

Connections • Fall 2024 Newsletter

My goal is for every polio survivor and health professional in the world to become knowledgeable about post-polio sequelae.

-Richard L. Bruno

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Richard L. Bruno – November 19, 1954 – October 14, 2024

Richard L. Bruno, age 69, of Hackensack, New Jersey passed away on Monday, October 14, 2024. “For more than forty years, Dr. Richard L. Bruno studied and treated more than 7,000 polio survivors and is acknowledged as the world's leading expert on Post-Polio Sequelae (PPS).” Dr. Bruno investigations led to many discoveries including the following conclusions:

- “Exercise - an additional load on the reduced number of remaining, poliovirus-damaged neurons - was contraindicated in the treatment of PPS: ‘When patients were recovering from polio, we made them exercise their muscles and told them to ‘Use it or Lose it.’ Now it is just the opposite. The bywords are ‘Conserve to Preserve.’”
- “PPS was neither a disease nor related to a lingering poliovirus infection, but ‘is caused when nerves damaged earlier by the poliovirus become tired and overworked.’ ‘However, ALL OTHER diagnoses must be excluded before a diagnosis of PPS can be made.’”

More about Dr. Bruno’s published works, commentaries, and information about post-polio can be found at the following resources:

- Post-Polio Library on the International Centre for Polio Education, <http://polioinfo.com>.
- Facebook group - [Post-Polio Coffee House](#)
- Pennsylvania Polio Survivor’s Network [Bruno Bytes](#)
- www.Polionetwork.org, click on Professionals and select Richard L. Bruno, HD, PhD.

Sources: <http://www.postpolioinfo.com/bruno.php>; CPPO Summer 2019 newsletter.



Dr. Richard L. Bruno

Rocky Mountain Getaway Summary

The 2024 Colorado Post-Polio Retreat, August 9 – 13, was a wonderful time of fellowship, relaxation, education and crisp mountain air. Participants from Colorado and five other states had the opportunity to consult with a physical therapist, be advised by Dr. Eulberg, receive a massage and attended ten different education sessions.

Educational sessions included an emphasis on mental health, technology, senior law, and the inconvenience of incontinence. Attendees participated in camp crafts, made s'mores, experienced ziplining and were able to enjoy wheelchair accessible trails. Thanks to the generous support of Easterseals Colorado and donor-directed gifts that made this camp a fun tradition for many campers and a great experience for new participants.

CPPO hopes to continue to have a bi-annual camp.



NOTICE

No 2025 Camp.

Next camp will be in the fall of 2026.

Sharing Our Stories

-By Bonda Zeller, NCC

Sharing our stories can be an emotional journey that is worth the effort. Each polio survivor has a unique story and experiences. Some share their experiences openly and others privately. Trauma-Informed Storytelling is the process of learning to tell your story in a way that is safe and healthy for you and your audience.- Bonda Zeller, NCC

Trauma involves singular, multiple events, or chronic conditions that happen to one person or a group of people. Trauma can occur naturally or be human caused. The experience of trauma is done subconsciously and is defined by how one interprets or assigns meaning to the event(s). The effects of trauma events can have lasting effects on our functioning and well-being (mental, physical, social, emotional, spiritual).
*Adapted from SAMHSA Tip 57

When considering sharing your own stories, below is a link to a helpful guide shared by National Health Care for the Homeless Council [Trauma-Informed Storytelling](https://nhchc.org/wp-content/uploads/2019/08/trauma-informed-storytelling-1.pdf) <https://nhchc.org/wp-content/uploads/2019/08/trauma-informed-storytelling-1.pdf>.

Storytelling is a way to use personal experiences to talk about issues in a broader way. We can use our own stories to challenge assumptions, generalizations and stereotypes.



Image by [Ri Butov](#) from [Pixabay](#)

Stories create bridges between people and can build community. Individuals develop empathy and understanding as well as expand their perspectives when stories are told or heard. In addition, policies and resource allocation can become more effective when personal stories are used for positive influence.

In *Developing Your Story*, they recommend that you contextualize your experiences (when and where, the whys, consider the happenings of the time). Follow your own instincts and process so you can feel safe within yourself. Find humor if you can. Know your triggers or the most difficult sensory experiences, topics or parts of your story. Talking about your stories and experiences with friends or a provider before speaking publicly can help you work through the pain first. Know that it is fine to share a little bit at a time in different spaces to get comfortable.

Sharing Our Stories (Continued)

When Sharing your Story, they offer these suggestions:

Be aware of the possibility of re-traumatization: Know things that help you relax and use them. Be prepared for the unexpected as you may come upon a trigger that you didn't know you had. Use your supports as needed (friends, family, a mental health provider, your post-polio support group).

Have a "safe story": Some parts of our stories we may not have healed from or may not be comfortable talking about with certain audiences. Figure out if you can tell it differently to talk about it, or if you have to leave it out.

Consider the audience when choosing how to tell your story: We don't know who is in the audience and what may trigger them. We don't need to expose all the details to make our point. Choose your language carefully to control the message and emotions. If you are feeling emotional, check in with yourself. Is it safe for you to experience this emotion? If it is not, modify how you tell your story.

It is fine to take a break, breathe, and revisit your work later. They suggest that you focus on where you are now and how your story got you there to get through emotional moments. Find your strength in your story. You will feel stronger every time you tell your story. Use your strength in yourself and in knowing you are having an impact on others.

You can share your story with friends, family, your local Rotary club or other community groups, in schools, in a book or on stage. You can share your story through art, humor or privately in a journal. You can tell it in first person, third person, in poetry or in song. You can tell it for change or in protest. Express your story in the ways you are most comfortable.



These are a few sites where you can add your personal story from home:

*StoryCorps Archive <https://archive.storycorps.org/>

*Submit your artifact | Post Polio <https://polioplacement.org/history/artifacts/submission-information>.

Resources

- National Health Care for the Homeless Council [Trauma-Informed Storytelling https://nhchc.org/wp-content/uploads/2019/08/ti-storytelling-1.pdf](https://nhchc.org/wp-content/uploads/2019/08/ti-storytelling-1.pdf)

Sharing Our Stories (Continued)

- [The Healing Power of Telling Your Trauma Story | Psychology Today](https://www.psychologytoday.com/us/blog/think-act-be/201903/the-healing-power-telling-your-trauma-story)
<https://www.psychologytoday.com/us/blog/think-act-be/201903/the-healing-power-telling-your-trauma-story>.
- [Medical Trauma Exists, and It's More Common Than You Might Think](https://psychcentral.com/ptsd/medical-trauma)
<https://psychcentral.com/ptsd/medical-trauma>.
- The National Child Traumatic Stress Network: [Medical Trauma in Children Bonda Zeller, NCC, presented "Telling Your Stories" as the opening event at the 2024 CPPO Rocky Mountain Getaway Camp in Empire, CO in August.](#)

Bonda Zeller, NCC, presented "Telling Your Stories" as the opening event at the 2024 CPPO Rocky Mountain Getaway Camp in Empire, CO in August.



World Wide Polio Update

By Dr. Marny Eulberg, M.D.

For those of you who were around in the mid-1970s there, was a character on Saturday Night Live—Mr. Bill. And a famous recurring line was “Oh, No, Mr. Bill”. That was my response when I reviewed the updated October numbers of wild polio cases from Rotary International via WHO and Global Polio Eradication Initiative.

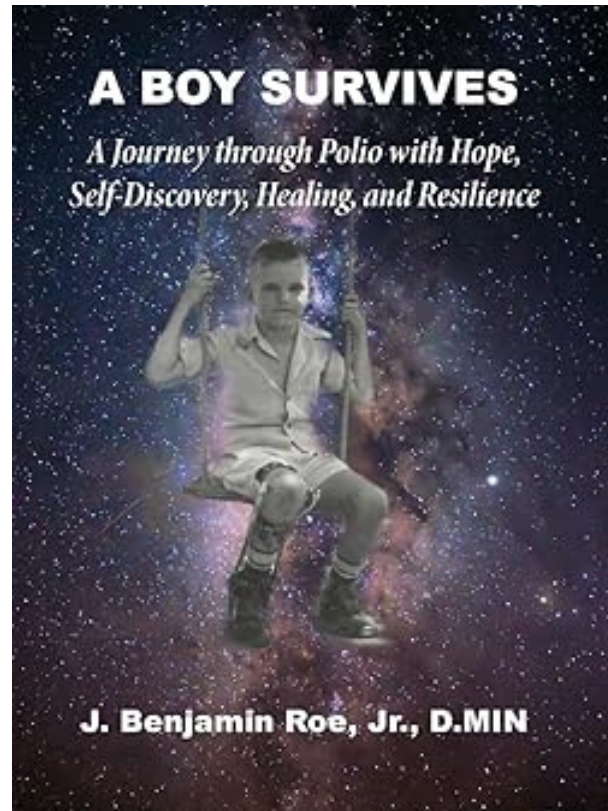
Six more cases of Wild Polio Variant 1 (WPV1) caused paralysis—three in Afghanistan and three in Pakistan! But only two cases of variant poliovirus caused—both in Democratic Republic of Congo. The number of cases caused by the variant polioviruses continue to be much lower than last year!

A Boy Survives, A Journey through Polio with Hope, Self-Discovery, Healing, and Resilience - By J. Benjamin Roe, Jr., D. Min.

Ben had polio as a two-and-a-half-year-old child in 1948 in Arkansas, spending months in hospitals isolated from his family during those very young years. The experience left him with a lifetime of trying to make sense of his life and his circumstances, including sexuality issues and where he fit into the world and in his family, but without having the emotional resources needed for doing so.

Not only has he had to deal with the trauma of the physical loss of function in a leg, arm and shoulder, but he has also spent a lifetime dealing with the emotional losses that occurred. Through stories and poetry, this memoir explores his emotional journey by recalling his life through the lenses of his polio experience, how it impacted his feelings of self-worth and how it guided his life decisions and where he is 75 years later.

This very personal story begins with the backdrop of medical treatment in isolation from family and the complete misunderstanding of the role of emotions in childhood development and the need to address those emotions. It explores how his life story has included dealing with the recovery from the trauma and by inference the developments in medicine to prevent and lessen its impact of the medical experience for children today.



"I found Ben's exploration of his experiences poignant and touching, tempered with information about how the medical experience for children has improved from the 1940s."

Dr. Marny Eulberg, M.D.

A Boy Survives is available on Amazon and at Barnes and Noble.

Food for Thought - Our Experiences

-By Margaret Hinman

Our experiences throughout our lifetimes impact who we are, how we deal with life and how we feel about ourselves. They are an array of ups and downs ranging from euphoric to traumatic and everything in between. The results of our experiences have made us who we are today.

We all have experienced multiple traumas in our lifetimes, some major, some not so. For those of us who are polio survivors, the trauma of having had polio can be significant, physically from the loss of part of our body functioning to the emotional impact of making sense out of that experience. It is a lifetime journey. It has colored how we see ourselves, how we interact with the world and the people who are in it, and the decisions we make. And we have had to address it in conjunction with subsequent experiences, often trying to make sense of what all of it means and often wishing that we didn't have that experience.



One way to address our polio experiences is by telling our stories. Telling our stories can take many forms. However, regardless of how we tell it, it needs to be done in a manner that is safe for our vulnerabilities and for those we tell, and only when and if we are ready to do so. How we do so can range from just telling people we encounter that we are polio survivors when their curiosity shows on their faces, to expressing it in music, like Neil Young and Joni Mitchell, to expressing who we are in our art, like Freida Kahlo, to writing a memoir, like Ben Roe; all polio survivors. We can choose who our audience is, from writing a personal journal, to talking with our family members, friends and others, to recording our thoughts, to teaching others, to sharing it in support groups, to addressing it with a trauma therapist

The result can be freeing and can bring some serenity, lessening the loneliness that comes with the isolation of feeling inadequate or feeling like we are the only persons who has lived that life, all the while acknowledging that the process itself is sometimes stressful and even painful.

Food for Thought - Our Experiences (Continued)

Regardless of whether you tell your story, how you tell it and to whom you tell it, remember that first and foremost you are a polio SURVIVOR, that you have accomplished feats in your life that defy conventional expectations and wisdom and also allow yourself to acknowledge that because of and in spite of that experience you are just a downright awesome person!



Margaret Hinman and friend.

Just some food for thought!



CPPO Statewide and Beyond Zoom Educational Meetings

Colorado Post-Polio's Statewide and Beyond Zoom Educational Meeting is open to all who wish to join from wherever your life takes you! Join CPPO November 30 from 10:30 – 12:30 MST. Preregistration is required.

Social & Introductions: 10:30 – 11:00 a.m. MST

Presentation "Well that is inconvenient – incontinence and bladder control": 11:00 a.m. – Noon MST

Questions: Noon – 12:30 p.m. MST

Registration: Contact Mitzi Tolman at mtolman@eastersealscolorado.org

Registration link:

https://us02web.zoom.us/meeting/register/tZ0sdOGqrzloG9C7HKLGnpS_nyk6OfekZFgk#/registration

Family Corner

-By Mitzi Tolman

Gift giving season will soon be upon us, so I thought I would highlight items that have been recommended and loved by others that have the late-term effects of polio and aging.

- Battery operated socks to help keep feet and legs warm.
- New soft, electric blanket for your favorite chair. The new ones are much nicer than the old scratchy ones of the past.
- Flowers or fruit delivery
- Puzzles
- Large print books or a subscription to an audio book service
- A service such as snow shoveling or lawn care. We live away from our loved one, but each year contract with a local youth from her church congregation or neighborhood to shovel the walks.

- Tickets to a play or accessible sporting event
- Upgrades to their home such as grab bars in bathroom, technology upgrades, or simple things like motion sensitive nightlights.
- Make and deliver a family favorite dish from their childhood.
- Find nostalgic candy, drinks or other gifts.
- A donation to a charity or organization they support.

The gift of time is one that I know all would appreciate. . .



Image by [Bruno](#) from [Pixabay](#)



CPPO Resource Book

Need more info? Check out CPPO's Resource Book of Articles Related to Polio and Post-Polio Syndrome.

<https://www.easterseals.com/co/shared-components/document-library/post-polio/july-22-resource-book.pdf>

Educating Your Medical Professionals

-By Margaret Hinman

A common concern among polio survivors is being able to connect with medical professionals who know about our polio and/or are willing to learn about it. We know that generally their polio education is inadequate or completely lacking, and that even if we provide them with written information many are reluctant to read it and, we often suspect that it goes in the circular file as soon as we leave their presence.



Image by Max from Pixabay

CPPO has developed a medical alert card, Medical Alert—the Late Effects of Polio and Aging, a comprehensive, brief, data-based summary that can be read in less than two minutes and discusses the basics of polio, what it is, what it does to the body, what to be aware of, and how to treat our polio. It has been developed to educate all medical professionals we encounter as well as educating polio survivors who carry the card, so during any discussion both the survivor and the

medical professional are on the same page. Having a conversation about our polio based on shared information allows us to be assured that we are getting the best care for whatever our other medical needs are with the polio concerns factored in.

It is printed on the last page of this newsletter to be copied and/or cut out and folded to the size of a business card that fits in a wallet, allowing us to have it with us at all times and allowing us to share it any time we meet new medical providers, whether they are doctors, nurses, PTs, orthotists, post-surgical rehab and assisted living personnel and beyond.

It is suggested that the polio survivor have the professional read it in his/her presence and return it so it can be used again and again. However, printing multiple copies and giving them to the professionals may be preferred.

The card has been road tested! And with great success!

I took a copy of the card with me to discuss it with my PCP at my annual physical and he read it, then we discussed its contents, zeroed in on several areas and had a good discussion about possible polio problems in the future.

Educating Your Medical Professionals (Continued)

Then, at my request he copied it into my chart so that it is in my records and others have access to it. I was surprised when he asked me if he could have the card, not necessarily because he has other polio patients but because he has patients who have other degenerative neural muscular difficulties and the information on the card might give him some guidance in working with them.



To replace this card or to get additional copies, download and print it from Easterseals Colorado's website at <http://www.easterseals.com/co/shared/components/document-library/post-polio/medical-alert-card.pdf> or request additional cards from mtolman@eastersealscolorado.org and offer a donation to defray mailing costs.



Input Needed for Upcoming Statewide and Beyond Zoom Educational Meetings

CPPO will have an educational session November 30, 2024 as well as be promoting other opportunities for people to join.

In 2025, this meeting may look a little different – CPPO encourages your input. Please let Mitzi know at mtolman@eastersealscolorado.org what you would like the meetings to focus on for 2025. Things to consider: regional in-person meetings, a large one-day statewide meeting, continuing quarterly Zoom meetings or moving to more specific Zoom meetings. CPPO is open to exploring all educational and community-building ideas. Then, keep an eye out for the 2025 winter newsletter when CPPO will announce its plans for its educational sessions.

Advisory Council Members

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Lois Tilley

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Advisory Council Meetings

Advisory Council Meetings are when planning takes place. Members are welcome to attend. **Meetings are held quarterly, the 4th Wednesday of the month at 4:30 p.m. via Zoom. If you are interested in attending, please let Mitzi know.**

2025 dates are: January 22, April 23, July 23, and October 22



Colorado Post-Polio Support Group Schedules

AURORA

Meets the 4th Thursday of every month from 11:00 a.m. to 12:30 p.m.

Meeting in-person at the New Hope Church, 17699 E. Hampden Ave.

Facilitator: Myrna Schmidt, 608.790.5755 or myrnaschmidt1@yahoo.com

COLORADO SPRINGS

Meets the 1st Wednesday of every month from 10:30 a.m. to 12:30 p.m.

Meeting in-person at the Colorado Springs Police Dept., 950 Academy Park Loop. Contact the facilitator for additional information.

Facilitator: Hal Goldberg, 303.212.0017 or halgoldberg@halgoldberg.net

DENVER NORTH

Meets the 3rd Saturday of every month from 10:00 a.m. to Noon.

Meeting via Zoom.

Facilitator: Jill Eelkema, LCSW, 720.675.9902 or jille@westerncarepartners.com

DENVER SOUTH

Meets the 1st Tuesday of every month from 11:00 a.m. to 12:45 p.m.

Meeting via Zoom. Contact the facilitator for the link.

Facilitator: Hal Goldberg, 303.212.0017 or halgoldberg@halgoldberg.net

GRAND JUNCTION

Contact Ron Carlson, 970.640.8052 or rpcarlson2@gmail.com for support and information.

No group meetings at this time.

NORTHERN COLORADO (Fort Collins)

Meets the 4th Saturday of every month from 10:00 a.m. to Noon

Facilitator: Peter Way, 970.460.6164 or NOCOPolio@gmail.com

PUEBLO

Contact Jill Eelkema, LCSW, 720.675.9902 or jille@westerncarepartners.com for support and information. No group meetings at this time.

ZOOM GROUP

Meeting via Zoom the 2nd Wednesday of every month from 2:00 p.m. to 4:00 p.m. PST / 3:00 p.m. to 5:00 p.m. MST / 4:00 p.m. to 6:00 p.m. CST and 5:00 p.m. to 7:00 p.m. EST.

Everyone is welcome to attend.

Facilitator: Jill Eelkema, LCSW, 720.675.9902 or jille@westerncarepartners.com

Join Zoom meeting at

<https://us02web.zoom.us/j/89008651033?pwd=TUZhVVpPc1hKOGJRTy9Bek8rZnppdz09>

Meeting ID: 890 0865 1033 | Passcode: 184185 | Phone number to call in: 719-359-4580

★ Donations

If you would like to donate to support Colorado Post-Polio efforts, **please complete this form, detach and mail it to Mitzi Tolman 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
 Attn: Mitzi Tolman
 393 S Harlan St, Suite 250
 Lakewood, CO 80226
 Memo line: POST-POLIO

Polio Medical Alert Card - cut along dotted line

Medical Alert—The Late Effects of Polio and Aging

Polio is a virus-caused neurological disorder that interrupts the nerve input to voluntary/skeletal muscles but does not affect sensation. Nerves and muscles that were impacted at the onset of polio have had to work harder and, in aging, continue to deteriorate leading to fatigue and increasing weakness.



Treatment of Post-Polio Syndrome includes lifestyle modifications and the use of assistive devices, including orthotic bracing and mobility devices. There is no proven cure or medication that will help.

Concerns may include swallowing difficulties, respiratory issues due to weakening of the respiratory muscles and the diaphragm, and/or some body placement positions, balance & stability and falling & broken bones in osteoporotic limbs.

Diagnosis and Treatment Considerations

- *Factor in/rule out other conditions that may have similar symptoms.
- *Critical—Manage/prevent neuromuscular fatigue—reduce activity frequency & intensity by pairing activity with rest when exercising, doing physical therapy and activities of daily living. Overuse and over stress causes neuron and muscle loss.
- *Some neuromuscular pain may be the result of poor body alignment.

*Factor in polio limitations when treating other conditions, including surgeries, and pre- and post-op recovery.
 *Discuss anesthesia options to allay polio survivors' fears of adverse affects, particularly those that effect the respiratory system.



Scan Code for More Info



Scan Code to Watch Video

**FREE MATTER FOR
BLIND OR DISABLED**



Colorado Post-Polio
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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 **Mitzi Tolman** at **720.940.9291** or email her at mtolman@eastersealscolorado.org, or write to: Easterseals Colorado, Attn: Mitzi Tolman - Colorado Post-Polio *Connections*, 393 S Harlan St, Suite 250, Lakewood, CO 80226.

If you prefer to receive this newsletter online or need to change your mailing information, please contact Mitzi Tolman at Easterseals Colorado at 720.940.9291 or mtolman@eastersealscolorado.org.