

Connections • Spring 2024 Newsletter

JOIN US!
Step out of your comfort zone.
CPPO Rocky Mountain Retreat
August 9 - 12, 2024
Empire, Colorado

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Join us for CPPPO's 2024 Rocky Mountain Getaway

Join CCPO for its 2024 Rocky Mountain Getaway August 9 – 12 at Easterseals Colorado's spectacular Rocky Mountain Village in Empire, Colorado, just forty 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. Activities include climbing wall, zip line, outdoor heated pool, hiking, wheeling and fishing.



The dining hall serves three meals a day. Dietary needs can be accommodated. On-site lodging options 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 are available for RVs. Off-site lodging is convenient in nearby towns.



Polio survivors, caretakers, spouses and friends can customize their experience by choosing from a menu of educational forums, exercise activities and fun. Healthcare professionals with experience working with polio survivors will provide information about post-polio and how it impacts individual conditions. Evenings are spent with live entertainment and social time.



Colorado Post-Polio Rocky Mountain Getaway

For polio survivors, spouses and/or caregivers

Friday, August 9 through Tuesday, August 13, 2024

*Easterseals Colorado's
Rocky Mountain Village (RMV) Camp
Empire, Colorado*

REGISTRATION AND FEES

Fees for the camp are for the entire camp experience. **There are no one-day fee options.** Registration fees for the camp are dependent on the housing and shuttle options chosen:

HOUSING (*please check your preference*):

- On-campus housing - \$450 per person; \$800 for camper and care person
- RV on-site in place of campus housing - \$300 per person + \$20 per day electrical hook-up fee. No other hook ups available (i.e. water/sewer).
- Day Camper with off-site lodging - \$300 per person

SHUTTLE FOR DENVER INTERNATIONAL AIRPORT:

The shuttle will leave Denver International Airport at 3 pm on Friday, August 9 and return by 12 pm on Tuesday, August 13 – please purchase your flights accordingly – new this year, a greeter will be available at the airport Friday from 1 pm – 3 pm to assist you to the shuttle.

- Each way - \$60 per person

To register, please complete the registration and application and submit with a \$100 deposit per person by June 30, 2024.

*Completed applications should be sent to Mitzi Tolman by email at
mtolman@eastersealscolorado.org or by mail to:*

*CPPO Getaway, Attn: Mitzi Tolman,
7411 W 95th Ave, Westminster, CO 80021*

Payment is accepted by check payable to Easterseals Colorado (Memo Line: CPPO Getaway) or by credit card (Visa or Master Card).

Rocky Mountain Getaway Application

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Home Phone: _____ Cell Phone: _____

Email: _____

How did you hear about the CPPO Rocky Mountain Getaway?

Have you been diagnosed with Post-Polio Syndrome? Yes No

If the answer is "Yes", How does Post-Polio Syndrome affect you now?

MOBILITY

I use assistance from: Another Person Orthosis/brace(s) Walker

Crutch(es) Cane(s) Scooter Manual Wheelchair Power Wheelchair

HOUSING

Sleeping accommodation assignments will be made on a first-come, first-served basis. While CPPO makes every effort to provide appropriate housing for all individuals attending the camp, bed options are limited, most are in a group room setting.

Your on-campus sleeping preference/needs:

Queen Bed (couples only) – *limited availability*

Private Room (camper & caregiver)

Adjustable Bed

Preferred roommate if registering separately _____

Solutions—Rocky Mountain Getaway 2023 Edition (Part 2)

Sharing Secrets of Aging Well with Polio - By Margaret Hinman

There were many assistive devices in use at camp. Present were braces, crutches, canes, walkers and rollator walkers; all helping to maintain mobility and to keep users safe from falling. Creative uses were shared including one person using a walker in her garden when tending her raspberry patch and others using a rollator-walker as a means to carry and tote items both around the home and when out shopping.



Electric wheelchairs and scooters are used with some depending on them as their primary mobility device at home. A lightweight electric scooter is one person's choice as she goes out and about, particularly when she determines that the distance between A and B is too far to walk comfortably and without getting fatigued. Grocery and other stores have courtesy electric shopping carts that allow riders to go about the store, without getting fatigued and often, store personnel will deliver groceries to your car.

Grabbers are commonly used. They come in different sizes and can be equipped with suction cups and other gadgets. And more than one person keeps expandible magnetic sticks of varied sizes/magnetic strength at hand to pick up and move metal items. Stair glide chairs help some go between house levels or navigate stairs between garage and house. There are many previously owned, more affordable ones available if one searches for them.

A shower bench, some on gliders that go into and out of the shower, allows for easier transfer, and a handheld shower head allow users to continue personal care. Using a Beasy Board (brand) or other transfer board helps persons safely transfer between seating when standing and walking is no longer possible. Closing doors when using a mobile chair or scooter can be difficult. One person has bent a wire coat hanger, another uses a crocheted door pull to reach behind the chair to close the door. Trays with sticky bottom mounts used on the lap help keep dishes or other items from sliding. One person lined her cupboard shelves with carpet backing to keep items in place.

Solutions - Rocky Mountain Getaway 2023 Part 2 (continued)

Changing one's behaviors and attitudes has made life easier: Choosing to make use of assistive devices and alternative ways of doing things allows us to continue to be independent and stay safe in our homes. By changing one's mindset about our decreasing mobility, a normal result of aging, we can then accept that at this point in our lives, we have the time and the energy to adapt to that reality. As a result, we can hopefully use our creativity in dealing with it in a positive way which can give us peace.

Using caregivers, either family, friends or hired help to help meet our needs reduces the sense of helplessness that can occur and gives us the gift of maintaining or making new relationships which can keep us young in spirit. This is especially true if we can also pay attention to their needs in a mutually beneficial manner. Having a caregiver/housekeeper do the laundry and/or having a housekeeper do the cleaning chores, including changing the bed, regularly frees up time and energy to do more enjoyable activities and minimizes fatigue.



Wearing clothing that does not have to be ironed can simplify laundry chores. When cooking, a person who loves to cook makes larger quantities, and refrigerates or freezes portions to not have to cook as frequently but can still enjoy favorite meals. This practice can apply to many personally enjoyable activities. Incorporating time and energy management practices in your daily routine can help manage fatigue, for example, by making it a habit of resting at least twice a day.



Resources—There are multitudes of items on the market that help with accessibility and adaptability. Many are affordable and sometimes can be used as inspiration to make your own. The Youcan Toocan Store in Denver specializes in all kinds of assistive devices. Physical and occupational therapists and other medical service providers often have catalogues of devices they will share. Search online by asking for what you want, seeing what comes up, then modifying your search and keep trying! Happy hunting!

Incontinence Supply Kit

-By Jill Eelkema, LCSW

Incontinence of any kind can be a dismal experience, in part because we don't talk about it.



When you think of how early on we learn to control our bladder and bowels (almost before we can talk!), it's clear how much we take for granted being able to control these parts of our body. It's also clear how often incontinence causes the protective emotion of shame. How many of us dread thinking about a time when we wet or pooped our pants? Think about it: shame signals to us that there is a situation we should not do again. From an evolutionary standpoint, our nervous system feels "shame" to remind us what we shouldn't do to avoid getting kicked out of the tribe. But the emotions tied up in having incontinence and the reality that we will all likely experience this at various points in our lives make this a topic we need to normalize.

Bowel and bladder incontinence happen to many of us at different stages of our lives. Incontinence can be the result of weakened pelvic floor muscles after having babies, surgeries that cut through the nerves signaling our brains as to when we have to "go," hormone changes and even stress and trauma.

Extremely scary things trigger the nervous system to "offload" anything extra so we can run away or fight – there's a biological reason why we say, "That scared the crap out of me!"

My personal strategy for finding the best fit has been to select professionals who, first of all, are competent in their area of expertise, whether it is a primary care person or a specialist. Then I need to trust them. Regarding my primary care providers, those that I see regularly, it is important to me that I can have a positive connection with them, that they care about ME and are looking out for my best interests. And they need to be willing and open to listening and learning about me and about polio in relation to my general health and also make appropriate referrals to specialists as needed.

Our primary care providers are our resources, first and foremost, in helping us manage our general health care and any problems that arise as we age, such as, blood pressure issues, heart issues, diabetes, fitness and weight management, etc. We need to remember that we are more than our polio and we are susceptible to the same conditions as everyone else.

Having bowel or bladder "accidents" is one of the biggest, least talked about reasons that we isolate ourselves from our social supports.

Incontinence Supply Kit (continued)

It's a combination of anticipatory embarrassment, fear and maybe even some sadness that we can't trust our bodies to not let us down. In looking at the rising incidence of colon cancer (often requiring abdominal surgery or radiation), the number of people living longer, and lack of awareness and discussion about what's going on "down there," it seems like this is a topic we can address by at least being prepared. (Hint: being prepared is one way to decrease anxiety).

So, in light of this, here is an incontinence kit you can put together, keep in your car or even toss in your purse (and yes, it's now socially acceptable for men to carry a supply bag, fanny pack or "murse"... man-purse):

Depends Silhouette: very stretchy, low-profile absorbent briefs. They make these big so you can often go one size down. Also you can create a profile on [depends.com](https://www.depend.com) and get a coupon for \$3.25 off, making them approximately \$9-10/box:

<https://www.depend.com/en-us/coupons>

YUNI Body Wipes: each packet contains one big shower wipe; these are not flushable but good for blowouts, and they have a great scent.



**Open Phone Camera
Scan Code
Visit YUNI Body Wipes Site**

Good Wipes: flushable wipes for down there (only flush one at a time tho!). These in single packets like teabags or you can buy 60-count packs and put some in a ziplock for your kit. They also are less "sting-y" than other wipes if your parts are chapped.



**Open Phone Camera
Scan Code
Visit Good Wipes Site**

Calmoseptine: consider this the superhero of diaper creams. Spread it onto dry, clean skin after an accident. It soothes, helps heal the outside part of your back passage (tush) and protects your skin if you have another accident. Note that it is light colored and can be hard to get out of regular underwear. You can buy it by the tube (Walgreens has a generic option that also works; it's just a little less thick) and put some in a small container for an incontinence kit.



**Open Phone Camera
Scan Code
Visit Calmoseptine Site**

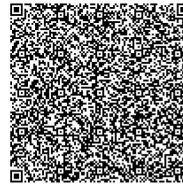
2 plastic grocery bags (opaque): one to throw away undies/Depends and one for if you have to bring clothes home to wash. These are also good if you're in the car and need to quickly slip something underneath you.

Incontinence Supply Kit (continued)

Lightweight nylon jogger pants (black):

in my opinion, if you have an accident, you should be allowed to wear comfy clothes the rest of the day so keep a pair of something like this in the kit. They're kind of athleisure wear and go with everything.

(Optional) chuck: some people also keep a chuck within reach of the driver's seat in case they need it (a doggie pee pad would work... plastic with one absorbent side and may be less expensive); they make disposable ones and washable ones.



**Open Phone Camera
Scan Code
View Nylon Jogger Pants**

For all of these items, you can put as many or as few as you need into your kit. You'll probably be able to fit this kit into a gallon-size Ziplock bag or smaller AND, if you want to be discreet, you can use the opaque grocery bags to hide the supplies. I've also thought that throwing in a pair of disposable gloves wouldn't be a bad idea either. Hopefully, this kit gives you confidence and maybe a start in knowing, yes, s**t happens to all of us.

Food For Thought—Good Enough is NOT Enough. Or is it?

-By Gary Crooks

“Good enough is not enough.” Or is it?

That's the lofty standard and catchy slogan Harvey Industries uses in building and advertising woodworking machines. But what about the standard we impose on ourselves?

History suggests our standards may be just as high. Polio survivors—both the famous and the not-so-famous rest of us—are typically over achievers.

(https://en.wikipedia.org/wiki/List_of_polio_survivors) Often Type A personalities, we have overcome the challenges of polio to achieve surprising success. And what's wrong with success? And doing your best?

Never did we want to believe we could not do something because of polio. And never did we ever want others to think polio could stop us. Or even slow us down. Sometimes, we would even take on activities or projects we might not have absent polio. And not just do our best but strive for perfection. Obvious is the powerful competitive drive, impatience, priorities and accomplishments of being Type A. *Not so obvious are the costs.*



Food For Thought—Good Enough is NOT Enough. Or is it? (Continued)

Looking back over my 76 years, I've been a Type A far too long. Was I born Type A? Or did I become that way to cope with and compensate for polio? Don't know. But I do know my mother was a strong Type A reinforcer during my formative years. She instilled a belief that I should always do my best. Hard to argue with that, right? But to her, that meant always striving for perfection.



One of countless examples: When in 3rd grade, I completed a glitter and glue homework assignment. To that little 3rd grader, it looked good. Really Good! But when Mom saw it, she said, "Let's do this right" and redid the entire project while I merely watched on. Her work was so perfect, I was ashamed of mine. It was late and the project was due the following day.

Too ashamed to submit my own work but knowing not to turn in the work of another, I was in a panic. But Mom convinced me that hers was mine because I'd done the first one and then learned all the techniques to make the second one perfect.

Like it was yesterday, I still recall my teacher's painfully penetrating reaction: "Gary, is this really your work?" Stammering and stuttering, I must have admitted the obvious and then she kindly asked if I wanted to give her MY work on which she wrote "Good."

Looking back, I see my Type A was also alive and well in my mother. Although Mom was well intentioned and trying to be helpful, I must also admit that I might have had this same experience with her even absent polio. What I do know is that so many of us deserve to give ourselves a break from the stress of such high, self-imposed expectations. As Jill Eelkema, our PP Support Group facilitator has observed: "We might not have many friends if we talked to others like we talk to ourselves." So profoundly true!

The price of all this needless wear and tear is well documented and can be so costly. Many times—indeed, often times—**Good Enough Really IS Enough!**

Just some food for thought!

Gary Crooks shares some of his thoughts about his polio experiences after years of hiding its presence in his life!

Family Corner - Time for a Visit?

-By Mitzi Tolman

Visiting friends and relatives can be stressful and exhausting, but with some thoughtful planning you can make a visit from your aging relative more relaxing and comfortable.

First prepare your house: remove items so there is room for them to get around without having to step over things and that they have room to maneuver their walker or chair as needed. Get a shower stool or lift for the toilet. Place a non-slip mat in the shower and remove any rugs that could be tripped over or slipped on. Get decent quality suction cup handrails for the bathroom and shower. Many local senior centers will have shower chairs and other items you can check out for the length of your visit.

Give them the priority parking spot that is easy to get in and out of. Make sure the walkway is clear of snow, ice, dirt, or other times that can cause a fall. Offer an arm or other help, many stairs do not have adequate handrails so be aware of areas that an assistant might be needed.



Help get any suitcases out of the vehicle and to the room where they will be staying. If you are a “shoes off” house pick up non-slip shoe covers, as many people rely on their shoes for stability.

Make their room comfortable with an easy to access outlet for them to plug in their devices or medical equipment, a heating pad or blanket for aches. Provide a nightlight in the bathroom and hallway. Put a chair in the room so they have a hard place to sit while putting on socks and shoes. When visiting, make sure you have a chair that isn't too low or soft so they can get up easily, provide a lap blanket to keep warm as they sit.

★ **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>

Family Corner - Time for a Visit? (continued)

For outings, plan ahead. Do you need to take your relative's car with a handicap license plate or do they have a hanging one you can transfer to your vehicle? Can you drop them by the door and then park? Bring a chair for them, especially for outdoor activities. Is there a mobility cart available at the large venue or shopping center? If you are in handicap seating, how many relatives can be seated with or near them? Always make sure to allow plenty of time to arrive and leave.



With some forward thinking and planning you can enjoy your visits and continue to build memories together.



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 & 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 mtolman@eastersealscolorado.org

Registration link:

https://us02web.zoom.us/meeting/register/tZ0sdOGqrzloG9C7HKLGnpS_nyk60feKZFgk#/registration

2024 Dates: June 29, August 31, November 30



2024 Advisory Council Members

Sue Brandon, *Chairperson*

763.377.2287

suebrandon1950@gmail.com

Marny Eulberg, MD, *Medical Advisor*

303.829.1538

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2024 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.**

2024 dates are: July 24 and October 23.



Colorado Post-Polio Support Group Schedules

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

NEW – MID-WEEK SUPPORT GROUP – ZOOM

Started January 2024, the new group meets the 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 area are welcome to attend.

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

Join Zoom Meeting at [https://us02web.zoom.us/j/89008651033?](https://us02web.zoom.us/j/89008651033?pwd=TUZhVVpPc1hKOGJRTy9Bek8rZnppdz09)

[pwd=TUZhVVpPc1hKOGJRTy9Bek8rZnppdz09](https://us02web.zoom.us/j/89008651033?pwd=TUZhVVpPc1hKOGJRTy9Bek8rZnppdz09)

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 myrnaschmidt1@yahoo.com

COLORADO SPRINGS

Meets the 1st Wednesday of every month from 10:00 a.m. to Noon

Meeting via Zoom. 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 further information.

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

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 at 1129 Colorado Avenue, Grand Junction

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



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.