

**General
 Membership
 Meetings
 Every Second
 Saturday of the
 Month
 10:00 am.
 HealthSouth
 Rehabilitation
 Center
 2650 Wyatt
 Road**

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What a Beautiful Autumn Day

What a beautiful autumn morning it was on Thursday, November 9th as we left Tucson for Green Valley. One van carried boxes of "Post-Polio 101" materials, an overhead projector, large display posters and new member packets, while the other had Polio Epic brochures and newsletters. Several board members had been asked to present "Post-Polio 101" to our Green Valley membership. Joanne Yager, Nannoe Westbrook, Frank Frisina and I were looking forward to the day as we traveled south through the pecan trees.

Ruth Westrate, a member of one of the Green Valley churches, had planned our location, made banana bread and muffins to ease those mid-morning hunger pains, arranged for other church members to be available to help us and alerted the local papers about the event. Ruth's efforts allowed us to focus on our presentation and brought close to 20 individuals to hear us speak. Out of that group of individuals there were at least 15 polio survivors that none of us had ever met! We were especially excited about those new faces who knew very little about post-polio syndrome. Some were in the middle of struggles with their doctors or with agencies that wanted to avoid the responsibility of offering assistance. You know what I mean. "Post-Polio syndrome??? That can't be your problem. You're in your 60's, 70's, 80's.....just old age." Or "We don't believe in that.....that post-polio thing."

The feedback we received showed that on three key areas evaluated in our presentation, everyone with the exception of one participant learned something new. Wow! I've been a teacher for over 35 years and I am still always excited to see people learning, making connections and feeling full of hope. I think that's what that beautiful autumn day in Green Valley was all about.....hope. I'm grateful I was part of it.

Blessings,
 Karla

While, I was preparing my statement for this newsletter, I received an important e-mail. I was prepared to discourse on the fact that although the United States is politically divided into 2 or 3 “parties”, there is a single political group which all of us who read this newsletter belong to. The polio survivor, or friends and loved ones of polio survivors. We are a group that are better educated, better employed, more married, more settled than any other group of people in the United States. There is no other group in this country that have these rare statistical ratings. Because of the age of the Polio Vaccine, we are the remainders of a virus that showed NO political boundaries, and no Social or elitist definition. We are lucky to live in the United States, where being a citizen is both a privilege and a responsibility. Before I print out what I found this week, I wanted to share a few statistics from that e-mail I mentioned earlier....once you review these statistics, then I want you to think of where you fit in this statistics as it relates to being a polio survivor.

Let us not be stopped by that which divides us but look for that which unites us

If we could reduce the world’s population to a village of precisely 100 people, with all existing human ratios remaining the same, the demographics would look something like this:

82 Non-White	60 Asians	67 Non-Christian
18 White	14 Africans	33 Christian
	12 Europeans	
	8 Latin Americans	
	6 North Americans (US and Canada)	

If we could reduce the world’s population to a village of 100 people, with all ratios remaining the same, the demographics would look like this:

- 5** would control 32% of the entire world’s wealth, and all of them would be US Citizens
- 80** would live in sub-standard housing
- 24** would not have any electricity – and of the remaining 76 % that do have electricity, most would only have it in evenings
- 67** would not be able to read
- 1** (yes, only 1) would have a college education
- 50** would be malnourished and 1 would be dying of starvation
- 33** would not have access to safe drinking water
- 1** would have HIV
- 1** would be near death
- 2** would be near birth
- 7** would have access to the Internet

If to take a look at the world from this condensed perspective, the need for acceptance, understanding and education becomes evident.

As Polio Survivors, we need to gain acceptance, understanding and provide education to the rest of the world about Polio, and Post-Polio Syndrome. The work that Karla, Frank, Nannoe do with PPS101, the work we do with this newsletter, and the work that all of us do in educating the medical community and the websites are part of the power that we have. On the next page, I have found that several of our leaders in Washington, D.C., are also polio survivors. No matter their political background, we need to be “part” of their work as fellow polio survivors. They are truly in a position to be voices for us. I know that in September, the house passed 2007 as the year of Polio Awareness (Sep-October 2006 Polio Epic Newsletter). The legwork has been started, we need to follow-through, and make sure that we are “spreading the word”.

Mitchell McConnell – Republican (Kentucky)

Meet the New Boss -- Quietly, Senate Republicans have already chosen
Mitch McConnell as their next leader

When Addison Mitchell McConnell was two years old, he was diagnosed with polio. Though he remained able to walk, doctors, fearing that pressure could make his legs develop abnormally, instructed his mother to keep her son off his feet for several years. Adhering to this stricture seems to have forged in McConnell a kind of dogged determination, as well as a faith that patient, disciplined effort will ultimately be rewarded. Today, the only sign of his childhood illness is a slight limp when he walks down steps.

Mr. Cohen – Democrat (Tennessee)

Suddenly a freshman, he'll keep his district close, way up there

He counts as friends Tanner and Reps. Bart Gordon, Jim Cooper and Lincoln Davis, all D-Tenn., some of whom he worked with when they were state lawmakers with him. He served with Marsha Blackburn, R-Tenn., and knows Zach Wamp and John Duncan, both R-Tenn., and has an acquaintance with several members about to become chairmen of powerful committees. Cohen is sensitive to accounts that he got into the race just days before the filing deadline and only after it appeared the number of black candidates would fracture the African-American vote, and he insists it's not true.

He said he had pretty much decided to run as early as December of last year, and hinted broadly at that prospect in media interviews in January. The 57-year-old Cohen said he visited Washington in late March to convince himself. Two factors weighed heavily on his mind: his 91-year-old mother's health (she talked to a congratulating Al Gore by speaker phone Thursday), and his own. He came down with polio when he was 5, and thinks he is suffering with post-polio syndrome, which includes exhaustion and a decided and worsening limp from an atrophied leg.



Skelton to Prioritize Pentagon Oversight By SAM HANANEL The Associated Press Saturday, November 18, 2006; 2:30 AM

WASHINGTON -- A student of military history, Missouri Rep. Ike Skelton recently pulled out his latest reading, a 1926 tome about the disastrous allied campaign at Gallipoli during World War I. The title: "The Perils of Amateur Strategy." "This administration seems to be writing its sequel," Skelton says, shaking his head. Poised to become the chairman of the House Armed Services Committee in January, the Missouri Democrat plans to devote top priority to tougher oversight of the Pentagon and the Bush administration's Iraq strategy. Known as a conservative Democrat and

one of Congress' most devoted supporters of the military, Skelton has become increasingly critical of the war and frustrated that no one in the Pentagon seems to be listening.

"In terms of knowing what the past teaches us about Iraq and the global war on terror, he's about as good as it gets," said Loren Thompson, a defense analyst at the Lexington Institute in Arlington, Va. Skelton, who turns 75 next month, speaks in careful, measured tones, his voice barely above a whisper at times. Growing up in a military family in Lexington, Mo., his heroes were those who went off in uniform to serve in World War II.

A bout with polio as a teenager limited the use of his arms and dashed his dream of a military career, but not his love of the armed forces. He devours books on the great battles of history and can talk with ease about the Battle of the Bulge or Pericles' defensive strategy against the Spartans. Skelton calls his study of military history a hobby, but his encyclopedic knowledge could rival that of some top generals. Earlier this year, the Joint Forces Staff College in Norfolk, Va., renamed its military library for Skelton.

STS research contributes to understanding disparities in success of medical treatments

Stephanie Schorow, News Office Correspondent
November 15, 2006

Does a person's race or ethnic background affect how he or she responds to medication? Does consideration of race reinforce preconceptions and prevent effective treatment for both minority and majority populations?

"STS can contribute to answering these questions," asserted Dr. David S. Jones, MIT assistant professor in the Program in Science, Technology and Society, during an Oct. 30 lecture on "Can STS be Good Medicine for Medicine?"

New treatments and medical technology can effectively eradicate diseases such as smallpox, yet social and political considerations have hindered similar success with diseases like polio, tuberculosis and AIDS, said Jones, director of MIT's Center for the Study of Diversity in Science, Technology and Medicine. "In 1985, we had all the technology necessary to eradicate HIV. As we all know, that did not happen."

Moreover, there are striking differences among populations on key health markers. Today, according to a recent study in New York City, black men are eight times more likely to die of AIDS than white men, Jones said. Even in this area, the mortality rate per 100,000 population is 530 in the Back Bay, 729 in the South End and 1,167 in South Boston, Jones said. The life expectancy of a Sioux man in South Dakota is 58 years and that of an Asian woman in Bergen County, N.J., is 91 years--a huge difference.

"The silence about this issue continues to amaze me," added Jones, who has degrees in both medicine and history and is author of the 2004 book, "Rationalizing Epidemics: Means and Uses of American Indian Mortality."

Pinpointing a cause for such disparity is, however, extremely difficult. For example, doctors have long recognized that people have individual, idiosyncratic responses to medication, despite medical trends to offer standard responses to standard diagnoses, Jones said. Such different responses can be due to non-adherence to drug regimens, environmental factors or genetic background. And while efforts to map the human genome have found "99.9 percent" similarity among seemingly diverse humans, that 0.1 percent might be responsible for differences among ethnic groups, Jones said.

Some evidence suggests HIV drugs have more serious side effects in African-Americans than

whites, but it's not clear why. "Is race something we should consider when trying to close the medical gap?" Jones wondered. "How do you explain variation in drug response? Should we attempt to match drugs to genes?"

African-Americans do suffer higher rates of hypertension than whites. In a controversial move in 2005, the FDA approved the heart medication BiDil, marketed by NitroMed of Lexington, Mass., for those who self-identify as black. Jones, however, questions why drugs that work well among African-Americans weren't marketed to whites when, for decades, drugs tested on white men were considered applicable to all races and often both sexes.

"It's easy to find differences. It's hard to know if the difference is significant," he said. STS, with its focus on history and culture as well as technology, may help answer that question, Jones said.

A version of this article appeared in MIT Tech Talk on November 15, 2006 (download PDF).

Editor's Note: Recently one of our own Polio Epic Members, had their DNA testing done, to see how different medications affected their individual body. They were quite pleased with the results, and feel that their medication program has been improved. I was dubious about this advancement, until I read this un-related article. Perhaps there is more in the way of treatment than I realized. The DNA testing is currently expensive, and insurance is not covering it. Our member paid approximately \$600 to have it done, and found that many of her medications had to be changed. If you are interested in this testing, please contact Kathy Zittlosen, and ask her about it!



Does anyone use the medications, GEMFIBROZIL, PROPAFENONE or VERAPAMIL, I would like to know if they have any reaction with your post polio symptoms. Even if you use them and feel no reaction please call me and let me know. Thanks for your help.

Frank Frisina 520-327-3252 or cell 360-9365 or email shinybear@msn.com

Bashas' Groceries On The Go

Bashas' Grocery stores in certain Tucson areas deliver groceries to your home?

Go to www.bashas.com and click on **GROCERIES ON THE GO** for more information, or call:

- Metro Phx #: (480) 968-9500
- Tucson, 800 Service: 1 (877) 968-9500

The cost for this service runs around \$10.00.

Bashas'

Thanks A Million Program is Back:

Bashas' is again offering a way for Polio Epic to raise money. All you need to do is take your Bashas' "Thank You Card" into any Bashas' and ask the cashier to enter our group number – **27169**. The program runs from **September 1, 2006 to March 31, 2007**. Polio Epic will receive 1% of the total dollars attributed to our group identification number – up to \$2,500. Don't forget to tell **all your friends & relatives** about this program. Our group number is:

27169

From the Treasurer...

Our new fiscal year began **September 1**. Please look at your mailing label containing the status of your membership to Polio Epic. The year above your name indicates the year you are paid through. If it says **2007**, then you are paid up-to-date.

After 20 years of keeping our dues to \$5.00, the Board of Directors, voted unanimously to raise the yearly dues to **\$10.00**.



DONATIONS

*Jacqueline Perry
Dana Vincil
Frank Wadleigh's Estate
Gail Watts*

*Jim & Reva Anderson
Al & Joan Bernardi
Barbara Janice Bulman
Richard Curlee
Linda Failmezger
Joy Johnson-LeBerger
Dorothy Mazer
Charles Root
Sara Snyder
Kenneth Walker
Nannoe Westbrook*

*BUILDERS \$100 and OVER
*FRIENDS UP TO \$99



Al Imhoff

In Memory of wife, **Nancy Imhoff**

Gene Sherman

In Memory of wife, **Laura Sherman**

Wray Dudley – deceased

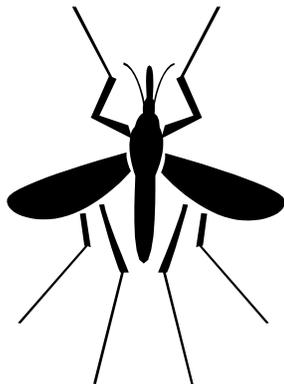
Ann Boyles – Winner of Army's Prestigious "Molly Pitcher" Award and Loved one for 60 years to our Member Ed Boyles.

West Nile Virus - associated Flaccid Paralysis

Sejvar JJ, Bode AV, Marfin AA, Campbell GL, Ewing D, Mazowiecki M, et al.

Centers for Disease Control and Prevention, Atlanta, Georgia, USA; Centers for Disease Control and Prevention, Fort Collins, Colorado, USA; Centennial Neurology, Greeley, Colorado, USA; Longmont Clinic, Longmont, Colorado, USA; McKee Hospital, Loveland, Colorado, USA; and Colorado Department of Health and Environment, Denver, Colorado, USA.
Emerg Infect Dis Vol. 11, No. 7 July 2005.

The causes and frequency of acute paralysis and respiratory failure with West Nile virus (WNV) infection are incompletely understood. During the summer and fall of 2003, we conducted a prospective, population-based study among residents of a 3-county area in Colorado, United States, with developing WNV-associated paralysis. Thirty-two patients with developing paralysis and acute WNV infection were identified. Causes included a **poliomyelitis-like syndrome in 27 (84%) patients** and a Guillain-Barré-like syndrome in 4 (13%); 1 had brachial plexus involvement alone. **The incidence of poliomyelitislike syndrome was 3.7/100,000.** Twelve patients (38%), including 1 with Guillain-Barré-like syndrome, had acute respiratory failure that required endotracheal intubation. At 4 months, 3 patients with respiratory failure died, 2 remained intubated, 25 showed various degrees of improvement, and 2 were lost to followup. **A poliomyelitis-like syndrome likely involving spinal anterior horn cells is the most common mechanism of WNV-associated paralysis and is associated with significant short- and long-term illness and death.**



Tucson Region

Lengthy West Nile virus season ends at last
By Carla McClain
Arizona Daily Star

Tucson, Arizona | Published: 11.17.2006

As the last reports of West Nile virus trickle in, it is finally time to declare an end to an unusually long, record-breaking year for this still-baffling disease in Pima County.

What may be the final two cases of West Nile illness this season were confirmed this week, bringing the Pima County total to an all-time high of 47 — nearly tripling the total tallied last year. Two victims, both elderly, died — the most recent on Nov. 1.

But signaling long-awaited relief from this threat now is the fact that no infected mosquitoes have been detected in Pima County in more than two months.

The most recent human victim was bitten almost two months ago, when mosquitoes were still overwhelming our monsoon-soaked desert. No more.

"The mosquito season is essentially over," said Dr. Michelle McDonald, the county's medical director. "Depending on how warm our winter is, some mosquitoes may winter over, as they did last year. But mosquito breeding is mostly finished. The numbers are way down and the infection threat is clearly ending."

Though there are still some mosquitoes out there, they are by now far less likely to be infectious, state experts said.

"By this time of the year, the virus activity drops off of its own accord, no matter what the mosquitoes are doing," said William Frank, an epidemiologist with the state health department. "In Arizona, we do have areas where mosquitoes stay active all year long, but we don't get any West Nile infections during the winter months. So, yes, it is over now."

Though we finally may be able to relax on our patios without fear of a West Nile bite, we are still trying to figure out why the virus spiked so dramatically in Pima County this year, and lasted so long.

As late as mid-September, we were congratulating ourselves that the county case count was well behind last year's pace.

But by the end of September, human infections began climbing at the rate of 10 a week,

climaxing in a "hot zone" of Midtown and East Side neighborhoods where many of the cases were clustered, and residents were issued special warnings. Tucsonans were ordered to clear their weeds and clean their stagnant swimming pools, under threat of fines, to try to get the mosquito—and the virus — explosion controlled.

Most experts are blaming our heavy monsoon rains for the late-season West Nile peak, but admit they remain unsure.

"This season has gone on longer than any of us anticipated, and we don't really know why," Frank said.

"You just never know with West Nile — it's new, it's weird, it's volatile. Those last rains in August probably did have a huge effect. But this thing has only been in this country since 1999, and we have to admit we don't fully understand it yet."

Also defying explanation is who and how this virus kills. All four fatal cases in Pima County since 2004 have involved elderly people. But several Arizonans who died or were permanently disabled by the virus this year were in their teens and 20s.

"We've had a lot of young, healthy people die or get badly hurt by this, so I'm not comfortable anymore with saying it's just the old and weak," he said. "It would be very misleading, even dangerous, to let young people think they don't have to take precautions about West Nile. They cannot let their guard down."

Four of Arizona's confirmed 143 human victims this year developed a rare polio-like paralysis, resulting in permanent disability. All were Maricopa County residents. Last year, there were 106 cases statewide, including four deaths. But that doesn't come close to 2004, the state's worst year, when nearly 400 cases were recorded, 355 in Maricopa County, and 16 deaths.

The good West Nile news broke in the horse population, where known infections fell statewide from a high of 109 in 2004 to 12 this year. An effective equine vaccine gets the credit. All bets are off about what to expect from West Nile next year, experts agree.

Most originally predicted a steady drop in cases each year, as immunity grew within the population. But this "weird" virus continues to defy all predictions.

Case counts in states such as Illinois and Idaho shot suddenly back into the hundreds this year after one or two fairly quiet seasons. No one knows why.

"We're still learning a lot about West Nile virus and its behavior," McDonald said.

"I'm gun-shy now about predicting what the virus will do," Frank said. "Don't ask me."

• Contact reporter Carla McClain at 806-7754 or at cmccclain@azstarnet.com.

West Nile Virus Statistics for Arizona in 2006 **Source: Arizona Department of Health Services**

<p style="text-align: center;">Total human cases 143</p> <p style="text-align: center;">Total deaths 9</p>	<p>Age range:</p> <table style="width: 100%; border: none;"> <tr><td style="padding-right: 20px;">0-10</td><td>4</td></tr> <tr><td>11-20</td><td>4</td></tr> <tr><td>21-30</td><td>8</td></tr> <tr><td>31-40</td><td>10</td></tr> <tr><td>41-50</td><td>30</td></tr> <tr><td>51-60</td><td>26</td></tr> <tr><td>61-70</td><td>22</td></tr> <tr><td>71-80</td><td>22</td></tr> <tr><td>80+</td><td>17</td></tr> </table>	0-10	4	11-20	4	21-30	8	31-40	10	41-50	30	51-60	26	61-70	22	71-80	22	80+	17	<p>Nature of Illness:</p> <table style="width: 100%; border: none;"> <tr><td>Uncomplicated fever</td><td>73</td></tr> <tr><td>Neuroinvasive (meningitis or encephalitis)</td><td>58</td></tr> <tr><td>Polio-like paralysis</td><td>4</td></tr> <tr><td>Unknown</td><td>8</td></tr> </table>	Uncomplicated fever	73	Neuroinvasive (meningitis or encephalitis)	58	Polio-like paralysis	4	Unknown	8	<p>County breakdown:</p> <table style="width: 100%; border: none;"> <tr><td>Pima</td><td>47 (2 deaths)</td></tr> <tr><td>Maricopa</td><td>73 (6 deaths)</td></tr> <tr><td>Pinal</td><td>15 (1 death)</td></tr> <tr><td>Cochise</td><td>- 2</td></tr> <tr><td>Mohave</td><td>- 2</td></tr> <tr><td>Santa Cruz</td><td>- 1</td></tr> <tr><td>Gila</td><td>- 1</td></tr> <tr><td>Coconino</td><td>- 1</td></tr> <tr><td>Apache</td><td>- 1</td></tr> </table>	Pima	47 (2 deaths)	Maricopa	73 (6 deaths)	Pinal	15 (1 death)	Cochise	- 2	Mohave	- 2	Santa Cruz	- 1	Gila	- 1	Coconino	- 1	Apache	- 1
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OPTIONS WHEN A POST-POLIO CLINIC IS NOT AN OPTION

By Carol Vandenaeker, MD
Physical Medicine & Rehabilitation

University of California, Davis, Health System, Sacramento, California

- 1) You must start with a good primary care physician.
 - (c) Aging changes should be discussed.
 - (d) Health promotion through:
 - (2) Nutrition - calories and weight control
 - (3) Exercise - stretching, strengthening and aerobic conditioning (see Guidelines for polio survivors)
 - (4) Stress management - psychosocial, emotional health
- 2) Keys to finding a good doctor:
 - a) Identify the best hospitals in your area and try to find a physician on staff there. The best hospitals attract the best doctors.
 - b) Get recommendations from trusted sources: hospital referral service, health plan directory, another physician or nurse, friends and neighbors.
 - c) Find out if the doctor is Board Certified.
 - d) Access your state's web site for information.
 - e) Your insurance choice may dictate what physicians you can see.
- 3) Look for a physician you trust and can communicate with.
 - a) You will be an "expert patient":
 - a) Good and bad connotations.
 - b) Provide a brief summary of PPS:
 - c) National Institute of Neurological Disorders and Stroke (NINDS) Post-Polio Syndrome Information Page
 - d) March of Dimes Quick Reference and Fact Sheets - Post-Polio Syndrome
 - e) Post-Polio Health International - Polio and Post-Polio Fact Sheet or The Late Effects of Polio-An Overview
 - f) Do not expect that the doctor will know much about polio.
 - g) Do NOT overwhelm a new physician.
 - h) Let the physician get to know you and evaluate your overall medical condition and health issues.
 - i) Do not go in with a shopping list of equipment needs or a stack of disability forms.
 - j) Be familiar with the summaries and provide the one most appropriate for your needs.
 - k) Give the doctor a chance to learn about you and PPS.
 - b) Symptoms should dictate diagnostic testing and/or referrals. A variety of specialists may be able to identify and treat problems. You may find one of your specialists most receptive to your needs.
- 4) Pain may be classified into different categories:
 - a) Post-polio muscle pain - caused by overuse of weak muscles
 - (2) Occurs in polio muscles
 - (3) Similar to pain of acute polio
 - (4) Associated with cramps, twitching, crawling sensation
 - (5) Increased at end of day
 - (6) Aggravated by activity, stress, cold
 - b) *Specialists: Physical Medicine & Rehabilitation (PM&R or Physiatrist), Orthopedics, Neurology- YOURSELF!*
 - c) *Treatment: Protection of muscles, activity modification, pacing*
 - d) (b) Soft tissue pain
 - (1) Injury or inflammation of muscles, tendons, ligaments, bursae
 - (2) Common examples: rotator cuff tendonitis, "tennis elbow", bursitis of the hip
 - (3) Often affects the "strong" limb
 - (4) Related to body mechanics
 - e) *Specialists: Orthopedics, Physical Medicine & Rehabilitation (PM&R or Physiatrist), Rheumatology*
 - (1) Treatment: Correct/adapt body mechanics, protect affected areas, rest, ice, NSAIDS, injections, therapy
 - f) Joint pain from degenerative changes
- 2) You will be an "expert patient":
 - a) Good and bad connotations.
 - b) Provide a brief summary of PPS:
 - c) National Institute of Neurological Disorders and Stroke (NINDS) Post-Polio Syndrome Information Page
 - d) March of Dimes Quick Reference and Fact Sheets - Post-Polio Syndrome
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 - i) Do not go in with a shopping list of equipment needs or a stack of disability forms.
 - j) Be familiar with the summaries and provide the one most appropriate for your needs.
 - k) Give the doctor a chance to learn about you and PPS.
- 3) The first step to managing symptoms of Post-Polio Syndrome is optimizing health. (Any good doctor can help you with this step.)
 - (a) Other conditions must be diagnosed and treated. "Diagnosis of exclusion"
 - (b) Monitoring for osteoporosis (strong limb/weak limb), hypertension, anemia, sleep apnea, thyroid dysfunction.

- (1) Affects joints in strong limbs due to normal or excessive "wear and tear"
 - (2) Joints in polio - affected limbs may have force changes resulting in ligament tears, joint deformity
 - (3) Joints with mild degeneration may be symptomatic because of abnormal body mechanics
- g) *Specialists: Orthopedics, PM&R, Rheumatology*
- h) *Treatment: Bracing, assistive devices, therapy, medications*
- i) Spine pain
- (1) May be in spine or referred into extremities
 - (2) Increased scoliosis increases risk of spine problems
 - (3) Spinal stenosis may mimic PPS
- j) *Specialists: Orthopedic Spine, PM&R*
- k) *Treatment: Therapy, injections, bracing, surgery*
- l) Nerve pain
- (1) Severe pain often associated with sensory shooting/ electrical symptoms
 - (2) May result from diffuse disease or localized nerve (carpal tunnel syndrome)
- m) *Specialists: Neurology, PM&R, Orthopedics*
- n) *Treatment: Activity modification, splints, therapy, medications, injections, surgery*
- o) Bone pain
- (1) Osteoporosis with small compression fractures
 - (2) Traumatic fractures/bruising
- p) *Specialists: Endocrinology, Orthopedics*
- i) *Treatment: Treatment of osteoporosis, immobilization of fracture, bone stimulation*
- 5) Fatigue
- a) Evaluation of causes/aggravating factors
- (1) Sleep pattern
 - (2) Other medical-illnesses: thyroid, CAD, obesity, anemia
 - (3) Reconditioning
 - (4) Depression
 - (5) Overuse
 - (6) PPS
- 6) New weakness
- a) Evaluation of possible causes:
- i) New superimposed neurologic condition
 - ii) Disuse atrophy/ deconditioning
 - iii) Weight gain
 - iv) Medical condition
- 7) Respiratory/Pulmonary problems
- a) Decreased muscle strength from polio causes restrictive lung disease similar to that seen with other neuromuscular diseases.
- (1) Polio survivors may have obstructive disease as well, especially with history of smoking or allergies.
- b) *Specialist: Pulmonologist, referral to local muscular dystrophy clinic pulmonary specialist may be most helpful.*
- 8) Swallowing difficulties
- (1) Should be assessed by a speech therapist and appropriate studies ordered as indicated
- 9) Post Polio Syndrome
- a) *Specialists: Most of the assessment can be done by the primary MD, with assistance from PM&R, neurology, and possibly psychologist, sleep specialist, physical therapist Treat all contributing factors, appropriate pacing, limited exercise program, protecting weak limb*
- b) *Treatment: Treat all contributing factors, appropriate pacing, limited exercise program, protecting weak limbs.*
- 10) Basic principles of treatment:
- a) Identify goals
- i) Improve body mechanics
 - ii) Correct or minimize postural and gait changes
 - iii) Protect weak muscles and joints
 - iv) Adjust the workload on muscles and joints to match their capacity
 - v) Control inflammation (sign of poor body mechanics)
 - vi) Control muscle spasm (sign of overstress of muscle)
 - vii) Alleviate nerve impingements
 - viii) Promote healthy lifestyle modifications
- (1) Determine appropriate treatment modalities:

- b) Behavior modification/pacing
- c) Physical therapy (provide resources)
- d) Occupational therapy
- e) Bracing
- f) Assistive devices
- g) Weight loss
- h) Joint/spine injections
- i) Medications
- j) Psychological counseling

or the other giving orders! If unable to find satisfactory treatment locally, I recommend a visit to a post-polio clinic for assessment and recommendations.

Note: Post-Polio Fact Sheets Available on the Internet

www.ninds.nih.gov/disorders/post_polio/post_polio.htm

11) Educate those who work with you

www.marchofdimes.com/professionals/681_4006.asp

Provide resources (*not stacks of printed material*)

Let your feelings and needs be known without becoming overbearing or too demanding

www.post-polio.org/educa.html

Treatment plan should result from discussion between you and your health care provider - not one

(Excerpt from Post Polio 101 - compliments of Polio Echo)

8. How to communicate with your doctor?

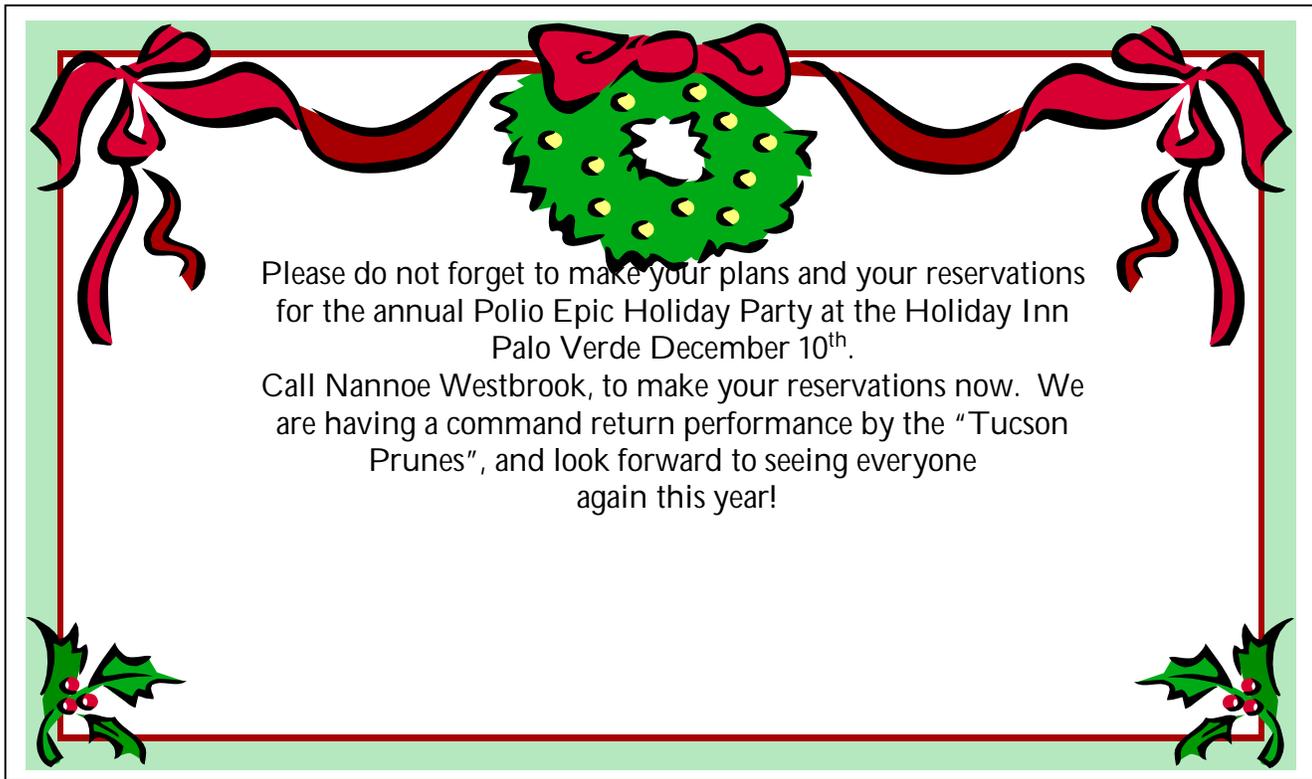
Three things you need to know before you go to your doctor

- You need to know how you feel.
- You need to know what has changed in the recent past.
- You need to know how to evaluate what the medical professionals are telling you.

To keep track of how your are feeling and how things are changing:

- a. Keeping a journal helps make it easier to report more accurately to your physician about how you have been feeling and how things have been changing
- b. Always start with the day's date
- c. Make simple entries -
- d. Don't need to keep this on a day-to-day basis, only until something changes
- e. If several days have the same symptoms just write "same as above."
- f. Be sure to also write down when you are have felt "good" all day.

**Take Charge of your
Medical Care,
You know your own
Body Best!**



Dues Form

**POLIO EPIC, INC. CURRENT MEMBERSHIP ANNUAL DUES ARE RENEWABLE
THROUGH THE FISCAL YEAR OF SEPTEMBER 1, 2006– AUGUST 31, 2007**

NAME _____ SPOUSE _____ DATE _____

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CITY _____ STATE _____ ZIP _____ - _____

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EMAIL _____

____ I am sending in my/our annual dues of \$5.00 per person for 2006-2007 fiscal year.

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

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

____ Please remove my name from the mailing list. I no longer wish to receive the newsletter.

____ Check here if you do not want your name, address, phone number and email listed in the **POLIO EPIC DIRECTORY**.

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

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