

December 2009 –
January 2010
Southern Arizona
Post-Polio
Support Group
Est. 1985

P.O. Box 17556
Tucson, AZ 85731-
7556
(520) 750-8608
(msg)
www.polioepic.org

**General
Membership
Meetings
every**

Second Saturday
of the Month
10:00A.M. -
12:00N

Education Room
HealthSouth
Rehabilitation
Hospital
2650 N. Wyatt
Road
Tucson, AZ

December 12th

Polio Epic's annual
Holiday Party
11:30am-2:30 pm
Holiday Inn
Palo Verde
Board Meetings
are the first
Thursday of every
month at DIRECT
offices on Tyndall
at 10:00 AM and
all are welcome!

POLIOEPIC, INC.

The Unexpected

A couple weeks ago I had an unexpected and incredibly frustrating experience with my insurance company. You probably know the kind of experience I'm talking about; the kind that happens when your insurance company changes the "rules" of your policy when you least expect it. The change required me to "try" a new pain medication even though the one I was taking was working well for me. To summarize, the insurance company refused to fill my regular pain medication and after three days of no pain medication they asked me to try something else, which did not respond to my pain.

By now you probably think this article is about the miserable time I had with my insurance company. It's not. I just needed to set the scene for you so that I could share with you the important part of this experience. This article is about **GRATITUDE**. It's about how thankful I was that during this most difficult time, I did not mistreat any of the people I had to talk to at the insurance company. I did not scream at the automated phone system when it disconnected after several minutes of "push #2", "push #4" and "thank you for your patience." Each day I prayed for the ability to cope with whatever came my way and for the knowledge to do whatever I could do to solve the problem. So at the end of this two week period, I focused on my gratitude. I am so thankful for that.

I am most thankful for my primary care doctor, Dr. Jim Martinez, who listened to me, saw me without an appointment, tried to advocate on my behalf, completed insurance paperwork within an hour of getting the request and finally, after 10 days, convinced the review committee that the pain medication I had been receiving was indeed appropriate and necessary for my post-polio syndrome. I'm back on my medication and able now to type this article one-handed without too much pain.

That's gratitude for you! It always helps you feel better!

Fondly, your president

Karla Carr

Feeling grateful or appreciative of someone or something in your life actually attracts more of the things that you appreciate and value into your life.

Christiane Northrup.

Board of Directors		
Frank Frisina	327-3252	Shinybear@msn.com
Virginia Hanson	292-0652	vrh13@earthlink.net
Bobbi Harmon	546-8111	Bobbi9672@cox.net
Lorna Kenney	744-7435	kc7wxy60@yahoo.com
Charlie Minner	743-1556	Canthmin@msn.com
Micki Minner	743-1556	Mickiminner@msn.com
Dave Marsh	327-3252	Davejonmarsh@msn.com
Barbara Stough	887-4731	chasbarstough@juno.com
Joanne Yager	296-1471	jyager@mailstation.com
Web Master 2010		
Hank Testa		
anything to be posted on the website, contact a board member		
Executive Board 2009-2010		
President, Karla Carr	318-1219	KarlaKrazies@peoplepc.com
Vice President, Frank Frisina	327-3252	Shinybear@msn.com
Treasurer, Nannoe Westbrook	797-6898	Nannoe1@aol.com
Secretary, CeCe Axton	495-5122	axton@cox.net

Follistatin Genes Strengthen Muscles in Monkeys

Injections of genes for the muscle-growth protein follistatin strengthened leg muscles in monkeys. Four macaque monkeys that received injections of genes for a protein called follistatin into upper leg muscles experienced pronounced and durable increases in muscle size and strength with no adverse effects, say researchers at Nationwide Children's Hospital in Columbus, Ohio, and Ohio State University.

The findings could have implications for people with muscular dystrophies and other muscle diseases, as well as muscle damage due to other illnesses, injury or aging. Jerry Mendell, a neurologist and MDA research grantee at Nationwide Children's Hospital in Columbus, Ohio, and Brian Kaspar, a research scientist at that institution who has also received MDA funding, led the study team, which published its findings Nov. 11, 2009, in Science Translational Medicine. Mendell is co-director of the MDA neuromuscular disease clinic at Nationwide, where he also heads one of five elite centers of excellence in Duchenne muscular dystrophy that comprise the MDA DMD Clinical Research Network. MDA has invited him to apply for funding to conduct a trial testing the safety of follistatin gene injections in people with a muscle disease.

Follistatin is a natural body protein that promotes muscle growth and strength by interfering with the actions of another natural protein, known as myostatin, which limits these. Myostatin blocking is a strategy for maintaining muscle tissue in the face of degenerative disease that MDA has been pursuing for several years. Administering genes for the follistatin protein is one of several ways to inhibit myostatin, a strategy that has the potential to help people with all nine forms of muscular dystrophy and possibly other types of muscle disease, such as inflammatory myopathies.



The monkeys used in the study published today did not have a muscle disease, but the researchers say they believe follistatin genes would probably help people who do, because such genes has previously helped mice with a disease resembling Duchenne muscular dystrophy, the most common childhood form of MD. Meaning for people with muscle disease. Follistatin genes and the protein molecules made from them could become a nonspecific treatment for muscle loss from a variety of causes. Since follistatin is a protein made by people with and without muscle disease, the immune system is likely to accept it without a fight. (Rejection by the immune system is sometimes a problem when researchers attempt to replace a missing protein.)

In addition, the results in the monkeys suggest that follistatin could specifically improve function in the thigh muscles, an important muscle group. "It's exciting to see profound improvement in muscle size and strength with no adverse effects on any organs or systems, including the heart," said R. Rodney Howell, a medical genetisist who chairs the MDA Board of Directors. "Improvement in treated thigh muscle is noteworthy, because the large muscle is so important when people sit and rise from sitting, and for mobility."Tests in humans will be necessary before the U.S. Food and Drug Administration (FDA) can consider follistatin gene or protein therapy as a treatment for patients.

The "Diva" of Mobility Devices



The author had to undergo a revolution in her thinking before she accepted the idea of using a wheelchair. - By Kathy Galletly

Mobility devices! You want to talk mobility devices? I am a polio survivor, and I can tell you about mobility devices before the word "technology" existed.

I remember the cumbersome steel braces, the wooden crutches, and those rickety wheelchairs. The only time a polio survivor had a "power" wheelchair is if the neighborhood kids decided to have some fun and pushed you down a hill at warp speed. Oh the thrill of it all; the wind in your hair, the bumps in the sidewalk, your mother screaming at the kids pushing you. Those were the days! After they got you at the bottom of the hill watching them run like the dickens so they wouldn't be in big trouble. Who knows? Maybe that's how the Para-Olympics began.

Some of us with polio were able to leave the mobility devices behind us and go on with our lives. Old rickety wheelchairs, braces, and crutches were something of the past, hidden in the dark corners of our memories. Little did we know that after discarding those mobility devices polio was going to come back and haunt us in the form of post-polio syndrome (PPS), causing fatigue, weakness, and pain in parts of our body that were affected by polio, and even in parts we thought that polio didn't affect.

When I was first diagnosed with PPS, my first reaction was "I'm not using any mobility device! I don't need a lousy brace; I am not using a cane or crutches. And I'm sure as hell not using a wheelchair!" I refused to "give in" to mobility devices. So, I kept falling. And as long as I was able to get back up by myself I wasn't

going to give in. I was not going to be a disabled kid again, being pushed down the hill by the neighborhood bullies, wondering if the blurs of the trees and houses as I whizzed by in my mobility device would be the last thing I would ever see.

In time it became harder to keep up with everyone else. Then I started to need help in getting up. What was even worse, I found myself yelling at my family for helping me. To say I was not a pleasant person to be around was an understatement. By this point I realized I needed help in dealing with the dreaded mechanical enemy. So off I limped, tripped, and fell over my own feet to look for help to accept the devices I needed. It took much therapy, and I offered a lot of diva resistance until I finally came to the conclusion that it wasn't the mobility devices that were the enemy. My thinking was the enemy. I had to accept what I am, that I am disabled, and that was not going to "get better" and yes, even that a mobility device-power wheelchair-was going to help me live a full, happy and fall-free life.

Once I discovered the technical advances of these new mobility devices, and that I was the one who was going to decide what hill I was going down and at what speed, I was off and rolling. When I finally made my way into the world of power chairs, I decided I was going to do it in style; and I was going to be the "Diva of Mobility Devices." My first wheelchair, which I recently had to retire after one-too-many high-speed shopping trips, was Pink Panther pink. I also bought a matching pink crutch and a cane decorated with absolutely lovely little pink roses. When I had to retire my chair, I had a ceremony for it and mourned its loss and moved onto a spiffy new chair. Alas, the new chariot is not pink, but a lovely cobalt blue. Since I'm just a little older now, the need for speed has left me and I took the high-comfort route.

It's seat rises so I can reach my cabinets; its arm swings away so I can get in closer to the table. And when I'm not in my chair in the evenings my cats enjoy the newest addition to our lives, and curl up on the cushion, sleeping in high-tech contentment. As I look over at them and hear the sweet sounds of their purring, one thought runs through my mind: Mobility devices-aren't they grand?

Kathy Galletly, a United Spinal member, has been published in New Mobility and won the 2007 VSA award for her story "Spats," about herself and her brother who was also disabled. She has also been published in a book of short stories entitled Gratitude with Attitude. Editors note: Remember as polio survivors, we are automatically eligible to join United Spinal like Kathy!



Adapt Achieve Inspire

Spinal Cord Injury - Multiple Sclerosis - Polio
Amyotrophic Lateral Sclerosis - Spina Bifida

Contributions and Donations



In Memory of Dorothy Cogan:

Cecelia Axton
Robert Kotterbery
Carol Mayfield
Ron & Judy Rinehart
Roger & Sara Tullis
Mary & Dan Wolterman

Ed Boyles *
L. John Felman*
Jacquelin Perry, MD*
Dana Vincil*
Marian Lundeen
Hal Myers
Lu Ann Pankratz
Richard Piskun
Arlene Wise

* \$100 donation or above

Support Polio Epic by shopping at Bashas'

Help Us Earn Funds! Log on to www.bashas.com/charity to register your **Bashas' Thank You card for our group ID# 2 7 1 6 9**. This will automatically earn credit for Polio Epic every time you use your *Thank You Card*. Bashas' is again offering a way for **Polio Epic** to raise money with its' **Shop & Give'** program. Here is how it works: Visit any Bashas' checkout or service counter and ask to have your Bashas' "*Thank You*" card linked to **Polio Epic** (our number is **27169**). You only need to link the card once. Even if you participated last year, you **must re-link our group ID# 27169** to your Bashas' *Thank You card*. Bashas' donates 1% of the total sales linked to Polio Epic, up to \$5000. The program runs until April 30, 2010, so remember the next time you stop at Bashas', show your support and link Polio Epic to your card. Don't forget to tell **all your friends & relatives** that shop at Bashas' about this worth while program.



Sleep and Breathing Symposium
for polio survivors
Videos of Presentations now online



POLIO EPIC, INC. CURRENT MEMBERSHIP ANNUAL DUES THROUGH THE FISCAL YEAR OF SEPTEMBER 1, 2009– AUGUST 31, 2010

NAME _____ Spouse/Partner _____ DATE _____
ADDRESS _____ PHONE(_____) _____
CITY _____ STATE _____ ZIP _____ - _____

Emergency Contact info: _____

Newsletter via Email? Address _____

____ I am sending in my/our annual dues of **\$10.00** per person for 2009-2010 fiscal year.

____ I am sending in a *tax-deductible* donation in the amount of \$ _____.

POLIO EPIC, INC. is a 501(c)(3) non-profit corporation. Tax ID # 74-2477371

____ I am UNABLE TO PAY dues at this time, but wish to receive the newsletter.

____ Please remove my name from the mailing list. I do not wish to receive newsletter.

____ Check here if you do not want your name, and address info listed in the

POLIO EPIC DIRECTORY.

____ I would like to be more involved. Please contact me at the number above.

Make checks payable to POLIO EPIC and return this form to: Polio Epic, P.O. Box 17556, Tucson, AZ 85731

Breathing Problems Caused By Post-Polio Syndrome by Lisa S. Krivickas, MD

Polio survivors may have difficulties with breathing related to their polio. There are three groups of polio survivors with respiratory difficulties: 1) those who had respiratory failure during their acute illness and were never weaned from a ventilator, 2) those who develop breathing difficulties later in life and 3) those with sleep disordered breathing (sleep apnea). This article will deal primarily with the latter two groups of patients.

As polio survivors age, they may experience accelerated strength loss both in muscles that were initially affected by polio but seemed to recover fully and in muscles that did not seem to be affected by the acute illness. These muscles may include those necessary for breathing such as the diaphragm, chest wall (intercostal), abdominal and even neck (sternocleidomastoid and scalene) muscles. If these muscles lose enough strength, the ability to breathe is impaired. Early difficulties with breathing may not be recognized by the patient. In addition to muscle weakness, scoliosis (curvature of the spine) and other superimposed lung diseases, such as asthma or chronic obstructive pulmonary disease (COPD) caused by smoking, can contribute to breathing difficulties.

In patients with polio who have breathing difficulties because of muscle weakness and do not have an additional form of lung disease, the problem is purely mechanical, i.e. due to inability to completely fill the lungs with air. One can think of the lungs as balloons that need to be fully inflated in order to work optimally. Muscle weakness can make it impossible to fully inflate the lungs. Once the lungs are inflated, the body is able to extract oxygen from the air in them without difficulty. Forced vital capacity (FVC) is a measure of the adequacy with which an

individual can inflate his lungs. FVC is normally expressed as a percentage of the predicted value for the patient's height and age. Most patients with polio do not experience symptoms related to under-ventilation until their FVC is 50% of predicted or less.

An arterial blood gas (ABG) is sometimes performed to assess adequacy of ventilation. A sample of blood is taken from the radial artery, near the wrist, so that both oxygen and carbon dioxide levels can be assessed.

Because polio patients do not have difficulty extracting oxygen from air, these levels are usually normal until the FVC falls well below 50% of predicted. With advanced respiratory failure, the oxygen level may fall below normal, and the carbon dioxide level becomes elevated. The ABG is not a sensitive screening test for polio related breathing difficulties, but it is useful in assessing polio patients who already use ventilators.

Symptoms that suggest difficulties with breathing often occur first during the night because patients with muscle weakness frequently have a lower FVC when lying down than when sitting up. These symptoms may include poor sleep quality with frequent awakening, early morning headaches, excessive daytime fatigue or sleepiness and frequent nightmares. Other signs of respiratory muscle weakness are inability to sleep lying down, frequent sighing and a weak cough with difficulty raising secretions. A sign of more advanced respiratory failure is shortness of breath with exertion or when eating or speaking. Of course, polio related muscle weakness is not the only cause of any of these symptoms, so other medical problems should be excluded. Heart disease is a common cause of shortness of breath.

Patients who had respiratory or bulbar (speech and swallowing muscles) weakness during their acute polio illness are most likely to develop problems with breathing years later, but all polio survivors are at risk. Thus, I recommend a baseline pulmonary function test for any patient who has had polio. If the test is normal, it does not need to be repeated unless symptoms suggesting a breathing problem subsequently develop. Pulmonary function tests are performed by a respiratory therapist in a standard laboratory that is part of all acute care hospitals. The test involves performing several maneuvers that all involve breathing or blowing forcefully into a tube. The test itself is not uncomfortable. Patients are often given a medication called a bronchodilator as part of the test to assess whether or not they have abnormal narrowing of the airways such as occurs in asthma and COPD. When assessing patients with muscle weakness, the FVC measurement and maximum inspiratory and expiratory pressure (MIP and MEP) measurements are most important. The MIP and MEP assess the strength of the muscles used for inspiration (breathing in) and expiration (blowing out). Good inspiratory muscle strength is necessary to fully inflate the lungs, and good expiratory muscle strength is necessary to cough up secretions. It is useful to also measure the FVC with the patient lying down because it may be less than it is sitting up. If any of the measurements discussed above are less than 80% of predicted (considered normal), the pulmonary function tests should be repeated regularly, usually annually unless symptoms dictate otherwise, to detect progression of breathing muscle weakness that may require treatment. Patients with an FVC or MEP less than 50% of predicted often benefit from treatment to assist their



breathing muscles. In addition, patients with values above 50% of predicted will benefit from treatment if they are symptomatic. The treatment for a low FVC is to provide mechanical assistance with inflating the lungs. This is done with non-invasive positive pressure ventilation (NIPPV) using either a bilevel positive airway pressure (BiPAP) machine or a portable ventilator to help blow more air into the lungs. The patient can use a mask over the nose or the mouth through which the air is delivered. Most commonly, patients are advised to use the machines at night to assist with their breathing. Oxygen is not needed unless the patient has a disease other than polio that affects the breathing. In fact, oxygen can be harmful in patients with breathing difficulties due to muscle weakness because it suppresses the body's natural drive to breathe. A respiratory therapist familiar with NIPPV techniques is very helpful for teaching patients to use NIPPV and recommending a mask and machine settings that are comfortable. Methods of assisting breathing, other than using NIPPV, exist but are less commonly used. These include a technique called glossopharyngeal breathing (frog breathing) and the use of body ventilators, similar to the old iron lung in mechanism of action, such as the portalung, chest shell and poncho. A detailed discussion of these devices is beyond the scope of this article. For patients with weak expiratory muscles (low MEP), a machine called an in-exsufflator, 'coughing machine,' or Cough Assist (J.H. Emerson Co., MA) is useful. The device has a vacuum cleaner type of motor and is used to suck deep secretions or mucus out of the lungs. It is especially useful when patients have an upper respiratory tract infection (common cold); good secretion clearance

helps prevent the development of superimposed pneumonia, a potentially serious medical problem that may require hospitalization.

In the past, polio patients have experienced difficulty getting their insurers to cover NIPPV equipment and the in-exsufflator. In January 2002, a new Medicare and Medicaid ruling was passed that supported reimbursement for the in-exsufflator in those with a MEP less than 60 cm H₂O (about 60% of predicted for most adults). Also, according to Medicare guidelines, NIPPV equipment should be reimbursed for any polio patient with an FVC less than 50% of predicted without the requirement that a sleep study be performed or a low oxygen saturation be documented.

Preventing infection is important in patients with breathing muscle weakness. A pneumococcal vaccination protects against one form of bacterial pneumonia and is only needed once. The influenza vaccination (flu shot) protects against common strains of the flu caused by influenza viruses. This should be received yearly.

There are no medications that can improve breathing difficulties primarily due to muscle weakness. Thus, inhalers and other medications commonly prescribed to treat asthma are not usually helpful to polio patients and may have adverse side effects. Sleep apnea is a second type of breathing difficulty that may be experienced by polio survivors. Sleep apnea refers to brief episodes when one stops breathing during sleep. If the episodes are long enough, they usually wake the patient. Oxygen levels fall abnormally low during the episodes of apnea. Patients with sleep apnea often feel fatigued during the day and unrefreshed by their sleep. If sleep apnea is severe, serious



medical complications such as heart rhythm disturbances, pulmonary hypertension and congestive heart failure can develop. There are 2 major causes of sleep apnea in polio patients. The first is weakness of the throat muscles that allows the airway to collapse when one lies down. The second cause is a direct effect of the polio virus on nerve cells in the brainstem that help control breathing. Sleep apnea should be suspected if quality of sleep is poor or if excessive daytime sleepiness occurs in a patient with normal pulmonary function tests. Family members of patients with sleep apnea may report loud snoring or actually may observe brief periods

where the patient appears to stop breathing in his or her sleep.

Sleep apnea is diagnosed by undergoing a sleep study.

Sometimes, sleep studies also are useful for determining if a patient with respiratory muscle weakness

would benefit from NIPPV and/or for assessing how well a patient using NIPPV is being ventilated. Sleep studies are performed in a special laboratory where the patient is required to spend the night. During sleep, brain wave signals (EEG), limb movements, heart rhythm and oxygen saturation are measured.

Once sleep apnea has been diagnosed, the treatment involves using a mask over the nose to blow air into the lungs with either a BiPAP or a continuous positive airway pressure (CPAP) machine. The airflow acts as a stent to prevent the airway from collapsing. CPAP is the standard treatment for patients with sleep apnea who do not have weakness of the breathing muscles. In polio patients who have both weakness of the breathing muscles and sleep apnea, a BiPAP machine is used to assist the weak muscles and prevent airway collapse.

Any polio survivor, who feels excessively fatigued, sleeps poorly or exhibits other symptoms discussed above should discuss with his or her physician whether or not an evaluation for breathing dysfunction is indicated. The appropriate treatment of polio related breathing problems can greatly improve the polio survivor's fatigue resistance, energy level and quality of life.

Abbreviations Used In This Article

ABG: arterial blood gas

BiPAP: bilevel positive airway pressure

COPD: chronic obstructive pulmonary disease

CPAP: continuous positive airway pressure

FVC: forced vital capacity

MEP: maximum expiratory pressure

MIP: maximum inspiratory pressure

Lisa S. Krivickas, MD, is Assistant Professor of Physical Medicine and Rehabilitation, Harvard Medical School and Spaulding Rehabilitation Hospital, Boston, MA.

Dr. Krivickas kindly wrote this article at the request of the GBPPA. Reprinted from Boca Raton Post Polio Group



How to Have a Successful Physical Therapy Experience

I've worked with a lot of patients with Post Polio Syndrome who have come to me after having a bad experience with Physical Therapy, often in worse shape than before they started therapy. Finding the right therapist can be quite a challenge, especially in communities where practitioners are not familiar with Post Polio Syndrome (PPS). But don't lose heart! Finding the right therapist can actually be easier than finding the right physician. Here are some basic guidelines:

THINGS TO LOOK FOR IN A PHYSICAL THERAPIST: (Assuming that you can't find a therapist who has knowledge and experience in treating PPS)

1. You need a therapist that is familiar with neurological and/or neuromuscular disorders, preferably with experience treating Multiple Sclerosis (MS) patients. Start by asking others that you know with PPS who have had physical therapy. This is the best way to start looking for any health care professional. If the therapist has a good understanding of MS, then they already know the basic treatment principles for Post Polio Syndrome, whether they are aware of it or not!! Although at times, you may be able to find this type of therapist at an outpatient orthopedic clinic, *most of the time you won't*. In fact, many of my clients first received their Physical Therapy treatment at an outpatient orthopedic clinic, and ended up in worse shape! You're most likely to find a qualified therapist in a hospital-based outpatient therapy clinic, so that's a good place to start.

Your doctor may be helpful with recommendations, but don't count on it!

Often times doctors refer patients to therapists that have done a great job for them in the past, but this may not apply to PPS. Just because a therapist is great at treating knee or back problems does not mean they are going to be able to help a person with PPS! You need to do your own investigation.

If your function has declined to the point that leaving your home for an appointment completely wears you out and you are avoiding activities outside your home, you may qualify for home health therapy services. Most home health therapists are competent to treat patients with PPS, as they see a wide variety of complicated diagnoses and situations. This would be an excellent place to start if you are finding that you need increased help with your activities of daily living and general mobility in your home.

2. Keep in mind that PPS affects everything! If you had polio, you are at risk for PPS. Even if you are getting PT treatment for something other than PPS (ie, a shoulder injury), PPS will influence your treatment plan and affect your recovery, so be sure to disclose all PPS related information to your therapist.

This can make finding the right therapist a little more difficult. Let's say you have a history of PPS, but you suffered a back injury. This would mean that your primary diagnosis for physical therapy is the back injury and related back pain, so you need someone who will treat your back injury appropriately...within the limits of your PPS! Again, the best place to start looking is at a hospital-based outpatient therapy clinic. Usually the therapists at these clinics are more general in their practice, treating a wide variety of clients, often with complex medical histories and multiple diagnoses.

Preparing for Your Physical Therapy Evaluation and Treatment Program:

1. If you are able to, prepare your medical history. (This is a good thing to do anyway.) Many PPS clients have thick notebooks full of information, and while this can be helpful to the therapist, it can be TOO much information! Here are the highlights of what you need:

General medical history: Diagnoses, with dates of onset; Allergies; Previous Surgeries, with dates, Date/age of original polio onset; Original effects of polio; Any devices/braces used during initial recovery; Level of function after initial polio recovery, History of PPS; Approximate date of symptom onset; Formal medical evaluation & diagnosis; Previous treatments for PPS symptoms and Medication list. Many of my clients have typed up a list which can be easily photocopied at the time of their therapy

evaluation. I've always found this to be very helpful!

2. Avoid telling your whole life story at the initial visit. It is tempting to tell your life story to your therapist. There is nothing wrong with this impulse, but try to avoid doing this on your initial therapy visit. Remember, you've hired the therapist to help you regain the function that you've lost. In order to do that, the therapist will need to conduct a focused interview and a thorough physical evaluation. This will include specific questions regarding functional mobility status and/or changes, assessing range of motion and strength in all of your extremities and trunk, balance, coordination, transfers (i.e., moving from lying down to sitting up, sitting to standing, etc) and walking. If all of your time is spent on talking, the therapist won't be able to look at everything YOU NEED them to look at. Remember, there will be plenty of time to get to know your therapist and share your story. You will likely be seeing them several times per week for approximately one hour per session.

3. It is important to work WITH your therapist. Give your therapist an honest report about your body's response to changes in activities or exercises. There may be times when a therapeutic intervention doesn't work the way you and the therapist hoped it would! Maybe it caused you to be too fatigued, or caused a significant increase in muscle soreness. In order to adjust the treatment appropriately, the therapist needs to know. Be as specific as you can! Physical Therapy can be tricky in the beginning, as each person responds to physical interventions differently. Medicine is more of an art than a science, and sometimes a little "trial and error" must occur in order to find just the right thing. Ever tried a new medication that didn't work and have to get a prescription for a different one? The same thing can occur with therapy. However, if your therapist is not listening to your feedback and not adjusting your treatment program (just pushing you to do the same thing regardless of your response), you need to find a new therapist!

Worst Case Scenario:

Sometimes, no matter what we do (or don't do), a client with PPS will continue to have functional decline. This may be in spite of 100% appropriate participation in treatment. In this case, therapy interventions must shift focus to adapting to the new level of disability with appropriate equipment and/or assistance, in order to maximize independence. Like many other chronic conditions, PPS ranges from very mild to very severe. Those who develop very severe PPS will likely continue to decline whether they participate in therapy or not. The problem is that there is no way to tell if this will be the outcome or not, until it happens. In the hands of the right therapist, a well designed and highly individualized treatment program

won't harm you, and may help you.

Best Case Scenario:

Some individuals actually experience resolution of their PPS symptoms with successful completion of their therapy program. They regain the functional independence that they were hoping. This is ideal! However, it is important to keep in mind the principles of energy conservation and activity pacing. You want to avoid exacerbation/recurrence of PPS symptoms. Don't start over doing it because you feel great! One patient of mine just recently had an exacerbation, after years of no PPS symptoms, because he started to "ignore the rules" and overwork himself at the gym. PPS is a life changing condition. If you have been able to resolve your symptoms, you need to continue with whatever program or modifications to your lifestyle that helped you achieve these results!

WHAT NO ONE WILL TELL YOU

Some of this may be hard to hear, but I believe every PPS patient should know there is a widely held perception in the therapy community that PPS patients are "high-maintenance": needy, emotionally draining, and never satisfied. In fact, many of the therapists I have worked with and educated about PPS treatment actually dread seeing that diagnosis come across their desks. Some have even refused to treat PPS patients. How could this be? Generally speaking, polio survivors have overcome huge obstacles in their lives, and are very educated, knowledgeable people. They should be an exciting group of people to work with, right?

Well, there is a trend in the complaints I've heard from therapists. Basically, their clients become argumentative and noncompliant. They are not willing to try following the therapist's recommendations, and don't want to take any responsibility for the therapy "not working." For example, let's say that a gentleman with PPS has started Physical Therapy. He is having increased loss of balance and has had a few falls, all of his transfers are more difficult, and he doesn't have the energy to go to his weekly investment group anymore. His therapist tries using a walker with him, and this greatly improves his balance and stability with movement. She recommends that he use his walker at this time to help safely increase his mobility. He, however, is very resistant to the idea, and refuses.

The therapist and patient then have lengthy discussion about the seriousness of potential injury related to falling, and the likely continued decline of function related to overuse and inappropriate activity pacing. She suggests the idea of utilizing the walker as a tool to safely increase his mobility and independence, while continuing therapy to see if he can regain enough endurance, strength and balance to resume his normal activities without a walker. Despite the safety concerns and benefit that the therapist

outlines, the patient continues to refuse. Could this be related to the stigmas associated with disability and assistive devices from the time of the Polio epidemic? Is it from this gentleman's denial regarding his current functional status? Is it just because the situation he now finds himself in is completely, inarguably unfair?

This gentleman needs to step back and take a hard look at the situation. Arguing with the therapist's recommendations, just because he doesn't like what he is hearing, is not helping him. Yes, it is unfair that after having overcome Polio once in his life, he is forced to deal with it's ongoing effects. It should be obvious to the reader, however, that the therapist has made an honest professional recommendation for the patient's safety, consistent with his goals of increasing activity and independence. Think of it this way: You hire a lawyer to evaluate a legal situation and give you sound advice on the matter. You're paying the lawyer for his expertise. Once he provides you with the information and recommendations, it is your choice to follow his advice or not. Would you sit and have a debate with him because you don't like what he has to say? Would you go and do the exact opposite of what he recommends, and then argue that his legal advice was no good?

I think sometimes patients have the attitude that Physical Therapy is like a magic pill, that the therapist is supposed to "fix" them. Unfortunately, this is not how things work. You have to actively participate in the process. If you have a bottle of pills that help control high blood pressure, but you never actually take one of the pills, your blood pressure will not change. You're probably thinking, "well, that's common sense." But many people fall into this mental trap, so to speak, of showing up to their therapy appointments and expecting some sort of magical results, without actually following any of the recommendations OUTSIDE of their therapy sessions. Unfortunately, there is no magic cure for PPS. Therapy can be helpful, but only if you really, actively choose to face the reality of your situation and give the therapy program a fair try.

Physical Therapist, and Polio Epic Medical Advisory Board, Leslie Drawdy, PT

Appreciation and Gratitude

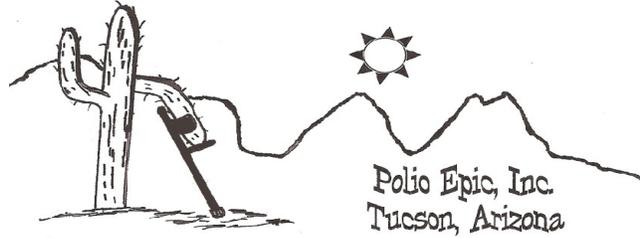
Polio Epic and the Board want to recognize and thank the following organizations for supporting us and helping us make Polio Epic of Southern Arizona, the Support Group, for Post Polio, the success it is.

March of Dimes – helps fund a portion of our Newsletter

DIRECT–Ctr for Independence–provides a room for our Board meetings

HealthSouth Rehabilitation–provides a room for our monthly meetings

**Polio Epic's
Annual Holiday Party**



We will be gathering at the Holiday Inn Palo Verde for Fun and holiday cheer on December 12th, 2009. Please view the insert to make your menu selections. Once again, Polio Epic is sharing the cost, so that everyone can join in with Holiday Spirit together. We look forward to seeing you there. Good Friends, Food, and Fun.

