

colorado post-polio • since 1981

#### POLIOVIRUS CONTAINMENT NEWS GPEI Polio News June 2020

COVID-19 has disrupted polio eradication efforts worldwide, and containment of poliovirus - needed to secure a polio-free future - has also been affected. In many countries, National Authorities for Containment (NACs) have been commandeered to assist in COVID-19 diagnostic and quarantine work. Lab and research facilities have had to pause inventories for poliovirus infectious and potentially infectious materials, unable to physically access samples. Face-to-face training of auditors and staff has been waylaid due to social distancing measures. And retrofitting of infrastructure and biosafety equipment in designated poliovirusessential facilities has been placed on hold. In spite of barriers, key bodies of work continue, mostly virtually, to advance the certification of facilities handling and storing poliovirus against the GAPIII-Containment Certification Scheme.



A polio laboratory specialist at work in the Netherlands. Photo: C. McNab/UNF 2018



#### Summer 2020

Jonas Salk's Son	3
<b>Executive Committee</b>	e
Meetings	4
Support Groups	
Update	5
Small Victories	6
Traveling Clinic	9
PHI new website	10
How to use Zoom	11
<b>Executive Committee</b>	e
& Support Groups	14

#### JONAS SALK'S SON SEES HOPE IN COVID-19 EFFORTS, STILL PUSHING FOR POLIO ERADICATION

## There would be 'poetry' if Pitt teams created COVID-19 vaccine.

### By Sean D. Hamill, Pittsburgh Post-Gazette, 4/12/2020

As horrific as it is, it is not lost on Peter Salk, that this year's 65th anniversary of the announcement on April 12, 1955, that his father, Jonas Salk, had created the polio vaccine, comes in the middle of the COVID-19 pandemic that has researchers across the globe racing to create a vaccine.

"We've seen so much success with vaccines over the years, with polio and even influenza," said Dr. Salk, who lives in California where he is president of the Jonas Salk Legacy Foundation, as well as a visiting professor of infectious disease and microbiology at the University of Pittsburgh, where his father created the polio vaccine. "But I know now with this coronavirus, there is the feeling of helplessness, that there is nothing you can do."

"And there is a lot of controversy over how this pandemic has been handled around the world," he added. "But what's stood out for me is the way people have come together and sheltered in place. The degree of societal cohesion, how humanity has coalesced around this. My hope is that this is the silver lining in this."

"I'm just hoping one side of this experience is that we'll come out of this on the other side as more cooperative, nationally and internationally," he said. His father spent seven years researching and creating the polio vaccine, which at the time was considered the most feared disease in the U.S. because of its impact on children in particular.

The infectious disease, spread through infected fecal matter and saliva, infected about 40,000 people a year in the U.S., and 600,000 a year around the world, many of them children, in the years before the vaccine was introduced. In many cases, people recovered from its effects of muscle weaknesses and other impacts, but in thousands of cases each year, people died, or exhibited various levels of paralysis.

Before his father's vaccine, one case of polio in a neighborhood or town could cause people to avoid a pool, park, building or town if people believed that was where a child was infected.

Dr. Salk, now 76, said he recalled one summer his parents said they were not taking a regular trip from their summer home on Lake Erie to Cedar Point amusement park in Sandusky, Ohio, "because of the possibility of a polio case there."

When the polio vaccine was in clinical trials, Dr. Salk's father signed him and his brother up as test subjects, as were thousands of other kids in the Pittsburgh area. Like the rest of the country, he cheered when polio was virtually eliminated from the U.S. just seven years later, with a 97% reduction in cases after the vaccine was introduced.

Dr. Salk said as proud as he is about his father's accomplishments, he remains troubled by the lingering presence of polio in pockets around the planet, primarily in poorer countries because of a combination of vaccine problems and poor decisions by local governments. Last year, he said, there were 175 cases of naturally occurring "wild" polio cases in Afghanistan and Pakistan. There were another 364 cases of polio caused by the oral vaccine version. which uses a live polio virus to create immunity in people. The problem, he said, is that the oral vaccine version can get lodged in people's stomachs and grow into the virus itself, triggering the disease instead of conferring immunity against polio. The vaccine appears to grow in locations where residents have high levels of malnutrition and there may be other, competing viruses running through a community. The result, he said, is an ongoing, frustrating battle to stamp out the last few cases in the world.

"On one side of the conversation, this is a tremendous amount of progress from where we were not so long ago," he said. "But on the other hand, there are too many cases occurring, when we had a chance to completely eradicate the disease."

He worries, now, however, that the coronavirus will end up causing problems in the fight against polio.

#### ?

Which board game was created in the 1940s during the polio pandemic?

- Clueda (AKA Clue)
- Stratego
- ♥Rook
- ▲Contact
- Candyland
- Chutes and Ladders
- ♥All Star Baseball
- ▲Make-A-Million

{Answer on Page 12}

"I think the [polio] eradication program is going to take a hit from some of the coronavirus efforts, because of the focus [in funding and research] on the coronavirus," he said.

He said he has watched happily as two teams of researchers at his and his father's academic home, the University of Pittsburgh, have announced two different COVID-19 vaccine projects.

"These are two, really important efforts at the University of Pittsburgh. I hope the best for them," he said.

He has taken particular note of one part of one of the teams' efforts, by researchers Dr. Andrea Gambotta and Dr. Louis Falo at Pitt. Dr. Falo has been working for some time on a so-called "microneedle array" to get a vaccine into a person's body rather than a needle injection, or an oral liquid, which both have problems. The microneedle would be placed on a person's skin, like a Band-Aid, and the vaccine would be in the needles themselves as a mixture of sugar and a target protein, and simply be absorbed into the skin.

"I have an affinity with the microneedle array for use in the polio vaccine," he said. "It may also have to do with my childhood dislike for needles."

Whichever vaccine ultimately is shown to work, Dr. Salk said he hopes the desires for speed won't outrun the desire for safety. "One has to be careful in introducing new vaccines," he said. "We have to go as quickly as we can but we have to go cautiously. We shouldn't just introduce a vaccine that came through just a basic clinical trial."

He said while he hopes any of the teams around the world put the first COVID-19 vaccine together, given his father's work there on the polio vaccine, there would be "some poetry" if the COVID-19 vaccine was discovered at the University of Pittsburgh.

Sean D. Hamill: shamill@post-gazette.com or call 412-263-2579 or Twitter: @SeanDHamill

SOURCE: <u>https://www.post-</u> gazette.com/local/region/2020/04/12/JonasSa lk-s-son-sees-hope-in-COVID-19-effortsstill-pushing-forpolioeradication/stories/202004110041?utm source=newsletter&utm\_medium= email&utm\_content=editors-picksfrontpagefrontpage&utm\_campaign=Headlin es-Newsletter

Posted on Facebook, April 2020.

Executive Committee Meetings Easterseals Colorado 393 S. Harlan St., Ste. 250 Lakewood 4:00pm

September 21, December 21

#### Support Groups Update



Myrna, Group Facilitator, is behind the camera!

The Aurora Support Group met outdoors on the lawn of New Hope Community Church, under two gorgeous maple trees.

The temperature went up a bit as we were winding down, but otherwise it was perfect. There were eight of us and except for spouses we were six feet apart and wore masks. Everyone brought their own beverage, treat and chair.

It was delightful to be together but separate and to just talk about challenges of the last three months. Our last in person meeting was February. We had a few with clinic appointments and one mourning the loss of a dear dog (card will be sent) so an okay size group.

There is a "greeting area" outside of the sanctuary of the church that will allow for meeting space when the weather changes. For now we will breathe fresh air and enjoy.

A **BIG THANK YOU** to Mary Agnes, Pueblo Support Group Facilitator, and Melanie, facilitator of the Grand Junction and Delta support groups. We are so grateful for the time and energy each of you invested in the members of your groups. You will be greatly missed.

CPPO is searching for new leaders for these support groups. Mitzi Tolman will be in touch with members as things move forward. If you need anything in the meantime, please contact her at mtolman@eastersealscolorado.org. The Colorado Springs group met for first time since the COVID-19 outbreak face-toface (mask-to-mask) in July at a lovely park with lots of shade. Each person brought their own food and beverage. Everyone sat six to eight feet apart and was very excited to see one another again.

The South Denver Support Group is seeking new members. Do you know someone who hasn't been to a meeting lately? Tell them about South Denver's Group and have them call Hal, its facilitator, <u>halgoldberg@halgoldberg.net</u> or (303) 212-0017.

#### Small victories for lifelong athlete Gunnison Man sees setbacks, triumphs following childhood illness

Chris Rourke Gunnison Times

Life is not without challenges. And through facing and overcoming challenge, one gains strength. Sometimes that strength is needed unexpectedly down the road, when a difficulty previously conquered once again rears its ugly head.

Such has been the journey for Gunnison's Chris Haas. The former owner of a bike and ski shop — and hardcore athlete himself — is a survivor of polio. He conquered the disease, only to have its symptoms return decades later and rob his body of the activities he loved so much.

Yet, his new normal has taught him many of life's lessons — including how to let go of expectations and the past, eliminating the guilt of not being able to grind on a mountain bike like he once did.

He's now telling his story to others with the hope that they can find gratitude in everyday moments, as well as to raise awareness of the importance of eliminating the life-altering disease.

#### From iron lung, to iron lungs

Haas contracted polio at the young age of 5, just six months before the polio vaccine was released. His only memories of the ailment are being encased in an "iron lung," barely able to see his parents through a window, and being wrapped in wet, hot towels every day and soaking in a stainless-steel tub of hot water.

While polio has almost been eradicated in the 21st century, the disease which attacks the central nervous system reached epidemic levels in the 1900s. The vast majority of those infected by the virus only manifest flu-like symptoms, yet some suffer paralysis and even death.

Haas recovered from the disease in six months but was left with a deformity in his left leg. His foot turned inward, and he was unable to walk normally because of damage to a tendon. But it didn't slow him down as a child. He could still run even with his braced shoe.

A decade later, when Haas was 16, he underwent what he called the "miracle surgery." Doctors removed a healthy tendon from his foot, stretched it and then replaced the damaged one with it. Eighteen months later, Haas was playing football and lacrosse.



Photo Courtesy of Chris Rourke

"It was like someone left the gate open," Haas said. "I had a lot of dreams. I wanted to ski. I wanted to play football. I wanted to go to college. Two years after surgery, I was off to college in Boulder and I stopped talking about (polio)."

With his new lease on life, Haas studied business at University of Colorado-Boulder. While he did not finish his degree, he began working in the outdoor recreation industry, learning all he could about skis. Unknown to him at the time, the experience would lead him to starting a successful business called the Tune Up — a Gunnison ski and bike shop — in 1976.

Haas experienced the success of riding the mountain biking boom, turning paper boy bikes into mountain bikes which led to advising top companies on equipment fabrication. He also became a hardcore athlete, biking on 100-mile rides, skating and skiing.

#### Lifelong impact

Polio, which is transmitted through the saliva or fecal matter of an infected person, has plagued mankind for centuries. Yet, it reached epidemic proportions in the United States in the 1940s and '50s with as many as 58,000 cases and 3,000 deaths reported annually.

With the introduction of the Jonas Salk vaccination in 1955, new cases fell almost 90 percent within two years. Due to widespread vaccination, polio cases originating in the U.S. were eliminated by 1979.

However, the disease still lingers, largely in countries like Afghanistan, Nigeria and Pakistan, and may be making a small comeback. Rotary International is now a partner in the Global Polio Eradication Initiative, with the aim of making those countries polio-free. "If all eradication efforts stopped today, within 10 years, polio could paralyze as many as 200,000 children each year," states the Rotary International website. So far, Rotary has contributed more than \$1.8 billion toward eradicating the disease worldwide.

Even with the few cases of polio which now occur annually, the disease's impact can still be felt today as a survivor develops what is known as post polio syndrome.

#### 'You need to get it together'

As the years progressed, Haas began to note changes. For example, a good bike ride would leave him exhausted, while his friends would easily recover. He noticed new pain, not only in his leg but in other parts of his body.

At first, he thought it was just the effects of aging and from working so long in a retail store. However, Haas learned in 2004 that he has post-polio syndrome. The years that followed were grim. He sold his share of the Tune Up and sank into a lifestyle of inactivity. He slowly started giving up the things he was so passionate about — the activities that defined him in so many ways, the things he didn't think he could live without.

The pain and lack of energy led to days of sitting slumped on the couch, watching hours of television. His nights were endless with limited ability to sleep soundly. "I think it was a realization that, 'Hey, man, you need to get it together,'" Haas said of the moment he knew he needed a change.

#### Therapy through 'hoga'

He started seeing a chiropractor, who gave him three specific exercises and taught him how to stretch his back and how to use rolled-up towels under his back and neck on the floor.

The initial work was painful, but he began sleeping at night. Then Haas put together a daily routine of meaningful movement. His "dome" — a greenhouse in his yard which resembles a hollow upper half of a glass sphere — became a refuge. He began gardening in raised beds while sitting on a rolling stool. He used the actions of pruning and debugging plants as therapeutic exercise.

For example, he calls watering the plants and laying out hose "hoga," rather than yoga.

But the former athlete had more to cope with than just moving his muscles — there was his mind to deal with as well. What he learned was to value what he was able to do, rather than focusing on what he could no longer do.

"I used to think, 'If you're not going to ride your bike for 25 miles, why bother?" Haas said, lamenting loss of the high an athlete experiences after a hard workout.

But the three exercises and stretching his back gave him a jump start. He realized he could become fit once again, and resolve some of his pain.

"It is real, it is doing me good," he continued. "No, it's not aerobic, but I'm doing something and its meaningful."



Photo Courtesy of Chris Rourke

#### A gallon of gas a day

Haas likened his condition to a motor that gets one gallon of gas a day. When the tank runs dry, he's done. But he uses that "fuel" the best he can and rejoices in the small victories, rather than the big rides.

He's learned to keep his active brain busy by reading books and playing guitar. In the evening he does his "jazzitation" — or meditation with music and movement.

"It's allowed me to ditch the guilt and not be ashamed of no longer being athletic," he said. "I've developed some other interests. I've always had other interests."

Perhaps most impactful for Haas was the recent death of a friend who also had polio. He visited her regularly. His friend, he said, never experienced a recovery such as his — both of her legs had been affected by the disease and she spent her life in a wheelchair.

During one of their final conversations, she told him that she was so thankful. Bewildered, he asked her why. Outside her window was a tree in full bloom with a dumpster behind it. "Because I have a tree," she said. He could only see the dumpster.

"I had to come home and reevaluate," he said. "I needed to start finding more joy in what I'm doing. I've learned I just need to milk whatever I've got and listen to my body constantly and when it's time to sit down, it's time to sit down."

(*Chris Rourke can be contacted at* 970.641.1414 *or at chris.rourke@gunnisontimes.com*) <u>https://www.gunnisontimes.com/content/small-victories-lifelong-athlete</u>

SOURCE: Gunnison Times, used with permission.

*(Answer from Page 3)* Candy Land was created in the early 40s by Eleanor Abbot while recovering from polio. The game was tested by the children in the wards at the same hospital. It was published by the Milton Bradley Company in 1949. Milton Bradley, now Hasbro, has produced Candy Land for more than 50 years. Candy Land was inducted in 2005 National Toy Hall of Fame.

# **Traveling Clinic**

Dr. Marny Eulberg and the Traveling Clinic will be visiting Ft. Collins this fall in October. Please call or email her to let her know you are interested. Based upon interest, she will schedule the day(s) the clinic will be open.

Dr. Marny Eulberg, (303) 829-1538, marnyeul@me.com

# POSTPONED

The 2020 Rocky Mountain Getaway has been postponed due to the COVID-19 virus.

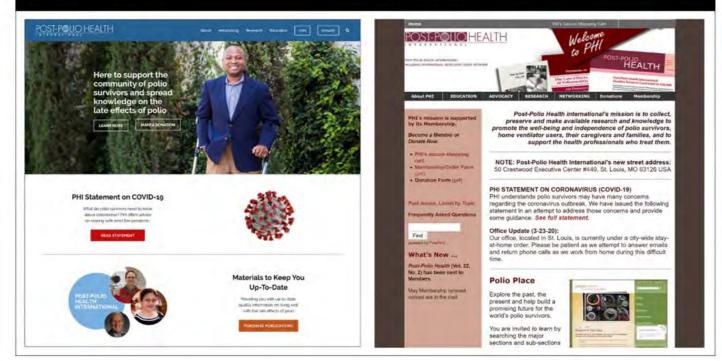
Look for upcoming information regarding new 2021 dates. If you have any questions, please contact Mitzi Tolman at (720) 940-9291 or mtolman@eastersealscolorado.org.

#### PHI'S NEW WEBSITE IS FINALLY HERE!

PHI's completely rebuilt website is now online. The new site can be found at the same URL as the old, **www.post-polio.org**. We've listened to many of your suggestions as to how we could improve the old site and hope the new site will provide a more user-friendly experience and aid your search for post-polio information and resources.

#### new website

#### old website





Colorado

#### William passed away in 2018.

692 people with disabilities will be helped because William included a bequest to Easterseals Colorado in his will.

Thanks to William, we are changing the way the world defines and views disabilities by making positive differences in people's lives every day. Include your favorite cause in your will or estate plan. Make a difference in the lives that follow.

We hope you'll become a member of the Sunburst Legacy Society, a special group of people showing extraordinary generosity by naming Easterseals Colorado as a beneficiary in their will, living trust, life insurance policy, pension plan or charitable trust. For more information, please visit our website at <u>www.eastersealscolorado.org</u> or contact Sharon Brown at 303.233.1666x266 or <u>sbrown@eastersealscolorado.org</u>.

#### **Getting Started with Zoom**

Here are some helpful YouTube videos:

• Zoom 101 Sign Up & Download Meeting Client

https://www.youtube.com/watch?list=PLKpRxBfeD1kEM\_I1IId3N\_XI77fKDzSXe&v=qsy 2Ph6kSf8&feature=emb\_rel\_end

• Join a Zoom Meeting

https://www.youtube.com/embed/hlkCmbvAHQQ?rel=0&autoplay=1&cc\_load\_policy=1

• How to use Zoom Online Meetings https://www.youtube.com/watch?v=-ik5o6WptX0

#### <u>Step 1:</u>

You will need a computer, iPad or smart phone with a video camera access.

If you do not have a video camera you can still participate via phone.

Each meeting has the phone in option for audio only.

#### <u>Step 2:</u>

Download the Zoom app on your computer, iPad or phone

You can do that by going to your app store and searching for Zoom



(look for this image to the right.)

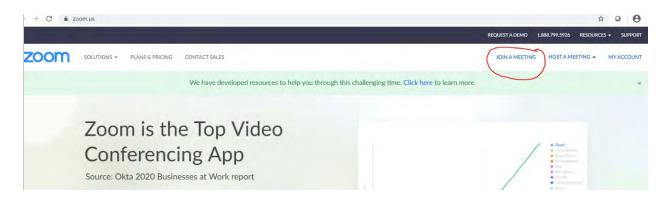
1st option called Zoom Client for Meetings is the best to select.

#### Step 3:

You can also do a google search for zoom or go directly to their website which is

<u>www.zoom.us</u> and from there you are able to join meeting by clicking on "Join a Meeting".

It will look like this below:



#### **Video Chatting Etiquette**

- Ensure your technology works correctly
  - Before the meeting, be sure to test your microphone, speakers, and camera to make sure you're ready to chat
- <u>Mute yourself when not speaking</u>
  - When there are multiple people in a video chat, it can be hard to hear everyone. When you're not speaking, try clicking the microphone icon on the bottom of the Zoom screen to mute yourself. This eliminates any background noises that could interfere with the meeting sounds.
    Note: If you choose to do this don't forget to unmute yourself when it's your turn.
  - Be mindful of taking turns while talking over video call. This ensures everyone gets a chance to speak. If someone is talking over another person, it is impossible to hear what either person is saying.
    - There is also a "chat" option where you can type in questions or comments if you do not want to interrupt or feel like you aren't being heard.

- Don't forget that the mic and the camera are on, especially when the meeting's over
  - Don't do anything you wouldn't want someone to see or hear during Zoom meetings is
  - Make sure you hit "leave meeting" and exit the Zoom screen at the end of the meeting to ensure the camera and microphone are disconnected
- Have fun! What a wonderful resource to keep in touch with those you care about.

#### **ADVISORY COUNCIL MEMBERS**

Sue Brandon, Chairperson	(763) 377-2287	Sue.Brandon@q.com
Marny Eulberg, MD, Medical Advisor	(303) 829-1538	marnyeul@me.com
Mitzi Tolman, Post-Polio Program Coor.	(720) 940-9291	mtolman@eastersealscolorado.org
Margaret Hinman	(303) 763-0013	mhinman12@icloud.com
Robert Burnett (Hablo Espanol)	(720) 394-5500	robert.v.burnett@gmail.com

#### **Colorado Post-Polio Support Groups**

**AT THIS TIME, AS A RESULT OF THE COVID OUTBREAK** some Support Groups are beginning to meet in-person with appropriate social distancing. Others are meeting virtually. Persons without a computer can call in to participate in the conversation. Contact your group's facilitator for the specific call-in phone number. We encourage you to stay in touch with your facilitator to find out how your group will be meeting.

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

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

**Colorado Springs** – Meets 1<sup>st</sup> Saturday of each month, 10:00-noon, Sand Creek Division, C.S. Police Dept., 950 Academy Park Loop.

<u>Contact</u>: Hal Goldberg – (303) 212-0017 – <u>halgoldberg@halgoldberg.net</u>

**Grand Junction** – On hiatus until new facilitator found.

Contact: Mitzi Tolman – (303) 940-9291 – mtolman@eastersealscolorado.org

**Lakewood** – Meets the 2nd Tuesday of May, June, September & November, 10:00am to 12:00pm at Easterseals Colorado until further notice bring a brown bag lunch.

Contact: Annette Beck – (720) 427-1789 – 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

Northern Colorado (Fort Collins) – Meets 4th Saturday of each month, 10:00am to Noon <u>Contact</u>: Peter Way – (970) 460-6164 – <u>NOCOPolio@gmail.com</u>

Pueblo – The next Pueblo meeting will be held September 19 in the afternoon. Please contact Mitzi Tolman for more info (303) 940-9291 <u>mtolman@eastersealscolorado.org</u> South Denver – Meets 2<sup>nd</sup> Tuesday of each month, 10:45 to 12:30, Colorado Club Building, 4155 E. Jewell, Ste. 218. <u>Contact</u>: Hal Goldberg – (303) 212-0017 – halgoldberg@halgoldberg.net



Pat Jenni, a member of the CPPO Board. is retiring. Pat is the daughter of Mary Anne and Ed Hamilton, who was the founder and leader of the Colorado post-polio organization. She has carried on her mother's legacy. We have treasured Pat's contributions, especially her design and artistic eye. She has been instrumental in producing all the print pieces that CPPO has published in the last six years. Pat has worked behind the scenes supporting many CPPO events humbling giving without any expectations of recognition. She will be missed, and we wish her the best.

#### 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 contact Mitzi Tolman at (720) 940-9291 or e-mail her at <a href="mailto:mtommation-mtom">mtolman@eastersealscolorado.org</a>, or write to:

Colorado Post-Polio Connections

c/o Easterseals Colorado

393 S. Harlan St., Ste. 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 <u>mtolman@eastersealscolorado.org</u>

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 **Mitzi Tolman at (720) 940-9291** or e-mail her at <u>mtolman@eastersealscolorado.org</u>, or write to:

Colorado Post-Polio *Connections* c/o Easterseals Colorado 393 S. Harlan St., Ste. 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