Feb – March 2007
Southern Arizona
Post-Polio Support Group
Est. 1985
P.O. Box 17556
Tucson, AZ 85731-7556
(520)-750-8608
(Message)
www.polioepic.org

POLIO EPIC, INC.

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

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February 10:
All Access Travel Cyndi Seagroves
March 10:
Sharing & Fun

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2006 POLIO EPIC ACCOMPLISHMENTS

Happy 2007!!! Set any new year's resolutions yet? I suggest we first look back, to reflect on Polio Epic's accomplishments in 2006. Doing that is sure to put a smile on your face and who wouldn't want an extra smile!

I've outlined at least a dozen specific successes that I believe speak to the hard work and commitment of our board and members. Congratulate each other for your work, for your concern for others and for your desire to make life better for all polio survivors. Here goes:

- 3 board members continued to work each month to teach medical students at University Medical Center about polio and post-polio.
- Polio Epic board has 2 new members.
- Our library books and tapes were re-organized and cataloged with a new "check out" system.
- Polio Epic continued to receive complements and words of appreciation from many people for its GREAT newsletter.
- "Post-Polio 101" materials developed in 2005 continued to be used in local presentations and in newsletters across the country.
- We provided a "Post-Polio 101" presentation to approximately 20 Green Valley polio survivors and family members that we had never met before.
- Members had the opportunity to review possible goals for Polio Epic and provide feedback to the board for 2007-2008 goals.
- Our by-laws and board member position descriptions were revised.
- Polio Epic teamed up with Rotary International Polio Survivors Action group to help educate rotary members about post-polio syndrome and the needs of polio survivors.
- One of our board members became involved in a national research study about "adaptation into late life and lessons learned from polio survivors."
- Polio Epic received a substantial donation bequest given by a beloved and long-time member.
- A "notebook" for board members was developed in order to assist new and current members with their work on our board.

Thank you to all who helped with these accomplishments! You know who you are. Remember, there's always room for more opportunities to make a difference. I look forward to the good times we can have in 2007.

*The opinions expressed in this publication are those of the individual writers and do not necessarily constitute an endorsement or approval by **POLIO EPIC, INC**. If you have personal medical problems, please consult your own physician*

Why is this wolf howling? Perhaps he misses part of his pack, just like we do.
Those that have left us behind:

Orville "Chris" Christensen – beloved long time member of Polio Epic. This is one notice that I didn't want to write; however, Chris meant so much to all of us. I can't put him in this newsletter without telling everyone how special he truly was. Chris battled his health in the last year, however, never lost his spark of energy. Chris waged the battle to get a website for Polio Epic, he answered the phones, he showed his care for everyone. Chris didn't want a service, and his family will be spreading his ashes. Perhaps when we listen to the wind, we will feel the comfort that was Chris while he walked among us.

Doug Burris – I've never seen a member of Polio Epic appear in both the donations column and the condolences column at the same time before we lost Doug. We will miss his support and presence.

Neil (Skip) Hoogenboom --Beloved husband, father and grandfather, passed away Thursday, January 4, 2007, at the age of 71 after a long battle with post-polio syndrome. Born in Wheaton, Ill., on January 15, 1935, to Corneilius and Marie Hoogeboom, he was one of two children. Stricken with all 3 types of polio at the age of ten, he was the only child in a room of 26 kids to survive. He attended Illinois Institute of Technology and earned a degree in Civil Engineering. Neal retired from Allis Chalmers, where he traveled all around the world as an expert in his business. He moved to Tucson, AZ, from Appleton, WI, in 1990 with his wife and two daughters.

Frank Wadleigh

Several months ago, we lost another long-time member of our group, Frank Wadleigh. Many of you may have attended the monthly "lunch with Frank's", and many more of you may have seen the notices in the newsletter for years. Below, I have some collected memories of Frank and his impact on our group.

Joanne Yager: Always a gentleman, Frank could talk about anything and hold your interest. Contracted Polio while stationed in Burma, during his Army service years. He was "Movie Star" handsome in his young days. He lived abroad during various times in his civilian life. Frank and Norman, Joanne's husband, often talked about politics. Frank loved living at Compana del Rio where the *Lunch Bunch* joined Frank on 3rd Thursdays for many years and Dec 05 was his last gathering.

Nannoe Westbrook: While Frank struggled in life, he never missed a meeting. When I became treasurer he was supportive. He was always thankful and expressed that to others. His ever ready jokes included his off color collection. A very generous character that always made donations when he paid his dues. He even helped pay for others so they could attend the Holiday Celebrations.

Bill Hatton: During the last 6 months of his life Bill accompanied Frank to the VA Hospital in what seemed like the power chair carousel. Frank was most grateful for my help at the VA and it seemed to cut down on the pain he experienced. I helped him get his chair in and out of the van and we had many fun distractions…he usually bought me an ice cream cone when we were finished with his errands.

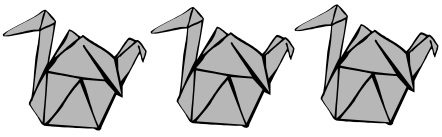
Suzie Hatton: He donated a lot to agencies, organizations and individuals.

Dorothy Cogan: I would not ever miss having lunch with Frank and the *Lunch Bunch* while I was in Tucson. We worked well together on the by-laws revisions one year. Frank and several other men had a card playing club from which he got much satisfaction he was well respected by all.

Ernie Richman: He smiled easily and made us all feel welcomed at the *Lunch Bunch!* His physical problems did not seem to keep him for being positive and humorous.

Mieko Iventosch: Although I knew him a short time he spoke of many memories…he taught English to a Japanese couple and when they left he kept in touch; however, he lost touch with them. He asked me to call them so they could reunite. When he suddenly became very sick in the VA hospital, I went to visit him bringing along a string of origami paper cranes (which translate to happiness and long life when they are made for persons who are ill.) While the cranes are being made the recipient is the subject of many prayers. Frank died before I could give him the cranes. In shock, I forgot and left the string of cranes behind at the hospital. When I called the hospital later to see if they found the cranes, I was told they were not found. Hopefully they went to someone who needed them, or Frank himself made sure they went where they were supposed to go.

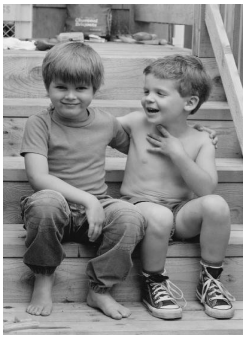
The Japanese couple that Frank coached in English sent a very touching letter of gratitude, which Mieko read at the memorial service.



Kathy Zittlosen: We met thru Republican Party and I remembered him and his diligent phone work.

Frank Frisina. Frank seemed to be lifelong Republican but his wry sense of humor motivated him to send a donation to the Democratic Party…a check for 1 penny. He was accepting of all people and seemed to appreciate diversity and affirmed how differences enriched us all. It was not unusual for Frank to share parts of life, which others knew little about; thereby building a level of intimacy with each of us. He had a way of making us feel as if we were the most important person in the room.

Frank Wadleigh will remain one of the most memorable characters in Polio Epic's history and one of our best friends.



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

DONATIONS

Merle Kyser
James LaDuc
DeAnn & Charlie Riley

BUILDERS $100 and OVER

Doug Burris
Dorothy Cogan
Ruth Creagh
Michael Cuthbertson
Joe Duchene
Grace Eccles
John Gieger
Gene Horman
Rita & Tom Huber
Fred Killion
Kent & Marlys Kloepping
Carol Mayfield
Denise Nielsen
L.W. Nichols
Richard Piskun
Sonya Scott
Kathleen Smith
Arlene Wise

*FRIENDS UP TO $99

We wish to thank these generous donors for our annual Holiday Party. Their continued support of Polio Epic is greatly appreciated.

Holiday Inn – Palo Verde
Bashas'
Albertson's
Sears – Tucson Mall
Bookman's
Sunflower Market
Native Seed Search
Debbie Korn Miller, Reader Advocate for the Arizona Daily Star

Notice: Ed Boyles has a power wheelchair and wheelchair lift available. The lift takes a 2" trailer hitch. Please contact him by e-mail at edintucson@netzero.net

Reminder 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. Any questions, please call me at **520-797-6898** or email me at **Nannoe1@aol.com**

What the Montana Polio Survivor's are doing!

January 19, 2007 -- Montana First Lady Nancy Schweitzer joined a group of Montana polio survivors Friday in promoting immunization as a way to safeguard Montanans against the potentially devastating effects of vaccine-preventable diseases.

At a reception in the state Capitol, Mrs. Schweitzer was welcomed as the new co-chair of the Montana Every Child by Two Coalition. The nonprofit group is dedicated to raising awareness of the critical need for timely immunizations and establishing a systematic way to ensure that all Montanans are fully immunized. Mrs. Schweitzer joins two of her predecessors, former First Ladies Theresa Racicot and Carol Judge, as well as Sen. Carol Williams of Missoula, in chairing the coalition. She will serve as an advocate and spokesperson for the group.

"As a parent, I think we owe our children the healthiest start on life that we can give them," Mrs. Schweitzer said. "Immunization is a lifelong weapon we can give our children to help them fight infectious diseases like measles, pertussis, and polio." Mrs. Schweitzer was joined at the reception by members of the Montana Polio Survivors Group, who are working to educate Montanans about the continued need for polio vaccination.

Last year, six cases of polio were identified in unvaccinated residents of Minnesota and Arizona, underscoring the fact that polio has not yet been eradicated. According to the Montana Department of Public Health and Human Services (DPHHS), 5 percent of Montana children under the age of 3 have not been vaccinated against polio. Nationwide, the rate is 10 percent.

"Polio is still a threat," said Barb Tabacco, of Great Falls, who contracted polio while a high school student in the 1940s. "Please do not take chances when there's a vaccine to fight this terrible disease."

In addition to the crippling effects of polio, many who get the disease experience symptoms of post-polio sequelae (PPS) about 35 years later. Symptoms of PPS include overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, sensitivity to anesthesia, cold intolerance, and breathing difficulties.

"We can't afford to be complacent about polio," said Marci Eckerson, nurse consultant with the DPHHS Immunization Program. "We've made great strides against it, but the 2006 cases are a stark reminder that polio and other deadly diseases may be only a plane ride away."

Every Child by Two is a nationwide organization created in 1991 by former First Lady Rosalyn Carter and former First Lady of Arkansas Betty Bumpers. The original goal of the group was to encourage parents to fully immunize their children by age 2. The group also advocated for state laws requiring children to be fully immunized before starting school. The Montana coalition works to maximize the health of all Montanans through vaccination.

Eighty percent of Montana 2-year-olds have received all recommended immunizations, Eckerson said, compared to 81 percent of 2-year-olds nationally. "Vaccination rates serve as a good marker for a community's health," she added.

To learn more about what immunizations your child may need, visit **www.health.mt.gov** and look under Programs for "Communicable Disease Control & Prevention."

Source: Montana Governor's Office

Tough battle against polio -Chronicle Herald Canada

IS THE global battle to eradicate polio, once dubbed the Great Crippler, stuck in a quagmire?

If so, then the usual questions regarding strategy and costs, always important to be sure, take on added urgency. The World Health Organization has twice missed its own deadlines for defeating the disease, first in 2000, then 2005. There have been enormous successes: The WHO's efforts have reduced the worldwide number of cases from 350,000 in 1988 to fewer than 2,000 in 2006. However, polio has proven extremely resilient, and the number of new infections has actually been climbing for the last few years. Critics are questioning everything from the choice of vaccines to the continued willingness of donor countries to foot the expensive bill for the eradication effort.

Yet the negativity should not overshadow the tremendous progress made to date. When the WHO began nearly two decades ago, new polio infections were occurring in 125 nations around the world. Today, the list of endemic states – those where new cases arise due to infection with the wild virus in that country, not brought in by travellers – is down to just four: Nigeria, India, Afghanistan and Pakistan.

In Nigeria, which accounted for more than half the indigenous cases of polio in 2006, eradication efforts went backwards a few years ago after some Muslim religious leaders claimed the vaccine was a U.S. plot to make children infertile. But more Islamic clerics are now backing vaccination drives in the crucial northern states, and plans for another national immunization campaign are scheduled for later this month.

India has also seen its number of cases rise, in its case dramatically, especially in high-risk, densely populated areas with poor sanitation, such as western Uttar Pradesh. But researchers have identified that new infections are occurring mainly in children under three, and hope newer vaccines that convey faster immunity will help to get the situation under control.

The newer, monovalent vaccines, available since the middle of 2005, individually target two of the three strains of the virus (Type 2 polio was declared eliminated in 1999, another success). The older, trivalent vaccine provided immunity from all three strains, but was slower-acting. Improved lab tests, which detect and confirm polio cases twice as fast as before, are also helping health authorities respond to and contain outbreaks.

Some experts have urged the WHO campaign to abandon oral vaccines, which carry an extremely tiny risk of serious side effects, in favour of the injectable vaccine used in Canada and other Western nations. But the latter's higher cost – five times the price of the oral vaccine – and its requirement that trained health care workers administer the shot, as compared to the volunteers who can hand out the oral vaccine, make the recommendation impractical where the front line in the battle against polio is taking place: the developing world.

What is crucial is for donor countries to meet their financial commitments to finally beat polio. The $1.4-billion US budget for 2006-2008 is under-funded by $440 million US. The WHO believes polio's eradication remains "feasible;" we just need the will to finish the fight.

HALIFAX, NOVA SCOTIA | Sunday January 21, 2007 ChronicleHerald.CA

We have what every place needs

By MIKE SCOGIN 1/21/07

Every community needs a Jerry Richardson. Someone who asks the politically incorrect question that everyone else wants to ask but doesn't. Since he arrived in Scott County some 11 years ago, Jerry Richardson has been challenging the status quo, often angering people in the process. Jerry has never learned to back down or give up, and he has sometimes made his arguments personal with caustic attacks. Today, Jerry is a different man facing a different challenge. On Feb. 16, Jerry will undergo eight hours of surgery at Vanderbilt University Medical Center. He has invasive bladder cancer. He is a man facing his own mortality.

"I've had an incredible life," he said Friday. "But I don't think people here understand me." A coal miner's son, Jerry contracted polio at age three and spent much of his early years in hospitals. As a child he had two spinal fusion operations. He developed a bladder infection after the last such operation that almost killed him. Attempts to straighten his spine led to Jerry being placed in a rack that pulled his spine straight and then being placed in a body cast. "I still remember the smell of that body cast," he said.

Those early challenges fueled Jerry's determination and sense of justice. Later, Jerry taught minority poor children at a middle school in Prince George, Maryland. He challenged them to be responsible even though he saw the injustice they faced from society. Arriving in Scott County, Jerry immediately became involved in the community, challenging leaders through appearances at public meetings and through letters to the editor. "I'm a tough, strong-minded person," Jerry said. "I care a lot. I don't think people know that about me."

Jerry became involved working with the Scott County Humane Society, the Georgetown & Scott County Museum and organizing a local book club. He was instrumental in pushing the smoking ban in Georgetown. That issue remains close to his heart. Jerry has respiratory problems related to his polio, and his mother died after years of smoking. "We must keep people from ever getting cancer," he said, talking about the smoking ban and his own personal challenges. "It's better not to get sick than to try and get well. "That's why the smoking ban is so important. We need a smoke-free Scott County, as well." Studies have shown that smoking bans such as the one in Georgetown actually lead to a decrease in the number of smokers, he said. "That's the key to beating cancer," he said. "Stop it before you get it."

Jerry believes he is blessed with the ability to look into people's eyes and see the truth. He also has a profound belief in his own sense of right and wrong. "I hate injustices of any kind," Jerry said. "I don't want to see anyone mistreated because they are poor or black or whatever reason. "It's a matter of principle with me." Challenging government and civic leaders was a way to effect change. But Jerry admits his methods sometimes overshadowed his intentions. "Sometimes my passion jumps too far," he said. "I have never intended to hurt anyone. I just have a heightened sense of justice, and when I see something I believe is wrong I get very determined."

Despite everything, Jerry believes he has had a positive effect on Scott County. "I don't think people really know or understand all the positive things that I helped to make happen," he said. "They just think of me as someone who hates God because I was opposed to a Christian prayer at a public meeting. Trust me, you don't go through all the things I've been through without believing in God. "But I hate injustice and I hate excluding people for any reason, including religion." He pauses for a moment, and then adds softly. "I want people to know that I care about this community - a lot."

Naturally, Jerry's newspaper column has been suspended until the surgery. Even though Jerry and I have clashed more than once over the years, his sincerity and love for this community was never in doubt. Our thoughts, and yes, our prayers are with you, Jerry. Every community needs a Jerry Richardson. Scott County is fortunate that we got the original.
Mike Scogin can be reached at MScogin@news-graphic.com

Editors Note: Every one of our Polio Epic members have a story to tell, a passion worth knowing about. When I read this story about Jerry, I knew that every one of us is just as determined, passionate and caring. If you have any stories about you, your passions, or another person, we should know about, please contact the newsletter editor, **Micki Minner** at (**520) 743-1556**, or e-mail at **MickiMinner@msn.com**

DI 24580.010 Evaluation of Postpolio Sequelae

B. POLICY SSR 03-1p POLICY INTERPRETATION RULING

TITLES II AND XVI: DEVELOPMENT AND EVALUATION OF DISABILITY CLAIMS INVOLVING POSTPOLIO SEQUELAE PURPOSE: To provide guidance on SSA policy concerning the development and evaluation of postpolio sequelae in disability claims filed under titles II and XVI of the Social Security Act (the Act).

For purposes of disability claims adjudication, what constitutes postpolio sequelae?

For purposes of disability claims adjudication, postpolio sequelae refer to multiple physical and mental disorders that may be manifested by polio survivors many years following acute polio infection. Any one or a combination of these disorders appropriately documented by signs, symptoms, and laboratory findings will constitute the presence of postpolio sequelae. The term "postpolio sequelae" includes the documented residuals of acute infection as well as all other documented clinical conditions that have an etiological link to either the acute infection or to its residual deficits.

Motor weakness is the most common residual of acute polio infection and is usually manifested by observable weakness, muscle atrophy, and reduced peripheral reflexes. These obvious clinical findings are used to document the history of poliomyelitis. Electromyographic studies may be used by clinicians in clarifying the cause and extent of neuromuscular impairment, but should not be needed for purposes of disability decisionmaking. Nonetheless, when electromyography (EMG) results are available for review, these data should be considered in decisionmaking. Typically, we will not order or purchase EMG studies.

In the absence of evidence to the contrary, and as long as the medical findings support a reasonable medical link between the prior polio infection and the present manifestation of any one or combination of the disorders discussed in the ruling, we will find that the individual has postpolio sequelae. For example, an individual with a history of polio affecting the left lower extremity who, on examination, has weakness and atrophy of the left thigh musculature with an observable limp now complains of chronic left lower extremity pain and is found to have lumbar stenosis documented by medically acceptable imaging. As discussed below, due to the chronic postural imbalance related to the effects of polio, a reasonable medical link exists between this individual's current medical condition (degenerative lumbar spine disease) and his/her prior polio residuals. Accordingly, we would make a finding of postpolio sequelae. currently, chronic pain, fatigue, problems with disrupted sleep, and difficulties with memory, demonstrates a reasonable medical link. On the other hand, an individual with a history of polio (for example, stating "I was in an iron lung") who, on examination, has normal motor findings, including normal posture and gait, now complains of pain clinically consistent with chronic radiculopathy, and has medically acceptable imaging demonstrating degenerative arthritis in the lumbar spine. This individual's current medical condition does not demonstrate a reasonable medical connection with the prior polio; instead, the degenerative arthritis should be adjudicated as a musculoskeletal disorder unrelated to the prior polio infection.

Postpolio sequelae include such disorders as postpolio syndrome (also know as the late effects of poliomyelitis), early advanced degenerative arthritis, sleep disorders, respiratory insufficiency, and various mental disorders. These disorders and documentation issues concerning them are discussed in detail below.

What is meant by the term "postpolio syndrome"?

According to the National Institute of Neurological Disorders and Stroke (NINDS), postpolio syndrome is a condition that affects polio survivors anywhere from 10 to 40 years after recovery from an initial paralytic attack of the poliomyelitis virus. The NINDS states that postpolio syndrome is characterized by a further weakening of muscles that were previously affected by the polio infection. The signs and symptoms include fatigue, slowly progressive muscle weakness, and, at times, muscular atrophy. The NINDS states that joint pain and increasing skeletal deformities such as scoliosis are common. Not all polio survivors experience these clinical problems, and the extent to which polio survivors are affected by postpolio syndrome varies.

The onset of new or worsening signs and symptoms is associated with a further reduction of the individual's capacity to independently carry out activities of daily living.

How does the presence of early advanced degenerative arthritis constitute an element of postpolio sequelae?

Polio survivors often manifest motor residuals in a single extremity and thus function day-to-day with chronic postural imbalance. Clinicians have described degenerative musculoskeletal disorders etiologically linked to long-standing postural imbalance. Abnormal weight-bearing in polio survivors produces exaggerated wear and tear on the bones and joints of the spine or limbs that are overused to compensate for limbs weakened by polio. Early onset of advanced degenerative arthritis can be found in a compensatory extremity or spine. Where such an etiological relationship is clear, clinically documented early advanced degenerative arthritis in a compensating limb or spine is considered one of the postpolio sequelae.

Documentation of early advanced degenerative arthritis may include medically appropriate imaging or abnormal physical findings of advanced arthritis on clinical examination.

Chronic pain disorders related to early degenerative osteoarthritis should be evaluated based on the impact of the pain and its treatment on the individual's physical and mental functioning.

Why are sleep disorders and respiratory insufficiency possible manifestations of postpolio sequelae?

Some polio survivors report the occurrence of sleep disorders that are determined by clinical evaluation to be related to respiratory insufficiency during sleep. The poliovirus has demonstrated a propensity to attack the motor neurons responsible for respiratory function, and, during the acute infection, some individuals require ventilatory assistance. For example, years ago patients with acute polio infection were placed in an "iron lung" for ventilatory assistance. Some patients who required such assistance recovered and may have returned to normal lives without obvious signs of respiratory insufficiency. Some polio survivors, however, have reported the onset of sleep disorders years following the acute polio infection, and physicians have linked these sleep disorders to weakening of the respiratory musculature. During sleep, even slight weakness of the respiratory musculature may become clinically significant and interfere with breathing capacity. Chronic sleep deprivation resulting from repeated episodes of sleep apnea may result in the development of excessive daytime drowsiness or cognitive and behavioral changes.

Respiratory insufficiency should be documented by abnormal pulmonary function studies. The presence of a sleep disorder related to respiratory insufficiency requires documentation by longitudinal treatment records, including such things as abnormal polysomnography or other appropriate evidence. Note, however, that we3 generally will not purchase a polysomnogram (also called a PSG, sleep study, or sleep test). See also 3.00H of the Respiratory System medical listings for additional information concerning sleep-related breathing disorders (see 20 CFR Appendix 1 to Subpart P of Part 404--Listing of Impairments).

What types of mental disorders may be seen in individuals with postpolio sequelae?

Some polio survivors report the onset of problems with attention, concentration, cognition, or behavior. Some researchers have suggested that certain cognitive and behavioral deficits are the result of the prior polio infection that involved the brain, although others do not agree with that concept. Other researchers have suggested that the traumatic psychological experiences associated with acute polio infection are revived when polio survivors recognize the onset of further weakness and functional loss.

Many polio survivors endured a life-threatening infection as young children. They may have spent extended periods away from their homes and families while hospitalized with paralysis or respiratory dysfunction, or while undergoing multiple orthopedic surgeries. Often they endured many months, or sometimes years, of hospitalization and rehabilitation. The psychological effect of perceiving the onset of further weakness, fatigue, respiratory dysfunction or joint pain, many years following the acute infection, can be significant. Signs and symptoms of anxiety and depression may produce further deterioration in function.

Any mental impairment that could have an etiological link to the acute polio infection or its chronic residuals may be considered a manifestation of postpolio sequelae. Deficits in attention, cognition, or behavior may be demonstrated by reduced concentration capacity, inability to persist in tasks, or memory problems. Also, behavioral abnormalities may be demonstrated by mood changes, social withdrawal, or other behaviors inappropriate for the individual. Mood disorders characterized by anxiety and depression may also be seen and clinically documented in these individuals.

How do postpolio sequelae affect an individual's functional capacities?

Individuals experiencing postpolio sequelae may complain of the new onset of reduced physical and mental functional ability. Complaints of fatigue, weakness, intolerance to cold, joint and muscle pain, shortness of breath and sleep problems, mood changes, or decreased attention and concentration capacity may hallmark the onset of postpolio sequelae. Weakness, fatigue, or muscle and joint pain may cause increasing problems in activities such as lifting, bending, prolonged standing, walking, climbing stairs, using a wheelchair, transferring from a wheelchair (e.g., from wheelchair to toilet), sleeping, dressing, and any activity that requires repetition or endurance. Changes in attention, cognition, or behavior may be manifested by reduced capacity to concentrate on tasks, memory deficits, mood changes, social withdrawal, or inappropriate behavior.

Many polio survivors who had been in a stable condition may begin to require new or additional assistive devices, such as braces, canes, crutches, walkers, wheelchairs, or pulmonary support. The reduced ability to sustain customary activities, including work, may result. A previously stable functional capacity may be further diminished.

Many individuals with medically severe polio residuals have worked despite their limitations. The new onset of further physical or mental impairments (even though they may appear to be relatively minor) in polio survivors may result in further functional problems that can limit or prevent their ability to continue work activity. Postpolio sequelae may effectively alter the ability of these individuals to continue functioning at the same level they maintained for years following their initial polio infection.

How will we document claims involving postpolio sequelae?

We generally will rely on documentation provided by the individual's treating physicians and psychologists (including a report of the medical history, physical examination, and available laboratory findings) to establish the presence of postpolio sequelae as a medically determinable impairment. In the absence of evidence to the contrary, we will make a finding that a medically determinable impairment is established if any of the disorders discussed above have been documented by acceptable clinical signs, symptoms, and laboratory findings.

However, if evidence indicates that the diagnosis is questionable, we will contact the treating source for clarification, in accordance with 20 CFR 404.1512(e) and 416.912(e). Of course, if a favorable disability determination or decision can be made based on the available evidence of record, whether or not a link to the prior polio infection is evident, no further development need be undertaken.

The careful development of postpolio sequelae should include descriptions of the past acute illness (old records are not required), as well as a report of the current findings on physical examination. The examination report should also include the severity of any residual weakness, as well as the onset, pattern, and severity of any new physical or mental deficits. A description of current functional limitations and restrictions on physical and mental activity should be obtained from the examiner.

When possible, detailed longitudinal treatment records from the treating source should be obtained. In cases where severity of the impairment is unclear, an examination by a physician or psychologist who is knowledgeable about polio and postpolio sequelae is appropriate, if such a specialist is available.

How will we use evidence from third parties in cases of postpolio sequelae?

Evidence from employers and other third party sources may be valuable in documenting a loss of a previous level of functioning and should be sought when there is a discrepancy or a question of credibility in the evidence of record and a fully favorable determination or decision cannot be made based on the available evidence. For detailed discussions regarding these factors, please refer to SSR 96-7p, "Titles II and XVI: Evaluation of Symptoms in Disability Claims: Assessing the Credibility of an Individual's Statements," and SSR 96-8p, "Titles II and XVI: Assessing the Residual Functional Capacity (RFC) in Initial Claims."

How are symptoms assessed in cases of postpolio sequelae?

Once postpolio sequelae has been documented as a medically determinable impairment, the impact of any of the symptoms of postpolio sequelae, including fatigue, weakness, pain, intolerance to cold, etc., must be considered both in determining the severity of the impairment and in assessing the individual's RFC. The adjudicator must make a comprehensive assessment of the cumulative and interactive effects of all of the individual's impairments and related symptoms, including the effects of postpolio sequelae. Evaluate all symptoms and their effects in accordance with 20 CFR 404.1529 and 416.929, and SSR 96-7p, "Titles II and XVI: Evaluation of Symptoms in Disability Claims: Assessing the Credibility of an Individual's Statements."

What is the expected duration of postpolio sequelae?

Most postpolio sequelae are stable or very slowly progressive disorders. The medical evidence should readily support an expected duration of at least 12 or more months.

Can the impairment of postpolio sequelae meet or equal listing 11.11?

The listing criteria under our current listing 11.11, Anterior poliomyelitis, may be applied both to cases of static polio (where there has been no reported worsening after initial recovery) and to cases presenting with postpolio sequelae. All documented postpolio sequelae must be considered either alone or in combination to determine whether the medical criteria of listing 11.11, or any other listing, have been met or equaled. If the impairment is not found to meet or equal a listed impairment, we consider the impact of the impairment and any related symptoms in determining an individual's RFC and we proceed to evaluate the individual's impairment under our sequential evaluation procedures in accordance with 20 CFR 404.1545 and 416.945.

It is essential that the cumulative and interactive effects of all of the individual's impairments, including symptoms, be carefully assessed in determining the individual's RFC in these cases.

How is a disability onset date determined in case of postpolio sequelae?

A disability onset date in cases involving postpolio sequelae is set based on the individual's allegations, his or her work history, and the medical and other evidence concerning impairment severity. Generally, the new problems associated with postpolio sequelae are gradual and non-traumatic, but acute injuries or events, such as herniated discs, or broken bones from falls, may be markers for establishing a disability onset date. For additional discussion concerning the determination of onset date, refer to SSR 83-20, "Titles II and XVI: Onset of Disability."

EFFECTIVE DATE: This ruling is effective upon publication in the Federal Register.

CROSS REFERENCES: SSR 83-20, "Titles II and XVI: Onset of Disability," SSR 96-3p, "Titles II and XVI: Considering Allegations of Pain and Other Symptoms in Determining Whether a Medically Determinable Impairment is Severe," SSR 96-4p, "Titles II and XVI: Symptoms, Medically Determinable Physical and Mental Impairments, and Exertional and Nonexertional Limitations," SSR 96-7p, "Titles II and XVI: Evaluation of Symptoms in Disability Claims: Assessing the Credibility of an Individual's Statements," SSR 96-8p, "Titles II and XVI: Assessing Residual Functional Capacity in Initial Claims," and SSR 96-9p, "Titles II and XVI: Determining Capability to Do Other Work--Implications of a Residual Functional Capacity for Less Than a Full Range of Sedentary Work."

Polio Survivors Pre-Operative Checklist
By Richard Bruno, Ph.D.
From the Winter, 1997 issue of TRIUMPH

- [ ] **Give articles to surgeon and discuss:**
  - [ ] **Pre-Op Lung Test**
  - [ ] **Lower blood volume and blood banking**
  - [ ] **No same-day Surgery!**
  - [ ] **Authorization for longer stay in Hospital**
  - [ ] **Orders for post-op anti-vomiting medications**
  - [ ] **Positioning on the OR table during surgery**
  - [ ] **Difficulty clearing secretions in the recovery room and on nursing unit**
  - [ ] **Orders for increased dose of pain medications**
  - [ ] **Physical therapy for stretching and range of motion in hospital**
  - [ ] **Placing articles about polio in the medical chart**
- [ ] **Give articles to anesthesiologist and discuss:**
  - [ ] **Lung Problems?**
  - [ ] **Lower dose of pre-op calming medication**
  - [ ] **Lower dose of anesthetic**
  - [ ] **Longer-term paralysis of muscles with spinal anesthetic and curare-like drugs**
  - [ ] **Orders for post-op anti-vomiting medication**
  - [ ] **Difficulty clearing secretions in the recovery room**
- [ ] **Give articles to nursing supervisor and discuss:**
  - [ ] **Longer-term sedation with anesthetic**
  - [ ] **Difficulty clearing secretions on the nursing unit**
  - [ ] **Orders for increased dose of pain medication**
  - [ ] **Needing help in moving in the bed and in the room**
  - [ ] **Not standing or walking until you are fully awake and able**
  - [ ] **Anti-embolism stockings**
- [ ] **Meet with PPS physiatrist *before* surgery and discuss:**
  - [ ] **Post-op Rehabilitation plan**
  - [ ] **Physical therapy for stretching and range of motion in hospital**
  - [ ] **Possible admission to a rehab hospital before going home**
  - [ ] **Physical therapy for walking and increasing endurance at home**

Last year, I had two surgeries, and both times had problems with longer term paralysis in recovery, even though I had a spinal instead of general anesthesia both times. The nurses had no idea about PPS. In the second surgery, the Charge Nurse was a personal friend of mine (and my husband, who is a retired RN and PPS'r himself) and was able to speak for me with the other nursing staff. Not everyone has a friend like mine, so PLEASE use this checklist! Allow the surgery to help you instead of hurt you. Micki Minner

POST-POLIO HEALTH INTERNATIONAL AWARDS RESEARCH GRANT TO UNIVERSITY OF ARKANSAS TEAM

-excerpted from Press Release

St. Louis, Dec. 19, 2006 – Post-Polio Health International, Headquartered here, announced that it has awarded a $25,000 research grant to a team from the University of Arkansas for Medical Sciences (UAMS), Little Rock. The researchers propose to determine whether there is a unique signature, or disease biomarker, in the immune system of individuals with post-polio syndrome (PPS) that would enable a more definitive diagnosis of PPS.

….”Biomarkers are biological measures found associated with specific diseases. They are useful because they can assist in disease diagnosis or provide a means of monitoring disease development and progression. The researchers at UAMS recently detected the increased presence of a distinct immune cell population in the blood of individuals with PPS but not healthy individuals, although the number of donors examined was small. The detected cells represent a recently described subtype of T cells, known as regulatory T cells (Tregs).

The research award from Post-Polio Health International will fund a small pilot study that will determine whether development of PPS is associated with increased numbers of Tregs and whether the Tregs found in individuals with PPS have unusual properties as compared with those in healthy individuals. “We are very grateful to PHI for their support of this research. Although the research is in its very early stages and our initial results need to be rigorously tested in a much larger group of individuals with PPS, a biomarker for PPS that can be potentially measured in an individual’s blood should enable a more rapid and more definitive diagnosis of this debilitating disease.” said principal investigator Dr. Rahnuma Wahid, Postdoctoral Research Assistant, Microbiology and Immunology Department, at the University of Arkansas for Medical Sciences. ….”

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