

# **Connections** • Winter 2024 Newsletter

# **CPPO to Host Camp Two Years in a Row**

Save the Date CPPO Rocky Mountain Retreat August 9 – 12, 2024 Empire, Colorado

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# Close, But No Cigar Yet - Status of Efforts to Eradicate Polio -By Marny Eulberg, MD

As 2023 began, many had hoped that this would be the year the world would see its last case of paralysis caused by the wild polio-virus, but as of December 26, 2023, there have been twelve children confirmed to have paralysis resulting from infection with wild poliovirus type 1. There have been six cases each in Afghanistan and Pakistan-all in a relatively confined area along the border between the two countries. The most recent case, which was in Pakistan, had an onset date of October 24, 2023. See the table the table on the next page for how this compares to the past few years. It is still possible that one or two more cases might be reported since the confirmation process can take a few months.

For the World Health Organization (WHO) to declare the world polio free, there must be no confirmed cases of poliovirus infection AND no positive environmental samples for the wild poliovirus for three years. In countries that have had cases of polio infections, environmental samples are routinely taken from sewage and from water supplies and tested for poliovirus. This is because wild poliovirus or the variant polioviruses that can be excreted by persons who have recently been immunized with the oral polio vaccine.

Persons paralyzed by the variant polioviruses (previously called circulating vaccine-derived polio-viruses) are just as paralyzed as those whose paralysis was caused by wild polio-virus.

So far attributed to 2023, there have been 430 individuals paralyzed by variant polio viruses (all except one caused by variant poliovirus type 2 and type 1). This compares to 577 at this same time in 2022, with a total of 877 for the entire year of 2022. The 300 additional cases, obviously, did not all happen in the last 5 days of 2022, but reflect delays in confirming that variant polio was indeed the cause of the child's paralysis. In past years, cases continued to be reported several months into the following year, but experts expect that total cases for 2023 will be down about 15-20% from 2022. This is due to use of nearly one billion (1,000,000,000) doses of a reformulated oral polio vaccine type 2 (novel OPV2 or nOPV2) which is much less likely to revert to a form that can cause paralysis after it circulates in the environment for several weeks to months.



## Close, but No Cigar Yet (Continued)

Type of Wild Poliovirus Case	2023	2022	2021	2020	2019
WPV (Wild Poliovirus) Total cases	12	30	6	140	176
WPV-Afghanistan	6	2	4	56	29
WPV-Pakistan	6	20	1	84	147
WPV- Other countries	0	8	1	0	0
cVDPV circulating vaccine-derived poliovirus cases	430	877	699	1117	378

I am still hopeful that polio will be only the second human infectious disease ever wiped off the face of the earth and that it will happen in my lifetime! I base that on the facts that in 2022 there were seven different strains of wild poliovirus type 1 causing disease in Afghanistan and Pakistan, but now it is only one strain of that virus; and that the variant poliovirus cases have been in 21 countries in 2023 compared to 26 countries in 2022.

You are all invited to a huge party when the WHO does declare the world poliofree!!





## Travels with PPS

-By Peter Way

My wife Frances and I both had overseas living experiences while growing up, and that developed our enjoyment of foreign travel. My early years in Venezuela, followed by residencies in Brazil, France and Germany, contributed to this passion. It helps that our son and family with three boys lived in Japan and my eldest daughter and family reside in England with four girls.



Aside from our international trips, family obligations demanded frequent round trips between Florida, New Jersey and Connecticut, totaling 21 trips since 2010.

Travel inconveniences seemed trivial for many years. In my 30s, I even managed to visit my future wife while she was working in England, despite a sprained ankle and only my trusty canes—why worry, right?

Polio rendered my quads unusable, so I depended on a robust core, arms, and glutes. Although my ankles remained strong, aging into my late 60s brought a gradual weakening of my overall strength – especially the glutes, making activities like rising from the ground challenging. My arms, once reliable, have become rather vocal complainers. Nevertheless, I feel blessed to have participated in various individual sports without bracing. I need to budget my energy every day but consistently run a deficit. (Could a financial planner help?)

As I have had to manage energy more, travel has changed quite a bit in amount and type. Recently I had a major tipping point, where something that used to work no longer did.

Encountering several such instances over the years forced me to acknowledge new realities, where denial (a favorite strategy) was no longer an option. During a Thanksgiving trip to Florida in 2021, treatment for an allergy with steroids rendered me virtually unable to walk. Upon returning home, dragging luggage from baggage claim to the car seemed an insurmountable task.



## Travels with PPS (Continued)

I swiftly decided to consider a scooter, as we were planning to return for Christmas, Margaret Hinman had shown me her TravelScoot and it quickly became the right solution for me. There was a moment of embarrassment as I used a scooter. All it took was one breezy scoot through DIA to put a grin on my face. I was also much less tired at the end of the journey.



The most important learning was: At some point, passive devices like canes, braces, rollators, are not as effective as getting help from a device that supplies energy. Some devices like rollators offer more efficiency and a place to sit and rest, However, they substitute energy provided by other parts of the body that then get weaker or more painful. Our guide is: how long does it take you to recover from an activity? If it's more than a couple of hours, change is needed.

### **Travel Tips**

If you can, spend more money to conserve energy. Travel in off-peak periods, book further ahead, redefine holidays with family before or after the rush. Always, always fly direct if possible. Arrive at the airport two hours ahead. TSA pre-check is a must at \$78 for five years. Most often they let you scoot through a gate with a manual check rather than walking through the machines.

Prioritize convenient ground transportation like automatic rental cars or ride shares over subways or trains. Before international travel, review accessibility options online. Mind the gaps on trains.



Identify flight comfort essentials. For me, it's a carry-on fitting under the seat, serving as a leg rest during the flight. I choose aisle seats nearer to the rear for easier restroom access. Remember that seats by transitions like exit rows or bathrooms don't recline.



## Travels with PPS (Continued)

Travel light – Weigh and minimize bag contents, consider a phone or tablet over a computer. I carry inflatable pillows for the seat, back, and headrest that collapse into minimal space. I still mask up at airports since friends have returned from trips with COVID.

#### **Scooter**

While a travel scooter excels in light weight, portability and maneuverability through tight spaces, four-wheel scooters offer better stability. Consider the overall utility, including fitting in cars/buses and lifting over steps or into vehicles. I prefer the scooter to wheelchair services at airports for its freedom and reliability. Wheelchair assistant availability can be uncertain, potentially jeopardizing your flight.

When traveling with a scooter, allocate extra time at the gate for battery tag issuance, avoiding last-minute lines. Check the scooter directly at the end of the jetway with strollers, but never pack it in a bag as it might be broken. Label each detachable part with a name and phone number to prevent separation.

Most of us with PPS are on our own special plan – therefore, we need to adapt solutions to our own needs. Able bodied "experts" can only give us options – we need to remain firmly in charge. I hope these tips enhance your travel experiences and encourage adventures you thought were beyond reach.



Peter Way is the facilitator for CPPO's Northern Colorado Group. At the December 30th statewide meeting, he shared his experience with extensive United States and world travel. If you would like to watch his talk, please follow the link below.

https://us02web.zoom.us/rec/share/F 6D4PTnVoDotGijTCyV0U2AsaqLQgs1U GUHOSIMy3neQnB22syWWa-67CVEt41t.L--jv0lbYYHUfPrW? startTime=1703955547000

Passcode: LWe4vQ3+



# Family Corner - Travel -By Mitzi Tolman

Traveling with my mother has given me so many memories, but as her post-polio syndrome has caused more fatigue, I have felt that taking her on trips lately was actually a burden for her. It is getting harder for her to "keep up" with us and she doesn't want to slow us down. We never want her to feel unwelcome or not part of the group.

This fall I decided that we would go on a trip to see my daughter in Florida and that Grandma needed to come to see her in her college environment. It took a little extra planning, but the memories made as family were worth the effort. We had so much fun together!



The first difference in this trip was the purchase of a travel scooter. Although my mother is still mobile, it is harder for her to walk long distances and she tires easily.

A trip that included lots of walking on a college campus, two major airports, and days at the beach, Disney, and nature centers were not something we usually consider. But with a scooter, the agenda could stay the same!



# Things we learned on the maiden voyage with a scooter.

- -Airport was so much easier yes we had to bypass the escalators for elevators, but man, can you really zip along in the scooter.
- -Ask at check in for the tag for the scooter although we flew the same airline, at one airport they said to get it at the gate, at the next they told us we were supposed to have gotten it at check in.
- -A portable backup charger costs less and weighs less than an extra battery for the scooter. Plus it allowed us the flexibility to charge other devices if needed.



### Family Corner - Travel (Continued)

We were at Epcot for twelve hours and plugged in the scooter twice while we waited for a show to start and when taking a meal break. We tried both of these - and both worked great.



SinKeu 146Wh Portable Power Station Charger



SinKeu 88.8Wh|65Watts Portable Power Station Charger

The second thing we changed was our approach to beach day. By taking a small three-legged stool, it made it easier for her to get up and down and be able to enjoy the waves as well as the sand. I also did more research and found a beach that had close parking and had a bathroom nearby.

The day at the nature center had a few hiccups as the trails were not very well marked as far as which one had boardwalks or packed gravel. But the travel scooter kept right up with our fast-walking explorers.

## A couple final tips:

- Allow rest time we planned to be in early most nights and enjoyed watching the birds on our vacation rental's lake. Having a peaceful place to spend our evenings was amazing.
- Book a rental vehicle that isn't too low to the ground and has room for the scooter as well as luggage.
- Hotels with breakfasts or a vacation rental in which you can cook allow everyone to get up on their own time and start the day rested.

Small adjustments on everyone's part made this trip a joy and we look forward to many more!





# Food for Thought - Body Alignment -By Margaret Hinman



Image by Elanor Smith from Pixabay

"There was a crooked man, and he walked a crooked mile,
He found a crooked sixpence against a crooked stile,
He bought a crooked cat which caught a crooked mouse, And they all lived together

in a crooked little house."

- Mother Goose Rhymes

We have no way of knowing who this early poet is describing, but what are the chances that Mother Goose was talking about a man who had polio? Not that it matters who that crooked man was. However, we know that polio has left many of us with crooked bodies which impact our daily lives and can lead to increasing physical difficulties as we age.

Our moms knew best in telling us to stand up straight and have proper posture. According to the Mayo Clinic, "proper posture keeps our bones and joints in alignment, decreases abnormal wear on joint surfaces, reduces stress on ligaments holding the spinal joints together and allows your muscles to work more efficiently.

Good posture can also help prevent muscle strains, overuse disorders and back and muscle pain.

Our polio caused crookedness (poor posture and body alignment) that can impact every aspect of our lives, from our mobility to our breathing to how our clothes fit to living with pain. We are stuck with leg length differences, knee and ankle valgus (knock knees) or varus (bow legged), knee hyperextension, spinal scoliosis, muscle weaknesses on just one side, and other alignment conditions that can impact our standing and walking posture, our sitting posture and how we sleep at night.

However, we can control and remediate some of our body alignment issues, improve our functionality, maybe reduce or alleviate pain and improve our body image in the process. A properly aligned body makes us look more balanced, makes our clothes fit better, and helps us conserve our energy.

More than fifteen years ago, I was casted for a new brace. The orthotist built in compensation for a leg length difference and straightened my valgus and hyperextension



### Food for Thought - Travel (Continued)

When I stood during casting with those corrections, my body which had been out of alignment since I was 11 years old still instinctively "knew" that I was in alignment, and it felt wonderfully right.



Some strategies for improving body alignment include correcting leg length differences by putting a heel lift in the shoe of the shorter leg, building up the outer sole on the shoe, using an in-shoe custom orthotic, wearing a brace that has a built-in lift with an in-shoe heel lift, or any combination of these. A skilled orthotist can cast and build a custom brace that treats the knee, ankle and foot alignment and straighten the leg.

A physiatrist, or an orthopedic specialist that treats back issues can guide in the treatment options for scoliosis, including bracing. Weak neck muscles can be addressed with a neck brace, and it does not have to be that bulky foam collar.

Using canes, crutches and rollator walkers when walking can improve balance and straighten posture. When sitting, a folded towel or a pillow under that smaller butt-cheek will level the hips and straighten the sitting posture. Placing pillows between the knees for side sleepers, under the knees for back sleepers, and under the head and neck placed at a proper angle will prevent stress to the body while sleeping. These will help us age with less pain and maintain our energy.

Finally, most of us are now of the age when our peers have caught up with us in the use of assistive devices, so we fit in seamlessly with the aging population. This means that we can now publicly embrace what we need to do to reduce pain, improve our posture, and treat our body with the kindness it deserves without feeling out of the norm.

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.



# Solutions—Rocky Mountain Getaway 2023 Edition (Part 1)

-By Margaret Hinman

### Sharing Secrets of Aging Well with Polio

In one of the discussion groups at this past summer's camp, polio survivors had the opportunity to share their secrets for aging well with polio. Ideally, sharing those secrets would have covered all the aspects of aging well. Below are some of the secrets shared.

Everyone's goal is to continue doing things that they enjoy and finding creative ways to modify activities as needed. Often, they have had to change their point of view to accept that they are slower and sometimes weaker. They also value the need to live safely, and to budget time and energy to manage and prevent fatigue, one of the late effects of polio.

Most have modified their homes, have come to rely on assistive devices and have changed how they do the activities of daily living. How they have modified their home environment takes many forms. Some have installed hardwood and tile floors to make cleaning easier by using a stick broom or a robot vacuum cleaner. At the other end of the spectrum, some have installed carpeting throughout the house, including in the kitchen and the bathrooms, to prevent slipping and falling.

Some have modified the heights of furniture, counters, stoves, sinks, beds and toilets (by installing comfort height toilets or adding portable height extenders) so that they can transfer more easily into and out of furniture, transfer from furniture to a wheelchair or walker or work from a seated position in the kitchen.

One person put blocks under his furniture to increase the seat height so he can get in and out of the furniture more easily. Another invested in an electric recliner that raises to a height that allows her to go from sitting to standing with less effort as well as reclining to read, watch TV or take a nap. Seat height and having seats with arms became priorities when another person purchased new furniture.

Several installed floor-to-ceiling poles beside their beds and other furniture to hold onto and help them go from seated to standing and to transfer to and from a scooter. One person installed a three-tiered oversized lazy Susan on her counter to hold not only dishes but cooking supplies. Some recommended installing a bidet in the bathroom, either permanent or portable, to make personal cleaning easier.



## Solutions - Rocky Mountain Getaway 2023 Edition (Continued)



Many have strategically located grab bars throughout the house, not only in traditional places such as bathrooms, but also beside beds, on walls next to furniture and beside doors between rooms and inside and outside of the house, helpful particularly when there are steps to navigate. Stools of different heights, including adjustable height models, strategically placed throughout the house, particularly in the kitchen, allow people to sit at a comfortable height when working at counters and are often easier to get up and down from than standard height furniture.

One person designed his new home to fit his needs including benches in the showers, and a toilet wall mounted grabber with a combo toilet paper mount. And another had a half wall built in his house to allow him to hold onto as a second transfer point.



# **CPPO Statewide and Beyond Zoom Educational Meetings**

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 every 5th Saturday during the year. Join CPPO March 30 from 10:30 – 12:30 MST. Preregistration is required.

Social & Introductions: 10:30 – 11:00 a.m. MST Presentation (topics TBD): 11:00 a.m. – Noon MST

Questions: Noon – 12:30 p.m. MST

Registration: Contact Mitzi Tolman at <a href="mailto:mtolman@eastersealscolorado.org">mtolman@eastersealscolorado.org</a>

Registration link:

https://us02web.zoom.us/meeting/register/tZ0sd0GqrzloG9C7HKLGnpS\_nyk60feKZFgk#/

registration

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





## **2024 Advisory Council Members**

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Robert Burnett (Habla Español) 720.394.5500 robert.v.burnett@gmail.com

Lois Tilley 303.638.4192 loistilley@live.com



## **2024 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.

2024 dates: January 25, April 24, July 24, October 23





**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





# Colorado Post-Polio Support Group Schedules

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

#### **NEW - MID-WEEK SUPPORT GROUP - ZOOM**

Beginning January 2024, the new group will meet on: 2nd Wednesday of the 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

Meeting via Zoom. Members outside the area are welcome to attend.

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

Join Zoom Meeting at https://bit.ly/cpposupport

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

#### **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 <a href="myrnaschmidtl@yahoo.com">myrnaschmidtl@yahoo.com</a>

#### **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.

Facilitator: Hal Goldberg, 303.212.0017 or <a href="mailto:halgoldberg@halgoldberg.net">halgoldberg@halgoldberg.net</a>

#### **DENVER NORTH**

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

Meeting via Zoom. Contact the facilitator for the link.

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

Meeting via Zoom. Contact the facilitator for the link.

Facilitator: Hal Goldberg, 303.212.0017 or <a href="mailto:halgoldberg@halgoldberg.net">halgoldberg@halgoldberg.net</a>

#### **GRAND JUNCTION**

Meets the 3rd Wednesday of every month from 1:00 to 3:00 p.m.

Meeting in-person at Hilltop Family Resource Center, 1129 Colorado Avenue, Grand Junction

Facilitator: Ron Carlson, 970.640.8052 or <a href="mailto:rpcarlson2@gmail.com">rpcarlson2@gmail.com</a>

#### **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





# **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:	 	 
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#### **MAIL TO:**

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

it doesn't mean you can push me around!



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

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.