

connections

colorado post-polio • since 1981

**Planning a summer vacation?
Save the dates!**

Colorado Post-Polio 2018 Rocky Mountain Getaway

Join Colorado Post-Polio and Easterseals Colorado

Sunday, August 19 - Thursday, August 23, 2018

Rocky Mountain Village Camp
Empire, Colorado

Relax at this all-handicapped accessible camp
in the Rocky Mountains near Georgetown, Colorado

Take advantage of the swimming pool and hot tub

Go fishing

Ride the zip line

Ride horses

Explore the accessible hiking trails

Take in evening entertainment

Breathe in the mountain air and

Gaze at the clear starry night skies

Enjoy old friends and make new ones

Engage in lively conversations

Have fun!

Participate in polio related educational lectures and
discussions, exercise sessions and
physical therapy, and craft activities.

We hope to see you there!



WHATEVER
IT
TAKES

Winter 2017

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Polio Feet

*"There is a reason you have cold feet
but you can keep warm and stay cool"*

Richard Bruno, Ph.D. - New Mobility

Reprinted: Polio Epic, Inc. • Arizona Post Polio Support Group • Oct.-Nov. 2017

The process that causes "Polio Feet" to turn blue and cold and become difficult to move when it's only cool is the same process that caused paralysis after the original polio. The Polio virus got into the spinal cord and either destroyed or damaged the anterior horn cell motor neurons that transmit the message to move from the brain to a muscle. When those neurons were damaged, or especially when they died, they disintegrated and the muscle fibers that used to be turned on by those cells no longer are.

There is another kind of motor neuron that was affected by the virus - the motor nerve that controls the muscle around your blood vessels. When these muscles died, there were no motor nerves to tell the blood vessel to contract; if the blood vessel cannot contract, blood pools: especially in the veins. When the blood pools in the veins, it is going to be blue, because venous blood is not oxygenated.

People who had polio should dress as if it is 20 degrees colder than it actually is.

Polio feet are caused by warm blood that should be in the center of your body, flowing out into the hands, arms, and especially the legs (since gravity is pulling the blood down). The warm blood pools in the surface of your skin, and because the blood vessels cannot contract, the result is "polio feet." The venous pooling causes your blood to radiate heat into the environment. People who had polio keep the world warm, unfortunately at their own expense. The price of this is a through cooling of the limbs and all tissues of the limbs.

When heat leaves the veins, the motor nerves that lie near the surface of the skin starts to cool. The muscles that lay just a bit below the surface then start to cool. The connective tissue that connects muscle to muscle, and muscle to bone starts to cool and stops being elastic so it is harder for it to move.

When the motor nerves aren't functioning well, the muscles aren't going to function well; if the muscles don't function well, there is going to be muscle weakness. We think that muscle weakness and the loss of body heat are causing fatigue; and we think that people who lose all their body heat into the environment are burning calories to maintain their body temperature, so there are fewer calories to keep moving.

People who had polio should dress as if it is 20 degrees colder than it actually is, but you should dress in layers so you can control your body temperature and not pass out from a rapid flow of blood away from your head as your arteries warm. *{Polio Feet continued on page 5}*

Bring the Traveling Clinic to Your Town



The clinic team would like to reach out to every polio survivor in the state, and invite them to take advantage of the opportunity to have a polio evaluation. Subscribers of the Connections newsletter have been contacted over the past three years and the clinic has been held in Colorado's major cities. Now it is time to reach out to the areas where there might be one or two survivors who could benefit from the clinic. The newsletter reaches about 800 people in Colorado, but there are others who do not subscribe and do not have the benefit of its information.

To maximize the availability of the clinics, please contact your polio friends and acquaintances, let them know about the clinic, and encourage them to contact Dr. Eulberg. The traveling clinic is unique to Colorado and is only possible because of generous donations and grants as well as Dr. Eulberg's commitment to using her skills as a physician and as a polio specialist to care for those who have had polio.

Save this information for reference and let your polio friends and acquaintances know about this information, especially those who are not subscribers to the newsletter.

The clinics operate in two locations, at Dr. Eulberg's office in Wheat Ridge, Colorado and in a Colorado town near you.

Polio survivors who are within driving distance of the Denver Metro Area are encouraged to make an appointment at Dr. Eulberg's office. Those who cannot travel to Denver are invited to contact Dr. Eulberg so she and her team can schedule the clinic closer to your home.

Dr. Eulberg is taking requests for appointments at the traveling clinic. Please contact: Dr. Eulberg before April 30, 2018 in order to allow time to schedule the 2018 clinics.

Metro area polio survivors can contact Dr. Eulberg at any time to schedule an appointment.

(303) 829-1538, e-mail marnyeul@me.com

The traveling clinic is sponsored and funded by Colorado Post-Polio (CPPO) and Easterseals Colorado. CPPO recognizes that as we age and perhaps become less mobile, we cannot travel as far as we did when we were younger. It also recognizes the need for polio survivors to have access to the information the clinic provides. The clinic evaluation includes: an assessment of muscle function, a review of the relationship between polio and other diagnoses, recommendations to address issues and a written report for you and your doctor, if you choose.



The evaluation is FREE to polio survivors as the Colorado Post-Polio Organization/ Easterseals Colorado cover any expense and the clinic team volunteer their time. However, any donations to CPPO/ Easterseals are appreciated.

To make an appointment or get information about the Colorado Post-Polio Traveling Clinic and/or the Mountain and Plains Post-Polio Clinic, contact Dr. Marny Eulberg, the physician for both clinics at (303) 829-1538, e-mail marnyeul@me.com

TYPE A BEHAVIOR IN POLIO SURVIVORS

By Richard L. Bruno, PhD

When polio survivors first came to us 35 years ago, we discovered that polio had had a profound effect on learning and earning. The subjects in our first post-polio research study made clear that polio survivors were very unusual. The subjects used power wheelchairs and had, not just bachelors, but also graduate degrees. It became apparent that polio survivors were unique, not only among individuals who had disabilities of equal severity, but also among non-disabled peers. Polio survivors had risen to high levels in their professions. More than the expected percentages of polio survivors are corporate executives, members of both houses of Congress and professionals of all types -- teachers, lawyers, doctors and nurses. This level of achievement points out a startling fact: Polio survivors, who were told that they would never go to college or even get a job, became America's "best and brightest."

Polio survivors apparently shared a personality type that first had been described in those who developed heart disease: The hard-driving, time-conscious, competitive, self-denying, perfectionist, overachieving "Type A" personality. We weren't surprised when our 1985 National Post-Polio Survey found that polio survivors reported 50% more Type A behavior than people without disabilities, even more than in those who'd had heart attacks. We also discovered that the more Type A behavior polio survivors reported, the more new fatigue and muscle pain they had.

The polio experience provided the ideal environment for becoming Type A. Lack of social support, low self-esteem, and loss of control and fear of punishment have been found to teach Type A behavior. Our 1995 International Post-Polio Survey found that polio survivors reported 34% more physical abuse and 94% more emotional abuse than in those without disabilities.

The Survey included a questionnaire measuring sensitivity to criticism and failure that found polio survivors were 15% more sensitive to the criticism of others and thinking of themselves as failures than were non-disabled respondents. Not surprisingly, the more abuse polio survivors experienced the more sensitive they were to criticism and failure and the more Type A they had become. So, polio survivors became Type A to prevent criticism and abuse by others and to protect against feelings of failure. That's why so many survivors discarded in childhood any evidence of polio – crutches, canes, braces, wheelchairs – and refuse to accept them now when they develop PPS.

Polio survivors want to both act and appear “normal.” Our 1995 Survey also found that protecting against criticism and failure was more important than polio survivors own emotional or physical well-being. Nearly three-quarters answered "yes" to the question "I often do what others expect, regardless of how I feel emotionally or physically." Said one of our Post-Polio Institute patients, "Polio survivors aren't just Type A, we're Type 'E'. We do everything for everybody every minute of every day!" For most polio survivors, it is more important to appear "normal" and take care of others than it is to physically or emotionally care for themselves.

Unfortunately, the ultimate price polio survivors have paid for being Type A – and “Type E” – is Post-Polio Sequelae. The sad paradox is that, in spite of survivors cheating death by polio, conquering disability and dealing with years of severe physical and emotional abuse and pain to become “the best and the brightest,” many polio survivors believe that they have no ability to survive PPS. This paradox is why psychotherapy for polio survivors is so important: To help them deal with terrible things that have happened in the past, to stop them from expecting more abuse and to help them accept that they are competent adults whose emotional and physical future is in their own hands.

It is exactly because of everything polio survivors have already experienced that they will survive in spite of PPS. To do this, polio survivors need to read these two words again and again and take in the full depth and breadth of their meaning: I am a POLIO SURVIVOR! If polio survivors can acknowledge the abuse they have survived, there is no question that they can cope with the past and make the physical and emotional changes necessary to survive and thrive with PPS.

Posted 11/28/16 <https://www.facebook.com/groups/PostPolioCoffeeHouse/permalink/1360768980631633/>

Polio Feet continued from page 2

The bottom line is to keep warm, stay cool and:

1. Use polypropylene socks and underwear by Gortex Thinsulate.
2. Dress in layers.
3. Never wear a skirt after Labor Day (first Monday in September) or before Memorial Day (last Monday in May).

INCREDIBLE WOMAN SPENDS 60 YEARS INSIDE IRON LUNG

Check It Out

By Barbara Diamond

Martha Mason was born May 31, 1937 in a small-town in NC. When she was 11, Martha realized she had polio, a dangerous and infectious disease that took the life of her brother. So as not to distress her parents further, Martha kept her illness a secret. But soon, Martha was placed inside an iron lung, which is a medical ventilator and tube-like contraption that enables breathing when a person loses muscle control or natural breathing becomes impossible. Doctors said she only had one year to live — but saying Martha defied the odds would be an understatement.

For the next 60 years, Martha lived inside the iron lung. Not only did she live, but she prospered. Her mother and colleagues helped her through high school where she was top of her class. She graduated from two universities. She wrote for her local newspaper, dictating the words to her dedicated mom. In the mid-90s, Martha used a voice-activated computer to write her memoir, which she dedicated to her mother.

You'd think the iron lung would limit Martha to the point of self-destruction, but she lived a rich, social, satisfying life surrounded by friends and family. In fact, Martha said her iron lung gave her a sense of freedom. Her home hosted dinner parties, book club meetings, and holiday celebrations. In 2003, Martha told the Charlotte Observer: "I'm happy with who I am, where I am. I wouldn't have chosen this life, certainly. But given this life, I've probably had the best situation anyone could ask for." Martha passed away 2009 at 71. She lived inside an iron lung longer than anyone in history.

Sources: [https://www.littlethings.com/martha-mason-iron-lung/?utm_source=LTas&utm_medium=Facebook&utm_campaign=shocking and](https://www.littlethings.com/martha-mason-iron-lung/?utm_source=LTas&utm_medium=Facebook&utm_campaign=shocking and Second Time Around) Second Time Around • Boca Area Post Polio Group, FL • Aug. 2017

**Borrow
Martha Mason's
Book,
Breath:
A Lifetime in the
Rhythm of an Iron
Lung: A Memoir
from the Post-Polio
Library housed at
Easterseals Colorado
393 S. Harlan St.
Suite 250
Lakewood**

OR

**Read about
Martha Lillard,
Paul Alexander and
Mona Rudolph,
three polio survivors
who use an iron lung
today at:**

**[https://gizmodo.com/
the-last-of-the-iron-
lungs-1819079169](https://gizmodo.com/the-last-of-the-iron-lungs-1819079169)**

Looking for Physical & Occupational Therapists

Colorado Post-Polio Organization (CPPO) is looking for physical therapists and occupational therapists who want to learn more about working with and treating polio and post-polio syndrome survivors as well as earn Continuing Educational Units (CEU) credits by participating in a CPPO sponsored educational workshop.

As polio survivors, we appreciate health care professionals who have some knowledge about polio when they work with us. And, we are drawn to using therapists if we know that when we tell them that we have had polio they don't look at us with blank faces or admit that they "really don't know anything about polio, but will try to treat us." Survivors have also learned that we often have to educate those providing services about symptomology as part of our relationship with them.

At this time, many of the health care professionals who have worked with polio survivors over the years are retiring or near retirement and may not have elected successors, so survivors are left with very few who know about our needs. CPPO is actively addressing this need via an educational workshop for health care professionals.

And, although many survivors graduated from PT and OT services years ago, we again need the services of physical therapists and occupational therapists as we progress through life, addressing the issues

of normal aging, aging with other medical issues, surgery and needing more care in order to maintain our independence and preserve our quality of life. It would be great to have a list of therapists to use for reference when polio survivors need services.

To help address this need, CPPO is offering physical therapists and occupational therapists, and PT and OT students, an opportunity to learn about polio survivors who are living with post-polio syndrome during a Saturday educational workshop the fall of 2018. Workshop topics will include: the physical and emotional factors related to polio and post-polio syndrome, how to work with survivors by addressing our specific needs and limitations, and bracing and assistive devices and their implications for polio survivors. The workshop will issue CEUs therapists can use to maintain licensure.

You can help publicize the workshop by passing the word about it to PTs and OTs that you know and any you meet. At this time, a date has not yet been set and the final program is in process. However, you can tell any PT or OT you know about the workshop and have them contact Dr. Marny Eulberg, (303) 829-1538, marnyeul@me.com for more information.

Thank you for spreading the word!

**PTs & OTs
Earn CEU Credits**

POLIO SURVIVORS BEING GIVEN TOO MUCH OXYGEN 4/15/2015

BRUNO BYTES provided by the Pennsylvania Survivors Network
Dr. Richard Bruno, PhD is the Chairman of the International Centre for Polio Education
and author of THE POLIO PARADOX

Reprinted: POLIO HEROS OF TENNESSEE *Support Group* • Polio Hero News • Fall '17

“Oxygen: Too Much of a Good Thing?”

“We will give you a little bit of oxygen.” “NO WE WILL NOT!”

Exactly right. Oxygen is like Tylenol in the hospital or in an ambulance. Don't feel well? They “give you a little bit of oxygen.”

As with any other drug, there needs to be a REASON for the prescription of oxygen (O₂), because O₂ DEPRESSES polio survivors' damaged breathing control center in the brain stem. Also, a weak diaphragm causes some polio survivors to retain carbon dioxide (CO₂) which is toxic. If there are medical or surgical issues that cause MEASURED blood oxygen to drop to the low 90s, then both giving O₂ and TREATING the cause could be lifesaving.

BUT, without a respiratory or other disease causing O₂ to be low – for example, coming out of surgery or using CPAP or Bi-Pap – polio survivors should NOT just be given a “little bit of oxygen” for no reason. If you just have apnea or shallow breathing during sleep, CPAP or Bi-Pap should bring your O₂ into the normal range without need for extra O₂.

CO₂: THE GAS POLIO SURVIVORS HAVE TROUBLE GETTING RID OF

Polio survivors retaining carbon dioxide is not discussed enough. I got a call from an anesthesiologist in N. Carolina about a polio survivor who'd had her gall bladder removed and in the recovery room was “fighting the tube” placed in her windpipe during the surgery. Well, nearly every post-op patient “fights the tube”. But, the nurses thought she was having trouble breathing, even though her measured O₂ was 96%, so they turned UP the O₂. Turns out the patient's trouble was retaining CO₂; the extra O₂ DEPRESSED her breathing, she went into respiratory arrest and died. The anesthesiologist almost cried when I explained this to him. “Why don't we know about this?!” he asked. I thought (to myself) “If only N. Carolina

O₂ depresses
polio survivors'
damaged
breathing
control center in
the brain stem.

CO₂:
The gas polio
survivors have
trouble getting
rid of.

had the Internet where doctor could search “SURGERY BREATHING + POLIO SURVIVORS” and find the Post-Polio Library and “PREVENTING COMPLICATIONS IN POLIO SURVIVORS UNDERGOING SURGERY”. (http://postpolioinfo.com/lib_surgical.php)

Yes, yet again, polio survivors *must always* have a discussion with the anesthesiologist BEFORE a test (e.g., a colonoscopy) or surgery using anesthesia. They need to understand that polio survivors can retain CO2 and the dangers of O2 suppressing breathing.

Executive Committee Meetings

Easterseals Colorado
393 S. Harlan, Lakewood (new address)
4:00pm
March 19,
June 18, September 17

Annual Meeting/Recognition Meeting

Wellshire Inn
11:30
May 19
Everyone is Invited
More Information to Come

Retreat

Rocky Mountain Village
August 19 – 23

Training for PT & OT Professionals

Date TBD

Mobile Clinics

Various locations based upon need.
Outlying areas TBD

Is This For You?

Are you looking for a way to make a big difference in post-polio thrivers' lives? Do you have a basic understanding of polio and PPS and how it can affect the body? Do you have good communication, listening and social skills? Can you lead a group discussion? Then this opportunity is for you!

Colorado Post-Polio is looking for a facilitator for the Colorado Springs support group. This is a vibrant group with 12-15 members who attend monthly meetings the second Saturday of the month at the Sand Creek police station.

The right person will provide emotional, social and educational support to group members in a safe environment where participants' thoughts and feelings are valued and group members are treated with fairness, equity and respect. To learn more about this job, please call Sue Brandon at (763) 377-2287.

OUR EXECUTIVE COMMITTEE MEMBERS

Sue Brandon, Chairperson	(763) 377-2287	Sue.Brandon@q.com
Marny Eulberg, MD, Medical Advisor	(303) 829-1538	marnyeul@me.com
Jan Hamilton	(720) 341-2879	Jan7271111@gmail.com
Nancy Hanson, Easterseals Liaison	(303) 233-1666 x237	nhanson@eastersealscolorado.org
Pat Jenni	(303) 880-3581	patjenni@gmail.com
Loran Dake	(970) 241-7825	lorandake@msn.com

Colorado Post-Polio Support Group Schedules

News of Note – Contact Sue Brandon if you would like more information about becoming the new Colorado Springs support group facilitator or to join the Executive Committee, (763) 377-2287.

Support Groups have an activity or program for each meeting. In bad weather, call the contact person to make sure the meeting will be held.

Aurora – Meets 4th Thursday of each month, 11:00am to Noon

Contact: Sandy Abbott – (303) 646-7346 – sandya65@outlook.com

Colorado Springs – Meets informally, call for time and location.

Contact: Sue Brandon – (763) 377-2287

Grand Junction – Please call for date, time and location.

Contact: Loran Dake – (970) 241-7825 – lorandake@msn.com

Lakewood – Meets the 2nd Tuesday of every other month, 11:00am to 1:00pm at the Belmar Library (NEW), bring a brown bag lunch.

Contact: Annette Beck – (303) 427-1789 – annette.beck242@outlook.com

Northern Colorado (Fort Collins) – Meets 4th Saturday of each month, 10:00am to Noon

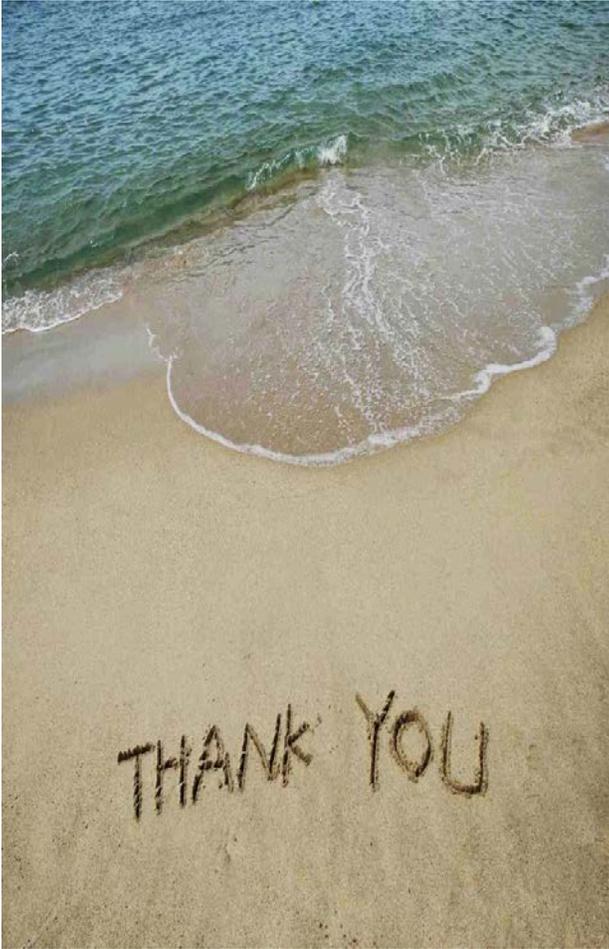
Contact: Peter Way – (970) 460-6164 – NOCOPolio@gmail.com

Pueblo – Looking for new time and location. Call for details.

Contacts: Maureen Sullivan – (719) 561-3182 – msmosul2005@yahoo.com – or

Mary Agnes Leonard – (719) 544-4789 – maryagnesleonard@gmail.com

*As long as you are breathing
It's never too late to do some good. - Maya Angelou*



Because of effective vaccination efforts in the US since the 50s, we no longer have new polio cases here. However, many immigrants from their 30s to 60s contract the disease abroad, travel here or become residents. Native-born survivors are now in their 30s - 80s. Support for these new survivors will be needed for the next four decades!

Colorado Post-Polio is blessed by major donors and continues to build reserves for the future. Our valued regular donors support our overhead and special programs. Our many valuable volunteers are the icing on our cake.

Please complete this form, detach it, and mail it to Nancy Hanson at Easterseals Colorado.

To insure that we receive 100% of your donation, contributions should be payable to Easterseals Colorado with "POST-POLIO" WRITTEN IN THE MEMO LINE. Your contribution will be gratefully acknowledged.

Thank you again!

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

E-Mail: _____

Mail to: Easterseals Colorado, 393 S. Harlan St., Ste. 250, Lakewood, CO 80226

Memo line: Post-Polio

**FREE MATTER FOR
BLIND OR DISABLED**

**Colorado Post Polio
c/o Easterseals Colorado
393 Harlan St., Ste. 250
Lakewood, CO 80226**



This Is YOUR Newsletter –

"Connections" is the official news publication of the Colorado Post-Polio Program. The opinions are those of the individual contributors, and do not necessarily constitute an endorsement or approval by either the Colorado Post-Polio Council or Easterseals Colorado. **Always check with your personal physician for all medical questions and concerns.**

We invite not only your comments about this newsletter; tell us what topics you want to read about in future issues. If you have article ideas or suggestions, are willing to write a short article, tell your personal story or you'd like to review a book, please call **Kris Lindsey at (303) 820-4767** or e-mail her at klindsey@eastersealscolorado.org, or write to:

Colorado Post-Polio Connections
c/o Easterseals Colorado
393 S. Harlan St., Ste. 250
Lakewood, CO 80226

If you prefer to receive this newsletter online or need to change your mailing information, please contact: Nancy Hanson at Easterseals Colorado:
(303) 233-1666, ext. 237 or nhanson@eastersealscolorado.org