

PPASS Times

Newsletter of Post Polio Awareness & Support Society of MN

Mar—Apr 2005

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Vol. 6, Number 2

On the Web at [Http://www.ppassmn.org](http://www.ppassmn.org)

Marilyn Rogers Passes Away

By Larry Kohout

By now I suspect that most of you have heard that our friend and long time member, Marilyn Rogers, has passed away. I had known Marilyn off and on since 1950 when we both attended Gethsemane Episcopal Church in downtown Minneapolis. She had already had polio by then; I had a few years yet to wait. Marilyn came to church in a chair of her father's design. She had no trunk muscles and couldn't sit upright in a normal wheelchair so he took an aluminum-framed canvas lawn chair and made it into a wheeled bed for Marilyn. By bolting the frame so it would no longer collapse and putting a pair of wheels on the front of it, he created a light-weight conveyance that he and his wife could pick up and put into the family station wagon with Marilyn in it. This ingenious feat of engineering along with Marilyn's amazing ability to frog breath¹ allowed her the freedom to get out for several hours at a time. It wasn't that Marilyn was breathing in a conventional fashion in

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Free Postage Gone

By Larry Kohout

If you look at the mailing label of your newsletter, you will notice that we are no longer mailing it under the "Free Matter For The Blind Or Handicapped" as we have for the past six years. The United States Postal Service has reevaluated and reinterpreted its regulations and is taking a much narrower view of who is entitled to use these services. While I disagree with their interpretation, at the urging of several of the editors of other polio newsletters, I have decided not to fight the ruling. To do so could put others who have not yet been challenged in jeopardy. However, according to the inspectors at the Main Minneapolis Post Office, inspectors all over the country have been instructed to reexamine all mailings using this designation in light of the new interpretations.

When we explored our options we found that we could mail our newsletter under a Non-Profit Bulk Mailing Permit for between \$9 and \$17 per issue over and above what it is currently costing us to mail the newsletter. Bulk mailing requires a minimum number of 200 pieces and up till now, we have been a bit

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From Where I Sit

By Gary Dunn, Chair

Over the past year I have read numerous articles about PPS and the effects it has on polio survivors. One thing I did notice was many individuals associated other illness or problems to be part of the PPS.

I would like to share my most recent experience that started to happen about thirty months ago. I began to lose strength and the ability to walk very far. Of course my first thought was this is probably PPS and old age setting in. I never felt it necessary to go to a doctor, even though I kept getting worse. As a matter of fact I got so bad I had to go out on disability in May of 2004 as I couldn't walk from my car to my office without stopping a few times to rest. Of course my doctor and I felt it was the onset of PPS and we proceeded under that assumption. However, within three months I went from walking with a cane to being confined to a bed as I had no strength to walk or even use my hands to eat. It was very discouraging as we couldn't find out what was causing such a rapid decline in

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Marilyn Rogers Passes Away

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those days, as many of my contemporaries believed, it was that she had mastered this exhausting technique of forcing air into and out of her lungs without being able to use chest muscles or diaphragm. She was breathing and even talking, but it required a mighty effort.

From the time she had polio in 1948 until she died at the end of March 2005, Marilyn spent the vast majority of her time in an iron lung. She was trached and did have a ventilator but it was not a comfortable method of respiration for her and tended to make her sick so she stuck with her iron lung. That did not stop her from graduating from West High School in 1959 (only one year behind her normal class after three years in the hospital) with a B+ average. After high school, Marilyn attended Augsburg College, Hamline University, and the University of Minnesota, and while she never completed her degree, Marilyn both got and gave a terrific education. She traveled to California to visit her brother Dan in 1970 and discovered a different world for the disabled out there. California was years ahead of Minnesota in its efforts to create an accessible environment for the handicapped.

On her return to Minnesota Marilyn began a career as an Activist. As a disabled person, Marilyn knew full well the world was "broke" and she wanted it fixed. According to an article in the StarTribune by Trudi Hahn, "By 1974 Marilyn was helping to

organize the United Handicapped Federation, one of the first citizen-action groups in the country to be organized by and for handicapped people." In the same article Hahn quotes Marilyn as saying in 1976, "I realized that was the way to go after watching blacks and women. We're not going to sit in our little bedrooms any more, leading marginal lives."

I talked with Frances Strong who remembers going to pick Marilyn up in those early activist days. Frances had just learned to drive and had gotten her own car but didn't know her way around the city too well. Marilyn, who wanted a ride to a meeting, volunteered to do the navigating. Frances remembers that they got Marilyn into the front seat and got her strapped in as best they could with the equipment available in those days and took off headed for St. Paul and the State Capital. It didn't take long before a turn or two had Marilyn slumped over in the seat leaning against a none-too-stable-Frances. "Hang on, Marilyn," yelled Frances, as she tried to manipulate hand controls and steering wheel and figure out how to get Marilyn pushed back upright again. Finally, an opening in the traffic gave her enough surrounding room that she could move her left hand from the hand controls to grab the steering wheel, thereby freeing her right hand, which she used to shove Marilyn back to a "more or less up right position." Assured that Marilyn was okay, Frances resumed her normal grasp of the controls and they were off once again with Marilyn shouting out the directions and Frances maneuvering the car. They made it to the meeting. They made it to lots of meetings and they made a big difference that we all are reaping the

benefits of today.

I deeply regret that a misunderstanding regarding my stand in regard to the position that Respirationics has taken relative to the repair and replacement of iron lungs led to an alienation between Marilyn and me. I feel sure that, had we ever been able to arrange a face-to-face meeting we would have resolved our positions. Unfortunately, that will never be. PPASS MN has lost one of its earliest members, the disability community has lost an able worker, and I have lost a friend.

1. Frog breathing is known technically as glossopharyngeal breathing. Glossopharyngeal breathing coordinates movements of the tongue, cheeks, and pharynx to force air from the mouth into the lungs.



Free Postage Gone

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short of that number. What we have decided to do is to print a few extra copies and mail the Chapter leaders a few extra copies to be used in their discretion. Several of the Chapter leaders have indicated that they would have liked to have had extra copies to give away to people to show what it is that we are doing. Now they will have that opportunity.

One of the most recently imposed rules of the USPS in order for us to maintain our Free Matter privileges was that we had to print our entire newsletter in 14-point type. This is a measurement of type size and in order for you to get a feel for what it means, the last several issues of

the newsletter have been printed in 14-point type. This newsletter has gone back to 12-point type.

This one sentence is printed in 14-point type so you have a one-to-one comparison right on the same page.

The difference is that we get approximately 20% more information in a newsletter when we use 12-point type. However, I know that there are a number of people who have difficulty reading smaller type so I would very much appreciate some feedback. This is your newsletter. Do you want it in larger type, or do you want more information in each issue. Let's hear from you.

The one down-side to this is that we will no longer be able to do mailings within a Chapter as there are no chapters that begin to approach the minimum required numbers for bulk mailings. Therefore, if any Chapter decides that they need to send out a mailing, it will have to do it at first class postage rates.



From Where I Sit

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my strength.

Finally, we decide to do an MRI and found that I had a number of vertebrae compressing against my spine thus causing the paralysis. I was immediately scheduled for surgery and thank God I did. The surgery opened five vertebrae and a titanium pin was used to spread the vertebra and take the pressure off the spinal cord. Surgery went well and I am now recovering. The doctors say it

will take 18-24 months to heal and get back to where I was. I am now able to walk with a walker and, on some strong days, I can use a cane for a small distance.

I am sharing this experience with you to alert you that PPS is not necessarily the cause of all your aches and pains. Every new symptom needs to be carefully evaluated. PPS is always a suspect but other things may be contributing to your medical condition.

Until next time I wish you all the best.



Group Happenings – Owatonna

By Dick Baumer

The March meeting was lightly attended so the meeting was primarily social. As we generally do, some time was devoted to discussion of health concerns, issues or successes resulting from recent doctor visits and discussion of periodicals or articles members may have run across. Breathing and swallowing problems are concerns for a few of our members so the topic of CPAPs and BiPAPs came up. Several of us use one or the other but some members don't know how these devices work so they will be the topic of discussion for our May meeting. How testing is done for swallowing problems was discussed again as a couple of members deal with that issue. Dilating (stretching) the esophagus was

of particular interest and as one might guess, the question was asked "how do they do that"? My doctor once described this procedure as a "cave man tactic" where we cram a tapered rubber tube down your throat! Yes Matilda, you are under slight anesthesia when they do this. You are aware what's going on but you don't care.

The April meeting saw the return of a few faces we had not seen during most of the winter because they were either traveling or just didn't want to venture out in the cold. The situation with polio in Africa seems to be a topic of interest so the 2005 statistics were presented and discussed. The latest figures from the World Health Organization shows 266 cases of polio being reported as of February 21, 2005. Nigeria and Ethiopia appear to have the highest numbers.

One member reported that she is taking part in a "Brace Study" at Mayo Clinic in Rochester. Brace users from various segments of the population will be using a new brace design. No other details are available at this time but the study involves young people, older people, and those in between who must rely on braces due to accidents or diseases such as polio. Look for more details on this interesting study in future issues

Another member who had complained about the weight of a built-up shoe has been successful in getting refitted with not only a lighter weight shoe, but a "more stylish" one as well.



Group Happenings –

March

By Larry Kohout

Our March meeting featured a panel discussion lead by Margy Hull and Larry Kohout. The subject of the discussion was “Putting Together Your Medical Team – Who’s In Charge?” and it was built on a paper by Margy and Larry re-printed elsewhere in this newsletter. While the leaders fretted that they may not have enough material to occupy the 90 minute session, there was sufficient interaction from the group that things had to be hussled up at the end to get everything covered before the time ran out. Just in case you don’t have time to read the accompanying article, you need to be able to answer, “I Am!” to the title question for the discussion. It was interesting to this writer to notice how the group has changed and matured in the five years since this subject was previously covered. There is now a real willingness on the part of the participants to take responsibility and a leadership role in their own medical care.

April

By Lois McIntyre

I missed a few meetings due to a vacation trip and then not being able to arrange transportation a couple times so it was good to be back and see everyone again. We did our usual introductions and signed a few cards for members that are having problems.

We decided to have our Spring Luncheon at the Timber Lodge Steak House, 7989 Southtown Center, Bloomington, MN 55431, 952-881-5509 on Saturday May 14th at 12:30.

Call Crystal Patrick (651) 638-0945 with your reservations.

Our topic for the April meeting was “Memorable Polio Experiences” of which we all have many, some recent and some from years ago. Darlene reminded us of the time she made a wrong turn with her scooter and went down a steep embankment, full speed, and rammed into a fence. No damage to her but the fence had a few loose boards. Members who were very young did not have many memories of their hospital stay, one was able to access her medical records and read about her treatment. Even the very young members did remember the cribs with the high sides and having blood drawn with the huge needle, the toys they were given as presents and could not take home with them (they had to be destroyed before leaving the hospital due to the possibility of contamination with the polio virus). Some felt embarrassed by strangers coming to visit or entertain and giving them gifts. We all remembered the hard beds, the hot packs, the stretching, our room mates in iron lungs, the short visiting hours on Sunday only, at least at Sister Kenny. One member that was at a different facility remembers a parrot that would screech “nurse, nurse” I wonder where he learned that? A recent experience for one member was being scolded by a stranger for parking in a Handicapped parking spot, even though she had the proper identification. I always enjoy listening to the stories, it is something we all have in common and understand each other.



Coming Meeting Dates

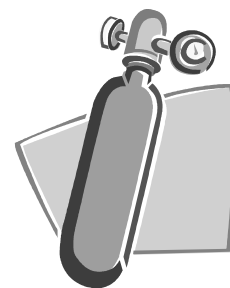
By Larry Kohout with Input from chapter Leaders

Brainerd/Baxter

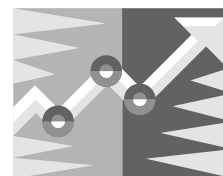
- May 2nd – Meeting in the Brainerd public library at 416 South Fifth Street. Meeting is from 10:30 until noon, and anyone that wants to can join us for lunch afterwards.
- June 6th – Meeting in the Brainerd public library at 416 South Fifth Street. Meeting is from 10:30 until noon, and anyone that wants to can join us for lunch afterwards.

Owatonna

- May 19th – Meeting in the Library at the senior high rise complex at 2211 Hartle Avenue on the south side of Owatonna – 6:30 to 8:00 – We will be discussing CPAPs and BiPAPs, how they work, and how they affect polio survivors breathing.



- June 16th - Meeting in the Library at the senior high rise complex at 2211 Hartle Avenue on the south side of Owatonna – 6:30 to 8:00 –



St. Cloud

May 13th –

June 10th –

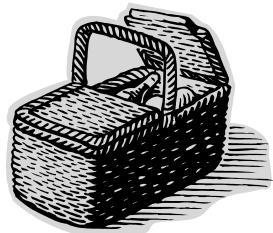
Twin Ports

May 16th –

June 20th –

West Metro

May 14th – Annual “Picnic”
meeting at Timber Lodge



Steak
House
7989
Southtown
Center,
Bloomington,
MN 55431,

952-881-5509 on Saturday
May 14th at 12:30. Call
Crystal Patrick (651) 638-
0945 with your reserva-
tions. (Southtown Center
is south-east of the inter-
section of Penn Avenue
and highway 494.)

June 13th – A talk by Margy
Hull on Finding Flow



Post-Polio Health International Awards Research Grant to Johns Hopkins Team

ST. LOUIS, January 27, 2005 –

Post-Polio Health International, headquartered here, announced that it has awarded a \$25,000 research grant to a team from Johns Hopkins University. The researchers propose to determine whether

early use of noninvasive positive pressure ventilation (NIPPV) prolongs survival in patients with amyotrophic lateral sclerosis (ALS) and to relate their findings to other neuromuscular diseases including polio and its late effects.

ALS, also known as Lou Gehrig’s disease, is a progressive neuro-degenerative disease that attacks nerve cells in the brain and spinal cord resulting in muscle weakness, atrophy and, eventually, death. The respiratory muscles are invariably affected, and respiratory failure is the most common cause of death in ALS patients. NIPPV is an increasingly common treatment for patients with chronic respiratory failure, and observational studies suggest that NIPPV prolongs survival, but it is not known whether it modifies disease progression or simply provides support in the terminal stages of the disease. Currently, guidelines recommend starting NIPPV when a patient’s forced vital capacity (FVC) – a measure of breath exhalation – falls below 50 percent of the predicted value.

The Johns Hopkins study aims to determine whether NIPPV is more beneficial in prolonging survival if it is started earlier in the course of ALS. The study will also attempt to determine if a point can be identified at which survival is maximized.

“If our study demonstrates prolonged survival in patients who begin using NIPPV earlier than currently recommended, it will have profound implications for how patients with ALS and other neuromuscular diseases are managed,” said Principal Investigator

Dr. Noah Lechtzin, instructor of medicine in the Division of Pulmonary and Critical Care Medicine at Johns Hopkins University. “It will suggest that a more proactive approach is beneficial. This study could alter this passive approach to patient care.”

“Although the patients in the present study have ALS, we believe that the results will apply to a majority of the people we serve with post-polio syndrome, as well as to those with other neuromuscular diseases such as muscular dystrophy, spinal muscular atrophy and multiple sclerosis,” said Joan L. Headley, executive director of Post-Polio Health International. Others on the Johns Hopkins team in addition to Dr. Lechtzin

(nlechtz@jhmi.edu) include Nurse Coordinator Lora Clawson, director of clinical research in the ALS Center, and Research Assistant Anne M. Lang, in the Division of Pulmonary and Critical Care Medicine. Dr. Gregory B. Diette, assistant professor of medicine, and Dr. Charles M. Wiener, associate professor of medicine, both also with the Division of Pulmonary and Critical Care Medicine, will act as consultants to the study.

Post-Polio Health International’s Research Fund was established in 1995 to seek scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases. This is the third grant to be awarded. Complete reports on the first two research studies – Ventilator Users’ Perspectives on the Impor-

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PHI Awards Research Grant

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tant Elements of Health-Related Quality of Life and Women With Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress are available on Post-Polio Health International's website, www.post-polio.org (click on Research).

Post-Polio Health International actively promotes education, research, advocacy and networking among the post-polio community to enhance the lives and independence of polio survivors and home ventilator users.

One Psychologists Perspective on the Polio Experience: Part 18 Mindfulness – Trust in Ourselves

By Margy Hull, Ph.D

We return to a description of the aspects of mindfulness meditation and a mindful approach to life as described by Jon Kabat-Zinn in his book, *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*. This time we will be thinking about trust in ourselves, in the basic goodness and wisdom inherent in our bodies and our minds. Again we will discuss both how this aspect was affected by our early polio experiences, and now how it relates to our dealing with the late effects of polio.

Certainly, for many of us, the initial experience must have been one of feeling our trust in our bodies had been violated, and suddenly they could not be counted upon to do many of the things that we took for granted. Added to that, the people that we had become so dependent upon – doctors, nurses, therapists – insisted that things like burning, smelly, itchy hot packs would be good for us, going against all that our bodies told us; they also told us that stretching our muscles until they hurt was somehow going to get us walking. Well, a lot of what they told us was validated with some degree of success. We developed a new kind of trust that our bodies and our minds would come through for us, and it would pay off, if we drove them hard and ignored the petty complaints they might make along the way.

Somewhere along the line, they decided to revolt, not to put up with the abuse we sometimes inflicted upon them. Older, wiser, more tired, and more in pain, it is time for rebuilding a new trust and mutual respect for ourselves, within ourselves, and between our minds and bodies. Kabat-Zinn has found this to be an essential ingredient for the beneficial effects of mindfulness.

When I was in graduate school, an undergraduate lived in my dorm in the room across from me, and she was very unhappy and anxious about being so far from home. She often came to me for support and reassurance, and it was often couched in terms of worry about physical processes like her sleep or her bowels. I chanced upon the phrase

“Your body knows what it’s doing”, that seemed to help her more than anything else I said. It seemed to work so well for her, that I started to use it for myself, and I still use it, especially in these times of new doubt.

Of course, there have been times when I had reason to doubt the truth of that phrase, especially when I had allergic reactions. But I do believe that my body always has the best of intentions for its and hence my overall well-being. In the times when troubles occur, I have taken to saying a litany of the things that it does well like keeping my heart beating all these years, and healing my sores and my broken femur, and fighting off by far the majority of colds that I am exposed to. And I do believe the truth of what my old nurse in elementary school used to say to me that “we are wonderfully and fearfully made”. So for me there is good reason to trust our bodies’ inherent goodness.

The next step, though, is to learn to trust and to listen to what our bodies are saying to us in the form of messages about level of fatigue, discomfort, and pain. No more can we afford to think that it is wimpy to pay attention to signs of exhaustion just because another part of us, usually our driving, conscious mind insists that it is imperative that this task be completed. Our need to listen to those signs is just as great when the messages to strive on come from outside ourselves, whether from a self-help book, an exercise video, a therapist, or even a physician.

Sometimes it is also important for us to learn to trust the mes-

sages we get from our intuition or some other part of our emotional being. If someone is telling us that we should move into an assisted-living facility and the idea just rubs us the wrong way, as long as we have other alternatives, we need to trust those feelings, perhaps explore them more deeply, but definitely not ignore them. A meditational strategy may work wonderfully well for my friend, and just be chalk on a blackboard for me.

Mindfulness, from which flows peace and healing, depends upon a trust of the messages that come from within. That sense of ourselves as basically good and worthy of respect then radiates outward to a trust in others and the world.



Putting Together Your Medical Team—Who's In Charge?

By Margy Hull Ph.D., & Larry Kohout

I remember the good old days when my grandmother assured me that old Doc Rooke knew everything that was worth knowing and a trip to his office cost you five dollars. But that was a simpler time and Grandma's health concerns were simpler than mine are now. If you can make it through life with nothing more than an occasional hangnail, or perhaps even a broken arm, you might be able to afford to let your doctor be in charge. However, for those of us living with a disability or a chronic medical condition the answer to the title ques-

tion can only be, "I am!"

When I say, you must be in charge, I do not mean that in any tyrannical sense nor in any patronizing sense. I simply mean that you must assert yourself and make it clear to your doctor that the two of you are in this together and that when it comes to final decisions, they are yours. You go to a doctor because you do not have the necessary medical training to diagnose nor to treat yourself. Even if you did, it would be a foolish mistake to treat yourself. But, when it comes to taking charge of the team providing your medical care, you must take charge.

A parenthetical note for any doubters: you could yield authority to your physician. Certainly, that was the practice up through at least the fifties. However, there are several very good reasons for not doing that. You are the one who is with you all the time and knows the most about your symptoms and your response to different treatments; you are the one with the biggest investment in the outcome. But more subtly, there are potent psychological factors in play when we feel and exert a sense of control. These factors have been studied extensively in research on how people's health is affected by stress, so-called stress hardiness. When people believe that there are things that they can do to make their situation better, their immune system is stronger, they recover more quickly from any injury or disease, and they even live longer. (The other two factors besides control, are feeling that a negative situation is a challenge rather than just a problem,

and feeling a commitment to a larger cause.)

So, what is the team? My American Heritage dictionary defines team as: [A group on the same side, as in a sport; A group organized to work together.] So, a medical team could be as small as you and your doctor. However, as most of you are aware, specialists keep getting added to the team. Sometimes they are just brought in to assist with the diagnosis, and sometimes they become longer-term players. At this point, it should be clear that the more players there are on a team, the greater need there is for a strong team leader. You must prepare yourself to play this role.

What You Need to Know -- to those of you who think you don't know enough to do this job, I say think again. You will need to develop some expertise but no one expects you to earn your medical degree. As team leader, you need to know three things. You need to know how you feel and that should be relatively easy since we are always telling one another just how we feel. You also need to know what has changed in the recent past, and to know that you should probably consider keeping a journal. Lastly, you need to know how to evaluate what the medical professionals are telling you.

Keeping Track of How You're Feeling. In order for you to keep track of how you're feeling, and especially how things are changing over time, it would be a good idea for you to acquire a spiral-bound notebook. Make simple entries in this book and always

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Putting Together Your Medical Team

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start an entry with the day's date. You don't need to write an essay, simply record the facts of your health and well-being. You don't even need to keep this on a day-by-day basis. If you have gone through a bad spell, you should have been noting what was making it bad. If several days all have the same symptoms, you can simply note "same as above." Let's assume you then wake up feeling good, and it stays that way all day long. It would be worth entering this in your journal with an entry like "have felt great all day." You needn't make another entry until something changes.

Keeping a simple journal will make it a lot easier for you to report accurately to your physician about how you have been feeling and how things have been changing. It can be helpful if you also use this journal to track your emotional well-being. All of us have our down days and there's nothing wrong with this, unless you are not having any up days.

Evaluating What Your Team Tells You. The issue of evaluating what your medical team is telling you can get a little more difficult. One of the biggest problems in this regard is that we can feel intimidated by the people that we're working with. If that is the case, something needs to change. Remember that we all put our socks on one foot at a time. Yes - - doctors have a lot of schooling, but a doctor isn't worth a plug nickel without a patient. Each of us has our own roles to play and

we need to play them with dignity and with mutual respect.

The process of evaluation can only start when you are sure you understand what you have been told. If you do not understand something a doctor has told you, you have to ask questions. Be as specific as you can in identifying what it is that you don't understand. Also remember, there will be times when you simply do not have the background training to understand a term that the doctor has used. That's not a big deal; just about any term can be defined in a sentence or two, so ask. The more questions you ask, and the more terms you come to understand, the easier your communication will become.

Once you are sure that you understand what your medical team is saying to you, you'll need to check out against that which you know, or at least think you know. If the information you have just received strikes you as somehow wrong, you must, as soon as possible, get this straightened out. One of the best ways to clarify a point is to say "excuse me, I think I just heard you say X, Y, Z. I have always understood that it was A, B, C." A sentence like that explains both what you thought you were told, as well as what your previous understanding of the situation was. This is both honest, and it does not challenge what your team member has just told you. It sets your communication squarely in a framework of your understanding. The team member you are talking with now has two choices. One, they can tell you, that you didn't understand correctly what they just said; or two, can explain why

your previous understanding was incorrect. You need to keep an open mind while listening to these things and if the new explanation makes sense then you need to accept it. However, if there is still a nagging doubt after the explanations have been served up, by all means, ask more questions. Raising issues in this manner keeps you out of the confrontational relationship and on the path of clear and honest communication.

What Do Players on Your Team Need from You? In order for you to be an effective team leader, you need to understand what their needs are also. The very first thing a new team member is going to need is your complete medical history. You would be well advised to sit down and write out your complete history and get it typed out so that you can make copies of it to give to the new players on the team. This also implies that you will keep your history up-to-date as things move forward.

When you make your list, make it as complete as possible. List all of your childhood illnesses, chronic conditions, and any surgeries that you have had. You do not want this to simply be a history of your polio experience, but rather your complete medical history. If you have the measles when you were three years old then put down "Measles -- 1943" or whatever year it was that you were three years old.

The next thing your team needs is to clearly understand what it is that you expect of them. You need to make it clear that you are looking for advice, for an understanding of what you can expect in the future, and for treatment

recommendations. Although you usually don't need to say it, you're not looking for them to patronize you nor to make any decisions for you.

Although I'm sure you do not want to hear this, your medical team will often look to you to be the expert in post polio syndrome. While there are a few post polio experts in our area, most of the people you meet will not have a very good understanding of the condition. Stop and realize that the most recent compendium of diseases and conditions that the doctor can reference, lists more than 2800 separate diseases and conditions. It is not possible for any single person to have an extensive knowledge of this many conditions.

There is a great deal of literature that you can study to learn about post polio syndrome. When you find good, well-documented articles, it would be helpful to make copies of these for your medical team. A well-documented article will clearly identify and provide background about the author and will cite source information for every statement of fact that is made. You will sometimes read things that don't seem to make sense but if you are able to check on the source documents that support these statements, you will be in a better position to make judgments about the accuracy of the information.

Another thing that your medical team needs is for you to keep an open mind. Don't arbitrarily dismiss any suggestion. If you are skeptical about a particular suggestion, it is fine to make your doctor aware of your skepticism, but don't dismiss the suggestion.

Discuss your reasons for being skeptical. Sometimes you may convince the doctor that a particular suggestion does not have merit. On other suggestions, your doctor may convince you that there is at least reason to do some additional testing. Remember, not everything that you experience can be attributed to post polio syndrome. Also, remember that PPS is a diagnosis that can only be made when everything else has been ruled out.

Who Should Be On Your Medical Team? The size and composition of your medical team depends on you. For instance, if you have not experienced anything to suggest that you have breathing problems, there would be no reason to have a pulmonologist on your team.

Almost everyone should have a Primary Care Physician. This person is the health care professional who will get to know you best and who will be your primary adviser in determining whom else should be on your team. In all likelihood, your primary care physician will also oversee all of your medications. Depending on your outlook, your primary care physician might be a general practitioner, an internist, a diagnostician, or an osteopath. This list is not comprehensive; it is simply an indication of the types of talents that you might be looking for.

You might also have a physiatrist on your team. A physiatrist is a medical doctor who specializes in physical medicine. Often they will be practicing in a sports medicine clinic or in something closely related. Although a physiatrist can prescribe medication, it would be more likely to have

them prescribe physical therapy, occupational therapy, orthotics, or other mobility devices.

Working in conjunction with a physiatrist, you might have a physical therapist as a regular part of your team. A physical therapist is a technician trained in guiding you through stretching and strengthening exercises. They might also use ultrasound, hot or cold packs, or whirlpools.

Another specialist that might be on your team is a neurologist. A neurologist is a medical doctor who specializes in the nervous system. Polio and post polio syndrome are neuromuscular disorders, and as such, it might be appropriate to have a neurologist on the team. Some people with a diagnosis of PPS experience the type of pain that has been diagnosed as "nerve pain." A neurologist might be able to help in diagnosing this condition and in recommending ways to ameliorate the problem.

There are also any number of other specialists that might be added to the team as indicated by your particular symptoms. These could be any of the practitioner of "western medicine," people who practice in the homeopathic field, or yet others who practice the various disciplines of "eastern medicine."

What Should You Look for in a Primary Care Physician? In selecting a primary care physician there is one all-important criterion, can the individual communicate with YOU? There is no other singularly important characteristic. The individual might be the best practitioner in the world,

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Putting Together Your Medical Team

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but if you are not able to communicate with that individual, he or she is virtually worthless to you.

The person that you select to play the role of primary care physician will be working as a generalist. Without regard to that individual's specialty, the role that they will be playing in your care is that of a generalist. They must understand all of the varying medical specialties and understand when to call in one of those specialists. Finding this individual may be a problem for you, since 70 percent of all licensed medical doctors are specialists. You are looking for someone who can help guide you and can help you interpret the medical advice that you will be getting.

How Do You Find a Primary Care Physician? The answer to this question depends a lot on what you have for insurance coverage. In many Health Maintenance Organizations (HMO's) selecting a primary care physician is a normal part of the care that you receive. If you belong to a fee-for-service provider you may have problems.

It would be a very good idea to develop a list of questions that you can ask of the person you are considering as a primary care physician. Talk with other people who are in similar circumstances to yours and get their recommendations for a person that you might want to see. If possible, interview your final selections over the phone. If that is not possible, and if it is financially prac-

tical, make an appointment to get your questions answered. Some of the questions that you might consider asking are: Are you comfortable with patients who want to take charge of their medical team? Are you familiar with post polio syndrome? If not familiar, are you willing to do some reading and some research about it? Have you ever treated anyone with PPS?

During the process of interviewing physician's or other practitioners, you must keep the good set of notes. How else can you compare and evaluate the various people with whom you have talked? Also, while respecting the physician's' knowledge and experience, you must convey to them that you also have faith in your own hard-won insights about what you need.

What Do You Need to Understand About the Conditions Your Team Works Under? We have all listened to, and many of us have participated in the practice of "badmouthing" the doctors and the medical profession. How many of us have spent any time trying to understand the conditions that the medical profession is working under these days?

In the United States, it is typical for doctor to have as little as 10 to 15 minutes per patient. This includes the time that they are in the examining room with you, and the time spent dictating notes and other things associated with your care. If you feel you need more time, be sure to make this clear to the receptionist scheduling the appointment. Ask the receptionist how much time they typically allocate for an appointment. If this is your first appointment or if you

have a long list of questions that you need to get answered, ask the receptionist to schedule the appropriate length of time; perhaps two or even three normal appointments. Also, be considerate of the time they are spending with you. It is a good idea to always come with a written list of questions or concerns. Identify these questions or concerns at the very beginning of the appointment so the doctor knows how to manage her/his time.

As much as you might dislike it, to the question: who's in charge, you must respond, I am. After all, it is your life.

Sources:

1. Building Your Medical Team by Darlene Hanson
2. The Keys to Managed Care, A Guide for People with Physical Disabilities, National Rehabilitation Hospital Center for Health and Disability Research, Washington, DC
3. Finding Doctor Natural vegetarian Times Oct. 1997
4. Looking for Doctor Natural prevention magazine, April 1998
5. Presentation by Dr. Robert Chen, PPASS BC March 2000
6. "Stress-Resistant Personality" by Suzanne C. Ouellette Kobasa in The Healing Brain: A Scientific Reader, edited by Robert Ornstein and Charles Swencionis (New York: Guilford Press, 1990)



Floating About on the Internet

By Larry Kohout

I'm an inveterate reader of the various polio groups on the internet and browser of the various polio related web sites. While there is a whole bunch of trash out there that you really have to watch out for, there are a number of good things out there also. Two things I've found in the past bimonthly period that I'd like to pass along to you. One is a do it yourself recipe and the other is a website that is a valuable resource and on which I uncovered two E-Mail discussion lists specifically for the polio partners.

The Recipe In the West Metro Chapter recently there was a discussion of the various devices you can purchase to apply heat to areas of your body that hurt. There was specific mention of a tube filled with rice. So I was particularly alert when a note appeared from Robert Gaines in Fort Lauderdale, Florida, and Robert has given me permission to pass along the following information:

How many have a microwave? Put about a medium size bag of rice, uncooked, into a tube sock, tie the end of it, and place this inside the microwave for No more than 3 minutes. It gives out a nice heat that can be located to the parts that are cold or uncomfortable. You can make several of these inexpensively.

If you are a crafty person, add about 1/4 cup of dried lavender

flowers to the rice before you tie the sock. My oh my how nice that smells and it is great when placed around your neck.

Be certain to use this heated rice with a towel because if you are not careful it can get pretty hot.

I use mine all the time.

In his reply note to me, giving me permission to use his recipe, Robert passed along these extra bits of crafty advice:

I have found while playing with my rice (I know momma told me not to play with my food.) that dried rose bud with a few drops of the oil of the lavender is just heavenly, smells like spring and lifts your spirits. I would think especially for those in our family who live in the cold north. Also, we have a tropical oil called Ylang Ylang. Most incredible smell, it too lifts the heart and is the basis for most of the ladies perfumes on the market.

Now to the two E-Mail discussion lists I found described on "Post-Polio Syndrome Central" which you can find at <http://www.skally.net/ppsc/> and you will find the link to the discussion lists right on the main page. The two that caught my eye on this read were:



PostPolio OtherHalves - This group is for supporters (spouses, family members, or friends) of those that are suffering from the late effects of Polio. The purpose is to allow a forum to discuss problems, fears, and concerns faced each day in dealing with your loved ones postpolio.

The majority of the members have spouses that are members of a main group called "PostPolio Bransongoes" who meet each year in Branson, MO. Membership is by approval only. Subscription: PostPolio_OtherHalves-subscribe@yahoogroups.com

http://health.groups.yahoo.com/group/PostPolio_OtherHalves/

PPS-CG - Care Givers for those with Post-Polio-Syndrome, "A caregivers E-mail list ... for those who love and care for people with PPS. The purpose of this group is to share experiences, questions, joys, and sorrows as we care for those who are suffering with this condition." To subscribe send an e-mail to: pps-cg-subscribe@yahoogroups.com with nothing or only a period (.) in the SUBJECT: area and in the message body. Or, use the form on the PPS-CG web page: <http://groups.yahoo.com/group/pps-cg/>

Please note, if you do not already have a membership in Yahoo Groups you will probably need to sign up before you can subscribe to these groups. It is not a big deal, point your browser at: www.yahoogroups.com When you get there you'll see a sign up button on the left. Click it and fill out the profile information. When you are done with that, (you don't have to give a whole lot of detail and fill in everything) send the E-mail or use the forms as noted above.

Now, if you have a few minutes to do some browsing, do check-out Post-Polio Syndrome Central.



Finding Support for Yourself

By Susan Fleming, Victoria, B.C.

Editor's Note

Over the years I have often heard this subject come up in various group meetings. While browsing on the Post-Polio-Med list I ran across the following post. I thought it was so well articulated that I wrote to Susan and asked if she would allow me to publish this. Obviously, she agreed.

Hi, [name withheld] - I think you are talking about finding support for yourself. We all need to be heard, and we need those around us who have the ability to listen with loving kindness.

Here is what I have learned: the support I have needed has not come from the people I wanted it from - my family, work colleagues, friends. This has been a disappointing realization, of course. Who doesn't want that kindness from those closest to us. (!) The truth is that, most people DO NOT KNOW HOW to give the support we need. Indeed, most do not know how to deal with their own feelings about seeing us in pain. Suffering is something most folks flee from - it's just too scary/painful. When I realized that this was the case with my family (my work colleagues left me in their dust long ago), I searched out a support group for people with chronic conditions. These are the people who give the best kind of support, because they know first hand what you might be going through. I looked all over for such a group and finally, in desperation, decided to start my own. I put a free ad in our local

rag and talked to many people looking for something similar - then I got a call from a woman who was a member of an existing group, on the other side of town. I had to admit, given my energy/pain level etc., that this was the better choice - even tho' it involved an hour of travelling time. So off I went, reluctantly at first, but willing to make the effort. After the first visit, I didn't think I would go back - everyone seemed so ill - it was depressing. Lucky for me, the facilitator stayed in touch with me. She phoned me every week, no pressure - just a friendly check in. That connection helped me realize that it was MY illness and MY depression that was in my way. I went back and have been attending, quite regularly, for 2 years. It has taken this time for me to build the trust I needed. I now have solid, rich relationships within that group. I receive loving kindness (not to mention great laughter and much wisdom) from them and, perhaps more importantly, I have the opportunity to give the same back. This is really important - to give back when the time is right. I arrived there needing so much, I simply wasn't able to give - but they were. Over this time I have grown so much. I am accepting of my family's limitations in this regard, and hold no animosity towards those who are unable, for whatever reason, to BE THERE for me. Being connected with my support group, and now with others who have come into my life, I am feeling more whole and healthy (in spite of my physical decline) than I have in years.

Be kind to yourself; be your own

best friend! Look for people who have similar concerns and understand that your needs will not all be met by one person, or one group. I have, and continue, to cultivate relationships that meet my many different needs. You may be surprised where you find what you need - don't waste precious energy banging your head against brick walls. I must say, too, that my relationships within my family are so much better since I stopped looking in their direction for these particular needs. Good luck, there is a light at the end of the tunnel - just make sure the tunnel you are in doesn't have train tracks! Cheers - Susan -----



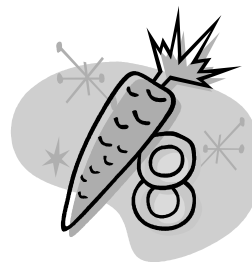
Carrots, Eggs, and Coffee Beans

From the Internet

You will never look at a cup of coffee the same way again.

A young woman went to her mother and told her about her life and how things were so hard for her. She did not know how she was going to make it and wanted

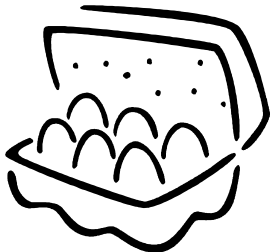
to give up. She was tired of fighting and struggling. It seemed as one problem was solved, a new one



arose. Her mother took her to the kitchen. She filled three pots with water and placed each on a high fire. Soon the pots came to

boil. In the first, she placed carrots, in the second, she placed eggs, and in the last, she placed ground coffee beans. She let them sit and boil, without saying a word.

In about twenty minutes, she turned off the burners. She fished the carrots out and placed them in a bowl. She pulled the eggs out and placed them in a bowl. Then she ladled the coffee out and placed it in a bowl. Turning to her daughter, she asked, "Tell me, what do you see?"

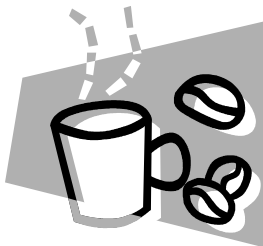


"Carrots, eggs, and coffee," she replied.

Her mother brought her closer and asked her to feel the carrots. She did and noted that they were soft. The mother then asked the daughter to take an egg and break it. After pulling off the shell, she observed the hard boiled egg.

Finally, the mother asked the daughter to sip the coffee. The daughter smiled as she tasted its rich aroma.

The daughter then asked, "What does it mean, mother?"



Her mother explained that each of these objects had faced the same adversity ... boiling water. Each reacted differently. The carrot went in strong, hard, and unrelenting. However, after being

subjected to the boiling water, it softened and became weak. The egg had been fragile. Its thin outer shell had protected its liquid interior, but after sitting through the boiling water, its inside became hardened. The ground coffee beans were unique, however. After they were in the boiling water, they had changed the water.

"Which are you?" she asked her daughter. "When adversity knocks on your door, how do you respond? Are you a carrot, an egg, or a coffee bean?" Think of this: Which am I? Am I the carrot that seems strong, but with pain and adversity do I wilt and become soft and lose my strength?

Am I the egg that starts with a malleable heart, but changes with the heat? Did I have a fluid spirit, but after a death, a breakup, a financial hardship, or some other trial, have I become hardened and stiff? Does my shell look the same, but on the inside am I bitter and tough with a stiff spirit and hardened heart?

Or am I like the coffee bean? The bean actually changes the hot water, the very circumstance that brings the pain when the water gets hot, it releases the fragrance and flavor. If you are like the bean, when things are at their worst, you get better and change the situation around you. When the hour is the darkest and trials are their greatest, do you elevate yourself to another level? How do you handle adversity? Are you a carrot, an egg, or a coffee bean?



Happiness Is Something You Decide On

From Cilla Webster in So. Africa

Editor's Note

Cilla posted the following to one of the internet chat groups but can't remember where she got it. She has, nevertheless, granted us permission to reprint it.

A 92 year old, petite, legally blind, well-poised, and proud lady was fully dressed this morning by 8 o'clock. Her hair was fashionably coifed and make up perfectly applied. She was moving to a nursing home today. Her husband of 70 years recently passed away, making the move necessary.

After many hours of waiting patiently in the lobby of the nursing home, she smiled sweetly when told her room was ready. As she maneuvered her walker to the elevator, she was provided a visual description of her tiny room, including the eyelet sheets that had been hung on her window."

"I love it" she stated with the enthusiasm of an eight year old who had just been presented with a new puppy.

"Mrs. Jones, you haven't seen the room yet, just wait!

"That doesn't have anything to do with it," she replied.

"Happiness is something you decide on ahead of time. Whether I like my room or not doesn't depend on how the furniture is arranged....it's how I arrange my mind. I already decided to love it.

(Continued on page 14)

Happiness Is Something You Decide On

(Continued from page 13)

It's a decision I make every morning when I wake up.

I have a choice; I can spend the day in bed recounting the difficulty I have with the parts of my body that no longer work, or get out of bed and be thankful for the ones that do.

Each day is a gift, and as long as my eyes open, I'll focus on the new day and all the happy memories I've stored away just for this time in my life.

Old age is like a bank account: you withdraw from it, what you've put into it.



Polio Particles

By Mary Westbrook

Editors Note:

This article is reprinted with permission from POST—POLIO NETWORK (NSW) INC. and the author. *Polio particles* is compiled by Mary Westbrook as items in the press or professional journals catch her eye. Mary's series is now being syndicated around the world as other post-polio newsletter editors pick up on the interesting items Mary includes. Mary can be reached at:

MTWestbrook@bigpond.com

Second wave of post-polio in Australia?

Professor Elizabeth Dean, prominent post-polio researcher, who has presented several seminars to the Network, was quoted by Canada NewsWire (15/3/04) as predict-

ing a second wave of people with post-polio syndrome in Canada. This is due to the large number of migrants from countries where polio is, or was until recently, endemic eg India, Pakistan the Middle East and Africa. Many of these people had polio when they were young and are unaware that *they may face the challenges of post-polio syndrome. Immigration support groups need to be alerted to post-polio clinics and their role*, says Dean. From emails to *Ask Mary* it is apparent that some Asian polio survivors who have migrated to Australia do not know that they had polio. As they try to make sense of the onset of post-polio symptoms they begin to recall vague stories of a childhood illness and to wonder what really caused mild polio symptoms they have lived with since childhood.

Death of Hugh Gallagher

American polio survivor, Hugh Gallagher, died in July. He contracted polio aged 19 and spent three months in an iron lung. On one occasion it broke down and he had to instruct the agitated nurses on how to pump the lung by hand. Gallagher played a vital role in the development and drafting of the US legislation, *The Architectural Barriers Act of 1968*. This was the precursor of the *Americans with Disabilities Act of 1990*. Gallagher's autobiography, *Blackbird Fly Away*, was reviewed in *Newsletter 41, 1999*. His best known book is *FDR's Splendid Deception* which describes how President Roose-

velt hid his disability. Among 35,000 photographs of Roosevelt in his presidential library Gallagher found only two showing him in his wheelchair. Gallagher said he understood Roosevelt's stoicism and near-disavowal of his disability because he himself had lived much of his life in the same way. *For years I tried to work harder than any able-bodied person would. My drive to become a super hero exacted a terrible price. I paid no attention to my emotions. I became an automaton.* Gallagher played a major role in having a statue of Roosevelt in his wheelchair added to the Roosevelt Memorial in Washington. *'Don't let them steal our hero!'* he repeatedly told reporters during this campaign. In another book, *By Trust Betrayed*, Gallagher wrote about the rarely remembered thousands of people with disabilities who were exterminated by Germany in the Holocaust.

Nigeria reels from new cases of polio

By July 2nd there had been 62 new cases of polio in Nigeria in the preceding fortnight bringing the total number of Nigerian cases for the year to 259. Health officials were waiting for results of tests on an additional 85 paralysed children. The 259 Nigerian cases accounted for 77% of polio cases in the world so far this year. The Nigerian state of Kano suspended immunisation in September 2003 due to Muslim leaders' belief that Western vaccines spread AIDS and cause infertility. In May Kano

agreed to resume vaccination using vaccine from Indonesia. However by July vaccination had still not recommenced as Muslim clerics considered more tests were necessary. WHO is fearful that the coming rainy season will provide ideal conditions for the spread of the virus and is attempting to create a firewall around Nigeria through vaccination of children in the surrounding countries.

Polio and a life of crime

I find references to polio in novels intriguing because of the attitudes they convey and the messages they may give readers. 'Doctored evidence' is the most recent addition to a series of very enjoyable detective stories set in Venice, by Donna Leon. The murderer in this novel is thought to be a past member of the School Board

and to have been blackmailed by the murder victim. A detective describes to Commissario Brunetti the various Board members but has left one out. Brunetti asks:

'And the other?'

'He's in a wheelchair'.

'What?'

'He's the guy who got polio when he went to India. You read about him, didn't you?'

The story rang a faint bell, though Brunetti had forgotten the details. 'Yes, I remember something. How long ago did it happen? About five years?'

'Six. He got sick while he was there, and by the time they managed to diagnose it, it was too late to evacuate him, so he was treated there, and now he's in a wheelchair....That might not be enough for you to ex-

clude him, but I think a man might have other things to think about after landing in a wheelchair than continuing to pay blackmail'

... 'I think I'd like to talk to the one who's not in a wheelchair. The rugby player'.

Will this exchange remind readers to have their polio shots before travelling to India? Should polio survivors who use wheelchairs feel safer from detection if they embark on a criminal career? Leon makes no further reference to the polio survivor and unlike other School Board members he is not even given a name. That's the problem: people consider that being in a wheelchair is all there is to say about such a person; they believe that being in a wheelchair is of itself a full



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Our support group feels an exchange of information between groups is important, and it is our hope for the future that all groups will join those of us who take the time and effort to research, contribute, and educate responsibly

PPASS Times

Newsletter of the Post Polio Awareness & Support Society of Minnesota

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