

Connections • Spring 2023 Newsletter

**"The mountains are calling,
and I must go."**

– John Muir

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CPPO Rocky Mountain Getaway 2023

Rocky Mountain Village Post-Polio Camp in Empire, Colorado August 6 – 10, 2023

Our Rocky Mountain Getaway is tailored for polio survivors, their spouses and their caregivers. Nestled in the beautiful Rocky Mountains, campers will partake in educational, comradery, outdoor activities and evening entertainment experiences. Attendees can customize their experience by choosing from a menu of educational forums, exercise activities and just having fun. Attendees can enjoy a massage, have their hearing checked, have a personal PT session, join a group PT session or have a health evaluation. Healthcare professionals with experience working with polio survivors will provide information about polio and the late effects of polio and how it impacts individual conditions.



What a daily schedule looks like—After a robust breakfast prepared by the camp chef, everyone will gather daily as a group to hear a keynote speaker, and

after that, attendees will have a choice of breakout sessions before and after lunch. The late afternoon is for trying a new activity (all accessible): archery, riding the zipline, scaling the climbing wall, fishing, yoga, swimming in the heated pool, or just resting. After dinner live entertainment is provided by local artists.

Speakers and events you won't want to miss include:

Our featured Keynote Speaker—**Phillip Yancey**—is an award-winning journalist, author and speaker whose life's work has been a search for "meaning and grace." For some twenty years, he edited the youth magazine *Campus Life* while also writing for a wide variety of magazines including *Reader's Digest*, *Saturday Evening Post*, *National Wildlife* and *Christianity Today*. In the process he interviewed diverse people enriched by their personal faith, such as President Jimmy Carter, Habitat for Humanity founder Millard Fuller and Dame Cicely Saunders, founder of the modern hospice movement. He is the author or co-author of 22 books, selling more than 17 million copies worldwide and that have been translated into 50 languages.

CPPO Rocky Mountain Getaway 2023 (Continued)

In 1992 he and his wife, Janet, a social worker and hospice chaplain, moved to Colorado’s foothills from Chicago.

Recently he has been diagnosed with Parkinson’s disease and has reflected on the personal and social meaning it has in his life, looking at what it means to become disabled. Read his blog: <https://phillipyancey.com/disabled>. This will be the topic of his presentation at camp.

Break out Session for family members and Caretakers – **Bonda Zeller**, a professional Counselor, has worked with families and individuals in a variety of clinical and group settings. As the child of a polio survivor, Mrs. Zeller will bring her unique perspective to this session.

Breakout session – **Paul Snell** will help you learn how to use today’s ever-growing technology to simplify your life and make your home safer.

Breakout session for caregivers and you – **Steve Medberry**, DPT, will teach you about falling, how to fall as safely as possible and how to recover from the fall. This is just a sampling of what you can experience!

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.

To sign up for the Getaway, complete the accompanying form and mail it to: Mitzi Tolman, program coordinator. Make checks payable to Easterseals Colorado and put CPPO Getaway in the “for” column. All deposits are refundable until June 10, 2023.

Contact Mitzi for more information, mtolman@eastersealscolorado.org.

Looking forward to seeing you in August!

CPPO Rocky Mountain Getaway 2023 Registration

Name _____

Age: Under 60 Over 60 Over 80

I have included my \$75 deposit.

Address _____

City: _____ State: _____ Zip: _____

Home Phone: _____ Cell Phone: _____

Email: _____

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 + shuttle options chosen:

HOUSING (please check your preference)

- On Campus housing - \$450 per 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:

- Each way - \$55 per person

HOUSING

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

Please rank your on-campus sleeping preference/needs:

(1 - your first choice, 2 - your second choice, 3 - your third choice, N/A - not a choice)

_____ Queen Bed (Couples only)
- 5 available

_____ Private Room (Couples or Person + Caregiver) - 2 lower level bunk beds

_____ Lower Bunk (Single persons will be sharing a room with at least one other)

_____ Adjustable Bed

*Checks can be mailed to Easterseals Colorado.
393 S Harlan St. Suite 250 Lakewood, CO 80226
All deposits are refundable until June 10th.*

Food For Thought – Finding the Right Medical Providers

- By Margaret Hinman

Dr. Marny Eulberg has given Colorado polio survivors a gift when she chose to practice medicine in the Denver area and then again when she established a polio clinic where she continues to see and evaluate polio survivors as well as leading the Colorado Post-Polio Organization Traveling Clinic. She continues to do this even in her retirement.



Dr. Marny Eulberg

Dr. Eulberg knows polio intimately as a survivor herself and from the study and research she has undertaken through the years. She is rare in the medical field today when almost all medical professionals probably have only glanced at polio literature in medical school, and many have probably not ever knowingly treated a person who is a polio survivor.

This not only applies to physicians but also to nurses, rehabilitation workers, extended care professionals, physical therapists, occupational therapists and orthotists.

So, as cloning her is not possible, the question becomes one of how you find medical providers that, as they treat you, know about polio or are willing to learn about polio.

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.

Food For Thought - Finding the Right Medical Providers (Continued)

The next criteria for me are that they know and/or are willing to learn the following polio basics: Polio is a virus that has impacted the voluntary nervous system and the muscles involved in that system, and does not impact the autonomic nervous system, such as the heart or the circulatory system. There is no cure for polio and usually the best that can be achieved when treating the aftereffects is to maintain what is. Also, polio in and of itself is not fatal.

However, as we age with polio, it can increase or speed up the normal aging process, resulting in fatigue of the muscles and nerves that have been overworked through our lives and can cause general body fatigue, all of which is best treated through time and energy management and the use of assistive devices. It is also helpful when they know how to isolate the effects of polio from other medical and physical ailments and diseases as they are treating us.

When looking for primary care providers, gerontologists who specialize in care of senior citizens, osteopaths (D.O) who generally have more training on the neuromuscular system as opposed to graduates from the traditional medical school (M.D.), or physiatrists (specialists in physical medicine and rehabilitation) might be a good place to start.

This is not to say that M.D. primary care or family medicine professionals do not necessarily also meet the criteria.

Physical therapists and occupational therapists who specialize in treating persons with neuromuscular disorders will probably be better equipped to treat the aftereffects of polio than sports medicine PTs or traumatic rehabilitation specialists.



Orthotists (brace makers) who understand our love-hate relationship with braces, who are creative in problem solving so that they can produce a brace that not only helps us stand and walk but also can perhaps correct some of the physical anomalies that we have are real gems. And, they need to be willing and able to work with us until the brace fits correctly, isn't uncomfortable or painful to wear and keeps us mobile.

Food For Thought - Finding the Right Medical Providers (Continued)

Finally, my last criteria is to find professionals that are willing to work in partnership with me. To have that happen, I need to know about myself, my polio conditions/circumstances, and my general health conditions so that we can work together to integrate my treatment plan with the polio aftereffects whenever necessary and appropriate. I can help the provider learn about polio in relation to me.

But I also need to know about polio itself, having knowledge based on data and information, and not on what I think are facts and what I feel. That way we can work together to give ourselves the optimum care that we need. That information can be found in many resources, but a good, reader friendly resource is the CPPO Resource Book that is available on-line for download at <https://www.easterseals.com/co/shared-components/document-library/post-polio/July-22-resource-book.pdf> or by contacting Mitzi Tolman at mtolman@eastersealscolorado.org to request a hard copy of the book. A donation of \$15 is requested to defray the cost of the printed copy.

A final thought, when our medical providers meet our criteria, we don't have to think about cloning Dr. Eulberg and can be assured that we can age with polio with confidence!

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.

The Role of the Primary Care Physician in the Life of a Polio Survivor

- By Dr. William DeMayo, MD.



Dr. DeMayo, M.D.

On each of my several trips to Post-Polio Health International conferences, as well as on my recent three-week lecture circuit in Australia, I have been amazed at the number of individuals who see my specific expertise as “the missing piece” in their future health, yet their local therapists and primary care physicians (PCP) seem to be relegated to some distant and less important role.

While I appreciate the importance of specific expertise in this sub-specialty area, I often find myself trying to bring folks back to their local resources.

In my opinion, regardless of expertise, it is local therapists and PCPs that can have a much bigger role in long term health. The most obvious reason to conclude this is that a polio survivor’s health is not solely dictated by their history of polio.

They are just as susceptible to the same medical conditions as everyone else. In fact, for some, a relatively sedentary life will make them more susceptible.

The following conditions each have an incidence of at least 10% in those over 65 and ALL ARE ON THE RISE in this age group:

- High Blood Pressure (55%)
- High Cholesterol (45%)
- Diabetes (20%)
- Cancer (>10%)
- Mental Illness (>10%)
- Back Problems (>10%).

Multiple other conditions pose a significant threat of disability as we get older:

- Obesity
- Coronary Disease/ Congestive Heart Failure
- TIA/Stroke
- Arthritis
- Bladder and Bowel difficulties
- Infection
- Lung disease
- Kidney disease

The Role of the Primary Care Physician in the Life of a Polio Survivor (Continued)

Most individuals develop MULTIPLE chronic conditions as they age:

- For 65-75 year olds
 - >20% had a chronic condition
 - Of these, >50% had two-four chronic conditions
- This trend increases after 75 years of age with
 - >20% having more than five chronic conditions.

Primary care physicians are the “go-to person” for nearly all the above conditions yet, somehow, their role seems to be minimized by many polio survivors.

It has been my sense that this is, at least in part, due to a frequent “disconnect” that occurs when the issue of polio or post-polio related issues come up. Most PCPs willingly admit to a lack of expertise in this area and, sometimes, this creates a dynamic that their opinion on other matters is also downgraded. In fact, from my standpoint, it is unreasonable to expect that a PCP have extensive post-polio knowledge.

“My polio slows me down enough, I’m really glad that you help me tightly control my diabetes, so I won’t have complications that worsen my disability.”

Rather than downgrading the PCP opinion on other matters, it is my opinion that polio survivors are better off being unusually grateful for the PCP. Since the vast majority of physicians went into medicine for good reasons, a statement like, *“I really need your help with ...”* goes a long way.

Consider comments like:

- “I really appreciate your keeping such a close eye on my blood pressure”.
- “My polio slows me down enough, I’m really glad that you help me tightly control my diabetes, so I won’t have complications that worsen my disability.”



These comments will increase the connection rather than allow a disconnection that may result when a PCP is not familiar with concerns that relate to adaptation to slow progress of weakness and chronic disability (aka PPS).

The Role of the Primary Care Physician in the Life of a Polio Survivor (Continued)

Having said all of the above, most of us have noticed that medicine has been changing. There may be PCPs out there that just won't engage. In this case: find another PCP. One physician's lack of interest should not dictate a polio survivor to poor future health.



Polio survivors, as a group, have a long history of focusing on goals and making things happen despite adversity. It is surprising that in dealing with the healthcare system, some can become passive or even fatalistic.

In my opinion, the same "Can Do" attitude can be applied to assuring optimal health care by working with the healthcare system to insure that it meets their needs. The stakes are too great not to address the issue.

If developing polio is seen as a strike, and post-polio is a second strike, one more unmanaged (yet preventable) chronic condition could be the last strike leading to severe disability and loss of independent living.

In this light, one can say that the role of the PCP becomes even greater, not less, for aging polio survivors.

Revised from the original by William DeMayo, MD, 2019.

Originally published: Post-Polio Health Vol. 33, No. 1 Winter 2017 www.post-polio.org

https://www.papolionetwork.org/uploads/9/9/7/0/99704804/role_of_the_primary_care_physician.pdf

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:

Keeping warm while traveling—packing a large heating pad and an extension cord when you travel allows you to put it between the sheets to warm the bed before you crawl in and/or allows you to wrap it around that cold polio limb that will not let you sleep until it is warm.
-- Margaret Hinman

***Height adjustable scooter**—Jazzy Air 2 electric scooter/wheelchair. Those of us who are mostly wheelchair bound can use this around the house, particularly in the kitchen to raise you up to work at counter height. Small turning radius, electric charging range 15+ miles with a 12" rise of power adjustable seat height in 11 seconds. \$4500.
-- I. S.

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 Easterseals Colorado.



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/tZ0sdOGqrzloG9C7HKLGnpS_nyk6OfeKZFgk](https://zoom.us/meeting/register/tZ0sdOGqrzloG9C7HKLGnpS_nyk6OfeKZFgk)

2023 Dates: September 30, December 30



Just For Fun - An Ode to Spring

Today

By Billy Collins

If ever there were a spring day so perfect,
so uplifted by a warm intermittent breeze

that it made you want to throw
open all the windows in the house

and unlatch the door to the canary's cage,
indeed, rip the little door from its jamb,

a day when the cool brick paths
and the garden bursting with peonies

seemed so etched in sunlight
that you felt like taking

a hammer to the glass paperweight
on the living room end table,

releasing the inhabitants
from their snow-covered cottage

so they could walk out,
holding hands and squinting

into this larger dome of blue and white,
well, today is just that kind of day.



A Time Of Hope

By Catherine Pulsifer

As winter's chill departs
The warmth of spring arrives
Seeing daffodils and crocus blooms
Allows hope and rebirth to thrive.

Birds soar in the sky so blue
Nature flings open its door
Our hearts are filled with joy and delight
At this time of hope evermore!



Smile Of Spring

By John Greenleaf Whittier

A beautiful and happy girl,
With step as light as summer air.
Eyes glad with smiles, and brow of pearl,
Shadowed by many a careless curl
Of unconned and flowing hair;
A seeming child in every thing.
Save thoughtful brow and ripening
charms,
As Nature wears the smile of Spring
When sinking into Summer's arms.

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 meeting changes.

AURORA

Meets the 4th Thursday of every month from 11:00 a.m. to 12:30 p.m.

Meeting in-person at the New Hope Church, 17699 E. Hampden Ave.

Facilitator: Myrna Schmidt, 608.790.5755 or 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 every month. Next meeting April 19, 2023

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

Meets the 3rd Saturday of January, April, July and October.

Next meeting July 15, 2023 from 2:30 to 4:30 p.m. at Barkman Library, 1300 Jerry Murphy Rd.

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 further information.*

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
393 S Harlan St, Suite 250
Lakewood, CO 80226



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.