



Polio Hero News



We Appreciate Your Support.

Spring 2021



LAST MAILED NEWSLETTER: After 35 years, this will be the last mailed Polio Heroes of TN Newsletter. Logistics, printing, postage, age are all factors in this decision. We realize that many of you do not have internet, and have relied on the printed copy. Our newsletter is posted on Easter Seals TN web site under "Programs - Polio". We currently have about 500 polio survivors and their families in TN and Southern/Western KY in our group. From time to time we may post any new information about post-polio on our Easter Seals TN page. We will, however, remain as a "resource" and available by phone or US Mail. Thanks to the support of Easter Seals TN we have reached thousands of polio survivors over the past 35 years. We are now an aging population with the majority of our members over age 75 - many in their 80's and even 90's. We do have our youngest member in his 20's (US vaccine caused polio) and an increasing number of immigrant members (wild virus polio) who are in their 30's and 40's. Many of the other support groups in the US, Canada and other parts of the world we have shared information with have also ceased to operate for the same reasons.

Polio Heroes of TN educated many health care professionals. Last year ending 30 years of teaching Physical Therapy students about polio and post-polio. This was begun with the initiative of Dr. Cathy Hinton, PhD, Thanks to Dr. James Little, MD, Dr. Trevor Paris, MD, Karen Haynes, RPT and the now closed TN Christian Medical Center, we had a polio evaluation clinic for 8 years, beginning in 1988. This hospital was a vital part of our support system. Dr. Little had the hospital build a state of the art hot therapy pool which we enjoyed for 21 years. There were flat lanes for walking, grab bars, a chair lift and no slope to the floor. Our pool therapists Cordy Christopher and Keith Puttman made every visit a pure joy and happy experience. In the 94 degree water. We met so many wonderful people. Some of our members came from as far away as Owensboro, KY. Many stroke patients also joined us in the pool with great success. The new owner had no interest in polio patients.

Over the past 35 years we have met and gotten to know thousands of wonderful, inspiring polio survivors, their families, and physicians not only in TN, but around the world. We met so many people from around the world and other great support group leaders at the International Polio Conferences in St. Louis, Louisville and Texas. Many of these support group leaders became great friends - Carolanne Green, Frances Brown and Barbara Goldstein to mention a few. This has been a blessing all because of polio. Polio is still here, but like "old soldiers", we survivors are "fading away". Most of us were of the epidemic years. So many extraordinary, accomplished, remarkable people had polio. Names we will never forget: Hank Martin, Davine Levinson (also a Holocaust survivor), Hill Walker, Doris Holmes, Wendy Locke, Burdean Hickman, Roy Bush, Betty Oliver, Mary Agness Harper, Diane O'Dell (60 years in an iron lung), John Steinhauer, Peggy Wathen, Mike Smith and many, many more who have passed on. Thanks to so many of our loyal volunteers for our Belmont PT classes from the beginning: John Simms, Bill Thompson, Tom Box, Mary Ellen Shean, Chuck Albert, Ken Austin, Ron Haffkin, Barbara Tidball, Shirley Fults, Chris Neusbaumer, Elsie McKinney, Joan Doroughty, Clara Maurer, Joanne Gelup and all of the other volunteers who stepped up in our clinical classes created by Dr. Nancy Darr, RPT, PhD and Dr. Rene' Brown, RPT, PhD. at Belmont University. It is our plan that all of our records and archives will not be lost. Sometime in the future, we plan to donate them to the TN State Archives.

It has been my blessing to serve as the coordinator of Polio Heroes of TN these past 35 years. It all started with an admonition and encouragement of Dr. David Gaw, MD (my orthopedic doctor at the time). Jayne Perkins of Easter Seals TN stepped up to be our sponsor when others turned us down. The late Buddy Killen was always willing to help our group. Easter Seals TN has provided the printing, postage and mailing of our newsletter FREE all of these years. For a number of those years we had over 1,000 Members in our group. Our numbers are dwindling due to our age. Too often lately polio survivors are being told by physicians, "there is no more polio" or "you couldn't have possibly had polio". But WE'RE STILL HERE and as I like to say, "it is our doctors who are all dead".

We will continue to keep up with any of the latest information. We will still be available as a resource by phone or US Mail. Stay well, hang in there, you are not alone.
Nickie Lancaster, RN, Coordinator of Polio Heroes of TN



POLIO HEROES OF TENNESSEE Support Group • Nickie Lancaster, R.N., *Group Leader and Coordinator*
529 Albany Drive • Hermitage, Tennessee 37076-1422 • Phone: 1 (615) 889-3007
a program of Easter Seals Tennessee - Suite 228, 500 Wilson Pike Circle, Brentwood, TN 37027

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This newsletter is printed by and postage provided by Easter Seals TN free. If you move or no longer wish to receive the newsletter, please notify Polio Heroes of TN. Make donations to Easter Seals TN, Suite 228, 500 Wilson Pike Circle, Brentwood, TN 37027 for Polio Heroes Support Group. We could not provide this newsletter without Easter Seals TN.



DISCLAIMER: All articles in this newsletter are that of the individual writers and sources and do not constitute an approval or endorsement by Polio Heroes of TN or Easter Seals TN. **Always consult your physician if you have a medical problem.** You have permission to copy articles within this newsletter to give your health care provider.



Over the past 35 years, we have had many people who have shared their experiences and old photos with us. These are just a few. Some of these have passed on and no longer need braces or ventilation support.



John Steinhauer & Dad
Warm Springs



Karen Haynes, RPT & PH Roy Bush 1988



Dr. Trevor Paris, MD & PH Peggy Wathen 1989 TN Christian Polio Clinic



PH Gordon Pierson & Dad 1995



PH Jack Mraz & PH Florence Crawford TN Christian Therapy Pool



J.W. Faulton 2002 of Westmoreland



Cordy Christopher & PH Mary Agness Harper - 1991



Nickie Sedivi 1950



Wendy Locke 2014



In Loving Remembrance
Burdean Ray Hickman
Columbia, TN



Forced to wear an almost unbelievable number of braces and supports out of the water, Maggie Nel Tibbs, 10, of Hohenwald can begin gradual use of her legs in the warm waters of the physio-therapy pool. Miss Thomson aids her in muscle manipulation and movement so that the needed exercises leading toward eventual unaided activity may be carried out.



PH Mike Smith, 1943-2015, Woodbury



PH Charles Kulp Murfreesboro



Nashville Mayor Ben West and Carolyn Perry 1955 - both polio survivors



Buddy Killen & Nickie Lancaster -1989 ES



PH Dinah Shore



Eddie Macon 1951



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SPRING 2021





PA Polio Survivors Network Makes Available
BRUNO BYTES
by Dr. Richard Bruno, HD, PhD
Director of International Centre for Polio
Education and Author of
THE POLIO PARADOX

UNDERSTANDING
 AND TREATING
 "POST-POLIO SYNDROME"
 AND CHRONIC FATIGUE



Richard L. Bruno, H.D., Ph.D.

"Every polio survivor deserves to know the truth about pain and 'post polio syndrome'—its diagnosis, cause, and treatment—found in these pages."
 —Sir Arthur C. Clarke, polio survivor and author of 2001: A Space Odyssey

It is only fitting that the last mailed PH of TN Newsletter feature articles from Dr. Bruno. We first met Dr. Bruno in St. Louis in 1987 at a Polio Conference hosted by Gini Laurie who founded the International Polio Network (now, Post-Polio Health International). Gini brought polio support group leaders from all over the country to meet and share information. This was in the infancy of polio survivors knowing what post-polio sequelae (Post-Polio Syndrome or Late Effects of Polio) was. Over these many years Dr. Bruno has helped thousands of polio survivors understand what is happening in this second phase of our disease no one told us about. We have met with Dr. Bruno, not only in St. Louis, MO, but also in Texas and he even graciously came to Nashville by invitation of the Jr. League of Nashville and spoke to about 150 of our members at the Opryland Hotel. (Which he was afraid he would never find his way out of.) We also had the blessing of meeting and knowing his late wife, Nancy Frick, PhD who shared here experiences as a polio survivor. Dr, Bruno and Nancy were always there to answer our phone calls and graciously spend their precious time to help our members with any problems. Every polio survivor should own a copy of **THE POLIO PARADOX**. It will be your "go to" book on polio and the late effects we now experience. It will also guide you doctor as to what you can tolerate and what you cannot and should not tolerate. Dr. Bruno continues to be a prolific writer on the subject of polio, which he has researched for over 50 years now.

BRUNO BYTES, 4th Quarter 2020: Accurate Blood Pressure Readings and Upper Arm Atrophy

Q: How accurate is taking blood pressure on polio survivor's very thin upper arms with almost no muscle even if you choose a child cuff? I understand that home machines use a different method to pick up the blood pressure than the manual system of stethoscope and sphygmomanometer. So does monitoring at home using a machine give an accurate reading? My own readings seem to vary a lot even between arms and between readings. Could this be because of damage to the vagus nerve by polio impacts blood pressure?

Dr. Bruno's Response: I would ask you GP to use a child's cuff in addition to them taking your blood pressure (BP) in both arms. A BP cuff that is too large will give false low readings, while an overly small cuff will give readings that are falsely high. I would not use the home automatic BP machines without a properly sized cuff and without comparing your home machine's measurements to those in your doctor's office using a proper sized cuff. Blood pressure can be taken in the forearm, and there are machines that take BP at the wrist. However, these can give artificially elevated BP readings that also need be compared to measurements in your doctor's office taken with a proper cuff.

Certainly the automatic nervous system - the vagus and sympathetic branches, both damaged by the poliovirus - is central in determining BP. We found a relationship between low blood pressure, fainting and fatigue severity in polio survivors. But even without the extreme of plummeting BP and fainting, common bodily events can affect blood pressure: a big meal can lower while a full bladder and pain can raise BP. (For more information on BP and the autonomic nervous system in polio survivors search the ENCYCLOPEDIA OF POLIO & PPS - "Complete Index" and "Articles" (by subject)

MANY, MANY THANKS, DR. BRUNO FOR YOUR CONTINUED HELP AND CONCERN FOR POLIO SURVIVORS.

For other polio resources: To subscribe to POST-POLIO HEALTH contact them at PPH International, 50 Crestwood Executive Ctr #440, St. Louis, MO 63126 USA or 314-534-0475. They do charge a fee for membership and quarterly.



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COVID - 19 VACCINE INFORMATION FOR POLIO SURVIVORS

from Post-Polio Health , Vol. 37, No. 1, Winter 2021

50 Crestwood Executive Ctr #440, St. Louis, MO 63126 phone: 314-534-0475

(Most of the recent calls to PH of TN have been concerning the Covid Vaccines - this article was compiled by PPHI Medical Advisory Committee. This is a guide. Make your own decisions with your doctor.)

As the COVID-19 vaccines are approved for use and begin to be given to Americans and others, PHI began receiving questions from our constituents. Remember our knowledge about the COVID-19 virus is only about one year old and is continually being updated which means information and recommendations sometime change from month to month. Your primary care physician, especially one that has worked with you for some time, is the best source of information of what will be recommended for YOU and your particular situation. At this time, here is how our Medical Advisory Committee is responding to these questions:

DOES HAVING HAD POLIO OR HAVING RECEIVED THE POLIO VACCINE GIVE IMMUNITY TO COVID-19?

There has been a “theory” circulating that recent exposure to some viral diseases or vaccines to those viral diseases might “boost” the immune system and provide some protection against COVID-19 but that is not backed by any clinical evidence. (If history of receiving the polio vaccine did provide protection against COVID-19, then the older people living in the developed world, most of whom have been immunized against polio, would have a very low incidence of novel coronavirus infections, and that is clearly not the case!)

WILL I BE GIVEN PRIORITY BECAUSE I HAD POLIO? No, a history of polio does not in itself make a person more likely to get COVID-19 or get sicker than others of similar age and other medical conditions. So, a history of polio and/or PPS does not move an individual up the priority list. On the other hand, most people who contracted polio in the US and Canada are over the age 65 and several even over 80 years old. Therefore, they are already in the “high risk” group, which generally places them in the second tier of people slated to be offered the vaccine. Polio survivors with respiratory compromise may rise up one level over others of a similar age group due to their underlying respiratory condition; likewise for the polio survivor living in a nursing home or other senior living situation. In the US, each state, with input from the national health authorities, determine their own priority list, so where you fall in the priority tier system may vary slightly from state to state.

AFTER I GET THE VACCINE, EVEN THE FIRST DOSE, CAN I STOP WITH ALL THESE PRECAUTIONS?

We don’t know all the particulars, but studies have shown less than 50% immunity 2 weeks after the first dose which rises to greater than 90% protection 2 weeks after the second dose. Our colleagues in the British Polio Fellowship summarize the precautions as “Hands, Face, Space”, and the recommendation is to continue these precautions until enough people have received the vaccine to minimize the risk of exposure from the general public.

WHY DO I NEED 2 DOSES? Because tests to date with the vaccines that are currently available have shown only partial protection after the 1st dose and a much better immune response after the 2nd. This is not unusual for vaccines - to get full immunity from polio a minimum of 3 doses are recommended and 4 are usually given: the shingles vaccine is a series of 2 shots as are the measles, mumps, rubella, and chickenpox vaccines. As new COVID-19 vaccines are developed and approved, it is possible that, at some point, we will have a single dose COVID-19 vaccine that is safe and effective. *(Since this article was written the single dose JOHNSON & JOHNSON vaccine is available in some areas.)*

CAN I GET COVID-19 FROM THE VACCINE? No, the technology used to make the COVID-19 vaccine *does NOT use any live virus or even part of the virus particle*. All the new vaccines were made by breaking and then artificially duplicating part of the genetic code contained in the spikes on the surface of the COVID-19 virus. They work by blocking the virus from attaching to your cells and then invading your cells and causing infection.

WHEN ALL THE VACCINES BECOME AVAILABLE WHICH ONE(S) SHOULD I GET? The 1st one that becomes available to you, regardless of whether 1 or 2 doses!

WHO SHOULD NOT GET THE VACCINE? For now, it has not been adequately tested in youngsters under the age of 16 or in pregnant women, so it is recommended that the vaccine not be given to those individuals until studies show the vaccines to be safe and effective in these groups. There have been a few cases of severe allergic reactions to people with multiple significant allergies to other substances, for now, persons with allergies severe enough to carry an *Epi-Pen* should discuss with their physicians before being immunized. Any changes to this statement as new information becomes available will be posted at www.post-polio.org/covid-19-vaccine.



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