

PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org



September, 2022

Our Mission:

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

Inside this Issue:

The Poliovirus: Should we be cautious about being vaccinated? What Type of Polio did I have? [Richard L. Bruno, HD, PhD](#) explains why we should not depend on our original polio symptoms or family memory to determine the type of poliovirus we had and type of vaccine you *may* need now.

Polio Survivor, Stage and Film Actor and Advocate for the Disabled: Alan's life changed forever when he had polio. Even so, he is thriving in his acceptance of his disability and living his life filled with love for his family and in serving others. PA Network team member, Helen Urban discovered that when it comes to advocating for people with disabilities, survivor Alan Toy isn't just "playing" the part.

How do I apply for Social Security Disability? Do I qualify?: Although there is an assumption that due to our aging survivor population, this question is no longer necessary, [Marny K. Euberg, MD](#) has discovered that's not the case. She has given us an extensive article regarding all the information you need to apply.

Polio in Israel, the UK and the US? The Bill and Melinda Gates Foundation (part of the GPEI with the Rotary Foundation) has published a fascinating article. We've brought you two of those questions.

[Polio has been detected in places it was eliminated. Should we be worried?](#)

A Q&A with Ananda Bandyopadhyay, Deputy Director, Technology, Research, and Analytics
The Gates Foundation

Question: Should we be worried about the news out of New York and elsewhere?

Answer: "If you're fully vaccinated against polio, you have powerful protection against paralysis. Nonetheless, the case in New York, as well as cases of wild polio that were detected in [Malawi](#) and [Mozambique](#) this year, are warning signals that the virus is now in places where there hadn't been a detection in many years. It's a poignant reminder of the vulnerability of the global population and underscores the importance of achieving eradication. If there are pockets of under vaccinated individuals, poliovirus can pop up anywhere as long as the virus exists somewhere."

Question: "Wild polio." What does that mean?

Answer: "When we use the term wild polio, we're referring to the naturally occurring form of the virus. That's different from a vaccine-derived strain, such as the one that reportedly infected the man in New York. These strains are connected to oral polio vaccines (OPVs), which are a key tool for many countries in the fight against polio and are made from a weakened form of the virus. A vaccinated person can shed that weakened virus, which is actually a good thing, because it can indirectly protect a community."

"But if there is persistently low immunization coverage in a community—like the part of New York state where the man lived—the weakened virus can circulate for a long time, mutating and acquiring changes in its structure. Rarely, it can regain its ability to induce paralytic outbreaks. But the only right approach to stop vaccine-derived viruses is better vaccination, not stopping vaccine use."

[Source](#)



Dr. Bandyopadhyay navigates to a remote village cut off by flooding during polio campaign monitoring in Bihar, India

The “THREE TYPES” of Polio: Vaccination Caution for Polio Survivors

From [Richard L. Bruno, HD, PhD](#)

Director, International Centre for Polio Education



With the current reports of an American man in lower New York State paralyzed by polio and poliovirus found in wastewater in lower New York State, New York City and Long Island, there have been no statements by state or federal officials regarding the implications of community spread of the virus and whether polio vaccination – either all four doses or a single booster dose - is recommended for polio survivors.

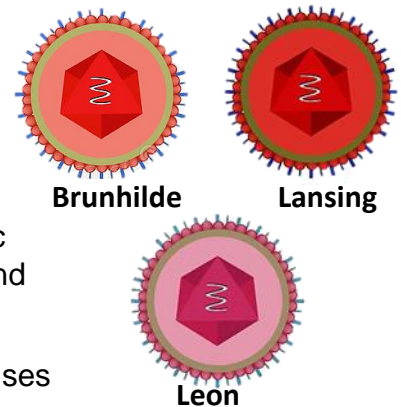
Polio survivors should be very careful about their belief, often without evidence or as part of family lore, regarding the “types” of polio they had when deciding about the need for vaccination.

During the polio epidemics, and still today, there is confusion about there being three types of poliovirus and three types of clinical polio.

THREE POLIOVIRUS TYPES. There are three polioviruses you could have had:

- Type I (Brunhilde, the epidemic strain that caused most cases of polio),
- Type II (Lansing),
- Type III (Leon).

Each of the three types of poliovirus is genetically different and therefore each requires its own unique polio vaccine type to get the body to generate the specific antibodies needed to counteract each type of virus. The injectable (killed virus) and oral (live, but attenuated virus) polio vaccines contain all three polio types.



THREE TYPES OF CLINICAL POLIO. Unfortunately, the three different polioviruses get confused with the “three types of clinical polio”:

- Bulbar Polio indicates the virus affected your brain stem and would cause trouble swallowing and breathing;
- Spinal Polio indicates the virus affected your spinal cord and would cause limb paralysis;
- Bulbar-Spinal Polio indicates the virus affected both your brain stem and your spinal cord, which would cause limb paralysis and trouble swallowing and breathing.

Some polio survivors were told that the body areas affected were determined by infection with specific types of poliovirus. So, someone who had bulbar polio might have been told that they had *one* type of poliovirus, while someone with bulbar-spinal polio might have been told that they had *two* types of poliovirus. Any of the three polioviruses could have caused spinal, bulbar or bulbar-spinal symptoms.

The symptoms that you experienced were *not* determined by the type of poliovirus that got into your body.

When you talk to your doctor about the need for vaccination or a booster dose, don't depend on your original polio symptoms or family memory to determine the type of poliovirus you had and type of vaccine you may need now.

FOR THOSE IN THE U.S. - CHECK YOUR STATE'S HEALTH DEPARTMENT AND CDC WEBSITES AND THEN TALK TO YOUR DOCTOR ABOUT THE NEED FOR VACCINATION.

- Adults who are unvaccinated or are unsure if they have been fully immunized (including polio survivors, who likely had only one type of polio) would need a total of 3 vaccine doses.
- Adults who only have had 1 or 2 doses of the polio vaccine would need to get all 3 doses.
- Adults who are at increased risk of exposure to poliovirus and who have previously completed a routine series of polio vaccine can consult with a health care provider and receive one lifetime "booster" dose of Injectable polio vaccine.

Source: www.cdc.gov/vaccines/vpd/polio/hcp/recommendations

Richard L Bruno, HD, PhD
September, 2022

This article is easily found for download and sharing, under the topic “[Poliovirus](#)” in the [Encyclopedia of Polio and PPS](#)

ALAN TOY

Polio Survivor, Stage and Film Actor, Advocate for the Disabled

Written by Helen Urban

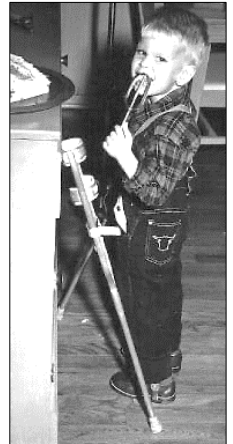
If you were one of the 5.2 million viewers who tuned in to [NBC's "Annie Live!"](#) in December 2021, you are already familiar with polio survivor, Alan Toy who starred as FDR. He joined an A-list ensemble of actors that included Taraji P. Henson and Harry Connick Jr. Alan was the first actor to portray the role of FDR while personally having the same disability. An old wheelchair from a prop company was brought in and rebuilt to make it more historically accurate for Alan to use during his performance. It was an ideal way to bring FDR's disability into the story line without it overtaking the story.

Alan's polio journey began in 1953 when he was just three years old. His father served in the military and were often transferred. While living in Key West, the little boy got polio. Mostly paralyzed from the waist down, he was transported to Miami Children's Hospital which at that time, handled most of Florida's pediatric polio cases. Alan's few memories of his early days in the hospital include being in a small dark room while he battled the fever, struggling for his life. Then, later he remembers lying on a gurney next to an iron lung - although he was never in one. It was a very scary experience for a three-year-old. He also remembers therapy sessions where, he had to lie on his stomach to work his back and buttocks muscles. He had to lift himself up to look up at a picture of a duck billed platypus on the wall. As a result, he learned quite a lot about that particular animal at an early age!



Alan Toy, age 3.

After months in the hospital, the little boy left with crutches and braces. He eventually worked his way out of one of the braces and has used crutches and a brace most of his life. In recent years he has shifted to using a Firefly battery-operated power mobility attachment.



Alan Toy as FDR

Source: 2021 NBCUniversal Media, LLC

Alan became comfortable being in the spotlight at a very young age. He participated in multiple fundraisers for polio and was the "cute little blond kid" sitting in the back of the convertible in the March of Dimes parades. (President Franklin Delano Roosevelt started the [National Foundation for Infantile Paralysis](#) which later became the March of Dimes). The President asked people to collect and send in their dimes to the White House in support of polio vaccine research and hoped it would lead to the eventual eradication of the disease. Fast forward to December, 2021 and that cute little boy in the back of the Cadillac is on national television playing the role of the man who started the March of Dimes!

When Alan was six, his father was transferred to an Air Force Base in England. While in his new English school, both his mother and teachers greatly encouraged and challenged him to participate in all activities. The teachers encouraged him so much that they even added a wheel barrel race at the end-of-year field day so he could compete in a race by using his arms. He has very fond memories of his time living in the UK.

The family's next move was to Norfolk, Virginia. After two years, his father retired from the Navy and moved his family to Winston-Salem, NC. While they were living in Winston-Salem, his mother became involved in the Winston-Salem Little Theater and young Alan helped out, mostly doing sound effects. This was his first exposure to the stage. While at Reynolds High, one of his teachers encouraged the students to get extra credit by volunteering in the community arts. Alan volunteered at UNC School of the Arts as an usher and worked the front of the house during productions. Planning to study political science, he met people there who helped influence his decision to pursue a career in the arts. He graduated from Reynolds High School in 1968 and has stayed active with his high school alumni.

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Alan Toy (continued) . . .

Alan loved the theatre and applied to the UNC School of the Arts. He was admitted and studied drama from 1969-1971. He feels that moving and living in several different places gave him a broader experience and exposure to people he would not have otherwise encountered. This resulted in helping shape his outgoing personality and his positive outlook on things. Alan always knew deep down that because he walked with crutches and a brace his acting opportunities would be limited. He was drawn towards directing and enrolled in the Goodman School of Drama in Chicago. His dislike of the cold and Chicago weather didn't mix. Alan transferred to the California Institute of the Arts in 1972 and found that the weather was much more appealing. He's never looked back and California has been his base ever since.



Alan Toy



Alan and Theresa Toy

Alan met his future wife Theresa, at the Media Access Awards held in Los Angeles. She was an actress, and unfortunately for the couple was based in New York City. After a 10 month bi-coastal romance Theresa moved out to California, where they were married in 1984. Their son John Henry, was born in 1991 while Theresa was pursuing a degree from the UCLA School of Social Welfare.

Although he was having some success, at that time actors with disabilities rarely got many jobs. While on the UCLA campus visiting Theresa with their young son, Alan discovered the UCLA Graduate School of Architecture and Urban Planning. This piqued his interest. In 1992 Alan received a one year Community Scholars fellowship to study there. Once he completed that year he enrolled in the program and earned a Master's Degree in Urban Planning. Ironically, it was during this period of time when he was in school that many of his more prominent acting jobs presented themselves. He managed to take a few days here and there to work at his acting gigs and still not miss much class

time. Alan feels that going back to school and getting his Masters was the best thing since it opened up so many more opportunities for him.

His social activism was sparked by a chance meeting with Frank Sinatra in 1969. While visiting a friend in Connecticut, he went to hang out at the local marina. A huge yacht pulled in and Alan spotted Frank Sinatra on board. His amazed reaction amused Sinatra, and so he invited the young man on board. During lunch, Sinatra was happy to hear that Alan was about to pursue a career in the arts. When Alan left, Sinatra gave him three \$100 bills. But the gift had strings attached. He asked that Alan accept the money with the condition that when he himself became successful in the arts, he should do the same for someone in his position and somehow pay it forward. Alan accepted Frank's challenge and has repaid that obligation many times over by advocating for and supporting those who are struggling to find their place in the world.

That advocacy was evident in his efforts to lobby the entertainment industry to create characters, storylines, and images that would depict people with disabilities in a more positive light. At the same time, as a member of both the Screen Actors Guild and the American Federation of Television and Radio Artists, Alan worked to make sure that the language in the union contracts included people with disabilities as part of the "protected groups."

Alan has not limited himself to working with other people to bring about change. He was tired of the negative stereotypical portrayals of people with disabilities. While he was president of the Media Access Office in Hollywood, he was persistent in lobbying the entertainment industry to create characters, storylines and images that would depict people with disabilities in a more positive light. He also helped create and co-chaired the first Inter-guild Committee of Performers with Disabilities.



Alan Toy and [Justin Dart](#) "the Godfather of the ADA" - Outside the White House in 1996

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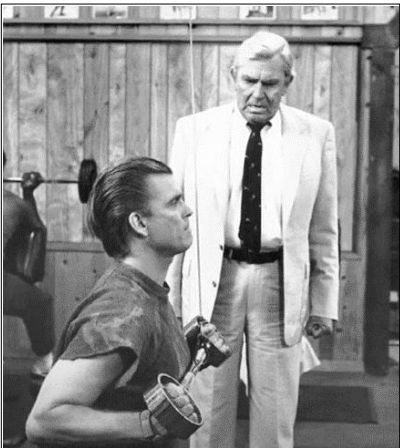
Alan Toy (continued . . .)

Alan has held various positions through the years which involved advocating for disability rights and community-based Independent living opportunities that included bringing more disability inclusion to the work of the ACLU. He has served on many local and state committees and boards. At UCLA, he developed the LILA website (Living Independently in Los Angeles) which assisted people with their day-to-day independent living needs. His last position was director of a Los Angeles Independent Living Center, working to improve housing options, accessible public transit, and homecare for those who would otherwise have to live in nursing facilities. He has given many speeches about Independent Living, and recently spoke to a Rotary convention about the importance of vaccines and the need to eradicate polio worldwide.

Alan's disability did not stop him from being able to act in both television and movies. His career was highlighted by his opportunity to play a wide assortment of characters including parents, lawyers, doctors, scientist, veterans, teachers, and even a wheelchair using mountain climber. Some of his most well-known TV roles have been in "Beverly Hills, 90210," "Trauma Center," and guest spots on "Matlock," "Highway to Heaven," and "M*A*S*H." He has had parts in film such as "The Aviator," with Leonardo DiCaprio, "Kansas," with Matt Dillon, and "In The Line of Fire," with Clint Eastwood. His advocacy has helped many other disabled performers become successful as well, giving audiences new perspectives on viewing people with disabilities.

Now retired, Alan lives in Santa Monica with his wife, Theresa, where he enjoys the beautiful weather year round. He has done some extensive travelling and is occasionally drawn back into advocacy, public service and consulting. No doubt, we haven't seen or heard the last from Alan Toy!

Alan's life changed forever when he had polio. Even so, he is thriving in his acceptance of his disability and living his life filled with love for his family and in serving others.



Alan Toy and Andy Griffith –
Matlock 1990 Source: CinemAbility



Alan Toy in "Swing Shift" – 1984



Alan Toy in M*A*S*H – 1980



Theresa, John Henry and Alan - 2016



Alan and Theresa - 2020

Note: Photo Source: Alan Toy unless stated.

This story and many others are available under Articles/Resources in the [Survivor Story](#) section of our website. 5



Applying for Social Security Disability in the US

By [Marny K. Eulberg, MD](#)
Primary Care Perspectives

Are you considering applying for disability?

First of all, if you have already reached full retirement age, there are no government funded disability programs for which you are eligible. Full retirement is the age at which you first qualify for the full payment of Social Security benefits. In years past, this had been age 65 but has gradually been increasing based on the year of one's birth. For persons born in 1960 (or later) it now is age 67.

I learned much about the process many years ago when several polio survivors recognized that they could no longer continue their employment, and began the process of applying for disability. Now that many polio survivors are age 65 or over, questions about disability rarely come up. But recently I have had multiple inquiries from polio survivors who are in their early 60s and are finding that, for various reasons, it is becoming very difficult for them to continue working. Each of them had several questions about the process.

The first part of this article addresses a few things you need to know and consider before even deciding when and whether to apply. At the end are several articles that deal with the nitty gritty of the applying and information that you can share with the physician(s) that you will be asking to provide the needed medical documentation.

A Person Considering Applying For Disability:

- Needs to determine if they have the option of private disability insurance either through an employer
- Or, from a disability insurance policy that they have purchased for themselves.
 - In general, private disability insurances have a slightly less difficult application process than Social Security.
 - The amount that an individual with private disability insurance will receive is usually available through the employee's HR department or written into the policy documents.

There are two programs within Social Security that provide disability benefits. Both programs require that the applicant meet the qualifications to be declared disabled.

- Social Security Disability Insurance (SSDI) and
- Social Security Supplemental Income (SSI).

Which one of these programs a person qualifies for is based on how long and how recently the applicant has been working in a job that has paid into Social Security (those funds withheld from your paycheck that are frequently abbreviated as FICA).

To be eligible for SSDI a person, in their 60s:

- Needs to have paid into Social Security for 40 quarters (totaling 10 years of employment) and
- At least 20 of those countable credits must have accumulated in the last 10 years.
- Persons who have less credits generally will be eligible for SSI.
- The amount of the SSDI payments is based on how much money has been paid into Social Security on your behalf (based on your earnings);

Typically, SSI payments are much lower:

- (Often around \$600-\$700 per month).
- Income from SSI usually allows a person to be eligible for Medicaid and other programs for low-income persons.

To find out your status:

- Call your local Social Security office or go to www.ssa.gov
- They can tell you how many quarters (credits) you have and when payments have been made.
- They can also inform you of how much you would receive per month if you were approved for SSDI or SSI and for what non-disability Social Security benefits you may be eligible.

You must determine the waiting time required prior to being able to receive benefits. The applicant needs to find a way to fund their living expenses during the period when they will not be receiving a paycheck and still are not receiving a disability check.

- The waiting time varies, depending on the type of disability insurance for which one is eligible.

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- Premiums for disability insurance are lower the longer the waiting time is.
- Most plans have a waiting time of at least 3 months, and many including Social Security, require a person not work for at least 6 months before receiving any benefits.
- Some employers offer both short-term disability and long-term disability. In that case, a person may be able to receive short-term disability benefits until they have completed the waiting period before long-term disability commences.

How Will Your Health Care Costs Will Be Covered When You Are No Longer Employed ?

Persons who are approved for SSDI or SSI are eligible to receive Medicare Health Insurance, *but* only:

- Beginning 2 years after the date of onset of the disability (as determined by Social Security) or
- When the person reaches age 65
- Whichever comes first.

If health insurance is routinely provided by your employer, you may be able to purchase health insurance through COBRA for up to 18 months.

The application for disability insurance will require a lot of paperwork including medical records that need to document the medical reasons that the person is unable to work.

- Post-Polio Syndrome is recognized as a legitimate medical reason for going on disability
 - The specific reasons that a person no longer can perform the essential duties of their position *must* be spelled out. These include:
 - increased weakness that has led to decreased functional abilities,
 - fatigue requiring rest periods that are greater than your employer can accommodate
 - and/or pain that interferes with job performance.
 - Although not required, it can be useful if any recent job performance evaluations done by your employer indicate that you are not performing at an acceptable level.

Many polio survivors tend to downplay/minimize their limitations, but when they are filling out an application for disability this is *not* the time to do it! On the other hand, never report anything false, because that is fraud. I tell people not to lie or exaggerate but it is useful to describe their worst day(s).

If You Receive Disability Payments Through A Private Or Employer Sponsored Plan:

- They may require you to have periodic medical exams to determine whether or not your condition has improved to the point that you could return to work. Won't that be wonderful if PPS miraculously went away? It is prudent to comply with this request, even if it means that you and your physician have a casual follow-up visit.
- Most private and employer sponsored disability insurances will ask you to apply for Social Security Disability after they have covered a person for about two years. Do not panic.
 - If you are denied by Social Security Disability the private disability insurance is obligated to continue making the payments for the durations of the policy (usually until full retirement age).
 - The insurance company frequently will help their covered insured person apply for Social Security Disability and do most of the work for the insured.
 - The insured will still get the same total monthly benefit, but if they are approved for Social Security Disability the insurance company frequently now only pays the difference between the amount they had previously paid and what Social Security now will be paying.

Here are some resources to consult with more details:

- [**Social Security Disability \(SSDI\): Procedure for Applying**](#)
 - [**SSDI Application Letter**](#)
 - [**SSDI Denial Letter**](#)
 - [**SSDI Online Application Form**](#)
 - [**SSDI Template for Physicians**](#)
- [**Social Security Evaluation for Post-Polio Sequelae \(Current\)**](#)
- [**Social Security Evaluation for Post-Polio Sequelae \(Original 2003\)**](#)
- [**Social Security Ruling for Post-Polio Sequelae**](#)



Working Together To Bring Greater Global Awareness of Post-Polio Syndrome
Join us for fascinating monthly meetings (via Zoom)

These meetings are Hosted by the Rotary Disability Advisers Group
and sponsored by the
Post-Polio Syndrome Advocacy Group
Everyone is welcome. You do not need to be a member of Rotary to attend.

These meetings, attended from survivors all over the world,
are held on the 2nd and 4th Thursday of the month – 10am EST.
The 2nd Thursday will feature a speaker. The 4th Thursday will be a general discussion.
Zoom Meeting ID: 878 0943 9212 Passcode: PPS
Join Zoom Meeting: <https://lnkd.in/e4QbpQm6>

For more information: please email: ppsadvocacy@gmail.com



In anticipation of World Polio Day on October, 24th,
there couldn't be a better time to become part of [Team Survivor](#) 2022.



[The World Health Organization added the US to it's List of Countries with Circulating Polio. It joins the likes of Somalia, Yemen, and Israel.](#)

Join Us as we help the Rotary Foundation with their extraordinary
advocacy to eradicate the terrible disease.
Every dollar we donate will be turned into three by the Gates Foundation.


A letter from one of our subscribers . . .



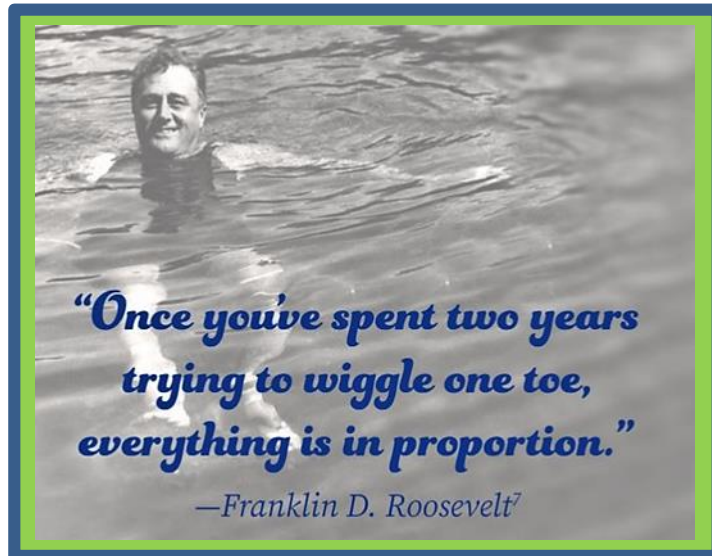
THANK YOU for the news letter. There have been some very interesting articles which cleared up some misunderstandings I had.

I can't under estimate how easy it is to "over do" even the simplest of tasks these days. At 75 years old and caring for my husband of 80 I now need help! I now employ for four hours a week someone to do those things I can't. It's not "giving into polio" it is pure practicality. I need to be a support for my husband so that we can both continue to live independent lives.....and so far it's working. I have a little more time to do the things I want to do and more time to support my husband.

It's very important that you have a support network of some kind, a friend who will pick up some shopping for you, or someone to help with difficult tasks such as changing bed linen or vacuuming the carpet. (It's amazing how much dirt a wheelchair can pick up). The other important thing is to pace yourself, don't get muscle fatigue by trying to do everything at one time. Make a list of the important things you need to get done and spread the workload over a longer period of time. Life is not a race and you are not in a competition. Take time out for yourself.

Annie Goodhall 

THANK YOU for your kind words.
This is the inspiration that keeps us moving forward.



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