

Connections • Spring 2025 Newsletter

"It is in the shelter of each other that the people live." — Irish Proverb

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Food for Thought - Polio Support Groups - By Margaret Hinman

My first experience with a polio support group was a bust! I didn't fit. The group focused primarily on loss and grief and long, sad stories that I wasn't ready to hear. Although the participants looked like me and walked like me, I was not ready to be seen with other polio survivors in "large" numbers. I avoided polio support groups for the next 35 years. However, six years ago when a new group was restarted in my area, I joined to see if it would be a fit for me now, of course, on a temporary basis, and I have not missed a meeting since.



Like me, the support groups have matured. My group meets my needs, helping keep our grief and concerns in perspective and in sharing our joy and our solutions for our experiences. We learn about all aspects of physical and emotional health, often having guest speakers at meetings. We have become a community, caring for each other, laughing a lot, sometimes crying, sharing our success and failures.

When I joined the group, I was only going to go once or twice to help get it restarted and now it is one of the highlights of my month. Originally, we met in-person and then went to online Zoom during COVID. Now we have continued our Zoom meetings because we would miss our out-of-area friends.

Each CPPO support group is unique, meeting on-line or in-person or some combination of the venues. Each has set meeting times, usually once a month. Each varies in size from as few as seven members to more than 20. And each group chooses the topics befitting its members' needs. Some groups have been active almost from the beginning of CPPO, while some are more recently established.





Food for Thought - Polio Support Groups (continued)

But there are common characteristics across the groups. They meet the unique needs of polio survivors and their significant others, speak to our common concerns, and are emotionally and physically safe places where we can share our fears, achievements and joys. We support each other. We have developed lasting friendships. We look forward to getting together.

Polio groups meet throughout the state of Colorado: In Aurora, Colorado Springs, Denver North (on Zoom), Denver South, the Grand Junction area, Northern Colorado (Fort Collins), and Pueblo (occasionally). To join an already existing group, talk to the leaders of the groups listed in the newsletter to get a beginning sense of a correct fit and then visit the group to make sure. And it's okay to shop for the group that fits you best. If there are no support groups near you, contact Mitzi Tolman at

<u>mtolman@eastersealscolorado.org</u> to see if a new group can be formed. CPPO is willing to help establish new support groups throughout the state of Colorado.

Just some food for thought!

Solutions — For Butterfingers - By Edmund Gallegos

> My sister bought me a dustpan from the dollar store, the kind with a long handle. It is not only good for sweeping up a floor, but since I am always dropping things, I can push them into the dustpan and not have to bend down to pick it up. I wash it when I do dishes just in case I drop a cookie or some food (five minute rule). Also if someone uses a cane and drops a pill, you can wad up some masking tape, stick it on the end of the cane then pick it up.

My sister also sent me a flashlight that extends from about six inches to about 18 inches, it has a magnet on the end. I

> am always dropping spoons, keys and paperclips. Once again, this picks things up.

I wonder what my sister will send me next?



Food for Thought II - Thank You CPPO - By Margaret Hinman

CPPO, (Colorado Post-Polio Organization), was established in 1981. At that time, it provided three programs: our quarterly newsletter, namely *The Connections*, educational meetings/ conferences, and support groups. Led by volunteers (still the practice of CPPO), programming was funded by donations, an annual raffle of an Amish quilt and partially by attendee-paid educational meetings/conferences. For many years, CPPO operated on an annual budget of +/- \$2,000, sponsoring educational conferences only when funds allowed.

I attended a few events in its early years and eventually volunteered to be the newsletter editor when our founder and leader, Mary Ann Hamilton, retired. In 2010, CPPO became an ongoing recipient of the C.H. Bernklau Charitable Lead Trust from the estate of a Grand Junction area polio survivor. During 2017 - 2018, CPPO received a gift from the Harriet Weltman estate. Together these gifts have enabled CPPO to offer its services free or at significantly reduced costs to survivors. The trust and the estate gift opened the door for program expansion, allowing CPPO to help meet the unique needs of polio survivors primarily in Colorado. The programs selected were based on an assessment of what polio survivors now need and could find beneficial, as well as on what aging with polio involves. The programs include:

Publications

- Quarterly Connections newsletter,
- Resource book of articles addressing all of the aspects of living with polio and the late effects of polio (PPS), available on-line at eastersealscolorado.org, and
- A wallet sized card that states all of the medical issues related to polio, to be used by survivors to share with any and all medical providers to help guide in treatment.





Food for Thought II - Thank You CPPO (continued)

Direct Services

- The traveling clinic provides Colorado survivors, who cannot travel to the Mountains and Plains Polio Clinic in Wheat Ridge, with polio evaluations in their hometowns, and
- Durable medical equipment grants help survivors with the costs of quality-of-life-enhancing and maintaining equipment and furnishings.



Educational Opportunities

- Rocky Mountain Getaway summer camp, and
- Lending library.

Emotional and Educational Support Groups

 Seven different groups throughout the state meet either in person and/ or online. Notably, the online groups meet the needs of survivors and families internationally as well as their local members.

Opportunities on hold and being evaluated

- Annual conferences,
- Training workshops to help physical and occupational therapists better treat polio survivor, and
- Zoom educational meetings, which recognize that many of us now don't travel easily.

The trust and the estate incomes have ceased and CPPO anticipates that within the next three or four years it will have to disband, a reality which has been the fate of other groups around the country. At that rate, polio survivors in Colorado will outlive the organization! So, at this time, we are seeking financial support, including individual donations, in order to continue our services. Any financial help will be appreciated and well used. If you wish to contribute, contact Mitzi Tolman at mtolman@eastersealscolorado.org or send your donation/gift using the Donation Form on the last page of this newsletter to CPPO at Easterseals Colorado and be sure to indicate that it is designated for CPPO.

Thank you, CPPO, for the difference you have made in our lives!

Just some food for thought! And maybe some action!



Educational Opportunities about Late Effects of Polio available from Post-Polio Health International (PHI)

-By Marny Eulberg, M.D.

PHI, based in St. Louis, Missouri, has been providing education and advocacy for polio survivors since 1958, with many name changes along the way. The current name, Post-Polio Health International, was adopted in 2003. There is a corollary organization, named International Ventilator Users Network, specifically for persons who use some form of mechanical respiratory assistance.

Information is in the form of printed materials and video recordings. Many past lectures, including the Town Hall Series from 2023 and 2024, are available on the PHI website, <u>https://post-polio.</u> <u>org</u> on YouTube. In late 2023/early 2024, PHI began offering an "Ask the Doctor" program whereby polio survivors or those concerned about them could submit questions online and have one or more of PHI's Medical Advisory Committee's physicians answer their questions. In early 2025, PHI began offering once monthly online (Zoom) inperson "Ask the Doctor" sessions. Due to the popularity, PHI plans to offer this service through June 2025. Check the PHI website, you might need to use the "search" feature on the home page or call PHI (314) 534-0475 to get dates.

Dr. Eulberg hosted the Ask the Doctor session on February 20, and likely will do one more in late spring/early summer. You do need to be a member of PHI to participate in the in-person Ask the Doctor sessions, but not for asking questions and receiving answers via email.

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

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Polio and the Brain

A compilation of research on the neurological changes from those affected with the polio virus By: Aspen Tolman



Polio patients may face limitations in daily activities and memory loss due to brain damage from the virus. However, the brain is flexible and can change.

Keeping your brain healthy involves consistent challenges, like trying a new game, solving a crossword, learning a new skill, or taking a different route to work. These activities create new neural pathways and help improve brain function.

Bilateral research shows that you can strengthen a weaker limb by practicing a skill with the opposite limb. If Polio affected your left leg; practicing kicking with the right leg can help your left leg grow stronger.

Relevant Stuides

- 1.<u>Cerebellar remodelling decades after spinal</u> <u>cord insult: neuroplasticity in poliomyelitis</u> <u>survivors</u> by: Stacey Li Hi Shing, Aizuri Murad, Jasmin Lope, Orla Hardiman, and Peter Bede
- 2. <u>Early and late losses of motor units after</u> <u>poliomyelitis.</u> by: AJ McComas, C Quarlty, and RC Griggs
- 3.Lesions in the White Matter in Acute Poliomyelitis by: Irwin Feigin, M.D.
- 4.<u>Polioenchphalitis, Stress, and the Etiology</u> of <u>the Post-Polio Sequelae by</u>: Richard L Bruno, PhD, Nancy M Frick, MDiv, and Jesse Cohen, MD





Help CPPO Make a Difference

Dear Readers,

So why donate to Colorado Post Polio? Your donations, along with money that we have received from benefactors, make the wheels of the CPPO bus go round and round. Without your assistance, we couldn't publish the newsletter or provide support groups. The traveling clinics, where so many polio survivors in areas outside the Denver Metro area have received evaluations, wouldn't happen. And what about the Rocky Mountain Getaway?

The Advisory Council meetings are held quarterly, the 4th Wednesday of the month at 4:30 if you would like more information about the budget. If you are interested in attending, feel free to reach out to any of the Council members or contact Mitzi.

I know that each of you have a very personal reason for being a part of the CPPO community. I'm glad that we have able to be there for you. Any financial help will be greatly appreciated and well used.

Thank you,

Sue Brandon, CPPO Chairperson





2025 Advisory Council Members

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Lois Tilley

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🛖 2025 Advisory Council Meetings

Advisory Council meetings are when planning takes place. You 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: April 23, July 23 and October 22.



Colorado Post-Polio Support Group Schedules

CPPO encourages you to stay in touch with your facilitator so you are aware of any meeting changes. 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 <u>myrnaschmidt1@yahoo.com</u>

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: Fran Weitzel-Callan 719-460-4764 <u>franweitzel@comcast.net</u>

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 <u>jille@westerncarepartners.com</u>

DENVER SOUTH

Meets the 1st Tuesday of every month from 11:00 a.m. to 12:45 Meeting via Zoom. Contact <u>erubin85248@gmail.com</u> for the link or contact <u>mtolman@eastersealsocolorado.org</u>

GRAND JUNCTION

Contact Ron Carlson, 970.640.8052 or <u>rpcarlson2@gmail.com</u> 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 <u>NOCOPolio@gmail.com</u>

PUEBLO

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



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 <u>**"POST-POLIO" written in the memo line</u>**. Your contribution will be gratefully acknowledged. Thank you again!</u>

NAME:	 	
ADDRESS:	 	
CITY, STATE, ZIP:	 	
PHONE:	 	
E-MAIL:		

MAIL TO: Easterseals Colorado Attn: Mitzi Tolman 393 S Harlan St, Suite 250 Lakewood, CO 80226 <u>Memo line: POST-POLIO</u>

Colorado Post-Polio Colorado Post-Polio 393 S Harlan St, Suite 250 Lakewood, C0 80226

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FREE MATTER FOR BLIND OR DISABLED

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.