

Connections • Summer 2021 Newsletter

**The point is not to
pay back kindness,
but to pass it on.**

- Julia Alvarez

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Changemaker Challenge

changemaker

CPPO always encourages readers to advocate on their behalf. After reading the spring newsletter, Bruce Murray of South Hutchinson Island, Florida did just that and now changes are happening in his community. Excerpts from his initial email to CPPO along with an update email follow. It is our hope his actions inspire you to be a changemaker.

May 11, 2021 - I just wanted to tell you how much I enjoyed the recent newsletter. I have passed Dr. Eulberg's article on swallowing to three people, all of whom have been very appreciative. In addition, having just transitioned from a rollator to a small power wheelchair (right arm does not permit using manual), I have become much more attuned to many of the issues in Margaret Hinman's

article on ADA implementation. Since I have worked closely with city officials here and my wife Chairs the Parks Advisory Committee and we have dealt with some handicap access issues in the past, I forwarded that article to the Mayor, City Manager and Public Works Director offering myself and others as consultants on design and construction and suggesting another inspection of parks for issues. I have already heard back from the Mayor, who sent additional comments to the other two. I think that article will be credited with stimulating some improvements in thinking at least in this city.

Looking forward to the May 22 discussion of balancing exercise and post-polio issues. The physical and occupational therapy technicians assigned to me during the wheelchair implementation and pain management effort the past few weeks got an education from me on why "building up strength" was not a great goal. One actually followed some links I gave him and came back admitting he had learned some things."

Changemaker Challenge (Continued)



June 16, 2021 - Things arising directly from increased sensitivity due to the article include:

- Pavement repairs and repainting of handicap parking spaces was completed in three popular beach parks.
- An access sidewalk that had sinkage and damage so it collected water and mud interfering with entry to a handicap pavilion was fixed to improve access.
- A handicap rest room stall that is roomy with well-placed sink and soap dispenser but no hand dryer or towel dispenser except outside the stall and fifteen feet away, was identified and being worked on.
- An accessible ramp leading to a nice pavilion in a beach park [with] a six inch step to get from sidewalk to ramp is being fixed.

- A citizen is leading an effort to get more van spots or protect van spots from use by vehicles that do not need ramp space.
- The new sensitivity to needs raised by the article will result in a review of the plan for a park renovation about to begin.

In other activities [not directly related to the article],

- A service club completed an update of an inland park and improved handicap access for adults and children in the playground.
- A service club proposed a complete modernization and access improvement of a playground, using \$250,000 donated funds to be matched by \$250,000 city funds, is under review and consideration.

All told, I think some eyes have been opened.

Resources for Aging in Place with a Disability, Part 1 by Denver North Post-Polio Support Group



During the past two years, our group has discovered and shared many resources, services, practices, equipment and gadgets that help us age in place and maintain our quality of life as mature citizens with polio. We are passing our discoveries on to Connections readers. The listed resources 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.

We live in our own homes, some of us with spouses and family, some of us alone. Regardless of circumstances, there are times when help will lighten our load, ease stress and connect us

with others without compromising our independence. Some resources are free and others private pay. Some are available nationwide, some local. For those that are local, similar services can be found across the country. Knowing services are available somewhere means you can search to find what is in your area. With any services, be ready to be your own advocate and give yourself permission to find what will work for you.

Getting Help at Home

It can be hard to “find” someone who can help you figure out what you're eligible for:

Call your local **Area Agency on Aging (AAA)** to discuss your situation with an Information & Assistance Specialist or an Options Counselor. AAA is a nationwide program funded by the Older Americans Act and free to you. Denver Regional Council of Governments (DRCOG) houses the AAA serving the eight-county Denver metro area. To find the nearest AAA, eldercare.acl.gov/Public/About/Aging_Network/AAA.aspx.

Resources for Aging in Place with a Disability, Part 1 (Continued)

Care Managers are wonderful to talk to and can perform an assessment to figure out what you need, how to plan for down the road, make sure you have your bases covered, etc. Aging Life Care Association lists members of the national care manager association, www.aginglifecare.org.

Other options for in home help and care include:

In home care can be provided by an agency or by an individual hired privately. In home care ranges from a companion who offers 1:1 emotional support and helps in the home, to aides who can also help with personal care, to a private nurse to monitor medical issues. Costs range depending on what care and help is needed. Keep in mind, many agencies require a minimum number of hours per week. A care manager or sometimes your local AAA can help you figure out what works best for your situation.

Family members and friends - keep a list of what you need to have done, ask them for help when they come to visit and let them know how much



you appreciate the help. Many are waiting for you to ask.

Kind and generous neighbors are often willing to help if you ask. Reciprocate with services you can provide or treat them with fresh baked cookies!

Neighbor "kids" often appreciate a chance to earn a little money. You can get help for those occasional tasks, such as putting out the trash, mowing the lawn and vacuuming. If you don't have a large list of tasks to be done at one time, consider a weekly retainer so you can call when you need help to take things down from or put things on a shelf or in a cupboard, or get things you can't reach or maneuver.

Resources for Aging in Place with a Disability, Part 1 (Continued)

Volunteers are a great resource. In the Denver metro area, Alittlehelp.org, voacolorado.org and Volunteers in Action (viadenver.org) help to keep older adults living at home. Volunteers of America has supports in every state.

Students of all ages volunteer through school DECA or VoTech programs or through other organizations such as Girl Scouts and Boy Scouts, 4-H, Police Rangers and others. Call your local high school for recommendations.

Health and Fitness

On-demand urgent care in your home—find out who can come to you! This is an alternative to going to urgent care facilities. Doctors and other health care professionals bring diagnostic machines and supplies to your home. Medicare and other insurances are accepted. Dispatch Health is a service provider in the Denver area 303.500.1518, Dispatchhealth.com. This service-type is available throughout the country.

Our hearing changes as we age.



Sometimes we don't want or need to rely on hearing aids. There are alternatives that can help us in those instances when needed.

- **Ava** is a useful app you can use on your phone, computer or iPad. It provides live voice-to-text captioning. Check it out at ava.com.
- Explore **accessibility features on your devices** (i.e. iPhone) or talk with friends about what they use to make listening easier.

Exercise, Getting Outside and Polio

- **Public recreation districts** now have online classes such as, Thornton Active Adult Center, thorntonco.gov/aac.

Resources for Aging in Place with a Disability, Part 1 (Continued)

- **PBS exercise classes**, [pbs.org](https://www.pbs.org) (search for "exercise").
- **Silver Sneakers** (paid for by most Medicare Advantage Plans) now offers free online exercise classes, including many you can do from your chair, tools.silver-sneakers.com/Learn/Live

More and more public outdoor places are becoming accessible and your brain needs fresh air! Find **accessible trails and parks** near you at AccessibleNature.info or dayhikesneardenver.com/handicap-accessible-hikes.

Look for non-profits that promote getting outside and outdoor sports when you have a disability. **Outdoor Buddies** is popular in Colorado, outdoorbuddies.org.

For those who travel, **Accessible Go**, accessiblego.com, helps with travel logistics. An inclusive go-to for accessibility and inspiration for the wander-bug in all of us.

The app **Sit or Squat**, charmin.com/en-us/about-us/sitorsquat helps locate the nearest public restroom. The filter feature finds ones that are accessible.



Mountains & Plains Post-Polio Clinic

Dr. Marny Eulberg sees polio survivors at her Mountains & Plains Post-Polio Clinic in Wheat Ridge, Colorado. If you would like to be evaluated by Dr. Eulberg, please schedule an appointment at 303.829.1538 or marnyeul@me.com.

Iron Lung Museum Exhibit



Ouray County Ranch History Museum will host ***"How an Iron Lung found its home in Ridgway: Polio, Survivors, and the end of an Epidemic"*** September 24 - October 13.

The accessible exhibit will feature a 1937 Drinker-Collins (Serial No. 345) with functioning motor, rehabilitated body and interior, chromed window and side openings. Videos about this iron lung's journey, the family

associated with it and the history of polio along with local survivors will help tell the tale of polio in Colorado's San Juan Mountains during the exhibit's opening weekend, September 24 - 26. Check the website for updates, museum hours and exhibit details ocrhm.org. The museum is located at 321 Sherman St. (Highway 62), Ridgway, Colorado.

The museum is also collecting stories about how individuals contracted polio. If you would like to help build the museum's exhibit, please send your story and photo by August 22, 2021 to ocrhm.museum@gmail.com or OCRHM, P.O. Box 190, Ridgway, CO 81432. Every effort will be made to include your story. Support is greatly appreciated.



Visit the San Juan Mountains

Fall is the perfect time to visit the San Juan Mountains and quiet Colorado mountain towns of Ouray and Ridgway.



★ **Rotary Rockies Night**



Rotary
District 5450



The Colorado Rockies and Rotary International District 5450 invite you to join us at Coors Field to have some fun while rooting for your hometown baseball team and help raise funds to eradicate polio!

Sunday, September 26th @ 1:10pm
Colorado Rockies vs. San Francisco Giants

\$28 lower level seating

**prices are subject to increase based on demand. Purchase early to guarantee lowest price.*

For more information and to purchase tickets, please visit

www.rockies.com/ROTARY

Food for Thought - Embracing Assistive Devices ***by Margaret Hinman***

Assistive devices—those braces, crutches, canes, respirators, wheelchairs and other devices—**no matter how long or how frequently we have used them, we all have stories to tell about the experience, not only about the devices themselves, but about how we live with them.**

My first experience with assistive devices was navigating around Shodair Children's Hospital in Helena, Montana with a pair of Canadian walkers (forearm crutches) while lying on my stomach on a hospital gurney. I was not allowed to sit up or stand until my back strengthened. I was 11 years old and a smart alec pre-teen. The hospital was wonderful in that they allowed kids as much independence as possible, letting us



travel to and from physical therapy, which was in the basement, or getting together in the solarium just to hang out. I envied those who were able to use wheelchairs because they could race each other through the halls, practice wheelies or balance on two wheels as they sped down the long hallways.

I left the hospital sporting a locked-knee long leg brace (KAFO) and my pair of Canadian walkers. It took me two years to ditch the walkers—I needed my hands free to function in life. Two years later, the brace went, although there was every indication I should have kept it, but I found I could walk without it, even with hardly any functioning lower leg muscles and severe distortion. Post-surgery before my freshman year of college put me back on the forearm crutches for two years, and then they again, went into the closet.

Then, after 20 years as a professional, being physically active, hiking and fishing and three babies, a new reality hit. I hurt so bad I could hardly walk. Getting rid of pain is a

Food for Thought - Embracing Assistive Devices (Continued)

good motivator for change! However, with memories of that heavy, iron and leather brace, the locking knee joint, the stirrup riveted under the heel of brown oxfords or saddle shoes, and wearing that uncomfortable nuisance that broke often because of the stresses caused by my leg weaknesses, I did not go gracefully into the brace I really needed.

I started with a couple of different knee braces that were of no help. I had no calf muscle to hold them around my knee and they really didn't correct the cause of the problem, my severe back knee and knock knee. I graduated to a plastic and metal full leg brace that broke like the old ones, but at least the foot plate was inside the shoe and, by allowing some hyperextension, did not require a locked knee joint. Then came a graphite composite brace that was not only pretty, but durable. Finally, I worked up to what I really needed, a graphite composite full leg brace that not only held me up when I stood and walked, but also corrected my hyperextension and valgus and realigned my body, so I was able to walk better, my posture improved and

my clothes fit better.

In addition to braces, I cycled through several canes and pairs of forearm crutches, added rollator-walkers and an electric scooter so I could get out more.

Reflecting on my journey, I recognize that I might be in better shape today if I had always worn a brace and/or depended on crutches. However, based on what I knew then and how I felt at the time, I would not have changed what I did. My decisions were always practical, the devices were inconvenient and sometimes uncomfortable, plus I was able to function well enough despite what, on the surface, should not have been physically possible.

Dealing with the need for assistive devices is always very personal and is as unique as each person who faces the issue. Many of us who have had polio are extremely creative in our solutions to the problems. For example, wearing cowboy boots rather than braces to hide weakness in the ankles from others, wearing long dresses or

Food for Thought - Embracing Assistive Devices (Continued)

wide leg pants to hide braces or cover the shoe with a lift on it, or wearing designer shoes that match clothing to distract from the limp. Or just not wearing braces at all and walking on weak legs that look like they should not hold a person up.

As we have reached our mature years, many of us are grieving the loss of our independence and going back into bracing or into a wheelchair or using walkers or canes after discarding them when we were younger. If our previous aversions were caused by fear of or by being teased, or stared at, or feelings of being looked down upon or not being able to fit in, there is now good news. Many of those “others” have joined us in needing canes, crutches, walkers, wheelchairs and other devices. I guess we could say that, on some level, there is justice, and we are one-up on them because we already know how to use the devices well and thrive with their help.

Although my main motivation for how I lived was not the need to “fit in,” it is always refreshing to now see all those people in grocery stores,



senior recreation or living centers, educational institutions, and all-around town who recognize the need for assistive devices and are using them to keep themselves safe and mobile. We have finally arrived at an age of social leveling that makes it okay to use these aids to maintain and enhance our quality of life with confidence.

We are also benefitting from technological advances in assistive devices that were unheard of in the mid-1950s, with new materials that

Food for Thought - Embracing Assistive Devices (Continued)

are stronger and lighter, are colorful and are more ergonomically designed. Additionally, improved customizing techniques provide products that better fit our unique individual needs, are more comfortable and often allow for ways to express our individuality!

Today, my supply of assistive devices includes my brace, two pair of forearm crutches (Canadian walkers!), two rollator walkers (one in the house and one in the garage), two lightweight wheelchairs (one manual and one electric) and an electric scooter. If I go beyond the traditional definition of assistive devices, I wear glasses, drive a car, wear an Apple watch with fall detection, use a shower chair, have strategically placed grab bars, reach with a grabber and use assistive kitchen devices to move pots and to open jars, for example. I am finally embracing any assistive device that will make my life easier and will extend my ability to age in place.

However, as much as I appreciate what those devices can do for me, I still look forward to the end of the

day when I can get rid of them all and snuggle into my bed without the restrictions they put on my body!

Just some food for thought!



The Human Gait Institute: To learn about all things related to bracing, go to humangaitinstitute.org. This website was developed by a team of six who wear leg braces, five of whom are polio survivors and who have a combined 150+ years of brace wearing experience. It includes the ins and outs about bracing including a workbook to help potential brace wearers and/or those who are in the process of getting an “up-grade” identify what they want and need in a new brace. You can then communicate with confidence with your orthotist (brace maker) about what you need.

Food for Thought - Embracing Assistive Devices (Continued)

CPPO Durable Medical Equipment

Grant Program: CPPO provides partial grants for durable medical equipment, including braces and other assistive devices, to polio survivors living in Colorado. It has also funded some non-traditional assistive devices. The fund is not based on need, just limited to being a Colorado resident. For more information and an application form, contact Mitzi Tolman at 720.940.9291 or mtolman@eastersealscolorado.org.

Your medical insurance: Each insurer usually provides some coverage for some durable medical equipment. Speak to a customer service representative when looking to purchase a device to see what is covered, understand its limits and how much it will fund.



Did You Know?



Did you know that more than 200 Polio Eradication news stories have been published in major news outlets since July 2020?

What is an IRA Charitable Rollover?

Change the way the world defines and views disability by making profound, positive differences in people's lives every day with a gift to the Easterseals Colorado Post-Polio program.

What is an IRA Charitable Rollover?

An IRA Charitable Rollover allows taxpayers age 70 ½ or older to transfer up to \$100,000 annually from their IRA accounts directly to a charity without first having to recognize the distribution as income. Making such a gift from your IRA, 401k, or retirement plan is called a Qualified Charitable Distribution (QCD).

A key point to the IRA Charitable Rollover gift is that it needs to come directly from the financial institution that holds your retirement plan that you are giving from directly to the chosen charity.

To complete the qualified charitable distribution (QCD) from your retirement plan to Easterseals Colorado's **Post-Polio program**, the IRA, 401k, or retirement plan owner(s) must:

1. Already be age 70 ½ on the date of distribution.

2. Submit a distribution form to the IRA, 401k, or retirement plan custodian, requesting that the check be made payable directly to the charity (aka Easterseals Colorado—but can be designated to **Post-Polio**).

3. Ensure that no tax withholding is being done from the QCD to the charity (as the money must go to the charity to qualify, and as a non-taxable distribution no withholding should be necessary).

4. Send the check directly to the charity (have it come directly from your financial institution).

Under IRS Notice 2007-7, Q&A-41, it is permitted for the check to be mailed to the IRA, 401k, or retirement plan owner, as long as the check is payable to the charity, but a check payable to the IRA, 401k, or retirement owner that is merely endorsed over to the charity does not satisfy the QCD requirements.

★ **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 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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Robert Burnett (*Habla Español*)

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 at 4:30 p.m. over Zoom. Upcoming dates are October 27 and December 20, 2021.**



Colorado Post-Polio Support Group Schedules

Support Groups are beginning to meet in-person with social distancing. Others still meeting 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 Saturday of every month from 10:00 a.m. to Noon.

Meeting in-person. *Contact the facilitator for further information.*

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

GRAND JUNCTION

On hiatus until new facilitator found. If you know someone who might be interested, please contact Mitzi Tolman at 720.940.9291 or mtolman@eastersealscolorado.org.

LAKESWOOD

Meeting in-person. *Contact the facilitator for further information.*

Facilitator: Annette Beck, 720.427.1789 or annette.beck242@outlook.com

NORTH AREA

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

Meeting via Zoom. *Members from North Denver 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.

Meeting in-person. *Contact the facilitator for further information.*

Facilitator: Peter Way, 970.460.6164 or NOCOPolio@gmail.com

PUEBLO

Meets the 3rd Saturday of January, April, July and October from 2:30 to 4:30 p.m.

Next meeting October 16th at the Rawlings (Main Branch) Library, 100 E Abriendo Ave.

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 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**



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 change your mailing information, please contact Mitzi Tolman at Easterseals Colorado at 720.940.9291 or mtolman@eastersealscolorado.org.