The Polio Post

Ohio Polio Network Newsletter

Spring 2016 issue

Paul Smith Croley 1921—2016

SILVER LAKE - Paul Smith Croley, 95, passed away May 13, 2016. Paul was born in Williamsburg, KY, second oldest of fourteen children of William and Ida Croley. One year after graduating from Cumberland College, he taught eight grades in a one-room school house, including seven of his brothers and sisters. Moving to Cincinnati, he worked at Curtis-Wright Aeronautical as a Supervisor before entering the service in WWII. He graduated from officer's candidate school as a Lieutenant. He and Helen Jean were married in October 1945. After the war, they settled in the Youngstown area. Paul then worked for Mahoning Valley Supply Company, starting as a truck driver and warehouse employee and later was sent to a newly opened branch in Akron to be in sales. In 1958, he became Branch Manager, then Sales Manager of the entire company. He attended an executive course at Wharton School of Finance and served on the Board of Globe International, Inc. Paul retired as President and CEO of Mahoning Valley Supply. He literally lived the American Dream. His life reflected his love for the Lord, & he was a wonderful husband, father, son, brother, Papaw and friend. Paul was an avid golfer. He taught 6th grade boys in Sunday School for 25 years & coached Boys Basketball at Richardson Elementary School & Boys and Girls teams at church. Paul was always a teacher and couldn't resist helping or encouraging someone when he saw the need. He was also commissioned a Kentucky Colonel.

In his retirement, Paul enjoyed his winter home in Venice, FL where their families gathered for spring breaks. He is survived by his wife of 70 years, Helen Jean, four children and many, many other family members. Having had polio, it was in his very late years that he contacted the Akron Post-Polio Support Group and inquired about being part of the organization, as post-polio syndrome had become quite difficult for him to manage. Unable to attend meetings in person, we greatly valued Paul being a member of the Akron Post-Polio Support Group. Paul will be remembered most fondly by us all.

Editor: Alice Sporar

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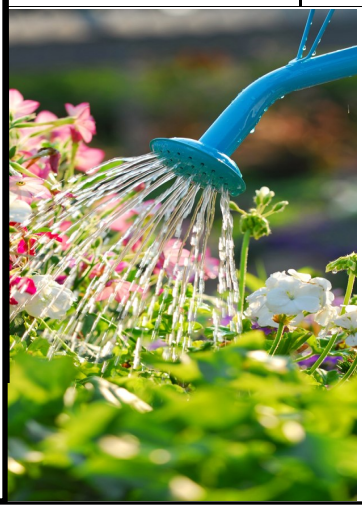

Easy Recipes for people with PPS

Baked Herbed Fish submitted by Pat Novak

2 lbs. white fish fillets
1/2 C chopped onion
2 tbsp. butter or margarine
1/4 tsp. salt
1/2 tsp marjoram
1/3 tsp. thyme
1/4 tsp. garlic powder
1/2 C. white wine or skim milk
paprika

Place fish in baking dish. Combine melted butter with salt and herbs.
Drizzle over fish. Top with onion. Sprinkle with paprika. Pour wine or skim milk around fish. Bake uncovered, 30 to 35 minutes in 350 degree oven. Serve with lemon wedges.

To make this recipe easier, skip the herbs and onion. Just use the plain butter and liquid and paprika for color.
Will be just fine. An easy way to make fish!

Tammie Tschappat 1947 –2016

Tammie Tschappat, born on April 15, 1947 in Cleveland, Ohio to Alexander & Marie (Hutchison) Tschappat passed away May 2, 2016 after a very lengthy illness in nursing care. She was preceded in death by her parents and her brother Timothy. Tammie has left behind a multitude of friends and her beloved dog Skippy. She was a member of Tallmadge United Methodist Church and one of her proudest moments was becoming a Stephens Minister. She enjoyed traveling, especially to Walt Disney World and on cruises. Tammie took her dream trip to England after she retired from Ryerson Steel in 1999.

Tammie and her brother were two of some of the first known children in Ohio to be stricken with polio in the 50's, thus leading her to being active in polio and post-polio groups on the state and local level. On the state level, she was a member of the Ohio Polio Network. Then on the local level, being such a "people person", Tammie greatly enjoyed being part of the Akron Post-Polio Support Group as well. She was a member for more than a couple decades and it was important for her to be with her fellow post-polio friends to discuss how to help and support one another. When she was healthier, she was very active in its activities, though as her health waned, it prompted her to give up her home and go into permanent nursing care. However, Tammie still stayed in touch with the support group members. What's so easy to remember about Tammie is her self-less way of putting others first. Tammie leaves very sweet memories for members of the Akron Post-Polio Support Group, as she was a very tender hearted person and most grateful and appreciative for all of her bless-ings.

Joanne Gellner 1929—2016

It is with great sadness to share that we have lost a long-time member of the Akron Post-Polio Support Group, and very beloved friend, Joanne Gellner, 86, who passed away on Tuesday, May 24, 2016.

Joanne was born August 31, 1929 in Akron, to Harold and Edythe Dickinson. She was a 1949 graduate of Akron North High School. She was a former member of Concordia Lutheran Church and most recently Northminster Presbyterian Church. She enjoyed summer trips to her family cottage in Pointe-Au-Baril, Ontario, Canada, on Kissin Kousins Island. An avid sports fan, she enjoyed bowling, golf, followed the Cleveland sports teams. Joanne was active in her community, involved in PTA, scouting, politics, running the voting booth, the Goodyear Boating and Yacht Club and the Akron Post-Polio Support Group.

Preceded in death by her husband, James, of 65 years, many, many family members. She is survived by her three sons, grand and great grandchildren, and many, many other family members across the U.S and Canada.

The Akron Post-Polio Support Group was a vital part of Joanne's life. She exuded such an open and warm heart to all who knew her. It was her husband, Jim (who passed away February 13, 2015) who had polio and she never missed being at a meeting with him, and even after he passed, she continued to show her love and caring for the support group members. She served in different capacities to help with the group's activities – the parties, our organization's historical scrapbook, but was probably most known for being the organizer of our huge annual fundraiser each year (the Acme Grocery cashback receipt program) which took a huge amount of time and effort. Joanne couldn't wait each year until the fundraiser concluded to announce to the group how much money we had made for our treasury. Her kind spirit will be sorely missed and we are thankful for all good memories she leaves with us.

Memorials may be made to the Akron Post-Polio Support Group, c/o Brenda Ferguson, 71 Donze Ct. Tallmadge, OH 44278-3608 or Hospice of Summa, P.O. Box 2090, Akron, Ohio 44398.

New book by Dr. Lauro Halstead: An Unexpected Journey - A Physician's Life in the Shadow of Polio

This is a book that was listed in the May Issue of PHI newsletter Communique. It can be obtained at www.amazon.com

It is a memoir of Dr. Halstead's life -- not an autobiography. Very entertaining, well written, and easy to read. I enjoyed it immensely -- couldn't put it down! I recommend it highly. – Pat Novak, Ohio Polio Network Board Secretary

Over the course of 14 chapters, Lauro Halstead, M.D. takes us on his unexpected life journey of challenges and growth in this memoir. As a young, vigorous college student in the early 1950s, he was suddenly paralyzed by a severe case of acute polio while traveling in Spain. He describes the struggle to leave behind the breathing machine that saved his life and develop the strength to pursue an adventurous life that included climbing Mount Fuji in Japan, living in Rome for a year and working in a tropical medicine hospital in India. Despite his polio disability, Dr. Halstead forged a pioneering career in medicine that included helping spinal cord injured men have biologic children and, when his own strength began to fail in midcareer, identifying a late phase of polio known as post-polio syndrome. In addition to his life as a successful physician, Lauro describes how he struggled to grow as a father of three children, to develop close, meaningful friendships with other men and to bond with his psychologically remote father. In a candid and emotionally revealing Afterword, Dr. Halstead answers common questions he is asked about sexuality, disability and the inexorable loss of function as he journeys into old age.

from: http://www.laurohalstead.com/index.html

ABOUT DR. HALSTEAD

Lauro S. Halstead, M.D. had polio following his first year in college and then had the good fortune to discover rehabilitation medicine early in his professional career. This led to a passion for bedside care and clinical research with a special interest in the challenges facing individuals with spinal cord injuries and post-polio health problems. He has published widely and is an international authority on the late effects of polio. Dr. Halstead was a founding member of the Medstar National Rehabilitation Hospital in Washington, D. C. from which he recently retired after nearly 30 years. He now has ample time to enjoy the company of his three adult children, his son-inlaw and new granddaughter, pursue his long-term love of the Italian language and play the euphonium in a brass quintet. Dr. Halstead lives in Washington, D. C. with his wife, Jessica.

from: http://www.laurohalstead.com/about-dr-halstead.html

What is post-polio syndrome?

Polio, or poliomyelitis, is an infectious viral disease that can strike at any age and affects a person's nervous system. Between the late 1940s and early 1950s, polio crippled around 35,000 people each year in the United States alone, making it one of the most feared diseases of the twentieth century.

The polio vaccine was first introduced in 1955; its use since then has eradicated polio from the United States. The World Health Organization reports polio cases have decreased by more than 99 percent since 1988, from an estimated 350,000 cases then, to 1,352 reported cases in 2010. As a result of the global effort to eradicate the disease, only three countries (Afghanistan, Nigeria, and Pakistan) remain polio-endemic as of February 2012, down from more than 125 in 1988.

Post-polio syndrome (PPS) is a condition that affects polio survivors years after recovery from an initial acute attack of the poliomyelitis virus. Most often, polio survivors start to experience gradual new weakening in muscles that were previously affected by the polio infection. The most common symptoms include slowly progressive muscle weakness, fatigue (both generalized and muscular), and a gradual decrease in the size of muscles (muscle atrophy). Pain from joint degeneration and increasing skeletal deformities such as scoliosis

(curvature of the spine) is common and may precede the weakness and muscle atrophy. Some individuals experience only minor symptoms while others develop visible muscle weakness and atrophy.

Post-polio syndrome is rarely life-threatening, but the symptoms can significantly interfere with an individual's ability to function independently. Respiratory muscle weakness, for instance, can result in trouble with proper breathing, affecting daytime functions and sleep. Weakness in swallowing muscles can result in aspiration of food and liquids into the lungs and lead to pneumonia.

Who is at risk?

While polio is a contagious disease, PPS cannot be caught from others having the disorder. Only a polio survivor can develop PPS.

The severity of weakness and disability after recovery from poliomyelitis tends to predict the relative risk of developing PPS. Individuals who had minimal symptoms from the original illness are more likely to experience only mild PPS symptoms. A person who was more acutely affected by the polio virus and who attained a greater recovery may experience a more severe case of PPS, with greater loss of muscle function and more severe fatigue.

The exact incidence and prevalence of PPS is unknown. The U.S. National Health Interview Survey in 1987 contained specific questions for persons given the diagnosis of poliomyelitis with or without paralysis. No survey since then has addressed the question. Results published in 1994-1995 estimated there were about 1 million polio survivors in the U.S., with 443,000 reporting to have had paralytic polio. Accurate statistics do not exist today, as a percentage of polio survivors have died and new cases have been diagnosed. Researchers estimate that the condition affects 25 to 40 percent of polio survivors.

What causes PPS?

The cause of PPS is unknown but experts have offered several theories to explain the phenomenon—ranging from the fatigue of overworked nerve cells to possible brain damage from a viral infection to a combination of mechanisms. The new weakness of PPS appears to be related to the degeneration of individual nerve terminals in the motor units. A motor unit is formed by a nerve cell (or motor neuron) in the spinal cord or brain stem and the muscle fibers it activates. The polio virus attacks specific neurons in the brain stem and spinal cord. In an effort to compensate for the loss of these motor neurons, surviving cells sprout new nerve-end terminals and connect with other muscle fibers. These new connections may result in recovery of movement and gradual gain in power in the affected limbs.

Years of high use of these recovered but overly extended motor units adds stress to the motor neurons, which over time lose the ability to maintain the increased work demands. This results in the slow deterioration of the neurons, which leads to loss of muscle strength. Restoration of nerve function may occur in some fibers a second time, but eventually nerve terminals malfunction and permanent weakness occurs. This hypothesis explains why PPS occurs after a delay and has a slow and progressive course.

Through years of studies, scientists at the National Institute of Neurological Disorders and Stroke (NINDS) and at other institutions have shown that the weakness of PPS progresses very slowly. It is marked by periods of relative stability, interspersed with periods of decline.

How is PPS diagnosed?

The diagnosis of PPS relies nearly entirely on clinical information. There are no laboratory tests specific for this condition and symptoms vary greatly among individuals. Physicians diagnose PPS after completing a comprehensive medical history and physical examination, and by excluding other disorders that could explain the symptoms.

Physicians look for the following criteria when diagnosing PPS:

- *Prior paralytic poliomyelitis with evidence of motor neuron loss*. This is confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neuromuscular examination, and signs of motor neuron loss on electromyography (EMG). Rarely, people had subtle paralytic polio where there was no obvious deficit. In such cases, prior polio should be confirmed with an EMG study rather than a reported history of nonparalytic polio.
- *A period of partial or complete functional recovery after acute paralytic poliomyelitis*, followed by an interval (usually 15 years or more) of stable neuromuscular function.
- *Slowly progressive and persistent new muscle weakness or decreased endurance, with or without generalized fatigue, muscle atrophy, or muscle and joint pain*. Onset may at times follow trauma, surgery, or a period of inactivity, and can appear to be sudden. Less commonly, symptoms attributed to PPS include new problems with breathing or swallowing.
- *Symptoms that persist for at least a year*.
- *Exclusion of other neuromuscular, medical, and skeletal abnormalities as causes of symptoms*.

PPS may be difficult to diagnose in some people because other medical conditions can complicate the evaluation. Depression, for example, is associated with fatigue and can be misinterpreted as PPS. A number of conditions may cause problems in persons with polio that are not due to additional loss of motor neuron function. For example, shoulder osteoarthritis from walking with crutches, a chronic rotator cuff tear leading to pain and disuse weakness, or progressive scoliosis causing breathing insufficiency can occur years after polio but are not indicators of PPS.

Polio survivors with new symptoms resembling PPS should consider seeking treatment from a physician trained in neuromuscular disorders. It is important to clearly establish the origin and potential causes for declining strength and to assess progression of weakness not explained by other health problems. Magnetic resonance imaging (MRI) and computed tomography (CT) of the spinal cord, electrophysiological studies, and other tests are frequently used to investigate the course of decline in muscle strength and exclude other diseases that could be causing or contributing to the new progressive symptoms. A muscle biopsy or a spinal fluid analysis can be used to exclude other, possibly treatable, conditions that mimic PPS. Polio survivors may acquire other illnesses and should always have regular check-ups and preventive diagnostic tests. However, there is no diagnostic test for PPS, nor is there one that can identify which polio survivors are at greatest risk.

How is PPS treated?

There are currently no effective pharmaceutical treatments that can stop deterioration or reverse the deficits caused by the syndrome itself. However, a number of controlled studies have demonstrated that nonfatiguing exercises may improve muscle strength and reduce tiredness. Most of the clinical trials in PPS have focused on finding safe therapies that could reduce symptoms and improve quality of life.

Researchers at the National Institutes of Health (NIH) have tried treating persons having PPS with high doses of the steroid prednisone and demonstrated a mild improvement in their condition, but the results were not statistically significant. Also, the side effects from the treatment outweighed benefits, leading researchers to con-

clude that prednisone should not be used to treat PPS.

Preliminary studies indicate that intravenous immunoglobulin may reduce pain and increase quality of life in post-polio survivors.

A small trial to treat fatigue using lamotrigine (an anticonvulsant drug) showed modest effect but this study was limited and larger, more controlled studies with the drug were not conducted to validate the findings.

Although there are no effective treatments, there are recommended management strategies. Patients should consider seeking medical advice from a physician experienced in treating neuromuscular disorders. Patients should also consider judicious use of exercise, preferably under the supervision of an experienced health professional. Physicians often advise patients on the use of mobility aids, ventilation equipment, revising activities of daily living activities to avoid rapid muscle tiring and total body exhaustion, and avoiding activities that cause pain or fatigue lasting more than 10 minutes. Most importantly, patients should avoid the temptation to attribute all signs and symptoms to prior polio, thereby missing out on important treatments for concurrent conditions.

Learning about PPS is important for polio survivors and their families. Managing PPS can involve lifestyle changes. Support groups that encourage self-help, group participation, and positive action can be helpful. Counseling may be needed to help individuals and families adjust to the late effects of poliomyelitis. Experiencing new symptoms of weakness and using assistive devices may bring back distressing memories of the original illness.

What is the role of exercise in the treatment of PPS?

Pain, weakness, and fatigue can result from the overuse of muscles and joints. These same symptoms also can result from disuse of muscles and joints. This fact has caused a misunderstanding about whether to encourage or discourage exercise for polio survivors or individuals with PPS.

Exercise is safe and effective when carefully prescribed and monitored by experienced health professionals. Exercise is more likely to benefit those muscle groups that were least affected by polio. Cardiopulmonary endurance training is usually more effective than strengthening exercises, especially when activities are paced to allow for frequent breaks and strategies are used to conserve energy. Heavy or intense resistive exercise and weight-lifting using polio-affected muscles may be counterproductive, as this can further weaken rather than strengthen these muscles.

Exercise prescriptions should include

- the specific muscle groups to be included,
- the specific muscle groups to be excluded, and
- the type of exercise, together with frequency and duration.

Exercise should be reduced or discontinued if it causes additional weakness, excessive fatigue, or unduly prolonged recovery time that is noted by either the individual with PPS or the professional monitoring the exercise. As a general rule, no muscle should be exercised to the point of causing ache, fatigue, or weakness.

Can PPS be prevented?

Polio survivors often ask if there is a way to prevent the development of PPS. Presently, no intervention has been found to stop the deterioration of surviving neurons. Physicians recommend that polio survivors get a good night's sleep, maintain a well-balanced diet, avoid unhealthy habits such as smoking and overeating, and follow a prescribed exercise program. Lifestyle changes, such as weight control, the use of assistive devices, and taking certain anti-inflammatory medications, may help with some of the symptoms of PPS.

What research is being done?

Scientists are working on a variety of investigations that may one day help individuals with PPS. Some basic researchers are studying the behavior of motor neurons many years after a polio attack. Others are looking at the mechanisms of fatigue and are trying to discover the roles played by the brain, spinal cord, peripheral nerves, neuromuscular junction (the site where a nerve cell meets the muscle cell it helps activate), and muscles.

Determining if there is an immunological link in PPS is also an area of interest. Researchers who discovered inflammation around motor neurons or muscles are trying to find out what causes this immunological response.

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Post-Polio Patients Have Swallowing Abnormalities that Increase the Risk of Choking

For release: Sunday, April 21, 1991

Many post-polio patients have swallowing abnormalities that increase the risk of choking but are unaware of their condition, according to a study directed by a scientist at the National Institute of Neurological Disorders and Stroke (NINDS) and published in the April 25 issue of the *New England Journal of Medicine* .* .

Of the 500,000 Americans who survived acute polio, more than 125,000 now have post-polio syndrome, in which progressive muscle weakness develops 25 to 30 years after the initial disease.

Previous reports have demonstrated that post-polio syndrome weakens the muscles of the arms and legs — causing patients difficulty when walking, lifting, or reaching. The recent study shows that this progressive weakness also affects the bulbar muscles of the tongue, mouth and throat and triggers swallowing problems — called dysphagia — in most patients.

"These findings should prompt physicians to check their post-polio patients closely for abnormal swallowing,"

said Marinos C. Dalakas, M.D., the NINDS scientist who directed the study. "Unlike new weakness in the arm or legs, which causes obvious problems with movement, deterioration in swallowing is easily overlooked — even with standard neurological exams," Dr. Dalakas stressed. "If dysphagia is not specifically tested, problems may remain hidden until the patient suddenly becomes aware of choking."

During the study, scientists examined swallowing among 32 patients randomly chosen from a larger group of post-polio patients. Using specialized imaging techniques, including videofluoroscopy and ultrasonography, they detected dysphagia in 31 patients — but only 14 were aware of this problem.

Typical signs of dysphagia included excessive tongue movements, a delay in the swallowing reflex and constriction of throat muscles, and uncontrolled flow of food from the mouth into the throat. These problems were often more severe on one side of the mouth and throat.

Dr. Dalakas and his colleague Barbara Sonies, Ph.D., of the National Institutes of Health also detected dysphagia using an index that assesses oral motor function based on 10 tests of muscle strength and motion, such as strength of tongue and lips, voice quality, and swallowing ability. "As the index score rises, the patient's risk of choking also goes up," Dr. Dalakas said. "Using this index, physicians can predict which patients are likely to choke."

Dr. Dalakas suggested that patients with post-polio syndrome visit their physician for a check of dysphagia and, in some cases, change eating routines to reduce choking risk. For example, patients with significant dysphagia should chew food on the less affected side, consume softer foods, use smaller bites when eating, and eat more slowly. He also recommended that family members or companions of such patients learn the Heimlich maneuver.

The exact cause of post-polio syndrome is unknown. During the first, acute polio infection, the virus destroys nerve cells that control limb and bulbar muscles. This causes symptoms that range from weakness to paralysis, depending on the number of nerve cells destroyed and how well the remaining, healthy neurons can compensate.

In post-polio syndrome, however, the compensating neurons become overworked and are no longer able to control muscles as effectively, Dr. Dalakas said. Post-polio syndrome may also be aggravated by the aging process, in which all individuals lose some neurons. In most individuals, half of the nerve cells controlling a muscle must die for weakness to result. Since the number of neurons is already abnormally low in post-polio patients, small additional losses can easily trigger muscle weakness.

"Studies of post-polio syndrome are rapidly advancing our knowledge of how motor neurons survive and endure and what causes them to dysfunction," said Murray Goldstein, D.O., M.P.H., NINDS director. "Thus, this research could have implications for other diseases that affect motor neurons — such as amyotrophic lateral sclerosis, or Lou Gehrig's disease, and the neuropathies. It may also help scientists to understand how aging affects the nervous system. "

The National Institute of Neurological Disorders and Stroke, one of the 13 National Institutes of Health in Bethesda, MD, is the primary supporter of brain and nervous system research in the United States.

"Dysphagia in Patients with the Post-Polio Syndrome." Barbara C. Sonies, Ph.D., and Marions C. Dalakas, M.D. New England Journal of Medicine; April 25, 1991; pp. 82-91.

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