

connections

colorado post-polio • since 1981

Looking for Physical & Occupational Therapists

CPPO is offering a one-day workshop for physical therapists and occupational therapists who want to learn more about working with and treating polio and post-polio syndrome survivors. The workshop will be held on Saturday, October 19, 2019 at Regis University in Denver and will offer 5 CEU hours to be applied toward the therapist's licensure.

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 their services 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."

Although we graduated from PT and OT years ago, we find that we once 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 we need their services. The purpose of this workshop is to speak to that need.

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Summer 2019

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Stem Cell Therapy Is Not For Polio Survivors

Dr. Richard L. Bruno, HD, PhD

Stem cells are remarkable, embryonic “baby cells” that will grow up to be any kind of cell that the body makes. With all the excitement about stem cells curing spinal cord injury, many polio survivors are asking if stem cells could cure PPS, or even reverse the damage caused by polio itself. The hope with spinal cord injury (SCI) is that stem cells, injected into the spinal cord, would “bridge the gap” in cut spinal cord axons, which are like long telephone wires that connect brain motor neurons to spinal cord motor neurons and allow the brain to “tell” muscles to move again. This notion requires intact motor neurons below the cut in the cord. Here lies the problem with stem cells “curing” polio or PPS. Even in “mild” cases, the poliovirus killed off at least 50% of neurons throughout the spinal cord. Stem cells injected into a polio survivor’s spinal cord would not have to just bridge a gap, but have to become new, functioning motor neurons. What’s more, those new neurons would have to send out their own axons to find and activate the specific muscles that were paralyzed when the original axons disappeared 50+ years ago after poliovirus-infected neurons died, by burrowing inches, or in the case of the leg three feet, through the tissues inside the arms and legs. Finally, the brain's motor neurons would have to send out new axons as well, since the brain’s neurons and axons also died. These axons would have to burrow through the entire brain, the brain stem and down through the spinal cord to get to the newly-implanted motor neurons, indeed a tremendous tunneling task! So, the idea of

rebuilding a polio-damaged spinal cord would require a “hat trick” of creating new brain and spinal motor neurons, new axons tunneling from the brain to the spinal cord and from the spinal cord to the muscles. Reconnecting a spinal cord that has been cut, would “only” require the physiological “goal” of bridging the gap between cut axons. Yes, a possible use for stem cells would be to inject them into the brain, as is done in Parkinson’s disease (PD) patients, where they could produce the main brain activating neurochemical, dopamine, which is decreased in polio survivors and causes post-polio fatigue. But, such injections are not widely accepted even in PD patients yet. So, if stem cells aren't the answer, is there anything polio survivors can do to help their remaining poliovirus-damaged neurons? Recently, there has been research on “neuro-protective” drugs (medications that protect neurons’ innards from overuse-abuse that causes post-polio symptoms). Several studies have focused on degenerative diseases, such as Parkinson’s (PD) and Huntington's diseases (HD), which involve damaged dopamine neurons. Minocycline, a common antibiotic used to kill a variety of bacteria, and creatine, which helps to provide energy to muscle cells, have been given to PD patients, who showed a less rapid a decline in function compared to those taking a placebo. However, a study comparing creatine and placebo in 60 PD patients found that, while their mood improved and their need for medication decreased, their symptoms did not lessen. Vitamin E has been found in

studies to have some neuro-protective effect in PD, while vitamin C and beta carotene were not helpful. Some research even links coffee's ability to limit blood vessels from opening to protecting neurons against PD, with one cup a day cutting the risk of developing PD by as much as fifty percent. Another dietary supplement, coenzyme Q-10, is being tested to see if it protects PD patients' neurons. Huntington's disease patients have also benefited from potential neuro-protective drugs. Huntington's patients given minocycline had slower progression or no decrease in physical ability, thinking and memory. Creatine had similar beneficial results in HD. Should polio survivors take minocycline, creatine and Vitamin E, or order a Starbucks' Grande, threeshot cappuccino to prevent post-polio brain fatigue? Not yet. There aren't enough studies to prove that any of these is truly neuro-protective in Parkinson's or Huntington's disease, let alone helpful for polio survivors, in which these substances haven't been studied at all. Double-blind, placebo-controlled studies of potential neuro-protective medications are warranted in polio survivors. For now, the only neuro-protective that we know works in polio survivors is: "The Golden Rule:" If anything causes fatigue, weakness or pain - Don't Do It (or) Do less of it.

SOURCE: Stem Cell Therapy Is Not For Polio Survivors

Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education www.postpolioinfo.com 2015

Who is Dr. Bruno?

For more than thirty years, Dr. Richard L. Bruno has studied and treated nearly 6,000 polio survivors and is the world's leading expert on Post-Polio Sequelae (PPS).

Richard L(ouis) Bruno is internationally known as the world's foremost expert on Post-Polio Sequelae (PPS, also known as "post-polio syndrome"), Bruno, a research and clinical psychophysicologist trained at the New York State Psychiatric Institute, began studying PPS and treating polio survivors in 1982, when he was a fellow in the Department of Rehabilitation Medicine, Columbia University College of Physicians and Surgeons. In 1984, Bruno organized and is chairperson of the International Post-Polio Task Force, which promotes PPS research, education and treatment in 25 countries.

Bruno left Columbia and, in 1989, created and directed the Post-Polio Rehabilitation and Research Service at Kessler Institute for Rehabilitation, the first center for the study and comprehensive treatment of PPS. Bruno is now director of the International Centre for Polio Education, the new home of the International Post-Polio Task Force.

Thank you North Area Support Group for the wanting to know more about post-polio syndrome and stem cell therapy.

Helpful Tool for You?

By **Kris Lindsey**, newsletter editor

My Mom live to be 87, had a myriad of chronic conditions and lived alone. She wore a Medical Alert necklace 24/7. This system was invaluable, notifying emergency services and my sister and I when she needed help. The medical alert operators knew a lot about my Mom including where her spare key was hidden so that first responders could use it to gain entry to her house. After multiple visits, we learned that our local fire department, Littleton, utilized Knox® Rapid Access System.

This system has been used by thousands of fire and law enforcement agencies for more than 40 years. The system provides first responders with immediate access into to your home during an emergency via a system master key.

How it works:

- Local first responder(s) have a Knox master key to open Knox Boxes in the community.
- A Knox Box is permanently mounted near the door or directly on your door. My Mom's was mounted discreetly on one of the front porch posts.
- The installed Box holds your house key, which first responders will use to enter your home. The Box is constructed to resist a physical attack, vandalism, and extreme weather conditions.
- First responders arrive to answer the emergency, use their master key to open the box on your front porch, and then use your house key to enter your home.

The primary benefits of this type of system are that it eliminates barriers to you home (no more searching for spare keys) and helps first responders to gain *rapid* access to enter the property to provide the help you need.

Contact your local first responders to see what rapid entry system they use.

Do You Use A Scooter or Power Chair? Pride XLR USB Charger

Have you ever been out in your scooter/powerchair and realized that your smart phone is almost out of power and there isn't a plug in sight?

The Pride XLR USB Charger is compatible with most iPhone, Android and mobile devices. Simply plug your USB cord into this charger and plug the other end into the charger port on your chair. Your device will charge whether your chair is moving or off.

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Opportunities to Participate in Research

NEW STUDY ON AFM AND POLIO

A new study concerning acute flaccid myelitis (AFM) and polio is being conducted by researchers at Johns Hopkins. They are currently recruiting polio survivors to participate in the study.

The objective of the study is described as follows: “We are trying to understand why some people get better quickly after an infection and others may have breathing problems, and still others may have neurologic symptoms or paralysis. We would like to compare the cells and DNA of persons with severe symptoms with those who may have been exposed to the same virus, but did not have the same severe outcomes. We plan to compare the DNA sequence of people with paralytic poliomyelitis to the DNA sequence of people with acute flaccid myelitis (AFM) following a viral infection diagnosed from 2012-present. We are looking for genetic variants that both groups share that can help explain why a virus can cause mild symptoms in some people (respiratory symptoms or non-paralytic polio), but severe outcomes like paralysis in others like you have experienced.”

Polio survivors are encouraged to participate. You will be asked to fill-out a questionnaire and submit a saliva sample by mail.

Contact information:

Dr. Priya Duggal (Co-Principal Investigator)

E-mail: pduggal@jhu.edu

Phone: 410-955-1213

Betsy Dee (Research Assistant)

E-mail: edee1@jhu.edu

Phone: 410-614-0146

(Posted 3/11/19)

You are invited to participate in a research study entitled, “Falls and Fear of Falling in Adults who Require Wheelchairs for Locomotion.” To participate you must be an adult who:

- Is at least 18 years old
- Has a neurological diagnosis (such as but not limited to post-polio syndrome, spinal cord injury, multiple sclerosis) for at least 6 months
- Use a wheelchair (manual or power) at least 75% of your mobility time inside your home and 100% of the time outside your home.
- Has a computer with internet access.
- Is able to read and understand English.

If you are interested in completing an anonymous on-line survey about your medical condition, falls, risk of falling, and fear of falling, please click on this link: <https://www.psychdata.com/s.asp?SID=183112>

It will take you up to about 20 minutes to complete it. People who complete the survey will be eligible for a drawing for a \$20 gift card.

You may contact Carolyn Da Silva, PT, DSc at cdasilva@twu.edu or 713-794-2087 for more information or questions. She is a professor in the School of Physical Therapy at Texas Woman's University and physical therapist at the post-polio out-patient clinic at TIRR Memorial Hermann Rehabilitation and Research in Houston, Texas.

(Posted 12/18/18)

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No need to be tethered to the wall!! The charger will switch off automatically when device is charged and will not discharge (drain) the chair battery.



SOURCE: *Second Time Around* • May, 2019 • Boca Area Post Polio Group, Boca Raton, FL

{PTs & OTs continued from Page 1}

In the workshop, the PTs and OTs will learn about the physical and emotional factors related to polio and post-polio syndrome, how to work with us by addressing our specific needs and our limitations, and about bracing and assistive devices and their implications for polio survivors.

You can help publicize the workshop by passing the word about it to PTs and OTs that you know and any you meet. Have them contact Dr. Marny Eulberg, 303) 829-1538, marnyeul@me.com for more information. Thank you for spreading the word!



William passed away in 2018.

692 people with disabilities will be helped because William included a bequest to Easterseals Colorado in his will.

Thanks to William, we are changing the way the world defines and views disabilities by making positive differences in people's lives every day. Include your favorite cause in your will or estate plan. Make a difference in the lives that follow.



We hope you'll become a member of the Legacy Society, a special group of people showing extraordinary generosity by naming Easterseals Colorado as a beneficiary in their will, living trust, life insurance policy, pension plan or charitable trust. For more information, please contact Sharon Brown at 303.233.1666 x266 or sbrown@eastersealscolorado.org.

Colorado Post-Polio Resources

The websites and organizations listed below have been recommended by polio survivors. Colorado Post-Polio and Easterseals Colorado do not have a process to certify the credentials/qualifications of anyone listed on the resource list.

Colorado Post-Polio Organization/Easterseals Colorado Resources

Post-Polio Connections Newsletter—Free quarterly newsletter containing polio related articles, resources and activities in Colorado. Contact Kris Lindsey (303) 233-1666 ext. 226, klindsey@eastersealscolorado.org to get on the mailing list or to change contact information.

Support Groups—currently active—Aurora, Colorado Springs, Grand Junction, Lakewood, Thornton/North Denver Metro Area, Ft. Collins, Pueblo. Meeting information in the Connections newsletter. For assistance and information to start a new group, contact Sue Brandon Sue.Brandon@q.com

Post-Polio Library—free lending library of polio related books and videos. Will be mailed free throughout the state. Contact Kris Lindsey (303) 233-1666 ext. 226, klindsey@eastersealscolorado.org

CPPO Durable Medical Equipment Fund—provides up to \$1,000 supplement toward the purchase of durable medical equipment to polio survivors in Colorado. For an application, contact Kris Lindsey (303) 233-1666 ext. 226, klindsey@eastersealscolorado.org.

Educational Meetings—at selected sites throughout Colorado. One-half to full day meetings for polio survivors and their guests to provide an opportunity to connect with other polio survivors and to listen to speakers on selected topics. Notification of times and locations are published through the Colorado Post-Polio mailing list and the Connections newsletter.

Colorado Post-Polio Rocky Mountain Getaway—Four nights, three days camp held at the Easterseals Rocky Mountain Village, an all handicapped accessible camping facility in Empire, Colorado. Hiking, swimming, fishing, climbing, zip line, evening entertainment, lectures, group activities, breakout sessions and connections with other polio survivors from throughout the country. The next camp is scheduled for August 2020. Notification through the Colorado Post-Polio mailing list and the Connections newsletter.

CPPO Traveling Clinic—Dr. Marny Eulberg, of the Mountain and Plains Post-Polio Clinic and her team will travel throughout Colorado to evaluate polio survivors and make recommendations. Locations are selected each summer for clinic visits. The team are volunteers. Free—recommend donation the Colorado Post-Polio/Easterseals Colorado. Contact Dr. Eulberg, (303)829-1538, marnyeul@me.com for further information.

Resource Book of Articles Related to Polio and Post-Polio Syndrome—Free—A collection of practical articles about polio issues including anesthesia, bracing, using assistive devices, aging with polio, and more. Contact Kris Lindsey (303) 233-1666 ext. 226, klindsey@eastersealscolorado.org

Other Resources

Mountain and Plains Post-Polio Clinic, Wheat Ridge, Colorado— Free polio evaluations and recommendations. Contact Dr. Marny Eulberg, (303) 892-1538, marnyeul@me.com

Outdoor Buddies—A non-profit volunteer organization that offers hunting and fishing programs for persons with disabilities. www.outdoorbuddies.org

Exploring Leg Bracing Options—A workbook that helps people who are considering getting brace(s), either for the first time or a replacement or upgrade so they can make decisions about getting the best brace for themselves. Human Gait Institute. www.humangaitinstitute.org

Websites

Post-Polio Health International—Information and articles, resources, the latest research on polio and post-polio syndrome. www.post-polio.org

Polio Place—Articles, stories, resources, videos related to polio and post-polio syndrome. www.polioplace.org

www.Coloradopolio.org—Centralized information website relevant to Colorado. Also offers connections to other great polio support sites and resources.

The Human Gait Institute (HGI)—Consumer information about acquiring and using leg braces. www.humangaitinstitute.org

Celebrating Our Founder

This June marks the 30th anniversary of the death of PHI's founder, Virginia "Gini" Grace Wilson Laurie. Sometimes referred to as the "grandmother of the independent living movement," Gini worked tirelessly for more than three decades as she campaigned against the institutionalization of people with disabilities, and for the rehabilitation and personal assistance services that would make an empowered life possible for them in their communities. Gini worked to develop international networks of polio survivors and other people with physical disabilities, healthcare professionals in the field of rehabilitation, policymakers and disability rights activists. To read more about the impact Gini Laurie had on the lives of the people she knew and how she changed disability in this world, visit www.postpolioplace.org. Newsletter Spring 2019 Volume 35 Number 2

Training
PT & OT Professionals
October 19
8:30am – 4:00pm
Regis University

Executive Committee Meetings

Easterseals Colorado
393 S. Harlan St., Ste. 250
Lakewood
4:00pm

September 16, December 16

Mobile Clinics

Contact Marny Eulberg
(303)829-1538

July 29 – August 23

Grand Junction & Montrose

September 4 – 6

Gunnison & Crested Butte

Contact Marny Eulberg
(303)829-1538

Educational Meetings

July 31 10:30am – 4:00pm
Western Slope

Center for Independence,
740 Gunnison Ave., Grand Jct.

August 10, 10am – 2:00pm
Colorado Springs

950 Academy Park Loop
Metro Denver

September 14, 10am – 2pm
5755 W. Alameda Ave., Lakewood

September 28
Ft. Collins

Time & Location TBD

Opportunity to Participate in Research Continued

A Multicenter, Multi-country Study of Immune Globulin Intravenous (Human) Flebogamma® 5% DIF is underway.

DePaul University researchers invite persons with ME, CFS, MS, lupus, cancer, post-polio syndrome or HIV to participate in a voluntary research study to determine which symptoms may be commonly experienced by individuals in multiple fatiguing illness groups, and which symptoms may be unique to each illness. Participation includes completion of a confidential online questionnaire, which takes approximately 45 minutes to complete.

Eligibility Criteria:

- Adults at least 18 years of age
- Must be able to read or speak English
- Have a diagnosis of multiple sclerosis, lupus erythematosus, cancer, myalgic encephalomyelitis, chronic fatigue syndrome, post-polio syndrome, or HIV.

If you are interested in participating, take the survey.

This survey is open to any English-speaking participant over the age of 18 with post-polio syndrome, regardless of location.

Our goal is to understand how the DePaul Symptom Questionnaire (DSQ; Jason et al., 2010), an instrument assessing frequency and severity of a variety of symptoms associated with chronic fatigue syndrome (CFS), can be used to differentiate post-polio syndrome and CFS as chronic conditions with differing symptomatology, given that both conditions do involve fatigue.

If you are interested in participating, follow this link to access the survey: <https://redcap.is.depaul.edu/surveys/?s=d9gSMwkGsW>

Pueblo Post-Polio Support Group

The Pueblo Post-Polio Support group will meet from 11am to 3pm on October 15 at Barkman Library, corner of Jerry Murphy and Bonforte Blvd. This is the same location at which we had our delightful, informative meeting, thanks to Marny Eulberg and Margaret Hinman, on May 23. The speaker on Natural Remedies for Post-Polio Pains and Problems, indicated as the main interest of those present, has yet to be identified. Please call Mary Leonard, Coordinator, 719-544-4789 for details; more info will be distributed after Labor Day, when speaker(s) are in place.

Sue Brandon, Chairperson	(763) 377-2287	Sue.Brandon@q.com
Marny Eulberg, MD, Medical Advisor	(303) 829-1538	marnyeul@me.com
Kris Lindsey, Easterseals Liaison	(303) 233-1666 x226	klindsey@eastersealscolorado.org
Pat Jenni	(303) 880-3581	patjenni@gmail.com

Colorado Post-Polio Support Group Schedules

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: Myrna Schmidt – (608) 790-5755 – myrnaschmidt1@yahoo.com

Colorado Springs – Meets 1st Saturday of each month, 10:00-noon, Sand Creek Division, C.S. Police Dept., 4125 Center Park Drive.

Contact: Hal Goldberg – (303) 212-0017 – halgoldberg@halgoldberg.net

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

Contact: Melanie McClanahan – (303) 638-3302 – melcoloradogirl@gmail.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

North Area – Meets 3rd Saturday of the month, 10:00 to Noon, Vibra Hospital Longs Peak Conference Room

Contact: Jill Eelkema – (720)675-9902 – jille@westerncarepartners.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 – October 15, 11am – 3pm, Barkman Library.

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



Thank you Nancy Hanson

After 28 years, Nancy Hanson, long-time Easterseals Colorado – Colorado Post-Polio liaison is retiring! Nancy and her husband are moving to Arizona. No more snow, lawn mowing and cold winters. Easterseals Colorado and those that we served have been blessed by Nancy’s heart and dedication.

If you would like to make a donation to support Colorado Post-Polio efforts. Please complete this form, detach and mail it to Kris Lindsey at Easterseals Colorado. To ensure 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 S. 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 change your mailing information, please contact: Kris Lindsey at Easterseals Colorado, at (303) 233-1666, ext. 226 or klindsey@eastersealscolorado.org