rely on day to day physical activity to stay fit, the message to polio survivors today is "beware of inactivity!" In the 1980s polio survivors across the nation heard and heeded a strong medical warning about the dangers of doing exercise, especially too much exercise and/or physical activity, but now post-polio scientists have qualified their advice. New knowledge tells us that no matter what our level of disability is, we should be encouraged to value exercise, enterprising enough to come up with a highly customized plan and enduring enough to reap the rewards. When it comes to exercise, we need to be smart, not scared! One woman in our University of Michigan wellness study told us that in the late 1980s she quit exercising completely out of fear of muscle loss, and gained 35 pounds. Dismayed, she joined the 1996 wellness study to find out what she could do to feel better and it worked! Exercise was put back on her list. She was guided to be selective and conservative as she designed her weekly plan for "working out." She found out that polio survivors need to:

1. First, gather the best medical literature from post-polio researchers, educators and clinicians such as Grimby, Agre, Perry, Halstead, Headley, Maynard, Birk, and Yarnell. They will all say that we must each have a custom-tailored plan since we were all affected a little differently by the capricious poliovirus. (See Selected References on Post-Polio Exercise at the end of this paper.)

2. Next, find professionals to work with. A well-selected physician and a physical therapist or exercise physiologist who each know or are willing to learn about post-polio issues would be most appropriate. There are no specific formulas for any individual that can be written in an overview article such as this. You must have one-on-one, in-person evaluation and testing to see what works and what does not work for you.

3. Then, together, literature in hand, establish a plan for exercise.

4. Start slowly, recognize limitations along the way, make adjustments in the weekly activity plan and keep going. Thomas Birk, Ph.D. (1997), recommends a two-month start up period in which your response to exercise is supervised and monitored by the professionals you have chosen to work with.

## **Gather Literature**

The best place to start a literature search on post-polio exercise is to tap the International Polio Network's resources. They have a variety of the latest articles from the best researchers in the world on this very specialized topic. They can be reached by calling 314-534-0475 or connecting with their website at [www.post-polio.org](http://www.post-polio.org). You may also want to do a literature search of the medical journals at your local library. Librarians can help you do a "Medline search" for pertinent medical publications or you can do one on your own by tapping into the internet, going to [www.medscape.com](http://www.medscape.com), then clicking on Medline.

## **Find Professionals**

You need to establish an exercise coaching team. This can include you, your physician, and a therapist. If you have a post-polio physician that you trust, he or she is the best person to start with. This physician can then recommend a physical therapist or exercise physiologist to work with as part of your new "exercise coaching team." If you need to first find these professionals, the journey will be longer since knowledgeable post-polio helping professionals can be difficult to find or cultivate. Be encouraged to begin your search however. Remember, if you sense that a professional is not interested in post-polio issues, move quickly on to find someone who will work with you and is willing to learn and help. Once again, the International Polio Network in St. Louis, Missouri can provide you with leads in this search. They publish a national/international directory of self-identified post-polio health professionals and support groups whose members know about the best helping professionals in their geographic area.

## **Establish a Plan of Action**

The experts now agree, when it comes to exercise, a

polio survivor doesn't have to do a lot, but one is highly encouraged to do something! Once you have gathered your exercise team, decide together what type of exercise is best for you and whether you want to join a group or exercise independently--or both! The amount of physical activity you do will also need to be addressed as you develop this action plan.

Maynard and Headley (1999) emphasize that the main focus of a new exercise program should be on stretching and general aerobic or cardiovascular conditioning exercises to improve endurance. Strengthening exercise, also called resistance training, needs to be approached much more cautiously, however, with a focus on very gradually building up functionally important muscles to a modest degree.

Ann Swartz, Ph.D. (personal communication, February 28, 2002), exercise physiologist at the University of Michigan Health System, describes each of these three types of exercise:

### **Stretching and Range of Motion Exercise Why is it important?**

Stretching our muscles and joints is important to maximize and maintain function. For instance, arm circles can help maintain the function of your shoulders, making it easier for you to reach for something, or move something out of your way. Preventing tightness in your hips, knees, and ankles will help maximize your walking ability.

### **What types of exercises are considered stretching or range of motion?**

These include arm circles, wrist circles, shoulder shrugs, calf stretches, lifting your knee up towards your chest, bending and extending your knee, knee to chest stretches, back stretches and ankle circles. Many people also enjoy the movements that are part of Yoga or Tai Chi. The following Yoga stretching exercise was part of the University of Michigan Wellness for Women with Polio Workshop and was particularly well received:

### **The Breathing Tree**

- Stand or sit erect. Feet apart, body balanced over hips. Arms at sides, palms forward.
- As you inhale raise your arms slowly up. Stretch up, up.
- Exhale arms to starting position
- Inhale arms to starting position
- Inhale arms slowly up. Stretch up, up
- Exhale arms out at shoulder level. Turn head to look at fingertips
- Exhale twisting from the waist toward the direction you are looking
- Inhale forward. Turn head to look at other fingertips
- Exhale twisting from the waist toward the

direction you are looking

- Inhale head forward and arms down to starting position.

### **Cardiovascular Exercise - Why is it important?**

Cardiovascular exercise is also known as aerobic exercise. It is exercise that increases your heart rate and blood flow, and makes you breathe a little more heavily than you would when performing your daily tasks. There are numerous benefits, some you may notice, and some you may not. The benefits you may notice include increased ease of accomplishing your activities of daily living and such things as getting in and out of the car, or going from place to place, and an improved mood. Benefits you may not notice include lower blood pressure levels, improved blood cholesterol levels, and lower blood sugar levels to name a few.

### **What types of exercises are considered cardiovascular exercise?**

Swimming, biking, and walking are examples of cardiovascular exercise. Machines such as the elliptical machines (low impact equipment that combines the movements of walking and stair climbing), stair climbing machines, rowing machines and a machine called the NuStep are also useful for cardiovascular or aerobic exercises. Swimming may be the best exercise for polio survivors because it minimizes mechanical stress on the body. However, you may not have access to a pool, or may not enjoy swimming. So, do what you enjoy, what feels good, and what is accessible.

### **At what intensity should aerobic exercise be performed?**

Health professionals will usually recommend a moderate or low intensity. This means that you should be exercising at a level where your heart rate increases and you are breathing heavier than you would normally (when you are performing your daily tasks.) If you cannot easily carry on a conversation, slow it down!

### **Strength (Resistance) Training - Why is it important?**

Strength training, also known as resistance training, improves muscle strength. When your muscles are stronger, it is easier to carry in your groceries, take out the garbage, and other tasks of your daily routine.

### **What types of exercises are considered resistance or strength?**

Any exercises that involve hand-held weights, weight machines, stretch bands, or even balls are usually strength exercises. These types of exercises, like the stretching exercises, can involve any muscle of your body-- from your head to your toes.

You may choose to exercise alone or with an

"exercise buddy." Often, sharing the experience with a friend can be more fun, a chance to learn from each other and stay

motivated. Joining or starting a wellness program with other polio survivors may also help. Our 1996-1999 study at the University of Michigan (Tate & Leonard, 2001) of a holistic wellness program for women who had polio found that the biggest change was in participants' exercise routines and resultant physical activity. Program participants changed dramatically in their reported regular participation in vigorous exercise. While prior to their participation 57% never regularly exercised vigorously and 23% did so often or routinely, after their participation, only 26% never did and 41% reported exercising regularly often or routinely. Similarly, program participants demonstrated a marked improvement in terms of the regularity with which they exercised with moderate exertion.

Prior to the program's onset, 63% stated that they did so three or more times per week. Following the program's conclusion, 78% of program participants reported conducting moderate exercise with this regularity. Also, while prior to the program's onset 42% of participants said they never engaged in stretching exercises and 23% said that they did routinely, following program participation only 11% said that they never did stretching exercises; 35% of participants said that they did them routinely. Six months following the conclusion of the program, 61% of participants said that they had increased their level of

physical activity during the last six months. We also found that exercising vigorously at least three times per week was associated with improved assessments of depression and distress.

Whether with a group or on your own, exercise programs can occur on land or in the water. It is important to do whatever works best for you. If swimming is not possible, you may want to exercise in your house, at a health club or gym, or outdoors. Pick an exercise you enjoy, whether it is walking, stretching, or any other exercise, and begin with small bouts. It is not necessary for you to perform only one activity. You can combine all your favorites. Also, you do not have to do the activity all at once. For instance, Tom enjoys biking, stretching and walking, so his exercise program was as follows:

Morning:

2 minutes stretching  
2-5 minute break  
2 minutes walking  
2-5 minute break  
2 minutes stretching  
2-5 minute break  
2 minutes biking

Afternoon:

2 minutes stretching  
2-5 minute break  
2 minutes walking  
2-5 minute break  
2 minutes stretching  
2-5 minute break

2 minutes biking

This is how he began his exercise program, and slowly, over the course of months, he began to increase the bouts of exercise and decrease the length of his breaks. It is very important to rest between exercise sessions. Make sure you rest long enough to fully recover after the exercise; otherwise you may remain in a constant state of overload, which has negative effects on function. Incorporating regular rest periods into an exercise routine is called "interval training."

Exercising in a warm pool is another way to work out. According to Lauro Halstead, M.D. Water therapy was the exercise of choice for many persons during their recovery from the original polio. It is still excellent therapy. Because of the buoyancy of water, it allows people to do things they can't perform on land. For especially weak limbs, inflatable cuffs can be used to float an extremity. For other limbs, water resistance provides a workout that can be fine-tuned to each person's strength. The principal disadvantages of hydrotherapy are that the temperature may not suit one's body and it may be difficult to find pools that have lifts (if needed). Also, the surfaces around pools tend to be slippery and dangerous for anyone with a tendency to fall.

Aquatic programs for exercise have been recognized as morale boosting and physically beneficial. An early study by Hoffman and Maynard (1992) describes a swimming program for polio survivors as having a "therapeutic effect." Emphasizing the added benefit of group exercise, the authors go on to say: "it is of great importance to recognize that perhaps one of the greatest benefits of a program that brings together individuals who share a common concern is the emotional support they receive from knowing they are not alone in their efforts to confront the late effects of polio." In a more recent Swedish study by Willen and Sunnerhagen (2001), 15 persons with polio's late effects worked out in a pool for 40 minutes twice a week for 5 months. At the end of the study, participants reported an increased sense of well being, pain relief and increased physical fitness. Additionally, at the end of the 5-month period, their heart rates during exercise were down. The study's investigators recommend this program of pool exercises in heated water.

In his 1998 book, *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*, Halstead additionally provides general guidelines for customized exercise based on his personal and clinical experience with the effects of polio:

**Individualized and supervised program.** Exercise programs should be supervised initially by a physician or physical therapist experienced in neuromuscular diseases, if not polio. Each program should be customized to your personal needs and residual strengths. Given these constraints, research studies have shown that some polio survivors (but not all) can improve muscle strength (as a result of new

muscle hypertrophy, or enlargement) and enhance cardiovascular endurance with a closely monitored training program. In fact, some studies have reported an increase in strength in muscles both with and without new weakness.

### **Type of exercise.**

There are numerous kinds of exercise. Finding the one that is right for you and each of your limbs often takes trial and error. Usually, it is a good idea to find two or more exercises that can be varied, exercising different muscles on alternate days. For example, walking or exercising the lower extremities one day and then performing an upper extremity exercise the next. This kind of schedule provides a period of rest for each muscle group and variation that keeps the overall exercise program challenging and enjoyable. As a general rule, muscles that have a grade of 3 or less (using the muscle examination scale: 0 = no contraction and 5 = normal strength) should be protected and not exercised; grade 3+ muscles can be exercised with caution; grade 4 and 4+ muscles can be exercised moderately; and grade 5 muscles can be exercised vigorously.

### **Start Slowly; Make Adjustments; Keep Going**

It will be important to gradually begin your personalized exercise routine-only do little bits at first. One approach might be to apply the "20% Rule." If you have chosen to do a conditioning program, Stanley Yarnell, M.D. (1991), post-polio specialist, suggests a general conditioning exercise program to restore stamina or endurance using this "20% Rule." You establish your maximum capacity (the point at which you begin to tire) for any one exercise. Then you begin your program by working at 20% of that maximum exercise capacity. Do that 3-4 times per week for one month and then increase the rate (time) of exercise by another 10%. Each new month, increase the time exercising by another 10% until maximum capacity is reached. Yarnell clearly warns polio survivors to stop if they become fatigued during their exercise program, or if they experience pain or aches in their muscles. Most survivors, he says, "are able to continue increasing their exercise program to nearly the maximum capacity." Rests are to be taken every few minutes. This 20% Rule can also be applied to home stretching and flexibility programs too.

Halstead also lays out the following guidelines as you begin your exercise program:

**Expect improvement.** Exercise should make you feel better physically, and even, mentally. If the activity is not strenuous enough to improve your strength, much less your cardiovascular system (e.g., stretching or yoga exercises), it still should give you a psychological lift just to be doing a special activity for yourself on a regular basis.

**Listen to your body.** Avoid pain, fatigue, and weakness. These symptoms are signals that your

muscles have overworked. A brief period of fatigue and minor muscle pain for 15 minutes to 30 minutes after exercise is usually normal. Symptoms that last longer than 30 minutes to 60 minutes reflect muscle overwork and possible injury. If this occurs, the exercise should be reduced or stopped. Any exercise that causes additional weakness should be discontinued immediately.

**Pacing.** Pacing [i.e., not going too fast and methodically taking breaks] has been shown to be safe and effective in increasing strength in some individuals. The intervals of exercising can be as short as 2 minutes to 5 minutes alternating with equal intervals of rest. The evidence also shows that secondary symptoms, such as generalized fatigue, can be reduced as individuals become conditioned and are able to perform more work with less expenditure of effort.

**Use your best muscles.** Polio is often a focal, asymmetric disease with variable amounts of weakness in different limbs. Exercise the limbs least affected or those completely unaffected by polio, while avoiding the more affected extremities. For instance, if only the legs were affected, then the arms can be used in a fairly strenuous program that includes swimming or using an upper extremity arm bicycle; meanwhile, the legs will usually get adequate exercise in the course of doing daily activities.

**Warm up and cool-down.** As with other exercise programs, a warm up [very light movements such as walking slowly, arm circles or leg lifts that are done for about 5 minutes to get your muscles warm, and to get the blood flowing through your body] followed by gentle stretching should be done to improve flexibility and reduce the possibility of injury. After exercising, a cool-down period [very light movements like the warm ups that will slowly decrease heart rate and prevent any feeling of light-headedness that can occur if exercise is stopped abruptly] should take place.

**Finally,** the type of activity should be one that the participant enjoys to minimize the potential for dropping out because of lack of interest.

Having the tenacity to stick with the program and make the proper adjustments is a real challenge, but polio survivors are good at setting goals and achieving them. Across the country men and women who had polio are beginning to apply these principles of exercise and are experiencing much success. The real reason to get into motion is that exercising can make you feel better! Joan Headley (personal communication, February 26, 2002), high profile polio survivor with a mild disability attests to that in her personal account:

"In 1994, seven years after I had switched jobs from teaching school (and being on my feet most of the day) to working at the International Polio Network where I consciously stayed off of my feet, several

observations caused me to rethink my approach to activity.

The pain in my 'good' leg was gone, but was replaced by a pain in the hip of my 'polio' leg. Shopping trips and other family outings were cut short because I did not have the stamina to be on my feet for more than a couple of hours. Each year it became more difficult to climb the stairs to reach my symphony seat because my legs were weak. Then one night, while walking up those stairs and "listening to my body," I also realized I was panting and "out of shape."

One day an elderly polio physician suggested that the pain in my 'polio' leg was not from muscle weakness, but from connective tissue tightness and perhaps I should 'stretch it.' It was at that point I decided to make a change. I visited Bally's with my brother and sister-in-law and we made the circuit trying each machine identifying my weakest muscles. So, I began an 'exercise' program using Dr. Stanley Yarnell's (St. Mary's Hospital, San Francisco) 20 % Rule. I did a select exercise to the greatest extent I could, and then cut it back to 20% and slowly added repetitions and distance carefully observing if there were any consequences.

Today, eight years later, I have eliminated the pain in my leg by doing 30-35 repetitions at least five times a week, as well as two exercises for my arms. I also walk one mile an average of four times a week and do about an hour of stretching exercises once a month in the pool.

For a few years, I walked in the neighborhood park and an added benefit was that I left all of my daily work problems there. I now walk at the YMCA on an official track with no worry about bumps in sidewalks or my safety when I walk in the evenings. I still leave my problems behind, however-the happily embraced extra benefit of a good exercise program.

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Call Gazette International Networking Institute at 314-534-0475 or visit their website at [www.post-polio.org](http://www.post-polio.org) to order:

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Reprinted with permission. We are referred to many physical activities on their WebSite <[www.ncpad.org](http://www.ncpad.org)> that are useful to people with postpolio.

**[Editors comment** - as mentioned in my Editorial I sent a draft editorial to Dr. Maynard and Sunny Roller for their comments. Other PPS Health Professionals have been added to the ongoing discussions. I have revised some paragraphs of my Editorial and will be sending copies of the newsletter to all who are taking part in the current discussions. We will keep you updated on this in the next newsletter.

Many Polio Survivors including myself have been given single one off Manual Muscle Testing as a base line looking for weakness. We have medically recorded Grade 5 muscles in limbs where we are reporting new and increasing weakness. 'Grip my hand, pull and push against me'. Recorded - 'power and tone of upper body normal'.

It may be of considerable surprise to readers to find that muscles in limbs that were paralysed at the time of polio, that recovered but retained functional weakness, for some, have also been recorded as '5 - normal'.

This is occurring because each muscle group tested can have enough power to perform the single task asked of it at that moment in time. As no weakness is found most often no further physical testing or observation is done in this area. The area is considered normal - grade 5 - and 'could be exercised



vigorously'. That single test is not testing pattern of movement or corroborating the fact that when we try to sustain or repeat a reported action past a certain level we are then experiencing weakness.

Many Polio Survivors are reporting to us that where they are being offered physio treatment it is totally exhausting them, causing them considerable pain, and their reporting this is being met with 'try harder'. I believe this could be the main cause of Polio Survivors stopping exercising.

In the UK we are for the most part **not** being seen by health professionals who have specialist polio and pps knowledge and experience like the authors of this article. We are mostly being seen by someone who may have seen one or two polio survivors over the last few years who genuinely believes that his form of testing is accurate. Who is unlikely to record medical gradings on your records if he thought that they were incorrect. He/she genuinely thinks that our reported problems are most likely 'all in our mind' because his testing has not found them.

On the Front Cover of this newsletter you will find two of the slides I use in my presentations which explain why our muscles are fatiguing.

Two researchers, W.C. Beasley in 1961 and Jaquelin Perry MD confirmed in 1995, that Polio affected muscles functioned at a lower level. Taking 30% as an average amount of muscle that is needed to perform a function would leave 70% of the remainder of the muscle resting. You can see from the lower slide that Polio Survivors have less functioning muscle and therefore less resting muscle available. Polio Grade 5 muscles functioning at 60% have half working and half resting. Go down to Grade 4 muscle with 40% function, 30% working leaving only 10% resting. No wonder we get fatigued when we push our weak muscles too hard.

UK Professor WJW Sharrard found in his research in the 50's that muscle weakness was not seen till more than 44% nerve damage and paralysis not until 60% plus nerve damage. Many medical articles on post-polio state 'also having problems in areas thought not to have been previously affected'. I believe the main reason is because our medical records and/or how we describe our polio only state the amount of damage that was 'seen' at that time. How do we find out how much damage we had you ask? Post Mortems - not a road any of us want to go down! We know that pacing and resting our physical activities and using aids and assistive devices so we do not waste energy helps us manage our lives more effectively with less pain and less fatigue. So stopping and resting our muscles before they get fatigued helps. See Dr. Perry's article that follows.

Sunny Roller responded that my highlighted section was a direct quote from Dr. Lauro S. Halstead, another highly respected PPS Specialist, who incidentally is also a Polio Survivor with PPS.

Dr. Halstead responds... Regarding the MMT you are correct. If done only a single time, it can give an erroneous idea of the true muscle strength and endurance. In a way, the key word here is "endurance" which reflects muscle strength on multiple contractions. Many polios will have good strength on a single contraction only to get weaker on repeated contractions. Lauro S. Halstead MD

Sunny Roller then sent us information regarding two new articles. "There is lot of truth to overestimating strength with one MMT in polio survivors and that's why in one of the new chapters coming out this year (actually one is just out - by Lippincott Williams & Wilkins in ACSM' Resources for Clinical Exercise Physiology - Musculoskeletal, Neuromuscular, Neoplastic, Immunologic and Hematologic Conditions) look on p. 71 **where I comment on doing 3-10 MMT on same muscle groups before rendering a "normal" or not diagnosis**, also on p. 74 is more detailed exercise prescription contingent on both medical and history info."

Excerpts from my reply. I do not think that repeating MMT 3 - 10 times will necessarily answer this question in all cases. There are other factors to take into account.

- What the Polio Survivor has been doing the day before and up to the time before testing.
- Is the Polio Survivor being tested as an outpatient or are they an In-patient where much of their normal daily living energy is not being used - no shopping, cooking, etc. - and therefore has more reserves available.
- Is the Polio Survivor using more muscles to achieve the task asked of them. .
- How much the Polio Survivor has come to terms with their symptoms and are they being honest in their answers about their ability and if not how much effort they put in even when having a test repeated more than once.
- Whether the previous history taking has been asking the Polio Survivor Can you or How do you? Most of us until we learn enough about PPS and accept the changes necessary will have replied 'Yes' we can get up a flight of stairs. Had we then been asked how do you do this? We are likely to have replied, 'Well I only go up once a day at night and I go right leg first and pull myself up with my right arm as well, but I CAN do it.
- How much testing is going to be done at one time.
- How much rest is being allowed between areas of testing.
- What order the muscles are tested in.
- The amount of pressure that the tester uses (for comparing results by different testers).
- Will the person testing now do it three times, four or 10 instead of once. There is limited time for assessment and the testing is exhausting for both patient and tester. I think its probable that you

would get different results between 3 and 10 repeats, and if the weakness does not show till nearer ten repeats and only 3 or 4 are done then the weakness could still be missed.

I also included another slide from my presentation showing the difference in grading that could be obtained between taking the first and seventh repeat. From the charts taken from this slide you can see the different muscle gradings that can be seen if my tests were repeated. If a single action alone is tested then the results would be and were Power 5 - normal. The newsletter is off to the printers tomorrow. So this is really hot off the press]. Dr. Maynard replies.

You have done a brilliant job of describing a real problem for polio survivors and professionals--that is, the limitations of the Manual Muscle Testing (MMT) scheme (a British invention, circa 1950, by the way). I quite agree with your comments and observations. When I say that a grade 5 muscle in a polio survivor can be exercised "vigorously", this must be qualified that it still must be exercised cautiously - not with abandon and stubborn determination. That is why we give guidelines about the amount of discomfort to accept as reasonably safe after exercise. This actually applies in anyone, both free of neurological conditions including pps as well as the latter, although the latter are more likely to get in trouble from overly strenuous exercise.

I believe Halstead's point is that it is appropriate to try "vigorous exercise" in grade 5 muscles of polio survivors, whereas in grade 4 muscles one must anticipate even greater caution and slower progress. It is a challenge to survivors and therapist/doctors to know "How Much". The dialogue between them and the care to detail are most critical to success, that is increased activity-either from increased strength, endurance, both or improved well-being. The point of the recent article was to decrease the fear of exercise among more and more US Polio survivors, albeit understandable and well-founded in many cases based on experience, as you have pointed out. It is Respect for the Power in Exercise (for benefit and damage) that must be made better known. I hope these comments are helpful and will add to the discussion of this important problem.

By the way Dr. Burke Jubelt is organising a Committee to develop Practice Parameters for PPS, and will likely be addressing the topic of exercise . Best regards, Fred Maynard

Further discussions are now taking place on the following excerpt from the bottom of page 7, top 8

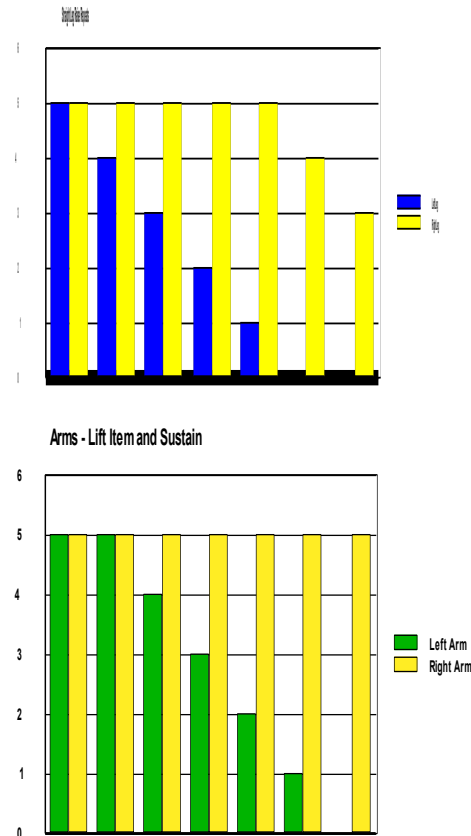
***Exercise the limbs least affected or those completely unaffected by polio..... For instance if only the legs are affected...***

Note the phrases in bold. How do we know which muscles were completely unaffected by polio? Muscles that had less than 44% damage were not seen to be clinically weak at the time of our polio. [Prof. WJW Sharrard referred to on page 9] What about the comments in many medical articles 'also

having problems in areas not thought to have been affected.'

Again I must express our thanks to all those who have been c.c.'d on this discussion for their prompt and informative replies.

So now you ask me what can we do in the UK. We are working both locally in Lincolnshire through the Lincolnshire Neurological Alliance - linking nationally through the Neurological Alliance - and the Long-Term Medical Conditions Alliance in an endeavour to improve the lot for polio survivors and



others with similar chronic neurological conditions. The local work needs doing all over the country as finances are now with the PCT's. There are 3 in Lincolnshire. If you are interested in helping with this type of work please get in touch with us.

Ideally we would all have full multi-disciplinary assessments, all the help and aids we need and be able to dip into a nice warm pool every day to stretch our muscles and get a little exercise. Even if we do achieve change in the NHS and better assessment and therapy for PPS happens it is not likely to happen overnight and all over the country. We do not have time to wait we must start now.

Try and find a supportive GP. We need to be able to provide accurate and pertinent information to him/her and it has to be concise with appointment times of 7 to 10 minutes. We must assess ourselves. Writing it down and seeing it in black and white can be hard to take, but if we are to get the best out of the rest of our

lives then its necessary. Compare what you are doing now to last year, five years ago. What is changing.

You must be honest and that starts with yourself. Start by telling them about a few of the changes in your functional abilities over the last few years. A couple of photos of you showing abilities that you had a few years back but do not now, often surprises those examining you.

We can provide other visual information as to our Polio Life (See suggested charts in our Information Pack). We can ask our G.P. for some help to start managing our lives **NOW** whilst we wait for the inevitable months that appointments take in the U.K. Ask him/her to, or arrange for someone to, ensure you have a correct assessment of our muscle endurance.

Remember, when asked a question remember to qualify your answers, do not just say YES. A recent phone call about a DLA assessment showed how important this is. The person was asked 'Could you walk as far as x' - and a point outside 60 yards away was picked. She answered 'yes', but her carer said 'But tell him how'. 'Oh, I would have to stop about three times and rest to get that far, about half an hour.'

Even if you are now severely disabled by your polio, or managing your dally living is as much as you can do, there will be some 'exercise or physical action' that you can do to improve your suppleness. For example:- If you are now finding it difficult to reach up and lift items down from a shelf do you raise your arms up above your head at all? If you cannot go upstairs now do you lift your legs or have someone do that for you as if you were going to go up a step at all?

With a health professionals help start low, start slow, and move at your pace. Keep as supple as you can. There is no reason why your 'exercise' should not be split up - a couple of minutes here and there throughout the day. Remembering to ask for instruction as to when to breathe in and out as you do these exercises. So many of us stop breathing to concentrate on what we are doing because we are using extra or other muscles to complete the task in hand. If you want to share all this with another polio survivor or two - contact Wendy our Secretary.

**[The following 'Ask Dr. Perry' provides additional relevant information. ]**

Dr. Jaquelin Perry is a world renowned Physiatrist who has worked with Polios and Post Polios for many years at Rancho Los Amigos, California.

**Question.** What is the natural progression of post-polio syndrome? Will a person return to the same degree of paralysis that was experienced at outset?

**Answer.** When focusing on the natural progression of PPS it is important to understand that muscle function depends on three systems:

- Control from the brain.
- Sensation for the Periphery
- The lower motor system from the spinal nerve cell (anterior horn cell) down to the muscle.

The third system is the most important for people with PPS because if you lose the nerve, you lose the muscle. We talk about muscle weakness, but polio is actually a nerve disease that damaged or killed anterior horn cells. This makes a lot of difference in terms of exercise, etc.

## ACUTE POLIO

During the acute phase of polio some spinal nerve cells died while others were injured but later recovered. Some people had paralysis, others did not. The effects were like spatter paint. If you had a lot of paint, you had a lot of damage, while others were just touched lightly. But all survivors were left with a damaged neuromuscular system.

## RECOVERY

Recovery from polio entailed all three methods of recovering function:

- **Neuro recovery** - between 12% and 91% of the nerve cells that were injured not killed by the polio virus recovered.
- **Axon sprouting** - New branches of the remaining nerve cells were sent out to adopt the orphaned muscle fibers. The result was that each nerve was then doing 50% more work or even up to four times as much as normal.
- **Hypertrophy** - The muscles enlarged themselves up to about 400% so they could function.

It is not known how much a survivor's recovery was due to spontaneous nerve generation, how much could be accredited to patching by the axon sprouting and what amount was due to hypertrophy. Upon recovery polio survivors had a random disability in regard to the amount of paralysis. The amount of muscle weakness a person had was pure chance; it depended upon the amount of polio virus a person had and where it went. Some survivors remained paralyzed whilst others looked or felt normal although they were not.

## RESEARCH.

During the 40's Bodian traced the polio virus in the motor cells of monkeys. He found that polio, a systemic disease, affects 95% of these cells by either injuring or destroying them.

Research confirms that there is some obvious weakness as a result of polio. Dr. James Agre found that

- Polio survivors with no current symptoms had only 80% of normal muscle strength.

# Ask Dr. Perry

- Symptomatic survivors had 60% or less muscle strength compared to the normal group.

Following a four year study Grimby reported

- a normal 2% to 5% loss of muscle strength in asymptomatic polio survivors but
- for symptomatic survivors this loss may be as high as 13%.

A study by Grimby confirms that weaker muscles work longer and twice as hard. **This research says that it is necessary to protect this overused muscle system. The muscles that are graded 3, 3+, and some 4's are getting all the exercise they can tolerate. In order to maintain this function, these muscles must be protected from overuse.**

## NOW

For many, many years polio survivors have been working with a damaged neuromuscular system that keeps working harder than ever to meet normal demands. We need to appreciate the fact that each anterior horn cell innervates several hundred muscle fibers and the surviving horn cells have been doing 50% more work than normal. Plus it appears they don't like being overworked!

Because of this overuse of the neuromuscular system, new weakness is now developing. Survivors may develop new weakness not only in polio muscles but also in other muscles that did not seem to be involved during the acute phase.

Although the amount of weakness a polio survivor develops in later life depends upon the original involvement, age is a factor. Anterior horn cells do not have infinite durability. They begin aging at about 60 years of age. So polio patients aged 70 and up have a natural weakness just from age that needs to be appreciated and put in perspective also.

## ADVICE

At least half of the 1.5 million people who had polio have post-polio syndrome. Nothing has been added; PPS is a loss of function. The problem is that a survivor's lifestyle now exceeds his physical ability.

Dr. Perry advises, Don't push the system. She believes a polio survivor can control loss of function by controlling overuse of muscles. The way to do this is by making lifestyle changes, modifying activities, and pacing.

Polio Survivors should know their own muscle strengths and plan accordingly. A study by Agre related to exhaustive fatigue confirms that:

- A person with normal muscles will recover fully from muscle fatigue in five minutes.

- An asymptomatic polio survivor will recover in ten minutes.
- A symptomatic polio survivor will have partial recovery in five minutes but then have further loss.

So it becomes necessary to make lifestyle modifications. Dr. Perry advises

- Figure out what you don't have to do.
- Get others to do the heavy work.
- Break up work periods with rest periods
- Don't pride yourself on working harder.
- Pain is a sign of injury and overuse so don't let it happen.
- Figure out what causes your pain and don't do it again.

## HOW YOU CAN HELP YOURSELF.

Dr. Perry's general activity guideline is that a polio survivor can do anything as long as it causes:

- NO PAIN and
- NO FATIGUE THAT LASTS LONGER THAN 10 MINUTES.

Survivors can control their destiny by avoiding overuse strain. But Dr. Perry cautions: Polio Survivors who overuse muscles will lose strength.

If you are experiencing new pain, weakness or fatigue, you can help yourself now by changing your lifestyle and pacing yourself.

Reprinted from Rancho Los Amigos Post-Polio Newsletter, September 1998.

[Editors note. Changing your lifestyle includes using any aid or assistive device that saves you wasting energy. This includes asking another another human being to do something for you, or help you do the bits you cannot do, or should not be doing as it will put too much strain on your system. Save the energy you have to do more of what you want to do. Keep a smile on your face and be proud of what you achieve no matter how small. If you overuse, are in pain, exhausted and grumpy then not only do you have a harder time but so do those around you. ]

[Whilst searching on the Internet for some information Chris Salter today found an extensive 52 page booklet. 'The Late Effects of Polio, Information for General Practitioners' from Queensland Australia with advice for GP's on PPS. We were pleased to find that it references the Lincolnshire Post Polio Network. More in next newsletter. It's too long to read today.]

## Why not have a cup of tea with me on my deck.

Come on out and have a cup of tea with me out on

my deck. We can watch the doves and red winged black birds argue with the woodpeckers over who gets the feeder.

Just past them we can watch a pair of Canadian Geese walk on top of the hay feeder for the cows - we can't figure out why they want to land up there and walk about but they do - maybe you will have an idea.

On our left the flower petals are "snowing" all over the ground as they twirl down from the wild pear tree and just a little closer on the ground it is all red from the fallen camellia blooms.

We can place bets on when the first bird will take up residence in the new birdhouse Tom put in the camellia bush or we can wander around the corner of the house and watch Tom try to get the extra dirt off the blacktop in the driveway.

On the other hand, we could just bask in the sun and enjoy our tea. I know, we can race our scooters up and down the driveway!

We'll face our "dragons" together.

Ginger in sunny California  
Member Ginger Ottonello. <tomgin@GVN.NET>

## **Can Stem Cells Help Polio Survivors by Edward B. Grebenstein, Jr. President. The Polio Society.**

In response to recent scientific developments regarding stem cells research, the Polio Society's board of directors asked Lauro Halstead M.D. to make an informed presentation on the topic at its July 16 2001 meeting. This article is based on his presentation and several excellent reviews of the field published by the National Institute of Health.

### **What are Stem Cells?**

Stem cells exist in every human being. Very simplistically, they can be compared to college undergraduates who have not yet declared a major. Just as most college students eventually major in business, law, or some other subject leading to a career, stem cells evolve in response to the right stimuli to become blood cells, bone cells, muscle cells or even nerve cells. This process is called differentiation and is usually triggered by a chemical stimulus. In adults, stem cells exist in bone marrow and probably play some role in the healing process. However, scientists do not yet know how stem cells repair damaged organs, or why some human organs can regenerate themselves and others cannot.

The current scientific consensus is that embryonic stem cells are more flexible, and therefore more useful, than stem cells from adults. Embryonic stem cells are pluripotent, which means that they can become any cells produced by the body. By contrast, adult stem cells are found in specialized organ tissues, and therefore may not be able to assume the functions of cells in other organs. Indeed, biologists at the University of Wisconsin recently reported that they were able to transform human embryonic stem cells into red blood cells, white blood cells and platelets - the three main components of human blood.

These developments have triggered a vigorous debate about the morality of embryonic stem cell research. Nevertheless, many private start-up companies are attempting to capitalize on this research. These companies are entering into partnerships with academic and other researchers and are looking for patient populations in which to conduct research. In general, these companies believe that stem cell research may provide a better investment with quicker returns than gene research. Although it is still very early, there have been small preliminary studies in humans with such diverse diseases as stroke, spinal cord injury, multiple

sclerosis, Parkinson's Disease, and Alzheimer's disease.

Does this mean stem cells might one day be able to help polio survivors? A number of leading researchers believe this could happen, although stem cell treatments are unlikely to completely restore all lost function. In an attack of acute polio, motor neurons die in the anterior horn of the spinal cord, causing the 'orphaning' of muscle cells which, in turn, can lead to muscle weakness and partial paralysis. According to the latest polio research, post-polio syndrome (PPS) results from overuse of the remaining healthy motor neurons. Some scientists believe that stem cells might be able to replace lost anterior horn cells or help remaining motor neurons work more effectively. Either way, the stem cell might ameliorate some PPS symptoms and, perhaps, even arrest their progression. Stem cells could therefore help polio survivors feel better even if they did not completely 'cure' the late effects of polio.

The Board discussed the idea that stem cells research for polio should be placed on 'fast track'. Specifically, the Board contents that while Federal funding is crucial to the ultimate success of stem cells research, the polio community should not wait for such funding alone to pursue effective treatments. The amyotrophic lateral sclerosis (ALS) community has been aggressive in pursuing private funding and private research; the Board believes that the polio community should consider doing likewise.

The Polio Society will continue to discuss its role in promoting this research, and OPTIONS will continue to report on important developments. We invite you, our membership, to let us know your opinions about this exciting new field with its potential to help polio survivors. Call us, write us a letter, or use our new email address [poliosociety@yahoo.com](mailto:poliosociety@yahoo.com) Our telephone number is 301-897-8180 and address. The Polio Society, 42100 Wisconsin Avenue, NW, PMB~106-273, Washington DC 20016. Reprinted from OPTIONS. The Polio Society Newsletter, Fall/Winter 2001.

[LincPIN Editors note:- write to us with your comments which we will share with The Polio Society]

# *Hints, Tips & Bits, from PPSers.*

## **THE SHADOW THAT LURKS IN RECOVERY** MY EXPERIENCE WITH POLIO AND POST-POLIO SYNDROME By Member Susan H. Conley

Yes, I am a polio survivor, and I have always known that I was "One of the lucky ones". I was able to walk away from the experience into a relatively normal life. My first memories are of FEAR: Fear, Pain and Feelings of Isolation. I capitalize these because I remember them so very strongly.

The scare of the summer plague known as Polio was over. It was the first week of September 1952, and I was eight years old. The school year was just starting, and I was ill. The doctor thought that I had the flu, but my mother had been reading about polio, and sensed that she should get another opinion. Overnight (it seems to me) I could not lift my legs to put my jeans on. I remember calling out for my mother and crying. My legs hurt so much. What was happening? The summer was over...this couldn't be the dreaded polio!

My life was about to change dramatically, and as a family unit, we could never have been prepared for this experience and the effect that it would have on each of us. I can only speak for myself, and I can tell you that I was terrified! My parents drove me to the County Hospital in Los Angeles, which was about 30 miles away from our home in the San Fernando Valley. County General was where polio patients were taken at that time. This was before freeways, so it seemed to take forever to me, lying in the back seat of the car and looking out of the back window at the streetlights going by.

We arrived at the emergency room, and all I remember is the spinal tap. To say that I was scared to death would be an understatement! After the ER, I was separated from my parents, and placed in a ward in this huge hospital, set aside for people like me. The life I had known with my mother, father, and younger brother, had come to an end. I was on my own in a very strange and isolating environment.

I spent three days at County in that ward. I became afraid to go to sleep at night, because when I did, I would awaken with sounds of another patient being rushed out of the room surrounded by loud voices and banging of the metal beds against each other. Later, that person would be brought back with a hole in his throat! I believed that if I stayed awake, that

might not happen to me. I also remember that whenever anything fell from the bed onto the floor, the nurse would take it away to burn it, because it was then considered contaminated. I lost a stuffed animal that way. So, when the picture I had of my family hit the floor, I cried and pleaded with the nurse not to take it away and burn it. Thankfully, she placed it in a nearby window, where I could see it but could not reach it.

I remember my mother visiting, all covered up, and unable to touch me. All I could see was her eyes. I had never before been separated from my family, and could not understand why my mother could not hold me.

After the three days I was transferred to a polio rehabilitation hospital in Santa Monica, where I stayed for almost four months. Four months can be a long time for anyone. For an eight-year-old, it is an eternity!

I was placed in a ward, surrounded by other children also scared and alone. It did not take long for me to be fit into the routines of the hospital. There were treatments at that time that I believe now, certainly saved my muscles:

The Sister Kenny treatment: staff would come in rolling a big metal bucket on noisy casters filled with steaming hot blankets inside. We would each be placed on a plastic sheet on our beds, and watch the attendant go from bed to bed, lifting the steaming blanket with long wooden sticks to wrap our bodies with. I could not understand, how it was too hot for them to touch, but not too hot to wrap around my small body.

Pool therapy: lifted down on a stretcher into the water for therapy. I could not swim yet, and had so little strength in my legs, that I feared drowning on a daily basis at first. I soon learned to trust the strong arms in the pool to keep me safe.

Whirlpool baths: I was so embarrassed to be almost naked in front of others.

Physical therapy: countless sessions with heavy weights on my legs. These were very tiring, but I do not remember disliking this part. As some of my strength came back in my legs, I received positive feedback because I had been such an athletic child before polio. It was felt that this helped me tremendously in my recovery.

Electric muscle stimulation: so frightening that I was found hiding in a linen closet one day, trying to avoid this.

The nights were the longest. Many of us cried ourselves to sleep, seemingly, day after day, and night after night. Was this to last forever? But again, I was one of the lucky ones!

I came home just before Christmas. I do not remember going home, except in a picture taken of me soon after. In it I am wearing my new Blue Bird uniform (a junior level of Camp Fire Girls), looking so very pale, with hundreds of freckles standing out next to my dull-looking, dark eyes. I look like I had been put through the ringer, obviously exhausted from the experience. Thankfully, I had a loving family, with lots of support at home. My next year was filled with intense physical therapy until my strength returned, and my activity level and stamina became that of other nine-year-olds.

As a teenager, I began to put this experience behind me, and began excelling in sports in school again. I was once again the tomboy in the neighborhood, jumping hedges, climbing trees, and first picked by the boys for the baseball games. I worked hard to appear normal, and to fit in. However, when I would overdo, and get tired, my left leg would give out very suddenly and I would fall. I remember falling in the hallway in school; papers and books would fly everywhere, and the other kids would laugh.

I would trip over unseen objects. It felt like I excelled in stumbling. At other times I felt strong and agile. I majored in physical education in college, and even joined the women's track team for awhile. I was never a runner; I did not have any speed to speak of, but put a discus in my hands, and watch out!

So on into my adult years, I did not even think about polio. In fact, although I was quite young when I was hospitalized with polio, I had such unpleasant memories of that experience that for decades I blocked it out totally. It had happened in a different lifetime and as if to a different person. I actually had few memories of my childhood. I studied Nursing, became an R.N., and even specialized in Pediatrics for a few years. I felt as if I really identified with the children and their separation anxiety. I believe that I was of some help in that way. So I developed my career, married, gave birth to two children, and divorced, all in about ten years. Stress had become a major factor in my life, and I did not handle that well at all. I seemed to internalize everything, never feeling good enough to the task at hand, yet always striving toward goals. Yes, I fit into the mold of the A-type personality, so common in polio survivors.

Then, in my forties, I began to limp when I became tired. It seems that I was beginning to

drag my left leg a little again, and began to tire more easily. In 1988, at the age of forty-four, I began experiencing shooting pains down my left hip and leg, radiating from my lower back. It became painful to lower my left heel to the floor when I walked.

One day, at the hospital where I worked as a Nursing Administrator, I had the opportunity to hear a physician, an orthopedic surgeon, speak on the topic of Post Polio Syndrome. I was so very fortunate to have gone to that lecture. I spoke to him afterwards, then called for an appointment to be evaluated by him for my leg and back pains. The most traumatic moment of all, was when I was on the exam table, with two physicians leaning over my legs, looking at my feet, and mumbling to each other.

Suddenly, I was eight years old again! I was frightened as I flashed back to all of those feelings I had when I was a child, and was separated from my family. I felt overwhelmed as the doctor scheduled surgery and explained what was happening to me. I cried for two days after that, and could not sleep for many days. All that I had stuffed deep down in my past, far behind me, came flooding back. Insecurities abounded.

I soon was able to put things into perspective, and again moved on with my life. The surgery, and a support in my left shoe, seemed to manage the problem for a few years.

Then, three years ago, my tripping and stumbling began in earnest, and again my left leg would give way without warning, and down I would go. Just like back in school 35 years before. Then it happened. I fell down a few stairs when my leg gave way once again, badly injuring my right knee. That was my "good" leg. The injury required surgery and many weeks of physical therapy. I talked to my present doctor about Post Polio Syndrome. He believed that I needed to exercise more to strengthen my weakened muscles. He did not seem to know about PPS.

By then I was using a cane for support whenever I was outside. I began doing my own research, getting a computer for that specific purpose, finding local PPS support groups, and discovering wonderful newsletters. I was not alone. I was not crazy and just feeling sorry for myself. I was going to be okay. I could do this! My life was changing, and not in a way that I would have chosen. Who knew that we would have to go through this again? I grieved for awhile, but I am an adult now, and I have choices. I can educate myself, and learn the best way to cope with this. This certainly is the challenge that I will deal with for the rest of my



life. I still believe that I am one of the lucky ones.

I came to the conclusion that I needed an expert medical opinion and evaluation. I had read about the Post Polio Clinic at Rancho Los Amigos Rehabilitation Hospital in Downey, California. I had read articles by Jacquelin Perry, MD, and was already receiving the Rancho PPS newsletter in the mail. I called, and waited the requisite six months for an evaluation. I will be forever grateful that I ended up at that clinic, being evaluated by Dr. Perry. By that time, fall of 2001, I was significantly weakened on my entire left side. Even my right arm and leg were measurably weakened. Dr Perry and her professional team were very understanding and supportive of the effort my life had become. The weakness and the chronic fatigue were now having a major impact on my life. I could no longer walk around the block without major effort. I tired quickly when gardening. I became exhausted and irritable at the end of each day. I was aging before my time, and before my eyes.

Dr. Perry ordered a brace for my left leg, and talked to me about resting three times each day, and to pace myself to lessen the demands in my busy life. It was suggested that I sit or lean on a stool while preparing meals in the kitchen, and to feel free to ask others in my life to help me. I have found that there is a lot of gray area between dependence and independence that I need to explore further. I see this as another challenge in my life; to accept my physical limitations, as well as to do whatever I can to pace my activities, rest frequently during the day, and stay as optimistic as possible.

So, I wear my brace, use my cane, and have even added "Scooter" to my life recently. Scooter is an electric scooter that I find already is worth its weight in gold. Wearing my brace has removed much of my daily pain, and along with my cane, has kept me from falling. Using the scooter is not only a godsend when I have to travel distances "by foot", but I find that riding it is a lot of fun. Actually, I feel very independent when using it.

I cannot underestimate the importance of a support system, as well as education in PPS, and a doctor who understands PPS and can help me. As my life evolves, I am energized by these changes. The more I know the more I grow, preserving the nerves and muscle strength that I have left. I am ready for the next chapter in my life.

Susan H. Conley <colbys@pineknot.com>  
P.O. Box 1825, Big Bear Lake, CA., 92315, USA

**Groceries chosen and delivered with NO energy output except fingers on keyboard! I'm thrilled!!**

A TALL "Peapod" truck backed into my driveway (poor tree branches), and out came a TALL driver (6 foot 8), who proceeded to bring into the house all the groceries I had ordered, plus a big box of strawberries as a first-timer gift.

I will do this regularly!! All I had to do was put them away. And I found I did a much more thoughtful job of shopping online than I would have in the store. Easier to compare prices, find the brand. No groping around, no forgetting something and backtracking through all the aisles. I went back over my order a couple of times and added and subtracted items. The running total shows up in the top left, so you always know what your total's going to be.

I learned tonight that if I have coupons, I can give them to the driver, and the value will be deducted from my next order. All the specials are marked. All the sale items are marked -- online, that is. You can get the category of food you're looking at sorted any way you want: by brand name, by size, by price, alphabetical, by calorie count or fiber count, by total price or unit price. Now that I've done it once, I know better (for instance) how many frozen dinners will fit in my fridge (more than I ordered). And my one half gallon of milk looked awfully small. Next time I'd get more. And now I'm going to bed! Gotta rest up from putting it away, and dream of fresh strawberries for breakfast tomorrow! Why not see if there is a store in your area that does this.

Jeanne - SEACAIRN@aol.com

### **Our PPS Get-together by Life Member Sue Karnes.**

Some background info. I emailed the LincsPPN, talked with Hilary, joined and she suggested that I also join the SJU Polio email list. This was in May of 2001, being at the denial, depressed, etc. state of mind. Since May I've gained some very special friends via the list. During our emailing back and forth and talking on the phone with each other we realized that some would or could be travelling through Georgia during the winter.

My mind got to reeling. These dear friends were going to be close by and had helped me so much in such a short time. We started talking about a possible get-together and one day I decided to tell them that the Lazy Acres Bed & Breakfast, jokingly calling my house, was taking reservations for any PPSers who would be near. It was planned for January, but had to be postponed due to snow. At which time my heart became so heavy, but everyone rescheduled for February.

I was so excited it seemed the day would never get here, but it did and it turned out to be the best time of my life. There was so much love, laughter, joy, etc. Everyone was telling the others, 'Oh, you are nothing like I had pictured you to be' and we'd all laugh. We all just fell into a family as if we'd been meeting like this for years.

For me it was awesome, because for the first time since my original bout with Polio and now my PPS years, no one asked me what was my problem. They didn't joke about wishing **they** had a scooter or how **lucky** I was to have a power chair, etc. I realized that by the end of the first day this was the most relaxed and enjoyable time I had had in years. Then it hit me that we were all alike and didn't even notice each others PPS difficulties. If I went to get up and moaned no one jumped up to see if I was ok and told me to stop being such a baby or to get tougher. For the first time in my 54 years I didn't have to work hard at being a passer when I had always been on edge. I would hang to the outside of gatherings, feel as though I was nothing more than an inconvenience or the joke between others. I was tired of trying to explain what PPS was only to have them reply "well, you certainly don't look like you've got a problem." For the first time I truly felt "normal" and that we were all just part of one big loving family.

Know that until I found the list and the wonderful people on it, I had become almost completely home bound and thought I was perfectly content to stay at home. Would only see my girlfriend - who is my house cleaner and shopper - on Fridays and Sunday when she takes me to church and to bible study.

The get-together has rejuvenated me, there is still life out there to enjoy. I want to go to the PPS meetings, conferences and reunions now. I have already signed up for the North Carolina PPS Conference in late April. I have learned from this meeting that all I need to do is to plan it carefully, fitting in rest times, not be embarrassed at using my electric chair, oh and knowing that when I get back I will be exhausted for a few days but with a big smile on my face and wonderful memories.

I could go on and on, but the one thing I'd like to pass on is for all the PPSers out there, if at all possible, to try and meet up with some other PPSers. Life is so very short and the difference this has made to me is incredible. My daughter sent me an email to pass to the others thanking them for visiting, as we are now able to talk more openly about all that is happening. Love to all my friends out there and Thankyou, this was the greatest gift I've received in many years.

Sue Karnes <SEKARNES722@aol.com>

The following two emails - printed with permission - are informative replies to discussions taking place on the St. Johns Polio Email List.

### **I'm quitting work - Roger Brown, Australia.**

This has been an interesting discussion as I also am in the process of a decision about my working future. Currently I am on extended long service leave from my bank lending manager employment (half pay rate) - once that concludes I will be within a few months of being able to retire on perfectly adequate (indexed) superannuation.

Why did I decide to consider early retirement from employment that provided both enjoyment and success?

Well five years ago I would have disregarded any such suggestion. I was at that time working hard and having little difficulty maintaining all my music activities including two hours organ practice at 4am daily). All that suddenly changed when the residual (and very severe) effects of a seemingly minor lifting incident years earlier left me writhing in pain and virtually unable to move. (This was polio related of course, in that I had attempted an unwise lifting task - given my lack of upper body strength due to polio.)

Surgery was successful and I was back at work within three months but rehabilitation was tiring and reduced my overall effectiveness. It was not for two years that my leg strength started to approach normal.

At about that point, and still feeling very tired and stressed (but trying very hard to cope with work, rehab and a very active round of music activities) I was diagnosed as having type 2 diabetes. Although being a non drinker and smoker and not overweight reduced the lifestyle adjustments then required, this obviously complicated matters.

My work performance at that stage had fallen away. I was finding it difficult to maintain intensity and cope with stress and my colleagues were noticing the change. Things needed to change.

One solution would have been to curtail outside interests and activities. This is a strategy often used by mid level employees as pressures mount but is I believe an unwise choice. So many employees, after shutting down outside activities then find that in the event of retirement, redundancy or other inability to work, there is nothing left in their lives. This does nothing for longevity - especially for men.

I was also determined to ensure that I retained the time required to look after my health and fitness. Recovery from back surgery had required a very determined effort at rehabilitation. Diabetes management requires much the same commitment to regular exercise. I was determined not to let these matters slip as the consequences of doing so are quite severe.

It was clear I needed a break to cope with these factors - hence the leave arrangements I have now made.

Oddly enough the twelve months prior to commencing leave have been the best at work for some time. That was probably partly due to the knowledge of my impending break but it also had a great deal to do with the quite sudden change in energy levels once diabetes control had been established. I just had not realised how much this had affected my ability to cope with work and with stress. In addition to this, my general fitness is now much

better than for some time (apart of course from the upper body effects of polio/PPS).

So what of the future:

1. Although I enjoyed work and the associated responsibility I have not missed it in the least. 35 years was quite long enough thank you.

2. This is partly due to my having many outside activities and commitments - mostly of a musical nature. Readers of my web page will probably realise that but for polio, music would have been my career.

3. What occurs once my current leave concludes is to some extent up to my employer. But I think it highly unlikely I will want to return to work.

And out of all that, what is it that I want to pass on to others?

1. Your health is the most valuable asset you possess. If your work is affecting your health then work needs to be modified or even abandoned if possible.

2. I think it is essential to have other pursuits planned and active. These need not be, and for many cannot be, physical. But mental activity is essential for well being - so is self esteem. It is the people who have put their whole being into work who come off worst when work is no longer possible.

If you are working now, plan ahead. Plan the activities which will sustain you in retirement. Good luck  
Roger Brown <[rbrown7@BIGPOND.NET.AU](mailto:rbrown7@BIGPOND.NET.AU)>  
<http://rogerbrown.tripod.com>

**I elected to have a trach.  
I have no regrets!**

I had pulmonary failure in 1984. After trying several non-invasive options I elected to have a trach. I have no regrets!

For several years I used the vent only when lying down. Now I use it almost full time. I have one vent next to my bed and another vent on my power chair.

Having a trach and using a vent requires some lifestyle adjustments, but it does not mean the end of an active life (sometimes I wish my life were less active).

Four members of our seven member board of directors have trachs. All continue to remain active members of their communities. All live at home. All have the ability to speak. And all are in good health.

I strongly believe that your friend will have more energy, regain a sense of well-being, and quickly learn to deal with the peculiarities of having a trach.

I've said this before, but it might bear repeating: When it gets harder to read the fine print we get glasses. If our hearing is impaired we use hearing aids. If our

legs are weak enough we use a wheelchair or scooter. Is it such a leap of faith to believe that when our pulmonary function is impaired we should start using some form of ventilatory assistance?

A trach is the most efficient way to move air in and out of our lungs. It doesn't mean the end of life. Actually, it's no big deal.

Richard Daggett, President  
Polio Survivors Association, USA.

To:  
[linpolio@LEGEND.CO.UK](mailto:linpolio@LEGEND.CO.UK)  
CC:  
[Vonnejo@aol.com](mailto:Vonnejo@aol.com)

**A GREAT LADY'S CENTURY OF  
ALCHEMY**

She was  
a great lady  
Britain's Queen Mum  
(Elizabeth) epitome  
of grace and dignity  
beloved for a century  
of  
pomp and pageantry  
white roses  
signal  
the end of her  
rein of majesty  
and this great lady's  
century of alchemy.

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(an American's POV might not be politically correct)

**Weird Things You Would Never Know!!**

>>>>  
>>>> Butterflies taste with their feet.  
>>>>  
>>>> A duck's quack doesn't echo, and no one knows why.

## Depressed or Distressed?

Over the past months, talking with people with polio, and specifically the late effects of polio, I've heard the word depression again and again. Last week I learnt of a friend of a friend, who had just been diagnosed –'she's very depressed' was one of the introductory comments.

But I wonder how often we misuse this word. I have been through black periods since I began to recognize symptoms of unusual fatigue when I was 16. But I'm not sure whether I've ever been clinically depressed, and writing the following I don't wish to upset anyone for whom depression is a reality. However, I wonder how often we confuse the word depression with what our bodies are trying to tell us.

When we get tired, and run on empty for long enough, our bodies, with their failing nerve endings have to find a way of telling us. We have, very successfully, trained ourselves to ignore the usual fatigue and pain messages; in order to continue as we feel is necessary, if not normal. So, when tired we switch off the message.

Weakened muscles, function increasingly less efficiently, and eventually stop working. Neighbouring muscles and trick movements then take over. These muscles, unused to the acquired function, begin to fail more quickly. At this point we are probably aware of pain in the original muscles, and the 'trick' muscles. So, the muscle balance in our bodies becomes affected by one set not functioning. We are prone to fatigue anyway, and the imbalance sets off more fatigue as the body is stressed by coping with the extra strain.

Perhaps it is a dropped foot that has got overused, attempting not to fall over it, we overuse knee and hip muscles. There is pain in ankle, knee and hip, and this sets off back pain, potentially pain in the other leg, and maybe spasms elsewhere in back and neck.

So, we have fatigue, causing muscle stress, causing more fatigue, and putting more strain on us. Pain, as part of its natural patterns, lowers our mood. Serious pain can remove the capacity for clear thought, even conversation.

Our bodies are shouting at us to stop and rest. We insist on ignoring them, and wonder why we grind to a standstill. Often, we only stop because the stress we are imposing becomes manifest in a physical disorder, gall stones, a collapse, heart problems, even some cancers are stress induced.

We feel awful, we can't cope and think we are weak, useless and lazy for desperately wanting to sleep... that's if we can cope with the levels of pain we've caused. All we can think about though, is doing more, and coping and okay, achieving.

But we're not depressed, we're distressed.

The golden rule is 'Pace yourself, avoid fatigue, and avoid stress'.

We have to learn to cherish our bodies, and listen to what they are desperately trying to tell us. We have to stop the constant torture we've imposed on ourselves. Forced to keep up, cope, and retain the ultimate stiff upper lip, we have instead to impose a strict regime of love and care. People with ME are often advised to take 2 x 30 minute rests during the day. These are taken lying down, without the stimulus of TV, or radio, or reading matter, although relaxation tapes are allowed. To fit this into one's routine takes discipline.

We have to build in the expectation that our damaged nerve endings may take up to ten times as long to recover from trauma, and 'big-fatigue' counts as trauma. You won't get over it in a day, it may take a week where it once took a day, sometimes much longer.

But start to listen to your body, keep a journal if it helps, to remind you of what works with what exertion; to remind you of what exertion is stacking up

Let us learn to cease the discipline of whipping ourselves, and learn the discipline of self-love instead. The distress doesn't disappear entirely, there will be plenty of ways to berate ourselves, but we will be more understanding, and gentle.

Val Thorne. Now living near Reading.  
Age 46, polio October 57, Leicester.  
<valmthorne@hotmail.com>

### BRISTOL AREA - SECOND MEETING.

The second meeting of Polio Survivors in the Bristol Area is being organised for lunchtime either Monday 13th or Monday 20th May. Venue to be arranged depending on numbers will be somewhere near the M5/M4 junction. Hilary will be passing by on both dates on her way to and from Devon. Apologies from us both that this can't be a weekend but we both have parents birthdays either side of these dates. If you would like to join up with us - even if you can't make this meeting - please get in touch with me by phone or email. Phone 01594 530670 mornings or email <MirRah2@aol.com> Up to 7 years ago I was a Piano Accompanist, Duetist, and fully qualified Piano Teacher. Anyone else with similar interests?  
Mary McCreadie.

## *Nutrition Question's Answered by Life Member Jann Hartman*

### **Question: Can you give me some advice on diet and PPS?**

Susan Creage, a research fellow at the Post Polio Institute (Drs. Bruno and Zimmerman), has found that those with PPS seem to do better on a Hypoglycemia Dietary Plan. In order to keep blood sugar as constant as possible you divide your total calories into 5 or 6 meals a day (usually 3 "meals" and 2 or 3 healthy protein snacks).

Dr. Bruno: "We aren't recommending one of those 'all protein, no carbohydrate' diets. We aren't recommending a 'diet' at all, but a method for eating healthy every day. We suggest 16 grams of protein at breakfast; that's about 1/4 of the daily protein requirement (70 grams) for a 150 pound person. (Always check with your doctor, especially if you have kidney problems, before changing your diet and ask to have your cholesterol measured at your yearly check up.)"

A hypoglycemia dietary plan is an exchange type diet that can be modified to meet your needs as well as likes and dislikes. It is good to have this explained by a nutritionist. It is not difficult, but you need to know how to set up the foods you need each day for optimal nutrition. It's what every good diet is based on. There is also a good one on the internet:  
<http://www.itlnet.net/users/k21/diet/diet.htm>

I hear many people talk about losing weight with high protein and fat diets, no carbs, and others. These "diets" can be dangerous! And, with our Polio compromised bodies needing more nutrients, we have to be even more careful. All you probably need to do is make a few small changes to your dietary plan. Bruno and others recommend a balanced diet of protein, complex carbohydrates, and good fat choices. They are all part of a good eating plan of real foods: all 3 are necessary for optimal nutrition.

We need to watch the simple sugars and eat more of the complex carbohydrates that are in the whole grains. Remember, too, that fats are not all equal: we should be eating more omega-3s (fish, olive oils and others) than the omega-6s. With the typical American diet, many are eating way too many of the wrong fats, and other foods. And, sadly, as I travel I see fast foods and other poor dietary choices being adopted in other countries, too.

One more caveat from the professionals is to never skip meals. If you can't cook or don't have the time, protein bars can be helpful as an occasional replacement (read labels). Learn to make smoothies with protein foods (like soy powder) and fruits or 100% fruit juices. Our Polio damaged bodies often don't have the ability to store nutrients that others have. Eating well is an easy way to be good to ourselves.

Recommended Book: "Power Nutrition for Your Chronic Illness" by Kristine Napier, MPH, RD (1998). Although there is no section specifically for PPS, Kristine has lots of information that relates to many chronic conditions. The author is a Registered Dietitian who lives with and manages her own chronic illness. The second half of the book is full of great recipes that are easy, nutritious, and tasty!

Hint: Look for books at used book shops (addall.com or half.com) or on sale at the bookstores, or from your library.

### **Question: I have high blood pressure, as well as PPS, what should I be eating?**

"Dietary Approaches to Stop Hypertension" (DASH) was developed from a clinical study. The research was funded by the National Heart, Lung, and Blood Institute (NHLBI), with additional support by the National Center for Research Resources and the Office of Research on Minority Health, all units of the National Institutes of Health. DASH's final results appear in the April 17, 1997, issue of The New England Journal of Medicine. The results show that the DASH "combination diet" lowered blood pressure and, so, may help prevent and control high blood pressure. The "combination diet" is rich in fruits, vegetables, and low fat dairy foods, and low in saturated and total fat. It also is low in cholesterol, high in dietary fiber, potassium, calcium, and magnesium, and moderately high in protein.

This DASH eating plan is based on 2,000 calories a day, but it can be changed to meet individual requirements. Depending on your caloric needs, your number of daily servings in a food group will vary:  
<http://www.nih.gov/news/pr/apr97/Dash.htm>

But, any good dietary plan can be made "heart smart" by choosing lower fat foods like low fat dairy and watch those saturated (animal) fats, and cholesterol to reduce your risk of heart attack (and certain types of cancer as well). There's more information on fats as well as other nutrients on this website:  
[http://www.pueblo.gsa.gov/cic\\_text/food/food-pyramid/main.htm](http://www.pueblo.gsa.gov/cic_text/food/food-pyramid/main.htm)

Jann Hartman, BS, Nutrition Educator, Baltimore, MD  
More PPS Nutrition (basics and links to other WebSites): <http://www.geocities.com/arojann.geo/ppsnutrition.html>

### **Question: My doctor says I need to lose weight, how can I lose weight when I have PPS?**

First off, just losing weight isn't the answer to all our problems with PPS. While less weight is better for our bodies, starving ourselves starves our Polio bodies as well. And, they can ill afford it. Don't ever go below 1,000 calories or you won't be providing the basic nutrition your body needs. Most dieters lose

## *From Wendy, Hon. Secretary.*

### **For anyone looking for an interesting hobby.**

One of our members has found a time absorbing hobby in making Greetings Cards. She has successfully sold these at various fairs and stalls in her area and feels that others that are housebound would be interested in doing something like this.

She has sent me various designs which can be copied, and which would cost 10p per sheet. The cards are all made from various bits of materials, scrap paper etc., with the card itself, glues, scissors etc., being bought from craft type shops, and I must say they do look really effective when complete. You can also join a card making club, for which she has the information. These work out quite inexpensive to make but, I would imagine, make an absorbing hobby for people with some creative ability.

If anyone wants any further information regarding making these cards please contact Dorothy Moss on 01925 823343 or email <DorothyMos@aol.com>

### **For anyone needing a couple of days break.**

Diane Newman of the Peterborough MEET (ME Group) has offered our members the use of their two-berth caravan which is situated at Huntingdon Marina. It is only a small one but the idea is that it could be used for a short break by people who need to have "a couple of days away from it all." Unfortunately it is not suitable for people totally confined to wheelchairs as access into the caravan could not be gained. There is only a chemical toilet in the caravan but the toilet block is close by.

Although I have not been there myself, I believe Huntingdon Marina is a quiet and lovely place to be. Time can be spent just watching the traffic on the river. There is a large Harvester pub which serves food and there are other places close by. There are also good food shops in town which will also deliver to the caravan. The local bus station is a few minutes away and the bus itself from Huntingdon stops outside the Marina. There are also fishing facilities.

The cost is £15 per night. If anyone is interested then please contact Diane. {Contact Details next item}

**12th May 2002**

### **OBITUARY - Mrs. Nancy Robertson, M.B.E.**

We received the sad news that Mrs. Nancy Robertson MBE of Harrow, Middlesex had passed away in February.

The Committee have sent condolences to her family on behalf of all members.

### **ME Awareness Day Cathedral Square, Peterborough, Cambs. BALLOON RACE 12.00 to 3.00 p.m.**

This event is to raise awareness of ME but also as a prelude to the September 18th 2002 launch of the Cambridgeshire Neurological Alliance.

In attendance will be John Holt - West Berkshire Neurological Alliance, Dr. Elizabeth Dowsett - an Internationally renowned specialist in ME and PPS [Life Member], Dr. Derek Parkin - a retired ME/CFS Specialist from Lincolnshire who ran a specialist clinic at the Pilgrim Hospital, Boston for 12 years, and Hilary Hallam, your Chair. Several local celebrities will be in attendance, Cllr Charlie Swift and some of his colleagues and members of a disability group.

This is a fun event and a chance for people living in the vicinity to meet up. We have access to the Guildhall where tables for information can be set up. There will be a quiet room available for anyone needing to crash out for a while.

If you would like to join us on this day then please give me a ring so that I can send you a map showing parking etc.

I look forward to meeting more Polio Survivors on this day. We have so much in common and the sharing of information with allied support groups and campaigning together is helping us make faster inroads towards our quest for medical help.

Diane Newman,  
Group Contact,  
Peterborough ME/CFS Self Help Group  
MEET [ME Empowerment Together]  
22 Glebe Road, Old Hetton,  
Peterborough,  
Cambs, PE2 8BG.  
01733 552872  
<mecfsmet@hotmail.com>

## MUSINGS - Musicals Wordsearch

THOSE SHOWING

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BETWEEN ARE IN TWO PLACES.

PHANTOM / OF THE OPERA

GIGI

SEVEN BRIDGES FOR / SEVEN BROTHERS

HALF A SIXPENCE

MY FAIR LADY

OKLAHOMA

BRIGADOON

THE DESERT SONG

FINIANS RAINBOW

THE MUSIC MAN

SWEET CHARITY

CABARET

ANYTHING GOES.

CAROUSEL

MAME

HELLO DOLLY

MISS SAIGON

THE KING AND I

LES MISERABLES

SHOWBOAT

GUYS AND DOLLS

FLOWER DRUM SONG

PORGY AND BESS

STARLIGHT EXPRESS

CATS

### ADVANCE NOTIFICATION FOR YOUR DIARY

#### LINCOLNSHIRE POST POLIO NETWORK

**Annual General Meeting and Afternoon of Speakers**

**will be held on Saturday 28th September 2002 in Lincoln**

**Further information - Next Newsletter.**

# A THOUSAND PLUS THANKYOU'S



**Dawnbusters Rotary Club**  
**Big Bear Lake,**  
**California**  
**U.S.A.**

April 17, 2002

Dear Hilary Hallam,

We at Dawnbusters Rotary in California, are pleased to donate to the Lincolnshire Post-Polio Network the enclosed check in the amount of one thousand U.S. dollars. Our hope is that this will assist you and your committee to fund the LincPIN newsletter, freeing up some of your funds to put toward other services that your group provides in aiding individuals around the world in learning more and living with Post Polio Syndrome (PPS).

As you may know, Rotary International has been working alongside other organizations toward the goal of eliminating Polio throughout the world by the year 2005. We in our club actively participate in that effort through Rotary's Polio-Plus Program. We recognize that the long-term effects of polio will not end in our lifetime. Post Polio Syndrome has recently come to our attention, and we have a strong interest in spear heading efforts by Rotary toward assisting polio-survivors cope with the effects of PPS. Through one of our members, we have learned of the Lincolnshire Post-Polio Network and your good work in assisting with the education, identification and treatment of PPS in a healthy and positive manner.

Our club is in the process of developing our own Post Polio Project in an effort to assist in shortening the learning curve of PPS, and in the interim would like to contribute to a group that is already doing a lot for this cause.

Dawnbusters Rotary is one of two Rotary clubs in the city of Big Bear Lake, a mountain

community in Southern California. We are a club of 38 business people who work with the citizens of our community to support the Bear Valley community through a number of activities:

- Operation Bootstrap: helping women help themselves
- Annual Holiday Dinner: serving 500 senior citizens in our community
- Life to Life Donor Program: recruiting people to join the National Marrow Donor Program
- Helping Hands: assisting with home repairs for local seniors and the disabled
- High School Scholarships
- International Exchange Student Program
- Contributions and support of local youth activities.
- Reach For A Book Program: donating books to the local elementary schools in the name of program speakers at our weekly club meetings.
- Helping others in need as requested.

Each year we donate to an International Project, working with Rotary Clubs in other countries. This year it was funding the drilling of eight fresh-water wells in India.

Post Polio Syndrome is of growing interest for our club, and we are pleased to begin our effort in this area by contributing to the work of the Lincolnshire Post-Polio Network.

Yours truly,  
Sheila Hamilton, Club President and  
Susan Conley, Co-Chair, Post Polio Project.



## BIRTHDAY CONGRATULATIONS

Mrs. Kathleen Burrell in Lincolnshire  
on the  
Occasion of her 90th Birthday

Congratulations were sent on behalf of the Committee and Members.  
Also thanking her for the donation of monies she had received as gifts.