

Connections • Summer 2023 Newsletter

"The glory of gardening: hands in the dirt, head in the sun, heart with nature. To nurture a garden is to feed not just the body, but the soul."

– Alfred Austin

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CPPO Rocky Mountain Getaway 2023 Schedule

Colorado Post-Polio Rocky Mountain Getaway At Rocky Mountain Village Empire, Colorado August 6 — August 10, 2023			
SUNDAY 8 am — 6 pm	3:00 — Check-in begins — Fishing pond staffed	6:00 — Dinner	7:00 — Welcome, Meet & Greet CPPO Advisory Board
Monday — Wednesday	Breakfast 8:00, Lunch 12:00, Dinner 6:00	2 sessions in morning 1 session after lunch	3:00 — Evening
Thursday 8 am — 10 pm	Breakfast 8:00	Checkout by 11 am	Shuttle to airport departs by 10 am
One on One Sessions	General Sessions	Breakout Sessions	Afternoon Activities
Hearing Evaluations Karen Carpenter Homebuilders Lodge	Philip Yancey — Dislabled Letting go of Ordinary Things	Bonda Zeller, LPC — Raised by F - Sharing Your Story Through Your Family	wheelchair accessible) - Archery
Individual PT Sessions — Personal Massage	Kay Adams — Bedside Witness: Stories of Hope, Healing and Humanity — The many sides of memory loss	George Ho, MD — End of Life Planning Hal Goldberg — Emotional Aging Dr. Marny Eulberg — Polio Q&A Deann Vink, PT — Energy	Bird identification Resting Swimming pool Accessible Zip line Wildlife viewing
Physical Assessment with Dr. Marny Eulberg schedule times at check-in	Lori Morgan, MS, Paramedic — Trauma Outreach and Injury Prevention Specialist	Conservation Techniques Jill Eelkema, LCSW — Handling Disagreement/Family Conflict Aspen Tolman — Activities an Exploration of Keeping Your Mind Young	Live entertainment, wine and cheese provided each evening.

About the Getaway:

Rocky Mountain Village, in Empire Colorado, is just 40 minutes west of Denver. It is fully accessible. Paths and walkways are paved, wooden or packed gravel for easy wheelchair access and perfect for exploring. The dining hall serves three full meals a day and has been known to provide campers with warm chocolate chip cookies on occasion. Special dietary needs can be accommodated.

On-site lodging accommodations include a limited number of rooms with queen-sized beds, a limited number of rooms with a private bath, and shared rooms with use of lower bunk beds and shared baths. Electrical hook-ups on campus are available for RVs. Off-site lodging is convenient in nearby towns.

Looking forward to seeing you in August!



Food For Thought — The Stop Button - By Paul Snell

Stop! Remember the first time you had a portable CD player? You could walk down the street playing your music impressing almost everyone with your great taste in music and technology. Along with the music player came controls that allowed you to Play, Rewind, Fast Forward, Pause and Stop.

I see a similarity of these controls and my life living with post-polio syndrome. I must say that these days I have very little need for a Fast Forward control in my life although moving forward is still important to me. And Pause seems to be used most days. A quick pause and rest can be very helpful at least a couple of times a day. And a lot of tasks are made easier with a quick Rewind and do over.





Paul Snell and Rexi

So what about Stop? Several years ago before being diagnosed with PPS I was up on my roof doing my normal fall maintenance on my evaporative cooler. I had done that for many years. When I tried to get on the ladder to come down, my leg simply wouldn't work. I was honestly terrified and confused. I knew I had to either just force my leg around the ladder risking falling or call 911. Somehow, I managed to get both shaking legs on the ladder and made it down safely.

As soon as I reached the ground, I immediately hit the Stop button. I didn't know then what had happened but I made the decision to never go up there again. I haven't! The important thing was that I made that decision based simply on my desire to protect myself.



Food For Thought - The Stop Button (Continued)

I'm fairly certain that most people reading this have needed to press your Stop button. Simply put, we must make some changes in our lives to either live more safely or to make life easier/better with assistive devices or simple modifications. I've had to make several decisions since the day on the roof including the use of both mechanical (like a lift chair) and electronic (home devices controlled by my mobile phone) devices that make life easier and more pleasant. Most of those decisions started with a touch on the Stop button.

The only concern I have with all of this is that I need to keep control of my Stop button. This past year I've had several well intentioned people suggest to me that I hit my Stop button because I'm old and/or disabled. I've seen a couple of disabled friends give up a lot of life because someone else wants to control the Stop button. My object is to make life and my activities either safer, more accessible or more enjoyable. I try to keep that in mind as I make daily decisions. Maybe I should try Fast Forward just for fun!

Medicare to cover wheelchairs with power-seat elevation

The Centers for Medicare and Medicaid Services has said Medicare will cover some wheelchairs with power-seat elevation under the durable medical equipment benefit and will consider coverage of standing wheelchairs. For more information and to read the full story,

https://www.statnews.com/2023/06/05/cms-power-wheelchairs-seat-elevation-coverage/





Solutions - For Living Better with Polio

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:

Gardening—When you want to get your hands in the dirt, grow your own flowers and/or vegetables and you are no longer able to get down on the ground or bend over the rake and the hoe, or handle a shovel, consider either container gardening and/or gardening in raised beds. This allows you to have an accessible gardening experience anywhere you choose as containers and raised beds can be placed in your current garden, or on your patio, deck, balcony and/or your porch.



Accessibly to the space is key to a rewarding gardening experience. This means:

- 1. The height of the container or bed should be such that you can comfortably reach into the bed or container while sitting, either on a bench, a chair, or a mobility device such as a scooter or wheelchair. And for some, it may require a knee space under the bed.
- 2.The width of the bed or container should be such that you can reach the center of the bed if you have access all the way around the bed or to the far edge if you will access the bed from only one side. This allows you access to weeds and planting and harvesting your produce.
- 3.The area around the bed or container should be large enough that you can maneuver comfortably and easily in your chair. Accessible pathways, hallways, etc., need to be at least 30 inches wide, preferably 36 inches wide, and should have enough turning space to move in and out.



Solutions - For Living Better with Polio (Continued)

4. Container gardens and raised bed gardens require more frequent watering than traditional beds. This means good hose access, a maneuverable watering vessel, or soaker hoses/sprinklers that are easily accessible.

Colorado State University Extension www.ext.colostate.edu has fact sheets that can help you in planning and using your container garden or raised beds. These fact sheets are written specifically for Colorado growers, but the basic information is relevant to all. Extension universities in other states have the same information that are specific to them.



Two of these resources are:

Fact sheet #7.238, Container Gardens
 CMG Garden Notes #721, a Sample
 Planting Guide for Raised-Bed Gardens.



You can build your own raised beds or Home Depot, Lowes and garden centers have commercial options ranging in price from \$99 to \$2000.

Happy gardening!

Items, equipment, or strategies listed have been discovered by polio survivors, are not intended or used as advertisements and are not endorsed by Colorado Post-Polio Organization or Fasterseals Colorado.

If you have any great discoveries that you would like to share, send them to Mitzi Tolman at mtolman@eastersealscolorado.org and she will pass them on to the authors.

*This item may be eligible for Colorado Post-Polio Organization supplemental grant money to assist in the purchase by polio survivors who are residents of Colorado. Contact Mitzi Tolman for an application form.



April CPPO Statewide & Beyond Update

CPPO hosted its Statewide and Beyond educational meeting on Zoom in April. It featured Rachel Kaplan of Guide by Humanity https://guidedbyhumanity.org/. She led participants through a simple exercise and stretch routine that can be done entirely from a sitting position.

Guide by Humanity, a Denver-based organization, offers inclusive, accessible, and equitable yoga and wellness services for everybody and every ability. Classes are offered inperson and virtually. Workshops are also available, training fitness and yoga instructors teach how to adapt programs for people with varying physical and mental conditions.



It is common knowledge that our body feels better if one exercises regularly. However, fatigue, pain, and limited movement may keep many of you from regular exercise. In as little as 10 minutes a day, you can feel better by including a few new movements in your routine. Some tips to get started.

- 1. Pick a time of day that you usually feel good. For some it may be first thing in the morning after that first cup of coffee, but it could be midmorning, afternoon, or evening.
- 2. Don't try to do too much too fast.
- 3. Set an achievable goal and reward yourself for reaching it. It is recommended to try adding 10 minutes of stretching/strengthening for 10 minutes 3 times a week for two weeks as a start.
- 4. Learn the difference between discomfort and pain for your body. A little bit of discomfort is good. Pain is bad. The old saying "Pain or no Gain" is one of the biggest lies in the fitness world.



April CPPO Statewide & Beyond Update (Continued)

Any repeat movement can be exercise. Some examples of simple movements and stretches include:

Legs

- Lift your heels off the ground and back down flat 10 times.
- Then lift your toes up and hold for 5-10 seconds.
- · Repeat a couple times.
- Kick your foot out forward and using the muscles in the back of your control a slow descent back to the floor.
- Switch legs.

Arms and Shoulders

- Roll shoulders backward and then forward. Nice slow controlled motions.
- Lift shoulders up toward your ears and hold for 3 breaths.
- Slowly lower shoulders back down.

Just little controlled movements will increase the blood flow to your muscles and help relieve pain, swelling, and stiffness.

As polio survivors, do not work any one muscle group to the point of fatigue. It is best to only exercise each body part until it just starts to feel a strain. Increasing movement without expanding the energy you need for your daily task.

Happy stretching!





Make Your Life Better

Through generous donations, the Colorado Post-Polio Organization established a fund to help Colorado polio survivors offset the cost of items that might not be covered by insurance.

Over the last 15 years CPPO has helped fund ramps into homes, stairlifts, mobility devices, lift chairs, and much more. Named the Durable Medical Equipment Grant, or DME grant for short, does not accurately represent the breadth of the funding as it supports so much more. It is the "make your life better each day, maintain independence, be safe in and out of your house, and even find some happiness grant." CPPO is thrilled to help and is excited to increase the maximum grant amount to \$1,500 in 2023.



The grant's guiding principles are:

- Funds purchase equipment that promotes the safety, independence, and daily life of polio survivors in Colorado.
- Item is not typically covered by health/medical insurance.
- Payments are made to the vendor of the goods or to the polio survivor (if arranged with the post-polio program coordinator prior to purchase), with a valid paid in full invoice submitted to CPPO for reimbursement.

Please reach out to Mitzi or go to the Easterseals website, www.eastersealscolorado.org, to download a copy of the grant application!



Bruno Bytes – On the topic of Pain Sensitivity

-Dr. Richard L. Bruno, HD, PhD Director, International Center for Polio Education

Question: I've NEVER understood this. You say polio survivors are more sensitive to pain than non-polio survivors but have a higher pain tolerance. How is it that I can have a high pain tolerance and be more sensitive? It feels contradictory to me.

Dr. Bruno's Response: It has been known since the 1970s that the body produces its own morphine-like painkilling opiates, called endorphins and enkephalins. The problem for polio survivors is that the poliovirus killed off the brain and spinal cord neurons that produce the body's own opiates. So polio survivors can't "medicate" themselves against pain, which is why polio survivors need more pain medication than do non-polio survivors.

Our 1984 study showed that polio survivors are TWICE as sensitive to pain as non-polio survivors, likely due to the lack of endorphins and enkephalins (1) "Normal" levels of pain would be doubled in polio survivors and "intolerable" if polio survivors didn't develop a higher pain tolerance.

Here's another example of sensitivity and developed tolerance. Think about many polio survivors' emotional hypersensitivity to hospital smells (e.g., alcohol, the smell of wet wool from hot packs).

As adults, polio survivors had to develop an increased tolerance to these emotional triggers or they never would allow themselves to enter a hospital again. (Sadly, many polio survivors have indeed refused to get medical treatment because they didn't develop an increased tolerance for hospitals and medical facilities).

(2) References: (1) Bruno RL, et al. Motor and sensory functioning with changing ambient temperature in post-polio subjects. Late Effects of Poliomyelitis. Miami: Symposia Foundation, 1985. (2) Bruno RL, Frick NM. The psychology of polio as prelude to Post-Polio Sequelae: Behavior Modification and Psychotherapy. Orthopedics, 1991;14 (11):1185-1193. For more information, please read these two articles under the topic of "Psychology" in the Encyclopedia of Polio and PPS: Trauma and Illness as Precipitants of Post-Polio Sequelae and Psychology of Polio as Prelude to Post-Polio Sequelae SOURCE: The PA Polio Network February 2022 Newsletter: https://www.papolionetwork.org/uploads/ 9/9/7/0/99704804/february_2022_news_u pdate.pdf





CPPO Statewide and Beyond Zoom Educational Meetings

CPPO hosts educational meetings via Zoom. Meetings are open to all who wish to join from wherever your life takes you!

• Social: 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 mtolman@eastersealscolorado.org Registration link:

https://zoom.us/meeting/register/tZ0sd0GqrzloG9C7HKLGnpS_nyk6OfeKZFgk 2023 Dates: September 30, December 30

Please Join Colorado Post-Polio on June 30 from 10:30 – 12:30 MST. Social time and introductions from 10:30 – 11:00. At 11:00 will be a presentation followed by questions. Preregistration is required.

https://us02web.zoom.us/meeting/register/tZ0sd0GqrzloG9C7HKLGnpS_nyk6OfeKZFgk These educational meetings are offered once a quarter on the 5th Saturday of the year.





Just for Fun - Accessible Summer Activities

Denver Botanic Gardens

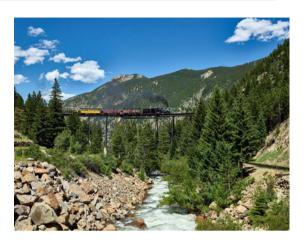
Take a trip to the Denver Botanic Gardens this summer to enjoy nature and view diverse flora. Most indoor and outdoor gardens and facilities at the Botanic Gardens are wheelchair accessible and Service Animals are permitted in all but one area. For more details about accessibility, visit

https://www.botanicgardens.org/yorkstreet/parking-transportationaccessibility-york-street

Rocky Mountain Arsenal National Wildlife Refuge

Located just East of Commerce City, at the Rocky Mountain Arsenal, you have the chance to view iconic plains animals. Bison, deer, eagles, and water fowl are just a few species you may see. In addition to driving through the refuge, there are multiple paved, accessible trails for walking and rolling.





Georgetown Loop Railroad

The Georgetown Loop Railroad features an hour long ride on a historic steam engine in the Colorado Rocky Mountains. Enjoy views of the river and gorge the loop travels over this summer. There are some wheelchair accessible train cars, but due to the train's historic nature there are some cars that are not accessible. You can call 888-456-6777 for accommodations

Rocky Mountain National Park

This Colorado summer staple has many accessible options for enjoying the park. RMNP has an all-terrain wheelchair for visitor use as well as accessible trails and facilities at Bear Lake, Coyote Valley Trail, Lily Lake, & Sprague Lake. Accessible campsites can be found at Moraine Park, Glacier Basin, and Timber Creek. Brail and large print park brochures are also available at the Beaver Meadows Visitor Center. Visit

https://www.nps.gov/romo/planyourvis it/accessibility.htm for more information.





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 are: July 26 and October 25





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 10:00 a.m. to Noon

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 1-3 PM.

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

Meetings on hold until Library completes renovation. Please join on of the zoom meetings. (North Denver or South Denver)

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





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!

AME:
DDRESS:
TY, STATE, ZIP:
HONE:
TONE.
MAII ·
ΜΔΙΙ ·

MAIL TO:

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

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.