

# connections

colorado post-polio • since 1981

## Changes Coming to Colorado Post-Polio

Colorado Post-Polio has grown significantly over the years, thanks to its hard working Executive Committee, other volunteers who make its programming successful and generous donors. Programming supports now include in addition to Support Groups (8):

- Annual PT & OT Workshop – Day-long professional training where therapists learn about post-polio syndrome;
- Rocky Mountain Getaway – 3 day/4 nights educational conference for polio survivors held on even years. The next Getaway will be held in 2020.
- Educational Workshops – Half-day educational workshops held throughout Colorado for polio survivors held on odd years;
- Traveling Clinic – Dr. Marny Eulberg sees patients living throughout Colorado;
- Grant Program – Supports purchase of durable medical equipment, and
- Colorado Post-Polio Connections newsletter.

As such, Colorado Post-Polio is pleased to announce that it is transitioning from a working volunteer



### Fall 2019

Meet Mitzi Tolman	2
Flu Season	3
Free Google Home	
Mini	4
Rocky Mtn. Getaway	4
Meet Robert Burnett	4
Polio Outbreak –	
The Philippines	5
Power Wheelchair or	
Scooter?	6
USB Charger	8
So. Denver & Pueblo	
Big Fall Conference	9
Advisory Council	10
Support Groups	10

## CHANGES COMING TO COLORADO POST-POLIO CONT.

Executive Committee, (committee members have for years been organizing all programming with supports from Easterseals Colorado), to a volunteer Advisory Council. All responsibilities will be transferred to its first-ever part-time staff.

We would like to welcome Mitzi Tolman to the Colorado Post-Polio family. She will be transitioning into this role this fall and will be fully onboard starting November 1. Until then, Kris Lindsey will remain your primary contact should you need anything and will continue as the newsletter editor ([klindsey@eastersealscolorado.org](mailto:klindsey@eastersealscolorado.org) or (303) 233-1666 ext. 226.

Colorado Post-Polio would also like to let you know that Robert Burnett will be joining our Advisory Council as will Margaret Hinman. Margaret has been a faithful volunteer organizing the Rocky Mountain Getaway including speakers, registration and facility logistics and other programming. Margaret's efforts will now focus on guiding the program.

### Meet Mitzi Tolman New Colorado Post-Polio Staff

Mitzi Tolman has always had a passion for health and wellness and believes that care needs to be holistic supporting the whole person. She is the daughter of a polio survivor and continues to learn about the long-term effects of the disease on health.

Mitzi's background ranges from athletic trainer to marketing to management. She is deeply involved with community programs on a volunteer basis. She has worked with city, county and state officials to ensure programs are consistent and equitable. She has experience with non-profit budgets, financial planning, program implementation and evaluation.

Mitzi has a B.S. in Health Education and Masters of Public Health Administration from Idaho State University. She lives with her husband and two high-school aged daughters in Westminster.

## Start of Flu Season Just Around the Corner

While the start of the 2019- 2020 flu season is still a month or so away, it's time to start thinking about prevention.

In an article in the November 2018 edition of the Pennsylvania Polio Survivors Network Newsletter, Dr. Richard Bruno said there is no reason for “polios” not to be vaccinated against flu or pneumonia, that you should talk to your primary care physician about it.

A recent CDC co-authored study published in the journal *Open Forum Infectious Diseases (OFID)* reports that people 85 years and older are much more likely to be hospitalized and die from flu than adults 65 to 74 years old. Re-searchers also found that the frequency of fever and several other typical symptoms of influenza decreased with age beyond 65 years, while the frequency of altered mental status increased with age. The OFID study adds to a growing body of evidence that supports the importance of vaccination in older adults and their contacts against influenza and Streptococcus pneumonia.

While flu seasons can vary in severity, during most seasons, people 65 years and older bear the greatest burden of severe flu disease.

Approximately 90% of influenza-related deaths and 50- 70% of influenza-related hospitalizations occur among people in this age group. Because of their increased risk, older adults are a priority group for vaccination. However, adults aged 65 years and older include a large and diverse group of approximately 46 million people in the United States. The prevalence of chronic diseases changes as age increases beyond 65 years, as does frailty and functional status, the CDC said.

Newer high-dose influenza vaccines available for persons aged 65 years and older may provide additional protection among people in this age group, the CDC said. Vaccination has been shown to reduce flu illnesses and more serious outcomes including hospitalization or even death in older people.

**SOURCE:** Sacramento Region Polio Survivors Group, September 2019 Newsletter

## GET A FREE GOOGLE HOME MINI

To celebrate the anniversary of the signing of the Americans with Disabilities Act (ADA), Google Nest is partnering with the Reeve Foundation to provide up to 100,000 free Google Home Minis. You may be eligible if you are living in the US and are either living with a physical disability, mobility challenge, or paralysis or are providing care to someone that fits that description.



The Google Home Mini is a smart device—

similar to Amazon's Echo devices—that responds to voice commands. Paired with smart plugs, smart thermostats or other connected devices, it can help make your home more accessible and ease the physical burden of your daily activities.

To apply, go to <https://googlenest.reevefoundation.org>. You can also find helpful tips there on how people with disabilities can get the most out of the device.

## Meet New Advisory Committee Member, Robert Burnett

Robert Burnett is a polio survivor who contracted the disease while growing up in Mexico. Robert has extensive knowledge in finances and is a CPA and executive. Robert was introduced to Colorado Post-Polio after experiencing health issues and consulting with Dr. Marny Eulberg. Robert is an avid soccer fan, fluent in Spanish and lives in Parker with his wife and two sons.

## MARK YOUR CALENDAR ROCKY MOUNTAIN GETAWAY AUGUST 16 – 20, 2020

A few years ago, I first attended an excellent post-polio syndrome retreat in Colorado sponsored by Colorado Post-polio. These occur every other year in a Rocky Mountains Easter Seal camp, and I highly recommend it. It was not until attending those retreats that I appreciated the diverse range of polio survivors and the range of impacts on mobility, atrophy of various limbs, breathing difficulties and post-polio syndrome effects. About half or more of those in attendance were on scooters or relied on other devices.

SOURCE: September 2019 Newsletter, Gregory Ptucha, Secretary, Sacramento Region Polio Survivors Group

# Polio Outbreak – The Philippines

## Disease outbreak news

On 19 September 2019, the Philippines declared an outbreak of polio. Two cases have been reported to date, both caused by vaccine-derived poliovirus type 2 (VDPV2). Environmental samples taken from sewage in Manila on 13 August and a waterway in Davao on 22 August have also tested positive for VDPV2.

The first case was confirmed on 14 September following testing by the National Polio Laboratory at the Research Institute for Tropical Medicine, the Japan National Institute of Infectious Diseases (NIID) and the United States Centers for Disease Control and Prevention (CDC). The case-patient is a 3-year-old girl from Lanao del Sur in the southern Philippines. The virus isolated is genetically linked to VDPV2 previously isolated from environmental samples in Manila and Davao. This indicates that the virus is circulating.

The second case was confirmed on 19 September and is a 5-year-old boy from Laguna Province, approximately 100 km south-east of Metro Manila. Investigations and further characterization of the virus are ongoing.

In addition, VDPV1 has also been isolated from environmental samples collected on 1 July, 22 July, 13 August, and 27 August from Manila.

Vaccine-derived polioviruses are rarely occurring forms of the poliovirus that have genetically changed from the attenuated

(weakened) virus contained in oral polio vaccine. They only occur when the vaccine virus is allowed to pass from person to person for a long time, which can only happen in places with limited immunization coverage and inadequate sanitation and hygiene. Over time, as it is passed between unimmunized people, it can regain the ability to cause disease. When the population is fully immunized with both oral polio vaccine and inactivated polio vaccine, this kind of transmission cannot take place. The gut immunity in people immunized with oral polio vaccine stops the virus from being passed on. Full immunization therefore protects against both vaccine-derived and wild polio viruses.

## Public health response

- Acute flaccid paralysis (AFP) and environmental surveillance are being enhanced to detect poliovirus.
- Field investigation is currently underway in Lanao del Sur to define the geographic scope of the circulation of the virus and inform planning for outbreak response including mass immunization campaigns.
- The Department of Health (DOH) reinforced its recommendation that all children should be vaccinated according to the routine immunization schedule.

*{Continued on page 8}*

## Power Wheelchair or Scooter?

A Bruno Byte

From Dr. Richard L. Bruno, HD, PhD

Director, International Centre for Polio Eradication

There is a Post-Polio Institute rule of thumb, or more correctly a rule of arms and legs: If you're wearing a short-leg brace you need to use a cane; if you're wearing a long-leg brace, you need to use two forearm crutches; if you have two braces, you need a wheelchair.

Obviously, there are lots of polio survivors with and without braces who need a wheelchair. But, after 35 years of experience, I no longer recommend either manual wheelchairs or scooters for polio survivors. If your arms are weak and your shoulders hurt too much to use crutches, you shouldn't be using a manual wheelchair...or a scooter. Both put tremendous physical stress on polio-damaged, overworked neurons, muscles and joints. The wheelchair requires that you propel yourself using your arms. You steer the scooter using your arms and shoulders to move a "T-bar" tiller that turns the front wheel while you use your hands to squeeze levers that make the scooter move. What's more, the tiller forces you to lean forward in the seat, putting you in a forward flexed position that causes neck and back pain.

On the other hand, there is the power wheelchair. Steered by a joystick, like those used for video games, power wheelchairs have a knob attached next to one of the arm rests. The joystick allows you to steer with only one hand -- or even just your fingers -- with arms at your sides and shoulders relaxed while sitting with "painless posture." Also, the new power chairs have mid-wheel drive, instead of the old rear

wheel motors, that allow the chair to turn in its own space, make it smaller and very maneuverable.

Power chairs can be fitted with special rigid backs that have adjustable foam inserts to provide the right amount of lumbar curve to insure proper posture. If you have trunk weakness or scoliosis, you can get a back made from custom-formed foam to cradle and hold your body in place. And if you have upper back or neck pain or muscle weakness, you can order a shoulder-high or head-high back, or an additional head rest, that will allow your muscles to be supported and relaxed while driving.

Power chairs can also accommodate custom seat cushions. If one butt cheek is smaller than the other, or if you have scoliosis and your upper body tilts, an adjustable cushion that has separate inflatable air bladders or foam inserts of different heights and firmness can lift one side of your pelvis and balance your body. Those with leg swelling can get manual or electric elevating leg rests. You can even get a special power seat riser to allow you to reach high cupboards and chairs whose backs recline and allow you to take your two, daily, 15-minute rests breaks (or even a nap) without leaving the comfort of your custom-designed chair.

Now that you know power wheelchairs are the way to go, how do you get Medicare or your insurance company to pay? Medicare and most insurance companies use the

## POWER WHEELCHAIR OR SCOOTER? Cont.

Medicare rule: You are eligible for a power chair “only if you need it in your home” and “your arms are either too weak or you have too much pain to propel the manual chair.” Your doctor and a physical therapist need to fill out the Certificate of Medical Necessity and write a separate letter of medical necessity for the power chair.

SOURCE: Power Wheelchair or Scooter?  
A Bruno Byte © [www.papolionetwork.org](http://www.papolionetwork.org)  
2018at TIRR Memorial Hermann  
Rehabilitation and Research in Houston,  
Texas.

(Posted 12/18/18)

*{Polio Outbreak – The Philippines Cont. from page 5}*

- WHO and other partners of the Global Polio Eradication Initiative (GPEI) are supporting the Department of Health and local health authorities in their detailed investigations and supporting efforts to enhance surveillance, strengthen routine immunization, communicate risk to the public and implement outbreak response in line with internationally agreed polio outbreak response guidelines.

### **WHO risk assessment**

WHO currently assesses the risk of international spread from the Philippines to be low. However, the risk of further spread within the Philippines is high due to limited population immunity (coverage of bivalent oral polio vaccine (OPV) and inactivated polio vaccine (IPV) was at 66% and 41% respectively in 2018) and suboptimal AFP surveillance.

SOURCE: World Health Organization, Emergency preparedness response;  
<https://www.who.int/csr/don/24-september-2019-polio-outbreak-the-philippines/en/>

***NOTE FROM DR. MARNY EULBERG: The injectable (killed virus) polio vaccine used in the US and other developed countries does NOT lead to the circulating vaccine-derived polio cases as described in the above article.***

## Do You Use A Scooter or Power Chair? Pride XLR USB Charger

Have you ever been out in your scooter/power chair and realized that your smart phone is almost out of power and there isn't a plug in sight?

The Pride XLR USB Charger is compatible with most iPhone, Android and mobile devices. Simply plug your USB cord into this charger and plug the other end into the charger port on your chair. Your device will charge whether your chair is moving or off. **No need to be tethered to a wall!!**



The charger will switch off automatically when the device is charged and will not discharge [drain] chair battery. **Specs:** 5V DC; 1-Amp charger; compatible with 24V/36V systems; 2" x 1" with lanyard.

The charger is offered at \$22.00. The internet has some for almost twice as much!

Just provide name, address, phone #, & mail check payable to BAPPG, 11660 Timbers Way, Boca Raton, FL 33428.

**Courtesy of a Boca Area Post-Polio Group member!**

## South Denver Post-Polio Group Needs YOU!

This Centennial post-polio support group is looking for new members. It meets **the second Tuesday of each month, 10:45 to 12:30**. Please join us at the Colorado Club Building, 4155 E. Jewell, Ste. 218. Questions, please contact Hal Golberg, its facilitator, at (303) 212-0017 or [halgoldberg@halgoldberg.net](mailto:halgoldberg@halgoldberg.net).

## Pueblo Post-Polio Support Group

The Pueblo Post-Polio Support group will meet from **11am to 3pm on October 15** at Barkman Library, corner of Jerry Murphy and Bonforte Blvd. This is the same location at which we had our delightful, informative meeting, thanks to Marny Eulberg and Margaret Hinman, on May 23. The speaker on Natural Remedies for Post-Polio Pains and Problems, indicated as the main interest of those present, has yet to be identified. Please call Mary Leonard, Coordinator, and (719) 544-4789 for details.



## What Happened to the Big Fall National Conference?

For many years, Colorado Post-Polio has held a big National weekend workshop every other year. After the one in 2017, the Executive Committee met to talk about everything Colorado is doing. This included:

- Bi-yearly Rocky Mountain Getaway,
- Annual fall, educational workshop to train Physical and Occupational therapists about the unique circumstances post-polio survivors experience with their health,
- Eight support groups spread across Colorado,
- Post-polio survivors are getting older and
- It is getting harder for survivors to travel.

After careful consideration, it was decided to forgo the big Denver conference and instead, hold half-day workshops around the State. As a result, late summer into early fall, educational workshops were held in Grand Junction, Pueblo, Colorado Springs, Lakewood and Ft. Collins. Between the first four workshops and the last workshop held in Ft. Collins, it is estimated that more people will have attended the local workshops than the number who attended the multi-day conference in Denver.

In 2020, Colorado will again host its Rocky Mountain Getaway August 16 - 20. It will continue to be held at Easterseals Colorado's **accessible** camp just 40 minutes west of Denver. Mark your calendars and start making plans to attend. You will learn a great deal about post-polio and how best to support yourself, meet fellow survivors and plain and simple, just enjoy the great Rocky Mountains.

Local workshops will again return in 2021 to areas around the State.

### **Advisory Council Meetings**

Easterseals Colorado  
393 S. Harlan St., Ste. 250  
*Lakewood*  
4:00pm  
December 16

## ADVISORY COUNCIL MEMBERS

Sue Brandon, Chairperson	(763) 377-2287	<a href="mailto:Sue.Brandon@g.com">Sue.Brandon@g.com</a>
Marny Eulberg, MD, Medical Advisor	(303) 829-1538	<a href="mailto:marnyeul@me.com">marnyeul@me.com</a>
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Robert Burnett (Hablo Espanol)	(720) 394-5500	<a href="mailto:robert.v.burnett@gmail.com">robert.v.burnett@gmail.com</a>

## Colorado Post-Polio Support Group Schedules

**Support Groups** have an activity or program for each meeting. In bad weather, call the contact person to make sure the meeting will be held.

**Aurora** – Meets 4th Thursday of each month, 11:00am to Noon

Contact: Myrna Schmidt – (608) 790-5755 – [myrnaschmidt1@yahoo.com](mailto:myrnaschmidt1@yahoo.com)

**Colorado Springs** – Meets 1<sup>st</sup> Saturday of each month, 10:00-noon, Sand Creek Division, C.S. Police Dept., 4125 Center Park Drive.

Contact: Hal Goldberg – (303) 212-0017 – [halgoldberg@halgoldberg.net](mailto:halgoldberg@halgoldberg.net)

**Grand Junction** – Please call for date, time and location.

Contact: Melanie McClanahan – (303) 638-3302 – [melcoloradogirl@gmail.com](mailto:melcoloradogirl@gmail.com)

**Lakewood** – Meets the 2nd Tuesday of every other month, 11:00am to 1:00pm at the Belmar Library (NEW), bring a brown bag lunch.

Contact: Annette Beck – (303) 427-1789 – [annette.beck242@outlook.com](mailto:annette.beck242@outlook.com)

**North Area** – Meets 3<sup>rd</sup> Saturday of the month, 10:00 to Noon, Vibra Hospital Longs Peak Conference Room

Contact: Jill Eelkema – (720)675-9902 – [jille@westerncarepartners.com](mailto:jille@westerncarepartners.com)

**Northern Colorado (Fort Collins)** – Meets 4th Saturday of each month, 10:00am to Noon

Contact: Peter Way – (970) 460-6164 – [NOCOPolio@gmail.com](mailto:NOCOPolio@gmail.com)

**Pueblo** – October 15, 11am – 3pm, Barkman Library.

Contact: Mary Agnes Leonard – (719) 544-4789 – [maryagnesleonard@gmail.com](mailto:maryagnesleonard@gmail.com)

**South Denver** – Meets 2<sup>nd</sup> Tuesday of each month, 10:45 to 12:30, Colorado Club Building, 4155 E. Jewell, Ste. 218. Contact: Hal Goldberg – (303) 212-0017 –

[halgoldberg@halgoldberg.net](mailto:halgoldberg@halgoldberg.net)



## THANK YOU JAN HAMILTON!

Jan is taking a step back from the Executive Committee. She, along with her parents, founding members Ed and Maryann Hamilton have helped make Colorado Post-Polio the success it is today. Jan, thank you for your love and dedication, you are greatly appreciated.

Easterseals Colorado Camp – Home of Colorado Post-Polio Rocky Mountain Getaway

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If you would like to make a donation to support Colorado Post-Polio efforts. Please complete this form, detach and mail it to Kris Lindsey 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, 393 S. Harlan St., Ste. 250, Lakewood, CO 80226

Memo line: Post-Polio

**FREE MATTER FOR  
BLIND OR DISABLED**

Colorado Post Polio  
c/o Easterseals Colorado  
393 S. Harlan St., Ste. 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 **Kris Lindsey at (303) 820-4767** or e-mail her at [klindsey@eastersealscolorado.org](mailto:klindsey@eastersealscolorado.org), or write to:

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c/o Easterseals Colorado  
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Lakewood, CO 80226

If you prefer to receive this newsletter online or change your mailing information, please contact: Kris Lindsey at Easterseals Colorado, at (303) 233-1666, ext. 226 or [klindsey@eastersealscolorado.org](mailto:klindsey@eastersealscolorado.org)