

The Polio Polio Post Ohio Polio Network Newsletter Spring 2019 issue



In Memory of Donna Kidner

Age 64 of Painesville Twp. passed away Dec. 25, 2018 at her home. Born April 29, 1954 in Painesville to Philip J. and Mary (nee: Chippone) Latona, she had been a longtime area resident. Survivors include her husband of 28 years D. Kirk Kidner of Painesville; step-daughters Rachael Kidner of Macedonia and Sara Kidner of Cleveland; step-grandson Edan Kidner of Euclid; mother-inlaw Louanna Kidner of Madison. She was preceded in death by her parents and her brother Phillip Latona. There will be a Service on Friday the 11th of January at St. Mary's church in Painesville OH

My wife of 28 years passed away on Christmas Day. - Kirk Kidner

I wanted to share what Donna's cousin Dennis said at her funeral, also some pics. This goes out to All the friends Donna had online, some she chatted with for over 20 years, even before Facebook.

A story of life

A very young girl at the age of 16 months standing along the edge of the couch looking at her mom who was laying down and smiling at her.

Who knew then that was the last time she would ever stand on her own, polio struck her down. It was very difficult for her parents making endless trips to the hospital to do everything they could for their daughter. When I went to see her in the hospital, sometimes she was in an iron lung with just her head sticking out, if they had her on her stomach, she would have to look into a mirror to see me. I did not know what to say as we were both at a very young age but no matter what she always had that smile. The nurses always knew if they put Donna next to a crying kid, she would calm them right down in no time with her charm. After many operations she was able to stand with braces and crutches. At 7 she became the poster child for United Way of Lake County. At age 10 she was the first of two patients to undergo the first spinal fusions ever conducted. They had to remove bone chips from her hips to fuse her entire back together. In order to keep the spine straight while it healed, they put a halo on her head to kept it from moving. She did not mind the screws they put in her head, but she did get a little upset when they cut off all her hair without telling her. I always asked her if it hurt, of course she said no. She had to keep that halo on for 6 months, and then a full body cast for another 6 months.

After this she continued to use crutches and braces but they were so heavy she finally gave up and figured out getting around in a wheelchair was much easier on her.

Donna's Dad would drive Donna to school every day as there wasn't any handicap transport available at the time. Whenever he bought any car, he showed me how big the trunk was. Donna would always come out with him and check it out beaming with her great smile every time.

She was so good at playing board games in our youth with my brothers and I and every kid on the street, she was unbeatable. She was so good at them all, but her favorite was scrabble. She had so many friends as I can see from everyone being

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Editor: Alica Sporar



here. She also had one special friend for 50 years. It was due to her brother Phil. Seems he sent in a letter to a teen magazine saying he was a teen rock star and to write to him. The sisters of St. Mary's tried to get all of us to find a pen pal, but Phil put a twist to it. Well he got plenty of letters from girls but only one from a guy. So, he tosses it to Donna, and she writes to him. Her pen pal for a life time-Robert. Kirk had some competition maybe!!! Not! He is such a wonderful man he even drove Donna to meet him in Boston as did her friend Margie as well.

Since Donna was 5, she went to Camp Harkness every summer but when she was 16 it was to be a fateful meeting. Kirk, then 15, volunteered as a counselor and met this cute camper. Who knew at that time she would fall in love with him and nearly 20 years later marry. They have been married 28 years.

She had a very well-trained supportive care her whole life through grade school and high school. When asked to go to special events with no hesitation she went.

Going places and taking her was such a thrill we went drinking while she was at Kent. We all know what we learned in college not much I'm going to say about that here in church. We took her to the dinner, movies, to weddings and down to beach in Fairport. I know she had a great time at the beer tent in Fairport. The drive-in theater was the best. We still called every time when we saw this one special movie, Kelley's Heroes playing anywhere.

She lived her life to the fullest she went to places, some of us haven't even been there yet. She worked hard at her job with the State of Ohio, and then for Lake County. She really enjoyed helping others as long as the piles of paperwork did not get in the way. She worked as long as she could contribute to society, but her body could only take so much but her mind was her strongest point. She was always kind to everyone and very quick to overcome differences among friends. When it came to politics her saying was let's just agree to disagree.

Did you ever go for a ride with her yes, she drove? I did! Not just once a couple of times. She had her own car, her own apartment she strived for her independence. She wouldn't even let me put her wheel chair in the back seat, she did that on her own. But she was also a realist, so when Laketran came along she started using that instead of taking 20 mins. to get her and her chair into the car - a five-minute drive to work and then 20 mins. to reverse the process.

Now she is gone but there is still more. Close your eyes and listen to this story

Imagine a meadow where she is standing for the second time in her life, bare foot, the soft grass feels funny kinds of tickle. She can run through the meadow as fast as anyone till she is out of breath. She gets to meet her father and brother who can both now hear her perfectly and is embraced by her mother who is not anxious in the least but overjoyed at seeing her Daughter again. In the distance is Jesus our savior his arms out stretched to come to him. Her family together at last.

Polio 1916

Polio History . . . Putting the Pieces Together By Daniel J. Wilson, PhD

In 2018 many noted the 100th anniversary of the deadly 1918 flu epidemic that killed 650,000 in the United States and perhaps 50 million world-wide. We should not forget, however, that two years earlier, in

1916, the United States experienced one of the most serious polio epidemics in the country. Centered in the northeastern states, and particularly in New York, the epidemic struck some 27,000 individuals, mostly children, and killed some 8,000. Pennsylvania had the third largest number of cases (2,181) after New York (13,223) and New Jersey (4,055).

There were 1,006 cases and 307 deaths in Philadelphia, which was the epicenter of the epidemic in the state. Cases were diagnosed across the state with Lancaster reporting 21, Wilkes-Barre 6, Hazelton 7, McKeesport 12, and Norristown 19.

Polio was a frightening new disease in the United States. It had been epidemic only since the 1894 epidemic in Rutland, Vermont. Doctors could diagnose the disease once paralysis appeared, but they could neither prevent it nor cure it. Doctors puzzled over the cause of the epidemic. They knew polio was caused by a virus, but not how it was transmitted from person to person. Many blamed the unsanitary living conditions in immigrant slums, but then how to explain why upper and

Polio 1916 (cont. from page 2)

middle class children in good neighborhoods came down with the disease. Perhaps flies carried the virus, and this theory inspired "screen the baby, swat the fly" campaigns.



We now know that polio is spread through water or food contaminated by the fecal discharges of those sick with the disease. We also know that only 3-5% of infections result in paralysis. The other 95% of infections result in a mild or "unapparent" case of polio, but one capable of transmitting the disease through their stools. No wonder doctors couldn't figure out what was happening or how to stop it.

Public health officials tried to stop the epidemic by quarantining victims either in their homes or in isolation hospitals. Immigrant children were often forcibly removed to hospitals over the strenuous objections of parents who feared hospitalization was a death sentence. Suburban communities around New York banned children from the city even as wealthy parents tried to flee the city with their children.

Little has been written about the 1916 epidemic in Pennsylvania. The epidemic in Philadelphia mirrored that in New York City, but on a

smaller scale. Schools opened late that year, and doctors tried quarantine to halt the spread of the disease. In Pennsylvania and throughout the northeast the epidemic only receded with the onset of colder weather as the virus was most virulent in the hot days of summer and early fall. The epidemic spurred an increase in polio research, but it would be the late 1930s and 1940s before medical scientists began to understand how the virus was spread and to develop the techniques that led Jonas Salk and Albert Sabin to create their vaccines in the 1950s.

For those interested in the 1916 epidemic, I recommend Naomi Rogers, Dirt and Disease: Polio before FDR, a fine study of the history of polio in 1916 and the early twentieth century.



Massage Therapy for a young polio sufferer in the 1916 US polio epidemic. The Historical Library of the College of Physicians of Philadelphia

Daniel J. Wilson, PhD, Professor Emeritus, Muhlenberg College January 2019



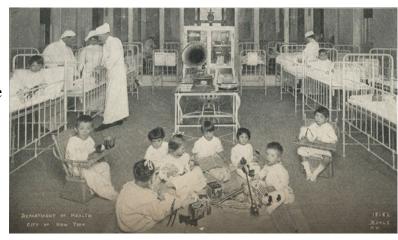
National Museum of American History

Polio 1916 (cont. from page 3)

These polio patients in a New York Hospital in 1916 all suffered eye paralysis.

The Historical Medical Library of the College of Physicians of Philadelphia

Polio 1916 article reprinted from the PA Polio Survivors Network Newsletter January 2019



WHAT TO EAT, WHEN TO EAT IT By Jodi Helmer

You know that a healthy diet has a balance of nutrients. But when you eat is also important. In fact, the timing of your meals has an impact on everything from weight loss to insomnia. Here are five tips that will help you make the most of your meals.

1. For more energy, have a protein-packed breakfast.

Maintaining steady blood sugar levels all day is crucial to avoiding energy slumps. Sweet foods — muffins or sugary cereals — may give you a quick energy spike, but the following drop in blood sugar can leave you feeling wiped out.

Instead, eat protein as part of the morning meal. In a University of Missouri study, people with Type 2 diabetes who ate a 500-calorie breakfast with 35 percent protein had fewer glucose spikes than those who consumed less protein and more carbohydrates. Also, "protein stimulates hormones that increase fullness while inhibiting hormones that stimulate hunger," says study author Heather J. Leidy, an assistant professor of nutrition at Missouri.

Try this: A spinach, tofu and cheese omelet.

2. To refuel after a workout, try a carb-protein combo.

Research shows that a snack containing both carbohydrates and protein is best for recovery after exercise. Carbs help boost flagging energy levels, while protein builds muscle mass. Stuart Phillips, director of the McMaster Centre for Nutrition, Exercise and Health Research at McMaster University in Hamilton, Ontario, says that for maximum effect, eat a post-workout snack within an hour of exercising that emphasizes the three R's: water to rehydrate, carbohydrates to refuel and protein to repair muscles.

People need more protein as muscle mass declines with age, Phillips says. Yet a recent AARP-Abbott survey found that just 17 percent of respondents knew how much protein they needed — 46 grams a day for women and 56 grams for men. Active older adults may need more.

Try this: Aim for a recovery snack with 30 grams of protein, like a protein shake or grilled chicken wrap with whole wheat tortilla.

3. For weight loss, load up at lunchtime.

Eating your biggest meal earlier in the day may help with weight loss. In a 2013 study published in the *International Journal of Obesity*, researchers found that overweight and obese adults who ate their biggest meal earlier in the day lost more weight than those who ate their main meal later, despite similar activity levels and calories. Your body burns twice as many calories after an earlier meal than a later one, says Frank Scheer, director of the Medical Chronobiology Program at Brigham and Women's Hospital in Boston.

Try this: Whole grain pasta topped with roasted tomatoes, basil, parsley and pine nuts.

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WHAT TO EAT, WHEN TO EAT IT (cont. from page 4)

4. For an afternoon brain boost, grab a handful of nuts.

Not only are nuts good for heart health, but a 2015 Spanish study found that older adults who ate a handful of nuts daily improved their memory over four years. Lead author Emilio Ros, M.D., a researcher at the Hospital Clinic of Barcelona, said eating nuts may help prevent cognitive decline in older people — especially when they're combined with a healthy Mediterranean diet. In addition, "eating nuts also reduces the brain responses that typically stimulate food consumption," Leidy says, so snacking on nuts can help with weight loss as well. **Try this:** 25 pistachios, which are packed with potassium and protein.

5. For better sleep, fill up on fiber.

A 2016 study published in the Journal of Clinical Sleep Medicine found that eating a meal high in fiber and low in saturated fat and sugar helped subjects fall asleep in less than 20 minutes, compared with 30 minutes for those who ate more fat and sugar than fiber. A high-fiber dinner was also associated with more time in slowwave deep sleep, which is essential for immune function, says study author Marie-Pierre St-Onge, assistant professor at Columbia University Medical Center in New York. Steering clear of the refrigerator after supper can also improve sleep, as snacking signals to the body that it's time to be awake and active, according to a 2014 study published in *Current Obesity Reports*.

Try this: Salmon broiled in sesame seed oil, quinoa, roasted cauliflower and an arugula tossed salad.

Reprinted from: Polio Network of New Jersey Newsletter, Winter 2017. Reprinted from: Second Time Around, Boca Raton PPSG Newsletter, January 2019.

In Memorial



LAMBERT, Paulette, age 76 of Beavercreek, passed away on Saturday, January 26, 2019. She was preceded in death by her parents Bob and Virginia Smith, and brother-in-law Jay Gall. She is survived by her husband of 44 years Terry Lambert, sister Mary Gall, brother Sherman Smith, nieces and nephews J.B. Smith, Laura (Matt) Aldridge, Mike (Jo) Gall, Jessica (Sean) Early, and numerous great-nephews and nieces. Paulette worked in civil services at WPAFB for 31 years. She was a member of Hawker United Church of Christ and the church choir.

> Post-Polio Health International Phone: (314) 534-0475 http://www.post-polio.org Email: info@post-polio.org

Polio Place: http://www.polioplace.org/ Post-Polio Directory 2018: http://www.post-polio.org/net/PDIR.pdf

Anita Cameron: In Disasters We Lose



I have been involved on a voluntary basis in emergency management and preparedness for 15 years in various areas around the country. My passion is getting people with disabilities involved in disaster preparedness because our community knows that during those times, we lose.

Why? Because jurisdictions do not include people with disabilities in their disaster plans. At best we are an afterthought. Because of this, we lose—we are displaced, unnecessarily institutionalized, often far from home, and we die—deaths that could

have been prevented but for reaching out and including us in preparedness planning before, during and after disasters.

On the federal level, there are several bad actors responsible for people with disabilities being discriminated against and suffering needlessly during disasters. The Federal Emergency Management Agency FEMA), the American Red Cross, and the Centers for Medicaid and Medicare Services (CMS) are three big players who must be held accountable.

FEMA

According to its mission statement, The Federal Emergency Management Agency is responsible for helping people before, during and after disasters. Unfortunately, this doesn't include disabled folks. FEMA recently disbanded almost its entire cadre of Disability Integration Specialists, who are responsible for ensuring that the disability community is served during this time. In fact, Linda Mastandrea, Director of the Office of Disability Integration and Coordination, effectively told attendees at the Getting it Right 2018 National Inclusive Disaster Strategies Conference in Washington, DC, that we were on our own. Puerto Rico was still reeling from Hurricane Maria and we were getting ready for the season that would include Hurricanes Michael and Florence. To hear this was frightening, indeed! With the subsequent unnecessary deaths of disabled people in those disasters, FEMA has blood on its hands and must be held accountable!

American Red Cross

The American Red Cross provides disaster relief, but is best known for running shelters across the United States where people go to when they need to leave their homes during disasters. These shelters are supposed to be accessible to people with disabilities, but we are often turned away, either because the shelter is not wheel-chair accessible or shelter managers mistakenly turn away people with service animals. Often, those with complex disabilities are turned away or sent to segregated medical shelters.

Centers for Medicare and Medicaid Services (CMS)

The involvement of CMS is especially egregious. They recently expedited the ability of shelters in South Carolina to send disabled people to nursing facilities, often far away, when shelters can't handle us and our needs. Once in a nursing facility, it is very difficult to get out. This is in violation of the 1999 Olmstead Supreme Court decision that says unnecessary institutionalization is discrimination under the Americans with Disabilities Act. That CMS is colluding with an agency that actively discriminates against disabled folks is beyond belief!

ADAPT and FEMA

FEMA was to have a meeting on their Strategic Plan (https://www.fema.gov/strategic-plan) with various stakeholders, including some disability groups, however, that plan was written without input from the disability community. In fact, but for a picture, there literally was no mention of us!

Then a meeting with ADAPT was scheduled for November 6th, and we provided our conference call number. But FEMA Administrator Brock Long preferred that we use FEMA's number. On October 29th, 30th and 31st, ADAPT members from all ten FEMA regions contacted Administrator Brock Long, asking that he postpone the original stakeholder meeting because the disability community was not consulted. Our request was

Anita Cameron: In Disasters We Lose (cont. from page 6)

denied so, in good faith, we went ahead with the November 6th call, hoping that at least, we could give input that FEMA would act on.

Administrator Long controlled the call so that we could not speak unless he opened each line. When we were finally permitted to speak after 20 minutes, we told FEMA our grave concerns and chided them for having us on a call where they had no intentions of listening to us. At that point, the call was abruptly ended by FEMA. If there was any doubt that FEMA cared for disabled people or wanted to address disability issues in disaster preparedness, that phone call more than confirmed it!

READI Act

On November 29, 2018, S. 3679, the READI (Readying Elders and Americans with Disabilities Inclusively) for Disasters Act, was introduced by Senator Bob Casey, (D-PA) after hearing from his constituents. It would ensure that older adults and individuals with disabilities are prepared for disasters, and for other purposes.

It will also coordinate efforts between federal, tribal, territorial, state, local and non-governmental agencies during the preparation, response, and mitigation before, during and after disasters.

The READI for Disasters Act will redefine how our government reviews the use of disaster response funds, will create training, and disability and aging technical assistance disaster centers, as well as a program to examine specific issues related to people with disabilities and older adults. This bill will create a National Commission on Disability Rights and Disasters, including Department Of Justice involvement and oversight Committee to review all ADA settlement agreements related to disaster response activities for the years 2005-2017 and to also direct the Government Accountability Office to investigate whether past federal funds have been used to ensure accessibility to emergency programs and services.

The READI Act will be reintroduced in the 116th Congress. Hopefully, due in part, to the hard work of the disability community and our friends in Congress, it, and a House version will pass, it will be signed into law and people with disabilities will no longer be losers in disasters.

Please share this information to help save lives in future disasters.

Reprinted from Ventilator Assisted Living, April 2017.

The Benefits of Having Friends with Similar Disabilities

What was this research about?

Friends play important roles in our lives. They can make us laugh, lift our spirits, and give us information or advice. People with physical disabilities may feel a special connection with friends who have the same disability, such as people they meet in support groups. One person with MS told us, "I think it's a matter of feeling less self-conscious around [other people with MS] because they don't see you the way other people see you." Another person, who is blind, said about her blind friends: "We all immediately share a common bond, and have an understanding and camaraderie with each other right away." In this study, we wanted to find out if people who had more friends sharing their disability were happier with their lives.

What did the researchers do?

We conducted two survey studies. First, we sent a survey to about 70 adults who were legally blind. On the survey, we asked the respondents to count all of their friends who were also blind, and all of their friends who were not. Then we asked them to rate how satisfied they were with their lives overall.

Then, we sent a similar survey to about 1,500 people with either muscular dystrophy (MD), multiple sclerosis (MS), post-polio syndrome (PPS), or spinal cord injury (SCI). We asked these respondents to count how many of their friends had their physical condition and how many friends had any physical disability. As in the first survey, we also asked them about their overall quality of life. Finally, we asked these respondents how severe their physical limitations were as a result of their disability condition.

The Benefits of Having Friends with Similar Disabilities (cont. from page 7)

What did the researchers find?

In both surveys, we found that respondents who listed more friends with disabilities said they were happier with their lives overall than respondents with less friends having disabilities. In the first survey, this connection held up no matter how many friends without disabilities the respondent had. In the second survey, we also found that almost half of the respondents listed no friends with disabilities. For these respondents, there was a strong link between having more severe physical limitations and lower overall quality of life. However, for the respondents with at least one friend having a disability, that link was weaker, meaning that their physical limitations had less impact on their quality of life. Interestingly, the results applied to having friends with any physical disability, even if the friends had different disability conditions.

How can you use this research?

If you have a physical disability, sharing experiences with others in a similar situation can bolster your well-being. Sometimes, it can be hard to find friends with similar disabilities. The following organizations may have support groups in your area:

- Post-Polio Health International (link is external)
- National MS Society (link is external)
- Muscular Dystrophy Association (link is external)
- United Spinal Association (link is external)

You may also want to find your local Center for Independent Living (CIL):

• http://www.ilru.org/projects/cil-net/cil-center-and-association-directory (link is external)

Things you should know:

To learn more about the power of social support, check out our research summary on <u>The Power of Social Support</u>, or our article on <u>How to Stay Physically Active</u> and <u>How to Bounce Back</u>.

Original Research Article:

Silverman AM, Molton IR, Smith AE, Jensen MP, Cohen GL. Solace in solidarity: Disability friendship networks buffer well-being. *Rehabil Psychol.* 2017 Apr 10. DOI: 10.1037/rep0000128. [Epub ahead of print]

Reprinted with permission from Post-Polio Health International, PHI Membership Memo, April 27, 2017.

In Memorial



Otto Larry Cullum, 82, of Guysville, went to be with the Lord, Tuesday, Feb. 19, 2019.

He was born Feb. 26, 1936 in Sanford, Florida, a son of the late Archibald L. and Thelma K. Battrell Cullum. Otto was an US Marine Veteran and a retired heavy equipment operator. He enjoyed NASCAR and hunting and was a member of the Faith Bible Church in Guysville.

Otto is survived by his wife of 58 years, Marie A. Brown Cullum; his children, Melissa M. Hicks of Bartow, Florida and Jeff Cullum (Janet) of Albany; one brother, Leon C. Cullum of Alabama; grandchildren, Adam Cullum (Jennifer), Amanda Hurne (Nick), Amber Locke, Casey Cardoso, and Rachel Nettles (Brett); and great-grandchildren, Jesalyn Cardoso, Layla Cardoso, Ava Cullum, Piper Cullum, and Gavin Hurne. In addition to his parents, Otto was preceded in death by his son, Terry L. Cullum; three brothers; and one sister.

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