



The Polio Post

Ohio Polio Network Newsletter
Winter 2016 Issue

Merry Christmas & Happy Healthy New Year in 2017

We are sad to report that long time Ohio Polio Network member Paul J Everson has passed away



PAUL J. EVERSON (July 13, 1922 - November 5, 2016)

beloved husband of Kay Everson (nee Welter) and the late Florence M. Everson; son of the late Rosella Everson; brother of Richard Everson (deceased); uncle of Gail Sue Everson and Cheryl (Russell) Young; stepfather of Lynda McIntyre, John R. (Rebecca) Roberts; step grandfather of Kristine (James) Betley, Amy (Travis) Shepherd, Erin Roberts; step great grandfather of Jay Betley, Samuel and Lillian Shepperd; cherished friend of Richard Johnson.

Paul died Nov. 5, 2016.

Mass of Christian Burial Thursday, Nov. 10 at 10 AM at Ss. Robert and William Parish, 367 E. 260 St. in Euclid. Private Interment.

In lieu of flowers, contributions to Catholic Charities would be appreciated.

Paul J. Everson retired as president of Paul J. Everson & Associates. Mr. Everson served as president of United Multiple Listing Services Inc., the Cleveland Area Board of Realtors (CABOR), the Ohio Association of Realtors (OAR), the Northeast Ohio Apartment Association, the Euclid Development Corporation and the Ohio Real Estate Commission. Mr. Everson was a director and trustee of the Real Estate Political Education Committee, the National Association of Realtors (NAR) and the Ohio Real Estate Commission. For his sustained contributions in the real estate profession, Mr. Everson was awarded an honorary degree of Doctor of Business Administration from Cleveland State University in the year 2008. The College and Cleveland State are honored by his generosity, dedication to education and founding of the Center. His gifts are lasting legacy that have benefited and will benefit students and the Northeast Ohio community for years to come.

Paul also supported the Ohio Polio Network for which we are very grateful.

Editor: Alice Sporar

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"Polio Above the Neck"

Written by Tessa Jupp RN for the Post Polio Network of Western Australia

In May 1999 Neurologist Dr Susan Perlman of the University of California-Los Angeles (UCLA) gave a talk to a post polio support group in California.

Complete article at www.skally.net/ppsc/neck.html

Dr Perlman notes that most people had polio that affected arms and legs but that not much is written about people who had non-paralytic polio.

De Perlman feels that these people had polio-enceph-alitis. From our own observations of polios in WA, people who had polioencephalitis often had a really bad headache, so bad that they still remember it as the worst headache they have ever had! Is this you?

Polioencephalitis could well have caused changes in the brainstem (bulbar polio), presenting as breathing and swallowing problems that may have been present even in people who ostensibly had non-paralytic polio and also in others who may have no complaints about their legs or arms. A few of our WA polios fit this scenario but others may also have had both paralysis and polioencephalitis too.

Autopsies performed following the epidemic polio of the 1940s and 1950s report signs of acute polio infection throughout the body, not just restricted to the spinal cord. Changes were found in central brain structures that control alertness, central fatigue, and autonomic functions such as temperature regulation and also in the brainstem itself.

It is estimated that more than 90% of a polio survivor's motor neurons were affected and damaged during the initial acute stage and some damage occurred even if there was no paralysis. Autopsy studies have shown that in the acute phase as few as 4% of motor neurons escaped damage.

Many of those with bulbar polio did not survive as if there is a 50% loss of the motor neurons that control breathing or swallowing, a person is going to be in real serious trouble. eg iron lungs.

Some people only had mild breathing weakness, chest wall weakness or a little diaphragmatic weakness. Recovery of injured or orphaned nerve cells was not as common in the brain and brainstem as it was in other parts of the body since the brainstem has less flexibility. This affected the pharyngeal and oesophageal muscles too.

Compensatory strategies, such as swallowing on the other side of their throat have long been used by polio people. Vocal cord paralysis is also evident in some of our WA polios and "new" problems occur when the muscles on the "good" side of their throat begin to weaken. Although facial, jaw and throat muscles are controlled by the brain stem, they have rarely been thought of in connection with polio.

Polios are more likely to have new problems if they have -

- * more residual disability
- * respiratory weakness
- * were older than 10 at time of acute polio
- * recent falls or injuries
- * surgical procedures in pharyngeal area
- * weight gain, because it puts more pressure on the diaphragm and pharyngeal area.

Continued on page 3

Our primary muscle for breathing is the diaphragm and if this tires or weakens then our rib muscles kick in and we chest breath. Accessory respiratory muscles can help lift the chest from the shoulders too

Poor breathing in polios can also be from decreased respiratory drive from the brain stem. This can be due to a carbon dioxide (CO₂) build-up as the sensor control in the brain stem weakens more.

Scoliosis can also cause restriction of breathing. Under-breathing develops as the scoliotic spine cannot expand the chest as well as before.

Measuring devices for patients with increasing respiratory problems include the forced inspiratory and expiratory measurements that we undertook with Dr David Hillman and Dr Peter Nolan at SCGH in 1990 as part of our initial WA Polio Clinic Research.

Monitoring CO₂ levels in the blood is another good measuring device. We have a machine to do this that is available for WA polios to borrow. It is not the amount of oxygen going in that is important but the amount of CO₂ going out. If you are not breathing well, your CO₂ levels are going to go up. Polios at risk should have regular checks of CO₂ levels and inspiratory/expiratory function - get a GP referral to Dr Hillman SCGH.

Swedish research on the impact of cardio-respiratory function in polios has found a significant incidence of deconditioning. Dr. Perlman says doctors are no longer saying post polios should do **no** exercise. Conditioning or aerobic exercise, is important.

Survivors can improve heart function, circulation, and breathing to some extent by doing activities that increases the heart rate. These researchers suggested increasing the heart rate to 70% of maximum by using a swimming pool or other exercise equipment.

Polio researchers in Toronto looked at 3 areas of muscles, (respiratory, diaphragm, chest wall), bulbar symptoms, the control rate and scoliosis. They found that the control panel in the brainstem was the least important of the group. Most people were having problems because of the diaphragm, chest wall fatigue or due to progressing scoliosis.

A few of Dr. Perlman's patients had experienced increased breathing problems at higher altitudes for example when flying. One of our WA polios was told he could no longer fly back to NZ when it was found at SCGH that half of his diaphragm had been permanently paralysed since childhood polio. He had not known this was why he got so easily puffed on exertion. Now adjustments can be made so those polios can travel at higher altitudes and not feel short of breath all the time. See a respiratory specialist.

Swallowing

The motor neurons that control swallowing are located in the brainstem. In order to have an effective swallow, we use various groups of muscles to insure that food is chewed, forms into a bolus, and goes down properly. The swallowing centre coordinates other activities related to swallowing: ie chewing, licking, gagging, coughing, sneezing, vomiting, belching and breathing to some extent.

When we swallow, we can't breath at the same time, because there is a flap that opens or closes the air pipe depending whether we are eating or breathing, so the two groups of muscles and nerves are competing against each other.

There are at least a dozen places in the body where a post-polio patient who had some pharyngeal problems or brainstem related swallowing problems could begin to have trouble now with swallowing – either in the steps or in the sequence of swallowing.

For example, people who have weakness in the jaw muscle as a complication of PPS will find it hard to chew when fatigued. People who have a weak soft palette can find that food is slipping into their throat before it is fully chewed and food or drink - drink especially - may be coming up out of their nose.

Swallowing problems have been identified in polios in more recent world studies. In WA swallowing problems occur in about 16% of our polios. However most polios do not have constant choking. If you concentrate on swallowing and eliminate distractions, like talking or watching TV, choking on food can be lessened. Any part of the gastro-intestinal tract - from the mouth all the way to the bottom - could be slowed, weakened, or not working properly due to worsening late effects. But don't assume that every symptom a polio survivor gets is due to PPS.

Dr Perlman says, although common pathways are used for breathing and swallowing, not everyone who has swallowing problems has breathing problems and not everyone who has breathing problems has swallowing problems. Bulbar muscles can slowly dysfunction and there can be silent swallowing problems. In a 1991 polio swallowing study by Dr Marinos Dalakas in Philadelphia USA, he concluded that “...in bulbar neurons there is a slowly progressive deterioration similar to that in the muscles of the limbs.”

Blood Pressure and/or Variable Heart Rate

Dr Perlman has been asked - “*Can high or low blood pressure be a result of polio and PPS*” and “*Can a variable pulse rate be made worse, not because of heart disease, but because of post-polio symptoms affecting the area?*”

She says that the average doctor may be hard pressed to believe it possible for polio to be related to current blood pressure or pulse rate problems. However, vaso-motor centres that control blood pressure and pulse rate are located in the medulla (in the lower brainstem) and also in the autonomic area of the brain. Since polio damage has been seen in the brain and in the brainstem, this relationship to blood pressure and pulse is an area that needs further study.

As we understand more of brain involvement in acute polio and the number of nerves in the brain that were involved, areas that might have looked okay on the surface could actually be functioning on very shaky ground. “*The majority of motor neurons, in whatever region the poliovirus got to, were probably affected in some way or another,*” said Dr Perlman.

Anesthesia Warning Card

<p>I am a POLIO SURVIVOR with POST – POLIO SEQUELAE (PPS)</p> <p>Unexpected midlife symptoms:</p> <ul style="list-style-type: none"> Overwhelming Fatigue Muscle Weakness Muscle and Joint Pain Sleep Disorders and Cold Intolerance Difficulty Swallowing and Breathing Heightened Sensitivity to Anesthesia 	<p>ANESTHESIA WARNING!</p> <p>I am a Polio Survivor ...</p> <p>EASILY SEDATED, difficult to wake Difficulty BREATHING and SWALLOWING with anesthesia;</p> <p>HYPERSENSITIVE to PAIN and COLD. Need heated blanket and increased pain medication post-op.</p> <p>For more information visit: www.ohiopolionetwork.org</p>
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Anesthesia Card resources:

Post-Polio Network of NJ: <http://www.njpolio.org/images/anesthesia/Anesthesia-Warning-Card.pdf>

Pennsylvania Polio Survivors Network: <http://www.papolionetwork.org/-anesthesia-warning.html>

10 Things You Should Know about Caregiving

1. Preparing to Be a Caregiver. While it may not be the first thing that comes to mind when everyone in your family is healthy, having a plan for your potential role as a caregiver can ease stress if a serious health issue or disability does arise. The Family Caregiver Alliance (FCA) shares [tips for talking to parents](#) – or any loved one – about what their needs might be if an illness or injury results in a disability. [Holding a family meeting](#) ensures that everyone involved in caregiving is able to share their opinions and agree on an action plan. [Medicare.gov](#)'s fact sheet on [what every caregiver should know](#) is a good starting place to learn the basics of caregiving, including [tips for talking about the future](#) and legal and financial considerations. Another planning resource for caregivers is the FCA's webinar, "[Caregiving 101: Exploring the Complexities of Family Caregiving](#)." Learn how to [plan ahead legally](#) and [what you should know about money](#). Finally, take some time to educate yourself about [first steps for new caregivers](#).

2. Financial Help. In addition to looking after the physical and emotional needs of loved ones, caregivers often take on their financial stresses and burdens, too. This can include paying bills, banking, filing insurance and benefits claims, managing savings and investments, dealing with housing issues and filing taxes. The Consumer Financial Protection Bureau's "[Managing Someone Else's Money](#)" publication has helpful information about matters such as [powers of attorney](#), [court-appointed guardians](#), [trustees](#) and [government fiduciaries](#). They have also released [guides for 44 states](#) for financial caregivers. [AARP](#) offers many resources for financial caregivers in the [Legal and Financial](#) section of their online [Caregiving Resource Center](#). [Disability.gov](#)'s [Guide for Family Caregivers](#) includes information on possible financial compensation for caregiving under the "[Can I Get Paid to Be a Family Caregiver?](#)" section.

3. What You Need to Know about Medicare and Medicaid. When it comes to managing someone's Medicare or Medicaid coverage, there's a lot a caregiver needs to juggle and understand. First of all, it's important to know [the difference between Medicare and Medicaid](#). [Questions and Answers about Medicare for Caregivers](#) is a good place to find information about what Medicare does and doesn't cover. In particular, while Medicare covers [hospital stays and skilled nursing facility care](#), it [doesn't cover long-term care](#) (also called custodial care) if this is the only type of care a person needs. Medicare's [Caregiver Resource Kit](#) contains several tip sheets, including information about taking care of yourself and how to find caregiver assistance near you. Regarding Medicaid, states run their own programs, so you'll need to contact [your state's Medicaid office](#) if you have questions about what it does and doesn't cover. Read [Medicaid.gov](#)'s [explanation of Medicaid benefits](#) to learn more. [Healthcare.gov](#) also has information about [Medicaid eligibility](#), as well as how to find out about Medicaid programs in your state. You can find more information about how these programs cover expenses on [Disability.gov](#).

4. Getting Additional Support. Your loved one may require additional support outside of a primary caregiver to fully meet his or her needs. Feel like you need a helping hand? The FCA offers a list of [25 organizations that take care of caregivers](#). AARP's [12 Resources Every Caregiver Should Know About](#) includes additional organizations that can help. Learn how to [ask for help](#) when caregiving becomes too much to bear. Your local [area agency on aging](#) and the [Family Care Navigator](#) can direct you to nearby services. The U.S. Administration on Aging's [Eldercare Locator](#) connects visitors to services for older adults and their families. You may find that [respite services or in-home care](#) are the best options for your situation. Learn how to [select and hire home help](#), including how to [perform a background check](#). [Medicare.gov](#) can also help you [find and compare home health agencies](#). You may also want to think about [finding the right kind of out-of-home care](#) for your loved one. An assisted living facility or other care community may provide the right environment where your loved one can receive the best possible care.

5. A Profile of Young Caregivers. According to the [American Association of Caregiving Youth](#) (AACY), between 1.3 and 1.4 million young Americans age 8 to 18 provide care for a member of their family; meanwhile, an estimated [10 million 18 to 34 year-olds](#) fill that role. At a time when most of their peers are focusing on school or careers, these individuals have the added responsibility of performing critical care tasks for a loved one, most often a parent or grandparent. Their age and inexperience can create additional challenges and

often there aren't many support groups focused on this age range. The [AACY](#) addresses the needs of pre-teens, teens, families and care professionals through education and awareness, research and direct services. Email your questions to info@aacym.org. If you're between 20 and 39 years old and have a loved one diagnosed with cancer, you can [register to join a 15-week online support group](#) through [CancerCare.org](#). It's also very important to learn [how to take care of yourself](#) while caring for someone else.

6. Caring for America's Heroes. In addition to [National Family Caregivers Month](#), November is also [Warrior Care Month](#). Wounded Service Members may require varying levels of care, depending on the seriousness of their conditions. Those injured while on active duty and their caregivers may be eligible for [special programs](#), including [respite care](#). The U.S. Department of Veterans Affairs (VA) offers [caregiver support programs](#) for families taking care of Veterans. Programs include [Comprehensive Assistance for Family Caregivers](#), which provides services for seriously injured post-9/11 Veterans and their caregivers. Use the [Caregiver Eligibility Checklist](#) to see if you might qualify. The VA's [Caregiver Toolbox](#) has information for family members [new to caregiving](#), including diagnosis and care [fact sheets](#), [checklists](#) and tips to help [caregivers take care of themselves](#). Caregivers of World War II and Vietnam era Veterans can visit the VA's [Geriatrics and Extended Care](#) section to learn about long-term care options for older Veterans, including [home and community-based services](#). Caregivers of Veterans can also take the free [Building Better Caregivers™](#) online training course. For more information call the VA Caregiver Support Line at 1-855-260-3274 or your local [Caregiver Support Coordinator](#).

7. Long-distance Caregiving. Caring for a loved one who lives far from you comes with a unique set of challenges. How can you provide help and support when you're not even in the same area? However, there are many tasks that can be accomplished long-distance, including helping with finances, providing emotional support, arranging for in-home care or finding an assisted living facility. [Caring From a Distance](#) (CFAD) offers information, support and resources for the 6.9 million Americans who are long-distance caregivers. Use CFAD's [service directories](#) to find [help](#) near you. Learn how to gather [important documents](#) and put together a [caregiver support system](#). You can also read the [stories](#) of other caregivers. The National Institute on Aging's guide, "[So Far Away: 20 Questions and Answers about Long-Distance Caregiving](#)," provides additional information, as does the Alzheimer's Association's [Long-distance Caregiving](#) page and Easter Seal's "[Tips for Staying Involved Long-Distance](#)." Read [this article](#) from the [Texas Department of Aging and Disability Services](#) to learn more about first steps to take, important things to know about your loved one's medical history and how to stay connected.

8. Taking Time for Yourself. Caregivers dedicated to caring for a loved one may find themselves feeling stressed out and unable to take time to care for themselves. Remember that even if your primary responsibility is to be another person's caregiver, you should also focus on your own wellbeing. Be sure to look out for any [signs associated with caregiver stress](#) to prevent harmful effects to your health and figure out how to manage what you're feeling. According to the [FCA](#), the stress and burn out experienced by caregivers often results in neglecting basic health needs, including sleeping, exercising and eating right, , taking time to recover from illnesses and seeking proper medical attention. To ensure that your caregiving responsibilities don't take a toll on any of these areas of your health, the Alzheimer's Association recommends [simple steps](#) you can take to care for yourself. Caregivers may also experience depression, so if you notice symptoms such as negative feelings or changes in certain habits or behaviors, it might be helpful to explore the [coping strategies and treatment options](#) that are available. Most importantly, know that you're not alone, and that there are [many support services](#) for caregivers.

9. Support Groups. One of the best ways for caregivers to get help is through family caregiver support groups. Under the [National Family Caregiver Support Program](#), all states and territories receive funding to provide support to family caregivers, part of which helps cover the organization of support groups. If you're searching for a support group, the Caregiver Action Network has [key tips about finding one that's right for you](#). Support groups can be found in your area by reaching out to local government agencies, or by connecting with any of the "[25 Organizations that Take Care of Caregivers](#)" recommended by the [American Society on Aging](#). You can also find information and support through [AARP's telephone support line](#).

Call 1-877-333-5885 (1-888-971-2013 for information in Spanish) Monday through Friday from 7:00 a.m. to 11:00 p.m. Eastern Time and Saturday 9:00 a.m. to 5:00 p.m. Eastern Time. Can't make it to an in-person caregiver support group? There are also ways to find online support for caregivers. For instance, AARP provides [an online forum for caregivers](#) to interact and post about their caregiving questions and stories. The [FCA also offers online support groups](#) for caregivers and loved ones. If no support groups for caregivers currently meet near you, consider forming one using this [toolkit on "Creating an Effective Support Group"](#) or guidance.

10. Providing Care for a Child with a Disability. Caring for a child with a disability can be a rewarding experience, but it can also present challenges. The Centers for Disease Control and Prevention shares [tips for family caregivers of people with disabilities](#), noting the importance of advocating for and empowering them. Parents of children with disabilities can find support through [Parent to Parent USA](#), an organization found in almost [every state](#). Another great resource for caregivers of children with disabilities is the [Center for Parent Information and Resources](#), which provides information on early intervention, school services, therapy, local policies and transportation. Additionally, the [Sonoran University Center of Excellence in Developmental Disabilities Education, Research and Service](#) at the University of Arizona has created "[A Roadmap for Family Caregivers](#)," which provides information and insights about caring for children with disabilities. If parents need assistance in caregiving for a child with a disability, local chapters of organizations like [The Arc](#), [United Cerebral Palsy \(UCP\)](#) and the [National Down Syndrome Society](#) can connect them to resources and information. *(From Disability.gov, November 2015)*

2016 Ohio Polio Network Donors

As we approach the new year, 2017, the Ohio Polio Network (OPN) would like to thank all of our members. OPN would not exist without the receipt of annual dues from its members. Your contributions help to defray the cost of Post-Polio Conferences, the cost of the quarterly newsletter and the cost for maintaining the website. In addition OPN has a policy of recognizing members who made a donation in any amount during the year. We would like to thank the following people for their generous donations.

We thank you for your generosity. It is greatly appreciated!!!

Robert Boyce

Gretchen Estreicher

Paul Everson

Brenda Ferguson

Vivian Gray

Jonas Hershberger

Patrick Kelly

Patricia Novak

Nelson Sommers

Nikki Wingerson

[ABLE Act: Achieving a Better Life Experience](#)

The ABLE Act is rolling out in some states. Signed in to law in December 2014, it allows people with disabilities and their families the opportunity to create a tax-exempt savings account that can be used for maintaining health, independence and quality of life.

The federal act stipulated that an ABLE account may only be opened in the state in which the beneficiary resides, which means all 50 states or contracting states need to implement ABLE. A state can choose to contract with another state and those state residents would be covered under another 529 plan.

Many groups are working together to assist states in enacting ABLE legislation. The National Down Syndrome Society [site](#) is tracking the legislation in each State.

The final version of the ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before turning 26 years of age. If you meet this criteria and are also receiving benefits already under SSI and/or SSDI, you are automatically eligible to establish an ABLE account. If you are not a recipient of SSI and/or SSDI, but still meet the age of onset disability requirement, you would still be eligible to open an ABLE account if you meet SSI criteria regarding significant functional limitations.

Steve Gleason Act of 2015

The Steve Gleason Act of 2015 was signed by President Barak Obama on July 30. The act amends title XVIII of the Social Security Act to provide Medicare beneficiary access to eye tracking accessories for speech generating devices and to remove the rental cap for durable medical equipment under the Medicare Program with respect to speech generating devices.

Steve Gleason is a former New Orleans Saints football player who was diagnosed with ALS in 2011. He and his Team Gleason led a grass-roots effort to persuade Congress and the White House to ensure all Americans have access to eye tracking devices for generating speech.

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<p>The Polio Post is published quarterly. All articles are due according to the following schedule:</p> <table border="1"> <thead> <tr> <th><u>Issue</u></th> <th><u>Date Due</u></th> </tr> </thead> <tbody> <tr> <td>Spring</td> <td>March 1st</td> </tr> <tr> <td>Summer</td> <td>June 1st</td> </tr> <tr> <td>Fall</td> <td>September 1st</td> </tr> <tr> <td>Winter</td> <td>December 1st</td> </tr> </tbody> </table> <p>Please forward letters and articles to the return address on the newsletter or e-mail to amsporar@worldnetoh.com</p>	<u>Issue</u>	<u>Date Due</u>	Spring	March 1st	Summer	June 1st	Fall	September 1st	Winter	December 1st	<p>Membership Categories:</p> <ul style="list-style-type: none"> • Basic - \$10.00 • Donations – An annual list of people who have made a donation in any amount will be published in the December Issue of <i>The Polio Post</i> and on the website. • Special Gifts <p>OPN is a non-profit & tax exempt organization under: IRS 501(c)3 and Public Charity 509 (a) (2)</p>	<p>Make checks payable to: Ohio Polio Network c/o Judi Jacobs 464 17th St. NW Barberton, OH 44203-6660</p> <hr/> <p>Alice Sporar - Editor</p> <p>Nelson Sommers - Formatting/Publishing</p> <p>Judi Jacobs & Brenda Ferguson- Printing & Mailing</p> <p>Patrick Kelly - Advisor</p>
<u>Issue</u>	<u>Date Due</u>											
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