

PA Polio Survivors Network

Information and Inspiration for All Polio Survivors and Their Families *Serving the Keystone State and Beyond* www.polionetwork.org

October, 2021

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

Inside this Issue:

- **Polio Survivors and Problems with Attention: Is ADHD the cause?** Polio survivors are certainly familiar with fatigue causing difficulty concentrating. <u>Richard L. Bruno, HD, PhD</u> has published an article that discusses why we have to be very cautious of quick, formal diagnoses (such as ADHD) for these symptoms.
- **Post-Polio Osteoporosis**. <u>Marny K. Euberg, MD</u> has given us the opportunity to publish multiple articles on the topic. These two articles and a fascinating graphic have raised lots of interesting questions from you. This month, she has written her second Q&A on this issue that so many polio survivors share.
- **One day he was climbing trees. The next, he was headed for a hospital in an ambulance.** Survivor John Munsick tells his fascinating story – not all of which was pleasant. Hospitalized in Pittsburgh, he was part of the Salk Vaccine Trials in 1954.
- **Polio Eradication.** As we approach World Polio Day, there have been only two reported cases of the wild poliovirus in the world this year. What's the secret? Community Health Workers. "When polio was widespread, communication strategies often used what is known as risk communication, targeting individual caregivers with facts about polio and polio vaccination to inform caregivers and educate communities about the need to protect and vaccinate children." "The eradication of polio depends on the success of polio programme health workers (e.g., community health workers, social mobilisers, vaccinators). Their success in the field revolves around a single pivotal moment: the short, interpersonal interaction between health workers and caregivers, or 'the knock' on the door." (Source noted page 3).
- **The Demands of COVID19 on Health Care Workers is significant all over the world**. Mothers in Nigeria feared the worst . . . that their children would not be able to receive routine immunizations. Nigeria is now free of the wild poliovirus. The infrastructure that has been created to eradicate it has shown once again that even in the midst of a terrible pandemic, no child has to suffer from a vaccine preventable disease.
- **There has never been a better time to join Team Survivor.** Since July, our newsletters have featured the amazing work that is being funded by the Rotary Foundation and their partners in the GPEI. We all share their dream to eradicate this terrible disease. Many of you have participated this year. We are optimistic that this generosity will continue. In lieu of any donations to our network this October, please join <u>Team Survivor</u> and make a donation to the Rotary Foundation for Polio Eradication.
 - Online There are two ways:
 - Directly to the <u>Rotary Foundation</u> (or) through <u>PA Polio Survivors Network</u>
 - By US Mail:
 - Make your check out to <u>The Rotary Foundation</u>
 - Mail it to: PPSN Team Survivor, PO Box 557, Doylestown, PA 18901



Polio Survivors and Problems with Attention Is it Caused by ADHD?

Richard L. Bruno, HD, PhD

Director, International Centre for Polio Education

Polio survivors are certainly familiar with fatigue causing difficulty concentrating. But we have to be very cautious about turning patients' symptoms into formal diagnoses. This caution needs to be applied when polio survivors' difficulty paying attention is taken to be a diagnosis of attention deficit hyperactivity disorder (ADHD).

The <u>CDC</u> outlines 12 criteria that may lead to a diagnosis of adult ADHD (Source: cdc.gov/ncbddd/adhd/diagnosis.html):

- Problems focusing on a task
- Excessive activity or restlessness
- Impulsiveness
- Disorganization and problems prioritizing
- Poor time management skills
- Trouble multitasking
- Poor planning
- Low frustration tolerance
- Frequent mood swings
- Problems following through and completing tasks
- Hot temper
- Trouble coping with stress

Of these symptoms mentioned above, two that are often associated with PPS, match the CDC criteria:

- $\circ~$ Problems focusing on a task (and)
- $\circ~$ Excessive activity (think Type A behavior)

Therefore, merely problems focusing and excessive activity do not a diagnosis of ADHD make.

This doesn't mean that polio survivors, adults and as children, did not have attention deficits (1). During the epidemics there were reports of brain "deactivation" from the first days of the poliovirus attack. Polio patients were described as lethargic, drowsy, sleeping constantly and being difficult to awaken. Some polio survivors were even in coma, the ultimate result of failure of the brain's activating system.

In B.H. Holmgren's study of Swedish polio patients at least one-third, whether they had paralytic or non-paralytic polio, had "disorientation, apathy, and pronounced sleep disorder." These symptoms of brain deactivation were associated with abnormal slowing of polio patients brain waves measured using an EEG, the electroencephalograph, which we saw an adult polio survivors reporting fatigue and impaired attention. (2)

In 1947, psychologist Edith Meyer studied American polio survivors ranging in age from 18 months to 14 years old. For 3 years Meyer followed these children's performance in school and measured their "mental abilities." She discovered that "a high percentage of children clinically recovered from poliomyelitis insofar as motor disability is concerned, had qualitative difficulties in mental functioning which, as a rule, do not appear in the conventional type of intelligence test." Using special psychological tests, or merely by observing their performance in school, Meyer found that the children had "fatigability and fleeting attention" for months after the polio attack. When tested she discovered that the children had short attention spans, difficulty concentrating and poor memory for visual designs. These problems were "present in cases in which the medical history notes drowsiness, severe headache, and, in some cases, only nausea" during the polio attack. Both Holmgren and Meyers found that even children who had "non-paralytic" polio – having no paralysis or even weakness – had "fatigability and fleeting attention".

It's fair to ask if polio survivors had attention deficits, if not ADHD, how is it that they did so well in school, went on to college and became teachers, lawyers, chief executives of international corporations, members of the British and Canadian Parliaments, the US Congress and Supreme Court and an

Polio Survivors, Attention and ADHD (continued)

American President? Here's where the psychology of being a polio survivor and developing Type A behavior superseded any problems with attention.

Another question is why it has taken polio survivors 40 years since polio to again show "fatigability and fleeting attention"? We can only speculate since the technology was not available in the 1950's to study the brains of young polio survivors. But it is likely that polio survivors' fatigue and fleeting attention improved for the same reasons that they were able to recover muscle strength: damaged brain attention and concentration neurons that survived the poliovirus onslaught may have compensated for the death of their compatriots by sending out new "sprouts" to stimulate orphaned neurons, eventually suffering themselves from overuse abuse. The notion of brain neurons "over sprouting" is supported by a 2021 MRI study of polio survivors that found an increase in the "volume" of neurons in the brain areas responsible for attention. (3)

References:

- 1. Bruno RL, et al. <u>The Neuropsychology of Post-Polio Fatigue</u>. Archives of Physical Medicine and Rehabilitation, 1993; 74: 1061-1065.
- 2. Bruno RL, et al. <u>Elevated Plasma Prolactin and EEG Slow Wave Power in Post-polio Fatigue</u>. Journal of Chronic Fatigue Syndrome, 1998; 4: 61-76.
- 3. Stacey Li Hi Shing, et al. Increased cerebral integrity metrics in poliomyelitis survivors. J Neurol Sci. 2021 May 15;424:117361.

This article and others can be found under the topic of "Fatigue" in the Encyclopedia of Polio and PPS.



For caregivers to make the choice to vaccinate their children for polio, Health Workers are the Key Within the Communities





"Their awareness and understanding of the

disease, including Its symptoms and disease traits – highly contagious, incurable and only preventable By polio vaccine."



DATES "Their awareness and understanding of the r

understanding of the polio vaccine and perceived side effects (i.e., knowing that the vaccine is safe, easy, painless, endorsed by religious leaders, conveniently available in the safety of one's home, and can protect the entire community as well as one's own children). They should also be aware of campaign dates in advance of a health workers' arrival and the need for repeated vaccination."



COMMUNITY PERCEPTION OF POLIO VACCINATION

"The perception of broader vaccination in general – and polio vaccination in particular – among neighbors, peers, leaders and extended family." COMMUNITY PERCEPTION OF HEALTH WORKERS "Their trust, respect,

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and openness to health workers who come to their community and home, as well as their trust of government officials and/or those whom they perceive to be responsible for organizing vaccination activities."



VACCINATE

"These factors build upon each other and the absence of one or more of these factors Increases the caregiver's uncertainty among caregivers increases

the burden put on our health workers, who must persuade uncertain caregivers to make the right choice."

Vaccination within Communities.

A caregiver's decision does not exist in isolation. It is both a personal decision, and a consideration of familial and community views about the act of vaccination itself.

Is it celebrated or discouraged? Does the community respect the role of health workers?

POLIC GLOBAL ERADICATION INITIATIVE



Post-Polio Osteoporosis A Second Follow-up Q&A

Marny Eulberg, MD

Question: I enjoyed your article(s) and diagram on bone health and have found them to be very well balanced and informative.* (See Below for earlier articles/diagram).



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I have a question about the risk versus benefits of taking bisphosphonates.

It seems that many studies only seem to measure risk markers like BMD (Bone Mineral Density) and the treatment duration tends to very short. Can you explain the benefits of these drugs? I'm also concerned about that age old/complex issue of exercise for polio survivors. In your experience is there any form of exercise that can be adapted for polio survivors that will improve bone health?

Dr. Eulberg's Response: Most studies about any of the drugs approved for osteoporosis have looked at the effect on BMD (because that allows a much shorter follow-up period and thus a higher rate of participant participation). We have learned that improvement in BMD does not always correlate with a decrease in fractures. Unfortunately, the long term use of bisphosphonates appear to not have much/any benefit over that of a shorter term use. In the U.S. the current recommendation is to limit the duration of bisphosphonate use to no more than 5 years. Since the majority of the polio survivors in the United States, Canada and the UK are now over age 65, the reality is that most of us don't have many years left to make a difference in our bone density. The kind of research that will

answer the questions about long term effects of medications, side effects and exercise will take at least a decade to provide the answers to your questions. This isn't likely to be very helpful to you, me, and most of our polio survivor colleagues (but it could be helpful to the "younger" polio survivors).

I am not a researcher—just a polio survivor who also happens to be a physician treating fellow polio survivors. The bulk of research seems to indicate that only weight bearing exercise through a particular bone(s) promotes increased bone density. Of interest is that exercise in pools/water has not demonstrated improvement in bone density. If a person has muscle weakness around a particular bone(s) it is very difficult to do weight bearing through that bone, and could possibly cause more muscle weakness.

It has been suggested that jolting/vibratory stimulation might increase bone density more than weight bearing that does not have a jolting/vibratory component. That being said, I have not seen much or even any published research that has demonstrated a proven effect on either bone density or a decrease in fractures.

I totally understand the significant obstacles to getting the answers we polio survivors would like to have. There is a significant cost of doing any research at all and especially research that needs to be done over decades. There is the challenge of finding a cohort of polio survivor research subjects that are reasonably similar in their physical characteristics and going to live through the long follow-up period needed. I doubt that there are any drug companies or other sponsors likely to financially benefit from this research (and hence be willing to fund or partially fund the research).

All that being said, the issues about osteoporosis and fractures in persons with weakness of their limbs, especially their lower extremities, not only apply to polio survivors but also to people with spinal cord injuries, muscular dystrophies, multiple sclerosis, etc. So, from my perspective, there may be a sufficient audience for that kind of information.

* Previous articles re: Post-Polio Osteoporosis by Marny K. Eulberg, MD Post-Polio Osteoporosis, Post-Polio Osteoporosis Q&A Response, Osteoporosis Graphic -Healthy vs Osteoporathic Bone

You can find Dr. Eulberg's entire collection of articles under: Primary Care Perspective

John Munsick

One day he was climbing trees.

One day later, he was headed for a hospital in an ambulance.



As this COVID pandemic continues, I have been asked how it compares to the polio epidemic of which I was a victim in 1953. One day I was an active 12-year-old riding my bike, playing baseball with my friends and climbing trees on my grandmother's farm. The next day, I remember feeling bad, missing school and developing a limp. When my dad got home from work I was taken to a doctor near our home in Clairton, Pennsylvania who sent me to the hospital. The next thing I knew, I was in an ambulance on my way to the Municipal Hospital in Pittsburgh. In our area, cases were sporadic and nothing closed except for some public swimming pools. To my knowledge, I was the only one in my school that was affected by the virus.

After a spinal tap confirmed that I had contacted polio, I was admitted to the hospital and placed in quarantine for about three weeks. My Mother and Dad stood outside my door in robes and masks, unable to come into the room. My back and legs were the most affected. No one told me much and it was a frightening experience to be alone, laying flat on my back and not knowing what was happening.

From the hospital I was sent to The Industrial Home for Crippled Children in the Squirrel Hill section of Pittsburgh for rehabilitation. I was placed in a ward with five other boys, one who had TB, two who were victims of cerebral palsy and a couple of other polio patients. The first step in the recovery process came from a physical therapist who put me through a difficult series of stretching exercises for every muscle affected. The PT was a very painful process of working to and past the point of pain. I went through this ordeal seven days a week. Once a week we were taken to the pool where we could swim. They had a submerged board were Miss Whitfield (the meanest PT in the eyes of a 12 year old) would work you over.

The hospital tried to replicate 7th grade but as I remember, I did not get much from a teacher that came in a few times a week. Other than PT and occasional schooling, there wasn't much to do. My days were spent listening to the radio. Our highlight was our weekly visits from Mr. Bob Conner, who owned a local hobby shop. I think it was the local Lions Club that paid for the model cars and planes he brought us. My parents were allowed to visit for one

hour on Saturday and Sunday. My dad worked Saturday, so my mother would come by bus. She never missed even one day.

I was fitted with uncomfortable splints which I had to wear all day and night. They did loosen some things during the night to make sleep more pleasant. The nurses were great and served us our three meals a day which growing teenagers certainly looked forward to! Speaking of the meals, we were taking in food and given our lack of mobility, we often found ourselves constipated. If a few days went by, one of the nurses would order an enema. Being bedridden made it necessary to use a bedpan. The enemas were really humiliating, but the bedpan was the worst of it. We knew



Industrial Home for Crippled Children December 17, 1954 Source: Pittsburgh City Photographer

of other wards in the home (such as a baby's ward and a girls ward) but we were not allowed to visit.

On December 22, 1953, Dr. Franklin Neva (who was part of Jonas Salk's team), asked my parents to sign a consent form allowing me to take part in a vaccine study at the Industrial Home for Crippled children. The study began in early 1954 and went on for a couple of months.

John Munsick (continued . . .)

I remember them coming in and giving a shot and then coming back and drawing blood a day or two later. I remember looking at my arms and noticing all the marks left by needles from the blood draws. My temperature was taken twice a day using the rectal thermometer (certainly not at all pleasant). The vaccine came out in April of 1955. Doctor Salk was not known for acknowledging other members of his team / or efforts that helped in research. The D. T. Watson Home was given credit for polio research but it also happened at the Industrial Home which was nearby to the University of Pittsburgh where Dr. Salk was doing his research.

In the spring of 1954 I was fitted for braces for both legs and then went all the way up my back. In addition, I was given a wheelchair so that I could occasionally leave my bed. I was moved from the ward to what was called "the house" (which was a series of single rooms housing other boys) which gave us independence. We were now going to the dining room for meals instead of being served. We had to navigate a long ramp to get to the dining room. Going down was not a problem as we cut it loose and got to do a circle at the bottom to slow down! Once I lost a wheel and did a tumble, but luckily did not get hurt. Going back up the ramp was definitely harder as it took some muscle power to get to the top.

My braces were made by a man named Si, on site in the brace shop. Si was a polio survivor just like me and he walked with a limp. I was given a pair of forearm crutches (also called Canadian Canes) and the work began with the physical therapists to teach me how to walk with braces and canes. They had me doing steps and I remember going out onto Shady Avenue one spring day to learn curbs and street crossing.

I was finally released to go home. I returned to the 8th grade at Thomas Jefferson Jr. high school. My dad and a neighbor made a ramp that my mother put up on the step of the school bus so I could get on and off. When I got more mobile I was able to do away with using the ramp. The kids welcomed me back and I seemed to fit in. I made a lot of new friends as the school had kids from a lot of different areas. I was very fortunate to have friends who included me in taking part in some of their activities.



I went on to Clairton High school as the new Thomas Jefferson high school was just being completed. After high school I went to Robert Morris School of Business in Pittsburgh where I compiled a certificate in accounting. I rode the bus every day for 3 years to complete it. I worked as an accountant for a short time in a



temporary position. In 1962 I was hired by Robert Morris and worked in scheduling students for classes. I was given responsibilities that included building the master schedule and the academic calendar. Robert Morris became a junior college, a four year college and a university offering Master and Doctorate degrees which I can say I was a part of. I retired in 2004 as Registrar after serving for 42 years.

I have been married twice, have four great children and four grandchildren. As I enter my 79th year I have been diagnosed with post polio syndrome which simply stated says I kicked your butt when you were a kid and I'll kick it again when you are old. My shoulders and wrists are worn out from using crutches for 65 years. As I look back perhaps I could have saved my upper

body by not doing a lot of things but when I think about it I have no regrets.

<u>John Munsick</u>, Bethel Park, Pennsylvania You can read our entire collection of these amazing Stories of Survival.⁶

COVID-19 Vaccines Help Routine Immunisation Become Routine Again In Nigeria

Routine immunisation took a hit in Nigeria amid the pandemic. Thanks to the arrival of COVID-19 vaccines, particularly for health workers, children are again getting the protection they need.

"My fears were justified," she says. "Nurses weren't at work, or so I was told, due to the pandemic. So who would then immunise my child?" Even after her husband tried to allay her fears, they persisted. "It's not a fear that easily goes away," Yemi says. "I've heard stories about what happens to children who are not immunised." But things changed with the arrival of COVID-19 vaccines in Ondo State in March this year.



Mothers attend a vaccination session in Ondo State, Nigeria

"I felt glad because I knew my child would be immunised," says Yemi, who gave birth in May. "And that's why I've been bringing her to the hospital for immunisation. It boosts her immune system. It makes her stronger. And it's a relief for parents because we don't have to pay for immunisation in Ondo State."

Like for Yemi, the availability of COVID-19 vaccines came as a relief for Debbie Ologundudu, a mother of one who lives in Isikan in Akure. When the pandemic swept through the community and news reached her that nurses and other workers had fled hospitals or

reduced the scale of their operations, the twenty-nine-year-old trader felt the grip of anxiety. "I almost had heartbreak during the period," she says. "I know what it meant. Only COVID-19 victims would be treated. And nurses might not even come to work, for fear of contacting COVID-19."

The arrival of coronavirus vaccines enabled Yemi to have her child immunised with the routine shots he was due: armed with the reassurance of the COVID jab, clinic nurses were carrying out their regular duties.

"My child is okay," Yemi says. "You can see that I've come for the routine immunisation. Since he's immunised, he's alright. He hasn't been sick. He's been strong."

She's echoed by thirty-one-year-old fashion designer Maria Adesanya, who likewise had the opportunity to immunise her child. "He hasn't fallen ill," she states. "And I'm sure it's because of the routine immunisation."



A child receives routine vaccinations in Ondo State, Nigeria

"During the early COVID-19 period, it was hell," says Victoria Afonja, a nurse in one of the hospitals in Ondo State. "You didn't know who was who. People were getting COVID-19 anyhow. In some families, everyone got it. There was little or no immunisation. Many of the nurses went away, because they were scared of getting the illness. In addition, many were deployed to take care of COVID-19 victims at the Isikan centre."

But, thanks to the arrival of COVID-19 vaccines, nurses' fears about the pandemic vanished. "Routine immunisation is now going on with full speed," Victoria says. "We do it on Monday, Thursday, and Friday every week. We're in full operation, with no fear of contracting COVID-19 again. Mothers are bringing their babies for immunisation every day."*

5 July 2021 –by Abjata Khalif

https://www.gavi.org/vaccineswork/covid-19-vaccines-help-routine-immunisation-becomeroutine-again-nigeria

Some Halloween Fun

From our friend in Australia, Bill Peacock.









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