

Connections • Fall 2023 Newsletter

**YOLO - You only live once.
 Oxford Dictionary**

Do you see yourself in the pictures of this summer's campers in this newsletter?
 YOLO!
 Plan NOW to attend CPPO's next camp.

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CPPO Rocky Mountain Getaway 2023 Recap

Early August, comfortably cool weather, ideal camping! Three days meeting new friends, trying new experiences, and sharing our wisdom! 27 polio survivors and their significant others from Colorado, Texas, Washington, Oregon and Pennsylvania!



We spent our days engaged in interactive learning:

Living with a disability and how we cope; handling disagreement with passive, aggressive and passive/aggressive people in our lives; end of life decision making; using phone apps for a more accessible home. Thank you, Philip Yancey, Jill Eelkema, George Ho, Paul Snell!

Keeping your mind active by setting and achieving goals; memory loss: forgetfulness, friendship and forgiveness; emotional aging; energy conservation techniques. Thank you, Aspen Tollman, Kay M. Adams, Hal Goldberg, DeeAnn Vink!

Polio and managing fatigue and the role of protein in muscle preservation; sharing secrets of aging with polio; caregiving in families of polio survivors; falling safety and prevention. Thank you, Marny Eulberg and DeeAnn Vink, Bonda Zeller, Margaret Hinman, Lori Morgan!

Interspersed with individual experiences and activities:

Individual physical therapy sessions, individual massages, hearing evaluations, bird watching and photography, seeing a restored iron lung, swimming, archery, zipline, crafts, chair exercises, walking in a mountain environment.



And capped off the days with great evening entertainment:

Warren Floyd on the guitar with music of the 50s, 60s and 70s, John Reed Austin on the saxophone with great oldies, Debrah Wooten-Williams, comedian, sharing her humorous take on living with polio.

CPPO Rocky Mountain Getaway 2023 Recap (Continued)

We had fun, learned a lot, shared ourselves, laughed and sometimes cried, and went home feeling good about a fulfilling experience in the Rocky Mountains of Colorado!

What's next?

Think about joining us next time!



Solutions - For Living Better With Polio in the Winter Months

There is no cure for polio. We are not going to restore what our bodies have lost so we must be creative and use whatever tools, devices, and strategies we can find to help us live full, independent lives. Here are some that polio survivors have discovered and use:

Electric Socks--As many of you know, winter can be very difficult to endure as we struggle to ensure we have blood circulation through our affected body limbs. Trying to keep these body parts warm has always been a struggle and a challenge. How many times have you wished we could go out and enjoy time with family and friends, but don't because our legs and feet get so cold that it hurts to think about it?



Well, good news, we live in a day-in-age where technology has come a long way. One of those great inventions are electric socks.

There are so many affordable electric socks out in the market today that can keep you nice and toasty for many hours; some even can be controlled from your phone to ensure you have control of the heat! These socks are light and the batteries are so small that they fit in a nice side pocket on the sock itself.

Solutions - For Living Better with Polio (Cont.)

So start saying "Yes" to those invitations to go out for a stroll. Or if you just want to have them for home and stay warm and cozy. Let's take advantage of what technology has given us and let's stop suffering and saying "No" to being outside during winter. Let's keep the cold to just our drinks and a nice bowl of ice cream!

--Robert Burnett

Winter is coming upon us. Some survivors have shared solutions to **getting warm and staying warm:** have a lap blanket handy, and/or maybe an electric throw. Wear a scarf around your neck. An electric mattress warmer allows the heat to rise instead of an electric blanket. Use a heating pad to warm the bed or to wrap around the cold limb(s). Wear woolen clothing, particularly woolen socks, for example Smart Wool, which is warm, is washable and does not irritate.

And they have shared strategies for staying safe when that weather outside is cold, wet, snowy and icy:

Stay home during inclement weather. Use your phone or Zoom for meetings and tele-health appointments. Plan to go out before the weather comes based on the long-term weather forecasts, including stocking up on food. Order food on-line either for delivery or pick-up. Cancel and reschedule appointments and entertainment.

Let someone else get you there—Uber, Access-a-Ride, some cities (e.g., City of Westminster, CO) have free transport services for us. Park as close as you are able to your destination. Most medical facilities and doctors' offices will meet you at your car with a wheelchair and transport you inside if you call ahead and alert them you need the help. Use that power chair and van ramp or your power scooter.

To clear sidewalks and driveways, hire help or enlist friends and neighbors to do it, and if needed, provide the snowblower or plow for them to use. If you can clear snow safely yourself, use a lightweight snowblower and clean frequently, rather than waiting for the end of the weather.

Use assistive devices such as canes and crutches or trekking poles, adding ice tips (\$10). Place Yak Tracks, cleats, essentially tire chains, on your shoes.



Modify your gait—If you must be out, walk flat-footed with the toes turning out, taking shorter steps.

Upside Down Polio -By Marny Eulberg, MD

Polio survivors with the majority of their muscle weakness in their upper body have sometimes been called “upside down polios.” This term is based on the fact that the majority of observable weakness and atrophy in most polio survivors is in the lower part of their bodies. Therefore, if a person has the reverse, with most of their weakness/atrophy in their shoulders, arms, and/or hand, it is “upside down” from what is usually observed.

The muscle atrophy in the upper extremity may not be obvious to the casual observer as it is in people with atrophy/weakness of legs because the atrophy can often be hidden under clothing such as keeping a polio affected hand in a pocket most of the time. Weakness, since it does not result in a limp, may also go unnoticed by an acquaintance and may take close observation in order to notice that these polio survivors perform daily tasks differently, such as using two hands to lift a glass or mug up to their mouth or use some different movements to put on/take off a coat/sweater. If the weakness involves a person’s right hand, they may choose to “shake hands” using their left hand or use other movements (nodding their head, a slight wave) to convey a greeting.

Polio survivors with marked weakness of both arms may need someone to feed them, dress them, and perform many activities of daily living. Some who had polio at a young age may have learned to use their feet to do many of the tasks that others normally do with their hands/arms such as writing, peeling vegetables, and even doing artwork; others do tasks using their mouth such as using a mouth stick to type, writing, and painting.

Individuals with upper extremity weakness are more likely than those with lower extremity weakness to have some respiratory muscle weakness because some of the same nerves that control the arms also control the diaphragm.

I have known two wonderful people who were “upside down polios”— the late Mary Ann Hamilton who started the polio support groups and organization in Colorado and the late Larry Becker who was the president of PHI for several years. Both had essentially no use of their arms and had significant respiratory compromise. Mary Ann typed the newsletter for many years striking the typewriter keys with a stick she held in her mouth.

Upside Down Polio (Continued)

She was very happy when computers came upon the scene because the “touch” required to make a letter appear on the document was much less. Larry had a brilliant mind, earned a Ph.D. in philosophy, and taught at the college level for many years.

Persons who have had significant lower extremity weakness and have used their arms to assist with many activities that require leg strength are quite likely to develop overuse problems in their shoulders, elbows, and/or wrists. Upper extremities were not designed to be used for long-term walking! This may be temporary after a particular period of overuse or can become chronic. It can be tendonitis, bursitis, wear-and-tear arthritis, or a tear of various tendons/muscles such as rotator cuff tears or biceps muscle rupture, etc.

All of these can initially result in pain which then can lead to weakness because if it hurts to perform certain motions, people stop doing that motion or severely limit the use of muscles that effect that motion. Bottom line: Even if a person’s initial polio primarily affected their legs, it is likely that over time they are at risk of developing some overuse symptoms in their upper body that can limit their use of their upper extremities.

Over the past few years, I began to have pain in my shoulders (right greater than left) that limits my ability to perform certain activities such as putting on or taking off certain clothing like sweatshirts, jackets, and blouses/shirts. After watching some polio survivors with upper body weakness, I learned that I could still do those activities with little or no pain, if I used techniques that those “upside down polios” used.

Paulette Bergounous, a polio survivor with little functional use of one hand/arm, has reported that many of the people accessing her blog and videos are previously able-bodied people that now are scheduled for shoulder surgery that will require little or no use of one arm for several weeks to months.

As in many aspects of aging, there are many useful tricks and techniques that can be learned from polio survivors and used as we develop some of the limitations of a long life.



Dr. Marny Eulberg

When Is It Time to Hang Up Your Car Keys?

It Is Time!

How do you know when it is time to
"hang up the car keys"?
I say when your dog has this look on his face!
A picture is worth a thousand words!



I bet you will send this one on
It made me smile too!

I hope that it doesn't take your dog or your passengers to have this look on their faces before you consider whether you should continue to drive!

Driving, for many of us, provides a world of independence, but likely there will come a time when it is no longer safe, prudent, or cost effective to own a vehicle and drive. I'd hope that it does not take a family member taking away your keys or the authorities taking away your license, but if they do, it is out of concern for your safety and for the safety of others.

Most of us who contracted polio in the developed world are now 65 years or older and many of us are octogenarians!

One of my friends who never had polio, was a nun. The religious order she belonged to required that all nuns over age 80 who were insured drivers using the order's vehicles have a formal driving assessment and she fiercely fought the process. She may have secretly known the outcome because the testing showed her reaction time and problem-solving abilities were significantly impaired.

Here are a few warning signs of unsafe driving:

- Delayed response to unexpected situations.
- Becoming easily distracted while driving.
- Decrease in confidence while driving.
- Having difficulty moving into or maintaining the correct lane of traffic.
- Hitting curbs when making right turns or backing up.
- Paint scrapes from getting too close to obstacles.
- Needing to use your hand to lift your foot onto or off the brake or accelerator.

When Is It Time to Hang Up Your Car Keys? (Continued)

Or you can answer these questions below for yourself using this National Aging and Disability Transportation Center’s checklist. More than 2 to 3 “yes” answers should make you seriously consider looking into an adaptive driving evaluation or giving up your keys.

- Other drivers honk at me.
- Busy intersections bother me.
- I avoid left-hand turns.
- Other cars seem to appear out of nowhere & drive too fast.
- I have been stopped by the police recently for driving.
- Turning the steering wheel is difficult for me. Tip: There may be some fixes for this!
- I’ve had more “near misses” lately.
- I have trouble seeing street signs in time to respond to them. Tip: Get an eye exam!
- I have recently caused a car accident or fender bender.
- I get confused or lost in familiar places.
- It’s hard for me to look over my shoulder when I’m backing up or changing lanes. Tip: Some technology in newer cars may be able to help with your visual field in these circumstances.
- My friends and family tell me they’re worried about my driving or that they are afraid to ride with me when I’m driving.

The AARP Driving Program, in person or online, now includes information on how to know when you should consider stopping driving and how to access alternative transportation options.

There are specially certified driver rehabilitation specialists or adaptive driving specialists, but they may not be available in less populated areas. These specialists often have driving simulators that allow them to simulate driving situations without any danger to you or anyone else. Many driver rehab specialists have an occupational therapy background. Health insurance may cover part of the cost, but this may also not be a covered service.



Many companies that install adaptive driving aids, such as hand controls, require that you have a driving assessment by a driver rehab specialist and any necessary training using the device so that you can safely drive using the adaptive equipment before they will install the adaptive driving aid.

Food for Thought – Being a Weather Hostage

-By Margaret Hinman

I don't like being held hostage to weather forecasts. This past year's winter months in Colorado were especially limiting in terms of allowing me to get out to take care of my needs and stay safe. Now, as a retired person, I do not need to navigate the icy, wet streets and sidewalks to get to work, a cause of great risk and anxiety during my working years. Instead, I live my life based on the weather forecasts, both long-term and hourly, and cancel or change everything from medical appointments to entertainment dates to missing holiday events with my family to seeing friends and to getting groceries.



I don't need to feel like I am being held hostage by the weather. I could move to a different climate, but my home is in Colorado where I have friends and family, nearby amenities, and access to a good medical community.

I could move into a senior community where my needs are addressed on-site, but I enjoy my comfortable home that has the accessible features which have helped maintain my independence. I can only hope that the weather this past year has been unusual, and this year will be more handicapped friendly!

By following the weather forecasts, I can make sure I always have necessities, such as food and daily supplies at hand and can change scheduled outings to a more weather friendly date.

I can make use of the resources that are available which will keep me safe and reduce my anxiety in bad weather. This includes ordering groceries either on-line or by phone and having grocery stores do my shopping, then picking the groceries up or having them delivered to my home. I like to select my own fresh fruits, vegetables and meats and my grocery store will deliver an electric shopping cart to my car if I ask. And, of course, most of us have able-bodied family, friends and/or neighbors who will pick stuff up for us.

If there is no other option but to go out, particularly for medical appointments, I have someone at the facility meet me at my car with a wheelchair and wheel me in.

Food for Thought – Being a Weather Hostage (Continued)

Also, some cities and health insurance plans provide a senior shuttle service to doctor and hospital appointments.

And, if I need other things right away, I can rely on the modern-day equivalent of the Sears & Roebuck catalogue by using the on-line services of Amazon, Costco, Walmart, Target and many other stores without risking health and safety and yet giving me everything I need.

Those strategies don't mean that I LIKE being held hostage to the weather forecasts any better, and that I won't get cranky when bad weather hits and I am homebound.

However, checking the weather forecasts is a habit that I won't break. When the weather gets bad, I just curl up in front of my fireplace and enjoy good book!

Just some food for thought!



Margaret Hinman is a retired middle school counselor, a CPPO board member and a polio survivor. She is a long term and frequent contributor to the Connections newsletter.

Working to Eradicate Polio

- World Polio Day provides an opportunity to highlight global efforts toward a polio-free world and honor the tireless contributions of those on the frontlines in the fight to eradicate polio from every corner of the globe. Celebrated on October 24, it honors Dr. Jonas Salk's birthday even though his actual birthday is October 28.
- As of July 1, 2023, Marny Eulberg has become one of two End Polio Now Coordinators for Rotary International's Big West zones that covers the entire Western United States from Colorado to Hawaii.
- Rotary has contributed more than \$2.6 billion to fight polio, including matching funds from the Gates Foundation, and countless volunteer hours since launching its polio eradication program, PolioPlus, in 1985. Find out information about Rotary Club(s) in your area by going to www.Rotary.org and clicking on "Club Finder" or contact me.

Family Corner - Working as a Family to Determine Long-Term Care

As my parents age, my siblings and I have started to think more about their long-term plan. Many times these discussions are done within our sibling group and although we think we might have all the answers, including our parents in the discussion would be more beneficial. Moreover, as you age, do not fool yourself into thinking that your family is not already thinking about how to keep you safe and happy as you grow older.

Discussion is the key to understanding. To get the narrative started, below are important living situation questions to ask.

- Do you want to live in your house for as long as possible? Are there things we need to do to your house so it's safe and comfortable for you as you age? Can we make some of those changes now?
- Are you willing to move into a smaller place that's easier to manage, like a condo? When?
- Have either of you thought about whether you would want to stay in the house if you were alone?
- Would you be willing to hire someone to help you at home if you can't do it on your own anymore?

- Would you consider moving in with me or one of my siblings if we all agree that you need help with your personal care or aren't safe at home alone anymore?
- How do you feel about moving into an assisted-living facility? Can I help you scout out quality assisted-living facilities and nursing homes now, so we know what's available and what you would prefer in case you need one in the future?



★ *CPPO Statewide and Beyond Zoom Educational Meetings*

Colorado Post-Polio hosts educational meetings via Zoom. Meetings are open to all who wish to join from wherever your life takes you! Meetings are offered quarterly on the 5th Saturdays of the year. Join CPPO December 30 from 10:30 – 12:30 MST. Preregistration is required.

- Social: 10:30 – 11:00 a.m. MST
- Presentation: 11:00 a.m. – Noon MST
 - Topic: “ Yes, you can still travel and enjoy it”. Tips and tricks by Peter Way.
- Questions: Noon – 12:30 p.m. MST

Registration: Contact Mitzi Tolman at mtolman@eastersealscolorado.org

Registration link:

[https:// zoom.us/meeting/register/tZ0sdOGqrzloG9C7HKLGnpS_nyk6OfekZFgk](https://zoom.us/meeting/register/tZ0sdOGqrzloG9C7HKLGnpS_nyk6OfekZFgk)

2023 Dates: December 30

2024 Dates: March 30, June 29, August 31, November 30



2023 Advisory Council Members

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2023 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.**

2023 dates: October 25

2024 dates: January 25, April 25, July 25, October 24



Colorado Post-Polio Support Group Schedules

CPPO encourages you to stay in touch with your facilitator so you are aware of any changes to group meetings.

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. *Members outside the North area are welcome to attend.*

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

GRAND JUNCTION

Meets 3rd Wednesday of every month at the Hilltop Family Resource Center at 1129 Colorado Ave in Grand Junction from 1:00 p.m. to 3:00 p.m.

Facilitator: Ron Carlson, 970.640.8052 or rpcarlson2@gmail.com

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

On hold until completion of Library remodel. Contact Jill with questions and concerns or feel free to join any of the zoom groups.

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

SOUTH DENVER

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

 **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

FREE MATTER FOR
BLIND OR DISABLED



Colorado Post-Polio
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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.