

**Connections • Fall 2021 Newsletter**

**Dare we believe/hope that there  
will only be two children paralyzed  
by wild poliovirus in 2021?**

- Mary Eulberg, M.D.  
October 15, 2021

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## We All Can Learn from Polio Survivors with Upper Extremity Weakness by Marny Eulberg, M.D.



*Jim Carr, CPPPO Advisory Council*

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

Persons who have had significant

lower extremity weakness and have used their arms to assist with many activities that require leg strength are quite likely to develop overuse problems in their shoulders, elbows, and/or wrists. Upper extremities were not designed to be used for long-term walking! This may be temporary after a particular period of overuse or can become chronic. It can be a tendonitis, a bursitis, wear-and-tear arthritis or a tear of various tendons/muscles such as rotator cuff tears or biceps muscle rupture, etc. All of the above result initially in pain which then can lead to weakness because if it hurts to perform certain motions people stop doing that motion or severely limit the use of muscles that effect that motion. Bottom line: Even if a person’s initial polio primarily affected their legs, it is likely that over time they are at risk of developing some overuse symptoms in their upper body that can limit their use of their upper extremities.

Over the past few years, I began to have pain in my shoulders (right greater than left) that limits my ability

## *We All Can Learn from Polio Survivors with Upper Extremity Weakness (Continued)*



*Paulette Bergounous*

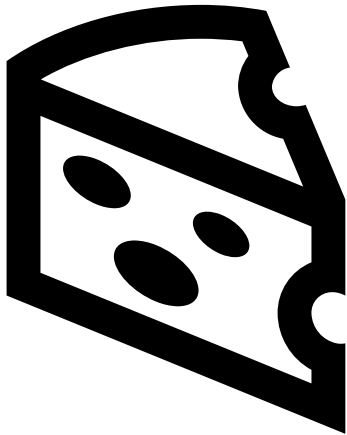
to perform certain activities such as putting on or taking off certain clothing like sweatshirts, jackets, and blouses/shirts. After watching some polio survivors with upper body weakness, I learned that I could still do those activities with little or no pain, if I used techniques that those “upside down polios” used. So, now instead of removing a sweatshirt by crossing my arms in front of my body and grasping the lower left hem with my right hand and the lower right hem with my left hand and then pulling straight up and over my head, I now lean forward (getting my trunk nearly horizontal), grasp the back of the neck opening with one hand and pull slightly up and

horizontally until the sweatshirt is over my head and off.

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

As in many aspects of aging, there are many useful tricks and techniques that can be learned from polio survivors and used as we develop some of the limitations of a long life. To learn more from Paulette, check out her blog at [navigatingpersonalchange.com](http://navigatingpersonalchange.com).

## *Food for Thought - Celebrating Individual Differences by Margaret Hinman*



Polio viruses are equal opportunity marauders, attacking the vulnerable and, to varying degrees, striking any and/or all parts of the person's body willy-nilly. Those of us who were zapped with paralytic polio usually have the visible signs in one or more of our limbs. And, although we thought that the weakness and paralysis stopped after the original onset of polio, we have discovered new weaknesses later in life that were not so obvious back then.

My favorite physical therapist describes what he has learned as he evaluates and works with polio survivors. He compares our bodies to Swiss cheese because we don't fit the traditional model of evaluation and treatment that he was taught in

school. He finds strengths and weaknesses throughout our bodies, sometimes in unexpected places, not just in the visibly affected limbs. And, because we are all part of that big block of Swiss cheese, each of us is a different slice and unique in who we are.

Before the polio vaccines were available, some of us were poster children for the March of Dimes or other organizations, either in a national campaign or locally. Often poster children were pictured in leg braces and standing or walking with crutches or seated in a wheelchair wearing braces and with concerned adults looking on. This depiction of a beguiling child who survived polio created that dramatic look of those braces and crutches and it hid the distortions of the affected limbs. This left the public, even today, with a partial picture of what polio did to the bodies of many of us. It didn't show the weakened arms, the mostly useless hands, the need to brace weak neck muscles to hold up the head, the difficulties with swallowing, the spinal curvature. And even the

## *Food for Thought - Celebrating Individual Differences (Continued)*

picture of the child in an iron lung really couldn't show the difficulty with breathing caused by weakened diaphragm muscles.

The holes in my slice of Swiss cheese are riddled with standing and mobility issues, with having to deal with wet or icy surfaces and constantly having to watch every step I take so I can stay safe and upright. On the other hand, the holes of the Swiss cheese of my "upside-down polio" friends impact their very survival in the activities of daily living, from getting dressed to brushing their teeth to fixing their hair to eating and swallowing to breathing and beyond.

The longer I am active in the polio community, the more I am constantly in awe of the creative ways we have addressed and overcome the challenges that polio has presented. But then, to survive, we all have had to rise to the top, learning to solve problems in ways that defy the logic and expectations of what is possible, and we just do it.

I have also discovered that our individual differences, our Swiss cheese bodies, do not define who we are, either individually or as a group. We are more than all those inward and outward signs we present. We are exceptionally resilient, creative people who are not just survivors but are thrivers. We have achieved superhuman heights in our daily lives despite the barriers that were thrown at us. So, when we start to feel overwhelmed or get down on ourselves, we need to remember the positives of who we really are, embrace that reality and celebrate it!

**Just some food for thought!**

## Ridway Post-Polio Forum by Jim Carr



Each fall, the Old West Fest celebrates Ridgway, Colorado's movie, ranching and railroad heritage in three packed fun-filled days. The event this year took place September 24 to 26. The Ridgway area is a favorite among film buffs, especially western lovers. The beautiful mountain peaks, canyons and historic landmarks make you feel as if you are still in the Old West. Visiting Ridgway this time of the year with fall colors from the changing aspen trees adds to the beauty of the area.

This year, Joan Chismire, President - Board of Directors Ouray County History Museum, added a new element to the weekend by having an information exchange session for

post-polio survivors as well as several informative exhibits about the history of polio in the museum.

Joan also had arranged for a retired anesthesiologist to give a presentation on potential problems polio survivors need to be aware of and share with their doctor when going under anesthesia. One thing she emphasized was to "squeak". The squeaky wheel gets the grease so don't be shy about making sure the doctors and nurses know that you have polio and certain precautions may need to be taken, especially those that were in an iron lung with breathing problems.

We also had a surprise visit from an ICU doctor that worked at St. Mary's Hospital in Grand Junction. He had been working COVID-19 cases since early last year and was interested in learning more about polio survivors. He had a lot of questions for us, and we had a lot of questions for him. It was interesting discussing the truth and misconceptions of COVID-19 with someone that has been treating patients since its inception.

## *Vera Junek's Story* *by Joan Chismire*



This is a story about a young 17-year-old girl who contracted polio and needed to use an iron lung to stay alive in 1940. Vera Junek, along with family and friends, attended the Days of 76 held in Deadwood, South Dakota in late July 1940. After returning home, a few of the group got sick. Everyone got better shortly afterwards except Vera. She continued to become weaker and had difficulty breathing. At first hard to diagnose, it was quickly determined that she would need an iron lung to survive. Vera's was the first

bulbar-spinal polio case on the western side of South Dakota (August 1940).

In 1938, the American Legion of western South Dakota fortuitously planned ahead and purchased (through extensive fundraising) a 1937 Drinker-Collins Iron Lung to be used in the Black Hills area for \$1,385. Vera remained in the iron lung for 10 months.

When she could breathe on her own and be free of the iron lung, she found that she was without the use of both arms. She learned to write with her foot and became proficient with doing everything right footed.

Denver, Colorado was a hub for polio doctors at that time. Vera later moved and stayed with a family in Denver to continue with treatments and doctor appointments. In 1953, Vera married Doyle Heilesen and they remained in Denver. They had two children, a girl and boy (1954,1959).

Vera died in August 1988 from post-polio syndrome, brought on by a fall

## Vera Junek's Story (Continued)



which created a need for gallbladder surgery (botched) eight years earlier. The muscles that had supported her breathing all those years weakened once again.

In 2013, Vera's daughter, Joan, received a phone call from a Mr. Larry David. He shared that he had found an old iron lung at a friend's junk yard in South Dakota and was wanting to confirm its history by using its serial number. Larry had located the 1937 Drinker-Collins Iron Lung first used by Vera 73 years earlier. Mr. David decided to rehabilitate the historic piece by taking the machine to American Restorations in Las Vegas, Nevada. This project was selected to be highlighted on the History Channel's TV show *American Restorations* in 2014.

The Ouray County Ranch History Museum (OCRHM), a 501(c)(3) museum created to protect, preserve, and educate the public about the ranching, equipment and lives of those in and around Ridgway, Colorado, became involved with this story through that initial phone call in 2013.

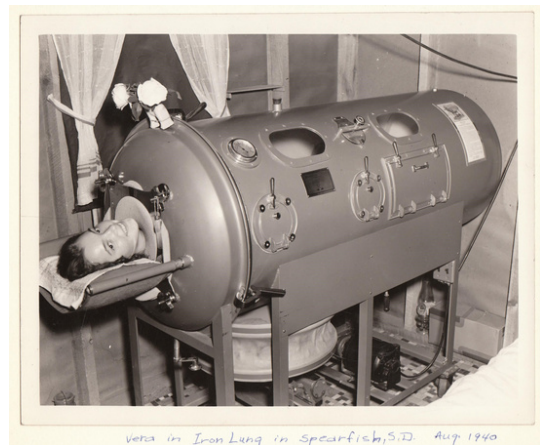
Joan Chismire, President of the museum's board of directors, is Vera's daughter. Her younger life at home had been groomed to be a problem-solver and helper to her mother. An interest in art and Occupational Therapy was a natural fit for Joan as her mother's artistic talents and interests rubbed off on her. Vera taught her daughter to sew and play the piano.

Throughout college and the next eight years, Joan became a companion for Mary Ann Whalen, a high school German teacher, who became a quadriplegic from polio. Together they even travelled Europe for one summer in conjunction with a Rhodes Scholar award Mary Ann had received for further German study in Germany.



## Vera Junek's Story (Continued)

In 2019, the extended Junek families purchased the iron lung from Larry David. Since then, it has been on permanent loan to the OCRHM for educational purposes and future viewing, as polio affected many families in Ouray County as well, although more so in the 1950s. An exhibit of the iron lung and local stories were recently showcased at OCRHM (September 24 - October 13, 2021), along with a Forum afternoon for individuals living with post-polio syndrome.

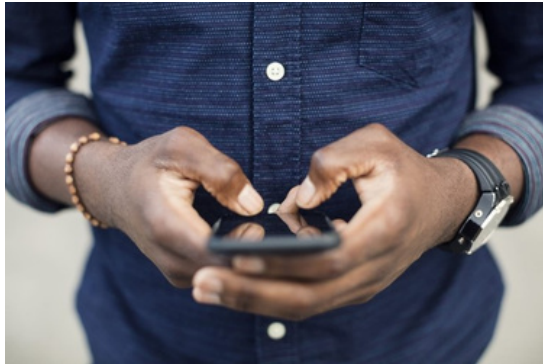


## ★ *Developing a Personal Philosophy about Disability* by Lawrence C. Becker, PhD



The late Larry Becker (1939-2018) was an “upside-down” polio survivor who contracted polio at age 13, studied and became a college professor in philosophy and who lived a long life without the use of his hands and arms and with compromised breathing. View his take on life with his disability at [polioplac.org/personal-philosophy-disability](https://polioplac.org/personal-philosophy-disability) in Post-Polio Experts Present. It can be viewed via the Vimeo app at [navigatingpersonalchange.com](https://navigatingpersonalchange.com).

## Resources for Aging in Place with a Disability, Part 2 by the North Denver Post-Polio Support Group



In the past two years, our group has discovered and shared many resources, services, practices, equipment and gadgets that some have found helpful to age in place and maintain our quality of life as we are mature citizens with polio. We are passing our discoveries on to the *Connections* readers. These are resources that are shared on a personal level and are not endorsed or recommended by the Colorado Post-Polio Organization or Easterseals Colorado and are not to be seen as advertising endorsements for any product.

### Technology

**iPhone Accessibility** - There are lots of new accessibility features in the operating systems of new mobile phones. All those listed here relate to

the Apple iPhone but some features are also on various Android phones. On the iPhone you can find these features under Settings > General > Accessibility.

- **Magnifier** - This fantastic feature allows your phone to be used as a variable strength magnifier. It is easily accessible and can also be used with the light on the phone to illuminate hard to see small print.
- **Zoom** - This magnifies the entire screen. It allows you to easily move around the screen but the part you are viewing is much larger.
- **Spoken Content** - Select this in the Accessibility settings, and a speak button will appear when you select text. You can also swipe down on any screen to hear the content of that screen. In addition, it can highlight content for you to see it as it is spoken. A nice feature is you can also control the speaking rate.
- **Hearing** - Pairing the iPhone with Apple EarPods or EarPod Pros allows you to turn on a phone setting when they are in your ears

## Resources for Aging in Place with a Disability, Part 2 (Continued)

and then lay the phone down in an area where you need to hear such as at a large dinner table. This is an option for slight to moderate hearing loss when hearing aids are not needed yet.

### Voice Control and Artificial Intelligence -

- Amazon and most Android phones have Alexa or Google as their voice command, and Apple has Siri through HomeKit. Of these, Google Home has more devices available right now. This huge developing market features everything from voice-controlled lights, drapes that roll up or slide to open by voice command, a remote-controlled deadbolt lock and even a voice controlled remote starter for your car.
- A light bulb made by Nanoleaf, the A-19, which can be controlled by Android, Google or Apple devices, lets you turn on a light (lamp) remotely from basically anywhere in your house either by a phone app or by voice. Until recently bulbs like this were extremely expensive, but this is one of the highest rated and is



under \$20. It also lets you set virtually any color of light that you would like – orange for Bronco games, green for St. Patrick’s Day and, of course, normal soft white for everyday use.

There are also many **commercially available assistive devices for hearing**. If you need help hearing the TV at a reasonable volume, you might try:

- **Earphones for watching TV -**  
Several companies make specific devices that can attach to your TV.
- **Sound bars for watching TV -**  
Many companies make sound

## Resources for Aging in Place with a Disability, Part 2 (Continued)

bars that you can add to your TV.

- Check for a dialogue mode which emphasizes the vocal spectrum of the sound to make dialog easier to understand. You almost need to try one to see if it works for you. If not, earphones are the best option.

### Exercise and Polio

- Online options for exercise:
  - Public recreation districts now have online classes such as, Thornton Active Adult Center:  
[www.thorntonco.gov/aac](http://www.thorntonco.gov/aac)
  - PBS - exercise classes:  
[www.pbs.org](http://www.pbs.org) (Search for "exercise" and see options)
  - Silver Sneakers (paid for by many Medicare Advantage Plans) now offers free online exercise classes, including many you can do in your chair:  
[tools.silversneakers.com/learn/live](http://tools.silversneakers.com/learn/live)

### Safety

- Apple Watch (needs to be paired with an iPhone) has many health monitoring features, but perhaps

the most useful is the **fall detector**, which activates when the watch falls, checks to see if you are okay, then calls 911 directly and guides services to your location through GPS if you do not respond. It is waterproof so it can be worn in the bathtub and shower.

- Carousel swivel transfer chair for tubs and showers fits in a regular size shower pan, slides in and out of the shower or tub. An inexpensive alternative to a walk-in bathtub -  
[www.platinumhealthllc.com](http://www.platinumhealthllc.com)

### Bracing

If you see a leg brace entering into your life or are considering getting a new leg brace, go to [www.humangaitinstitute.org](http://www.humangaitinstitute.org) to



## Resources for Aging in Place with a Disability, Part 2 (Continued)

research everything you need to know about bracing. It includes a workbook that will help you find the best brace available for your needs.

### **Mobility**

There now is light-weight transportation that uses rechargeable lithium-ion batteries. They can be transported in vehicles without ramps or lifts. Two examples:

- **Travel Scoot** - 35 pounds, folds up to fit in the trunk of a car or in an airplane's overhead compartment. A street bike, not an ATV. [www.travelscoot.com](http://www.travelscoot.com)
- **Fold and Go wheelchair** - 46 pounds, waterproof, folds to fit in the trunk or back seat of a car. Designed and manufactured by wheelchair users. [www.foldandgowheelchairs.com](http://www.foldandgowheelchairs.com)

The internet includes many other new, state-of-the-art creative solutions to wheelchair living.

*CPPO provides partial grants for these and other durable medical equipment, including braces, to polio survivors living in Colorado. Contact Mitzi Tolman at 720.940.9291 or [mtolman@eastersealscolorado.org](mailto:mtolman@eastersealscolorado.org) for further information and an application form.*



## 2021 CPPO Getaway Wrap-Up

The bi-annual Rocky Mountain Getaway sponsored by Colorado Post-Polio welcomed 32 campers to Easterseals Colorado's Rocky Mountain Village camp August 15th to 19th this year. Campers traveled from seven states and enjoyed a week of workshops, PT evaluations, inspirational speakers, music-filled evenings and fresh mountain air. Activities included a wildflower walk, swimming and water exercise, zip-lining, archery and fishing. Presentations ranged from self-care to learning how to fall and get up after falling. We look forward to seeing everyone in 2023!



**Mark your calendar for August 13-17 of 2023 for the next Colorado Post-Polio Rocky Mountain Getaway!**

## Porch Wheelchair for Sale

Greetings, I used to be on the Post-Polio board in Denver many years ago. I am a post-polio survivor (1951) and retired for 10 years. In September 2020, I broke my leg and was put in wheelchair mode for six weeks. I panicked and ordered a wheelchair porch lift to get to my car in the garage. In the meantime my son installed a ramp. So I have decided to sell my wheelchair porch lift. It is still in its original packaging, has one year left on its warranty and can be delivered by FedEx to anywhere. I paid \$4,600 for it and am asking \$3,600 or best offer. If you are interested and would like to receive more info, please email [reed@frij.com](mailto:reed@frij.com).

*Please Note: The Connections newsletter does not post items for sale. CPPPO made the exception to include this request to honor Ms. Reed's volunteer service.*

## ★ **CPPPO Statewide Zoom Meeting - Fires, Floods, Financial Scammers - How can you be prepared?**



The Colorado Post-Polio Organization will be hosting a Zoom meeting on **Saturday, January 29, 2022 from 10:30 a.m. to 12:30 p.m. (MST)**. Learn how to protect yourself from the latest scams and simple ways to prepare for unexpected emergencies. Advance registration is required for this meeting. Register at the following link: [bit.ly/cppozoom2022](https://bit.ly/cppozoom2022). After registering, a confirmation email containing information about joining the meetings will be sent.

★ **Planned Giving**



## *All abilities. Limitless possibilities.*

**Is the Easterseals Colorado Post-Polio program already in your will, trust, or estate plan?**

Thank you! Please let us know about your plans because it helps Easterseals Colorado plan for the future.

Notify Sharon Kay Brown in the Development Office  
([sbrown@eastersealscolorado.org](mailto:sbrown@eastersealscolorado.org) or 720.234.5976)  
and she will add your name to the Sunburst Legacy Society.  
Your gift may remain anonymous, if you like.

**Don't have a will?**

You're not alone! Now is a great time to start planning, and please consider including a bequest to the Easterseals Colorado Post-Polio program in your estate plan. Contact Sharon for suggested 'bequest language' and the Easterseals Colorado Tax ID for you to share with your attorney.





## 2021 Advisory Council Members

**Sue Brandon**, *Chairperson*

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**Jim Carr**

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720.394.5500

robert.v.burnett@gmail.com

## 2021 Advisory Council Meetings

Advisory Council Meetings are when our planning takes place. Members are always valued to comment on our future goals and activities. **Meetings are held quarterly on the third Wednesday of January, April, July, and October at 4:30 p.m. over Zoom. The next meeting will be held on January 26, 2022.**



## Colorado Post-Polio Support Group Schedules

Support Groups are beginning to meet in-person with appropriate social distancing. Others still meet virtually. Please stay in touch with your facilitator for further information.

### AURORA

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

Meeting in-person at New Hope Community 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, with a few exceptions.

Meeting in-person at Rock Family Church, 4005 Lee Vance Dr.

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

### GRAND JUNCTION

CPPO will host an information meeting and traveling clinic on the Western Slope in Spring 2022. Please contact Mitzi Tolman at 720.940.9291 or mtolman@eastersealscolorado.org for more information.

### LAKESWOOD

CPPO extends our thanks to Annette for her years facilitating this group.

Unfortunately, she needed to step down as facilitator. Mitzi will host a lunch in January 2022 to discuss the group's future. Please contact Mitzi Tolman at 720.940.9291 or mtolman@eastersealscolorado.org for more information.

### NORTH AREA

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

Meeting via Zoom. *Members outside of the North Area are welcome to attend.*

**Facilitator:** Jill Eelkema, LCSW, 720.675.9902 or jille@westerncarepartners.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 January 15, 2022 at 1:00 p.m.

**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 Noon.

Meeting via Zoom. *Contact Hal for the meeting link.*

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

 **Donations**

If you would like to donate to support Colorado Post-Polio efforts, **please complete this form, detach and mail it to Mitzi Tolman at Easterseals Colorado.** To ensure that we receive 100% of your donation, contributions should be **payable to Easterseals Colorado** with **"POST-POLIO" written in the memo line.** Your contribution will be gratefully acknowledged. Thank you again!

**NAME:** \_\_\_\_\_

**ADDRESS:** \_\_\_\_\_

**CITY, STATE, ZIP:** \_\_\_\_\_

**PHONE:** \_\_\_\_\_

**E-MAIL:** \_\_\_\_\_

**MAIL TO:**

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



**FREE MATTER FOR  
BLIND OR DISABLED**



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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](mailto: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 change your mailing information,** please contact Mitzi Tolman at Easterseals Colorado at 720.940.9291 or [mtolman@eastersealscolorado.org](mailto:mtolman@eastersealscolorado.org).