October-November 2009
Southern Arizona Post-Polio Support Group
Est. 1985
P.O. Box 17556
Tucson, AZ 85731-7556
(520) 750-8608 (msg)
www.polioepic.org

POLIOEPIC, INC.

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

October 10th
Presentations from our own members that attended the Warm Springs Conference. Updates/Information and Research

Board Meetings are the first Thursday of every month at DIRECT offices on Tyndall at 10:00 AM and all are welcome!

THE "WADLEIGH FUND": THE BEST OF GIVING AND RECEIVING

If it's September, it must be time for me to be President of Polio Epic again! That's right; I'm your trusted leader for another year. I'm grateful for the chance to serve and happy to be working with so many incredible people! I thought I would start this article by reminding you of a great opportunity for any Polio Epic members who live in Pima County. A few years ago, Frank Wadleigh, a senior member of Polio Epic, died and left us a good sum of money in his estate. He asked that we establish a memorial fund with his financial donation to be used to help other Polio Epic members live better and more rewarding lives. We did just that.

This past year several members have completed the simple form required when requesting financial assistance. These requests have allowed these members to purchase adaptive equipment, make vehicle adaptations and complete necessary minor remodeling in their home. At our membership meeting on Saturday, September 12, three members shared requests they made this past year. One member in particular stressed how hard it has been for him to accept help. He felt that the Wadleigh Fund process was simple and straight forward. The request form only asks for necessary information; nothing too personal or inappropriate. He received the maximum amount available at a time when he and his family needed it most. He got to "practice" accepting help, something we all need to do!

Typically requests must be for durable goods or for health care services provided by a qualified professional. Members can make a "one-time" request not to exceed $400. Of course, receipts must be supplied to: Polio Epic. Dave Marsh, Polio Epic Board member, is the contact for all Wadleigh Fund requests. If you are interested, call Dave at 327-3252 or email him at davejonmarsh@msn.com to receive the request form or to ask any questions. It is often said that "it is better to give than to receive."

With the Wadleigh Fund, both events can take place. Frank Wadleigh can have his last wish to **give** to his peers and we can **receive** from someone who loved us all very much.

Fondly, Karla Carr, President

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In Memory of Dorothy Cogan

Dorothy Cogan wasn't an unusual person. She wasn't someone who won a lot of awards. You might say that she was like a lot of other people you may have known. She had a quiet way about her. She cared about others and tried to do her best.

However, when it comes to talking about friendship, Dorothy Cogan was a star! Dorothy Cogan was a friend to many of us in polio epic. She was kind, generous, joyful and always willing to help our support group. She made phone calls to check on members who were unable to leave their homes because of their disability. She worked the registration table at the polio epic holiday luncheon, greeting everyone with her lovely smile. Dorothy was a faithful polio epic board member; rarely missing a meeting and ever ready to contribute to discussions about keeping our support group alive and well.

I don't know what makes two people love each other. I just know that from the time we first met, Dorothy touched my heart. I don't think I can tell you how or why. But we were both grateful that we had crossed paths. And when Dorothy became ill, I knew that it would hurt my heart greatly on the day that she would pass. I didn't know Dorothy for as long as many other people in Polio Epic, but I loved her and will never forget her.

Written by Karla Carr

UCLA scientists make paralyzed rats walk again after spinal cord injury

UCLA Newsroom *September 21, 2009 UCLA Home Campus Directory*
By Elaine Schmidt| 9/20/2009 10:00:00 AM

UCLA researchers have discovered that a combination of drugs, electrical stimulation and regular exercise can enable paralyzed rats to walk and even run while supporting their full weight on a treadmill.

Published Sept. 20 in the online edition of the journal Nature Neuroscience, the findings suggest that the regeneration of severed nerve fibers is not required for paraplegic rats to learn to walk again. The research may hold implications for rehabilitation after human spinal cord injuries.

"The spinal cord contains nerve circuits that can generate rhythmic activity without input from the brain to drive the hind leg muscles in a way that resembles walking, called 'stepping,' " said principal investigator Reggie Edgerton, a professor of neurobiology and physiological science at the David Geffen School of Medicine at UCLA.

"Previous studies have tried to tap into this circuitry to help victims of spinal cord injury," he added. "While other researchers have elicited similar leg movements in people with complete spinal injuries, they have not achieved full weight“bearing and sustained stepping as we have in our study."

Edgerton's team tested rats with complete spinal injuries that left no voluntary movement in their hind legs. After setting the paralyzed rats on a moving treadmill belt, the scientists administered drugs that act on the neurotransmitter serotonin and applied low levels of electrical currents to the spinal cord below the point of injury. The combination of stimulation and sensation derived from the rats' limbs moving on a treadmill belt triggered the spinal rhythm generating circuitry and prompted walking motion in the rats' paralyzed hind legs.

Daily treadmill training over several weeks eventually enabled the rats to regain full weight bearing walking, including backwards, sideways and at running speed. However, the injury still interrupted the brain's connection to the spinal cord based rhythmic walking circuitry, leaving the rats unable to walk of their own accord.

In humans, however, neuroprosthetic devices may bridge spinal cord injuries to some extent, so activating the spinal cord rhythmic circuitry as the UCLA team did may help in rehabilitation after spinal cord injuries.

The study was funded by the Christopher and Dana Reeve Foundation, the Craig Nielsen Foundation, the National Institute of Neurological Disorders and Stroke, the U.S. Civilian Research and Development Foundation, the International Paraplegic Foundation, the Swiss National Science Foundation and the Russian Foundation for Basic Research Grants.

The above study could be so IMPORTANT
For all Spinal Cord injury survivors, and Post Polio's.
Dr. Snyderman, from NBC news predicts this study will be ready for human trials in just 2 years.

SOCIAL SECURITY ADMINISTRATION

Social Security Ruling, SSR 03-1p.; Titles II and XVI:

Development and Evaluation of Disability Claims- ***Postpolio Sequelae***

AGENCY: Social Security Administration. ACTION: Notice of Social Security ruling. ***SUMMARY:*** This Ruling clarifies the policies of the Social Security Administration for developing and evaluating title II and title XVI claims for disability on the basis of postpolio sequelae. Postpolio sequelae refer to the documented residuals of acute polio infection, as well as other disorders that have an etiological link to either the acute polio infection or to the chronic deficits that resulted from the infection. These disorders typically manifest late in the lives of polio survivors, and include such things as postpolio syndrome (also known as the late effects of poliomyelitis), the early presence of advanced degenerative arthritis, sleep disorders, respiratory insufficiency, and various mental disorders.

At: http://www.socialsecurity.gov

Policy Interpretation Ruling

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).

Introduction: "Postpolio sequelae" refers to the documented ***residuals*** of acute polioencephalomyelitis (polio)\1\ infection as well as other disorders that have an etiological link to either the acute polio infection or to chronic deficits resulting from the acute infection. Disorders that may manifest late in the lives of polio survivors include postpolio syndrome (also known as the late effects of poliomyelitis), early advanced degenerative arthritis, sleep disorders, respiratory insufficiency, and a variety of mental disorders. Any one or a combination of these disorders, appropriately documented, will constitute the presence of "postpolio sequelae" for purposes of developing and evaluating claims for disability on the basis of postpolio sequelae under Social Security disability. Even though some polio survivors may have had previously undetected motor residuals following the acute polio infection, they may still report progressive muscle weakness later in life and manifest any of the disorders listed above.

The Act and our implementing regulations require that an individual establish disability based on the existence of a medically determinable impairment; i.e., one that can be shown by medical evidence, consisting of symptoms, signs, and laboratory findings. Disability may not be established on the basis of an individual's statement of symptoms alone.This Ruling explains that postpolio sequelae, when accompanied by appropriate symptoms, signs, and laboratory findings, is a medically determinable impairment that can be the basis for a finding of "disability." It also provides guidance for the evaluation of claims involving postpolio sequelae.Policy Interpretation: Postpolio sequelae constitute a medically

determinable impairment when documented by appropriate medical signs, symptoms, and laboratory findings. Postpolio sequelae may be the basis for a finding of "disability," as discussed below. When making a determination of disability in cases of postpolio sequelae, the adjudicator or decision maker must be sure that all of the individual's functional limitations have been considered. To do this, 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.

A. What Is the Definition of "Disability" and "Medically Determinable Impairment"? The Social Security Act (the Act) define "disability" as the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment (or combination of impairments) which can be expected to result in death or which has lasted or can be expected to last a continuous period of not less than 12 months. The Act require that an impairment result from anatomical, physiological, or psychological abnormalities that can be shown by medically acceptable clinical and laboratory diagnostic techniques. The Act further requires that an impairment be established by medical evidence that consists of signs, symptoms, and laboratory findings, and not only by an individual's statement of symptoms.

B. 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 decision making. Nonetheless, when electromyography (EMG) results are available for review, this data should be considered in decision making. 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. 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 known as the late effects of poliomyelitis), early advanced degenerative arthritis, sleep disorders, respiratory insufficiency, and various mental disorders.

C. 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.

D. 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 a relationship is clear, clinically documented early advanced degenerative arthritis in a compensating limb or spine is considered one of 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.

E. 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 we \3\ generally will not purchase a polysomnogram (also called a PSG, sleep study, or sleep test).

F. 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.

G. How Do Postpolio Sequelae Affect an Individual's Functional Capacities? **I**ndividuals 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.

H. 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. 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.

I. 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.

J. 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.

K. What Is the Expected Duration of Postpolio Sequelae? Most PP sequelae are very slowly progressive disorders. The medical evidence should readily support an expected duration of at least 12 or more months.

L. 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 impairment under our sequential evaluation procedures. 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.

M. 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***.

CHRONIC INFLAMATION OR AUTO-IMMUNE RESPONSE IN POLIO SURVIVORS

Dr. Trojan from Magill University in Canada, found that Polio survivors who are experiencing Post Polio syndrome, have a higher level of inflammatory markers. Until more research can be done, we can be alert to the fact that “Chronic Inflammation” can be treated and might help with our symptoms. They have also found this same unique condition in survivors of other viruses that attack the central nervous system.

In some diseases, however, the body’s defense system (immune system) inappropriately triggers an inflammatory response when there are no foreign substances to fight off. In these diseases, called **“autoimmune diseases”**, the body’s normally protective immune system causes damage to its own tissues. The body responds as if normal tissues are infected or somehow abnormal. ·

Symptoms include:
Redness,
Swollen joint that is warm to touch,
Joint pain, Joint stiffness, and
Loss of joint function

Often, only a few of these symptoms are present. Inflammation may also be associated with general “flu-like" symptoms including:
Fever,
Chills,
Fatigue/loss of energy,
Headaches,
Loss of appetite, and
Muscle stiffness

Contributions Thank you

Frann Miescher*
Margie & Heracio Clark
Dick Coleman*
Lorna Kenny
Patricia Lamb
Sara Snyder
Gail Watts
Nannoe Westbrook

** $100 donation or above*

In Memoriam of
Dorothy Cogan by Thomas Clark

Dues for the new fiscal year are now due!!

Check the date on your address label. If it says **2009** or earlier, then it's time to pay your dues. Polio Epic relies on your dues and contributions which help defray the raising cost of our expenses. So there is not an interruption in receiving your newsletter, **PLEASE** remember to let us know if you are moving, or vacationing.

Dues Form

POLIO EPIC, INC. CURRENT MEMBERSHIP ANNUAL DUES THROUGH THE FISCAL YEAR 0F
SEPTEMBER 1, 2009– AUGUST 31, 2010

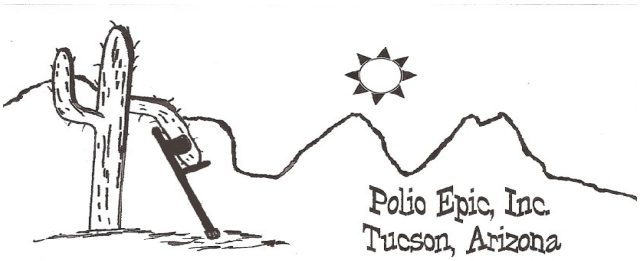
NAME_____SPOUSE_____DATE_____
ADDRESS_____PHONE(_____)_____
CITY_____STATE_____ZIP_____-_____
Emergency Contact info:_____
Newsletter via Email?Address_____
_____I am sending in my/our annual dues of **$10.00** per person for 2009-2010 fiscal year.
_____I am sending in a *tax-deductible* donation in 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 85731-7556

It's time!

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.