

Connections • Winter 2025 Newsletter

"There's no place like home."

Dorothy Gale, *The Wizard of Oz*

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The legacy of isolation is a double-edged sword for children in Nuristan, Eastern Afghanistan 08/21/2024



Two-year-old Roqia and her grandfather look out over the steep-sided Kamdesh valley in Afghanistan. When she contracted polio in February, Roqia's grandfather carried her down the mountain for treatment. © UNICEF.

Nestled against her grandfather's folded legs, Roqia looks solemnly at the strangers who have come to visit. Above them, the window opens onto steepsided mountains, where the last of the morning's rain clouds still linger, sticking to the highest trees. In February when the two-year-old developed a fever and weakness in her left leg, her grandfather made the two-hour journey down to the district hospital on foot, carrying his granddaughter in his arms.

The lab results came back positive: Roqia had polio. Roqia lives in the mountain village of Samarbagh in Nuristan, one of the remotest provinces in Afghanistan. Nuristanis have historically lived a sequestered life, cut off by towering, jagged peaks. The harsh terrain also compromises access to basic services like health care and sanitation, and a broad spectrum of nutritious foods. Samarbagh is at the top of a mountain, a 10-hour drive from the regional capital, Jalalabad, over the solitary, precipitous road that picks its way north along the Kamdesh River. Leaving the road, we cross a rickety wooden bridge over the roaring river and climb the path that zig-zags up to the village - a cluster of wooden-framed houses clinging to the mountainside. This is the main thoroughfare, for medicines and supplies as well as for people. Here, nature rules with an iron fist - Samarbagh can be cut off for months at a time by the winter snows and springtime melt, and the frequent rains.

The villagers eke out a living from subsistence agriculture, tending to goats – the only livestock to thrive in this precipitous terrain – and harvesting the walnuts growing wild on the mountain. They mostly eat what they can produce – milk products, seasonal fruits and nuts, and what grains and pulses grow in this climate. The husband-and-wife team who provide rudimentary health care out of a one-roomed hut also double as the village schoolteachers. Their pharmacy cupboard contains mostly oral rehydration solution, antibiotics and paracetamol.*



The legacy of isolation is a double-edged sword... (Continued)

For children to grow up well-nourished and resilient to polio and other diseases, nutrition interventions must begin long before birth. Samarbagh's low-protein diet means the majority of women of child-bearing age are anemic, and many children show signs of malnutrition.

It's perhaps of little surprise that Roqia was malnourished in her first years of life. She was exclusively breastfed until she was more than a year old, which is not enough: above 6 months, a growing baby needs more nourishment than breast milk alone can provide. In communities like Samarbagh where food can be scarce, especially during the winter, complementary feeding is often delayed.

Malnutrition impacts a child's development and opens the door to diseases like polio. This is a common story across the province: almost 60 percent of Nuristani children are stunted, and 6 percent are moderately or severely wasted – 25 percent higher than the national average.[1]

Moreover, Roqia, like 95 percent of children in Nuristan, has missed some of her basic vaccinations. Her house doesn't have a sanitation or sewerage system: the small percentage of Nuristani homes that do are down in the valleys. Combine inadequate nutrition, a lack of basic sanitation and low



Roqia's grandfather carries her up one of the steep wooden staircases that connect the different levels of their mountainside in Afghanistan. She has regained the ability to walk since contract polio last winter, but she still spares her left leg. © UNICEF.

vaccination rates and you have a critical mass: thousands of children in these mountain villages face an elevated risk of contracting polio and other preventable diseases.

Today the little girl looks healthy. Although she spares her left leg, Roqia is walking, and upper-arm measurements confirm that her nutrition status is in the normal range. All being well, under the watchful eye of her parents and doting grandfather, her cognitive development will not be impaired – although she will probably always suffer weakness in her left leg.

In some ways, Roqia is lucky. The district hospital is within sight of the village, down in the valley far below. For children in the next valley or the next, precipitous mountain passes make for a perilous journey, especially for someone carrying a sick child.



The legacy of isolation is a double-edged sword... (Continued)

To keep the children of these mountains safe from polio, the intersecting needs that escalate their vulnerability to the virus must be addressed. comprehensively and holistically. Combined polio, routine immunization, nutrition and WASH schemes recently piloted in other high-risk parts for polio of the East Region are showing signs of success, and the argument for adapting them for Nuristan is strong, however challenging it may be. The geography that isolates villages like Samarbagh does not quarantine them from polio. These children are more at risk, not less, because of it.



Roqia and her grandfather visit the health post in Samarbagh which serves every village on this mountain in eastern Afghanistan. Staffed by a husband-and-wife community health team, it offers first aid and nutrition screening services, and dispenses basic medicines. © UNICEF.

[1] All data in this article is from UNICEF's most recent Multi-Indicator Cluster Survey for Afghanistan, accessible here: <u>UNICEF MICS</u> (2022-23).

SOURCE: Global Polio Eradication Initiative (GPEI). (2024, August 8). The legacy of isolation is a double-edged sword for children in Nuristan, Eastern Afghanistan. Retrieved December 21, 2021, from

https://polioeradication.org/news/thelegacy-of-isolation-is-a-double-edgedsword-for-children-in-nuristan-easternafghanistan/.

* Paracetamol is the term used in the United Kingdom and other countries for what is known in the U.S. as Tylenol or generic name acetaminophen.



Food for Thought—Home -By Margaret Hinman

I love my home! It is my sanctuary, my safe place, and it gives me joy, peace and serenity! It is accessible, having modifications that make my life easier such as wheelchair and walker wide doorways, strategically placed grab bars, high rise toilets, and a stair chair, to name a few. (The recliner and the stair chair lift are part of my home courtesy of the CPPO DME grant program.)



My home provides me with the tools to live an active, stimulating life: TV, computer, of course a phone, Zoom access, space to do hobbies and jigsaw puzzles, welcoming spaces to entertain friends. It provides me with warmth and physical comfort, furniture I can get into and out of, an electric recliner, heated throws, a stool that allow me to sit at my kitchen counter.



However, my home is more than a practical place to live. It feeds my soul. It speaks to my senses. Over the years I have enjoyed the challenge of furnishing and decorating it with items that I love, cleaning out unnecessary clutter, including all of those obsolete small appliances and that still "good" furniture that no longer has use and decorations that I no longer REALLY like. And this continues to be a work in progress!

My spaces are opened up, providing greater accessibility, but more importantly the resulting spaciousness is calming and allows me to focus on my special things. My décor consists mostly of pictures, artifacts, and plants that I enjoy just looking at and caring for, and it includes pictures of my family and the people I love, and special gifts given to me over the years.



Food for Thought (Continued)

I have music at my fingertips, and scented wall diffusers. I can go into any room in my house and sit and just be, take in the ambiance, relax, maybe read a good book, be content and relish the peace and serenity it provides! I love my home!

My goal is to continue to age in place in my home for the rest of my life. However, if at some time I need to downsize or move to assisted living, a high priority will be to furnish and decorate my new home with items that make me happy, give me joy and serenity, even if it is limited to only a few pictures and maybe fresh flowers that need to be replaced every week! Until then, I cherish living in my practically perfect home!

Just some food for thought!



Margaret Hinman (L) and friend (R).

Polio Medical Alert Card enclosed in this issue of the newsletter!

The Polio Medical Alert Card enclosed in this issue of the newsletter fits into your wallet like a business card so you can have it with you at all times, particularly when you are being seen by any medical professional. This compact card contains all of the information polio survivors and their medical providers need to know about polio in order to treat whatever condition is being addressed with or without the interaction of polio. Carry this card with you at all times, and when you encounter medical professionals have them read it and return it to you. This will open up conversation about your polio and alerts the professional about it in relation to your other conditions.

To get additional copies of this card, contact Mitzi Tolman at mtolman@eastersealscolordo.org. A two-dollar donation would be greatly appreciated.



Family Corner - Growing Up -By Coral Tolman, Age 20

When I think of my relationship with my grandma and great-aunt growing up, I don't ever think of them as having to miss out on activities due to their polio or post-polio syndrome. Maybe this is due to child-like ignorance or more likely, due to them making a point to involve themselves in my life. They each found a passion of mine and found a way for us to do it together.



With my grandma I crafted, whether it was making Christmas cards or sewing 4-H projects, grandma was always managing my mess-making. The best part about crafting with grandma was that she didn't dismiss my crazy ideas; I vividly remember taking a project and starting to cut it how I thought I wanted without any pattern or measuring and although my grandma looked like she might die, she let me do it anyway. I learned so much from my grandma in the craft room and am very thankful for her patience and willingness to spend hours upon hours helping me.

The best part about going to the cabin with my Great-Aunt Marny was she never got annoyed at my insistent questioning "Why?". Instead of giving me the typical-because I said so-response, she would either give me an explanation or encourage me to find it. I would go off into the woods searching for flowers, mushrooms, and scat, all of which I would bring back to the cabin and Aunt Marny would help me go through and identify all of them. I was able to get my wiggles out and learn something in the process.

Spending time together and being allowed to learn from them and with them has made our relationship an important part of my life.



CPPO DME Grants of over \$20,000 have been awarded between 2008 and 2024 -By Mitzi Tolman

Due to the generous donations from the Bernklau Trust and Harriet Weltman's estate, in 2008 CPPO began offering grants to assist with the purchase of medical equipment, devices and other services that would enhance the lives of polio survivors in Colorado. It was recognized that some devices that could improve polio survivors' lives were not covered by most health insurances.

These items included lift chairs, chair lifts for stairs, powered mobility devices that could be used outside the home, portable oxygen generating devices such as Imogen, devices/equipment used in the bathroom, or devices used to transport power scooters or wheelchairs. In addition, some had difficulty paying the co-pays/deductibles for braces or wheelchairs that were partially covered by health insurance.



Initially, CPPO asked for financial information to ensure that those most in need would receive the grants. We have learned, over the years, that polio survivors are a "proud group" and many who could have benefited have been reluctant to apply. About five years ago, all questions about finances were removed from the application, but it is still an expectation that applicants use health insurance benefits first if those benefits are available.



Unlike insurance companies, CPPO does not have a list of what will be covered and what will not. Applicants are asked to explain how the requested item will improve their lives and then it is carefully reviewed. In one instance, CPPO helped finance the cost of removing an old, wrinkly carpet that was causing falls and replaced it with a smoother floor covering!



Are there devices/equipment that would make your life safer, easier or allow you to do things that you would like to do but don't because it is to hard or unsafe? Or do you have trouble paying the co-pay/deductible for needed mobility equipment or is it not even covered by insurance?











C.P.P.O. Durable Medical Equipment (DME) Fund makes grants up to \$1,500 per calendar year. Funds are paid directly to the vendor. To learn more, contact Mitzi Tolman, (720) 940-9291 or <u>(mtolman@eastersealscolorado.org).</u>

Input Needed for Upcoming Statewide and Beyond Zoom Educational Meetings

CPPO is currently reviewing educational meetings and needs your input. Please let Mitzi know at mtolman@eastersealscolorado.org what you would like the meetings to focus on in 2025. Things to consider: regional in-person meetings, a large oneday statewide meeting, continuing quarterly Zoom meetings or moving to more specific Zoom meetings. CPPO is open to exploring all educational and communitybuilding ideas. Then, keep an eye out for the 2025 spring newsletter when CPPO will announce its plans for its educational sessions.



Solutions for Living Better with Polio - Kitchen Gadgets

There is no cure for polio. We are not going to restore what our bodies have lost so we must be creative and use whatever tools, devices, and strategies we can find to help us live full, independent lives. Here are some that polio survivors have discovered and use:

Who knows if food jars lids are made tighter or if our hands and wrists are getting weaker as we age. The answer is it probably a little bit of both. So, the solutions to this quandary are assistive devices that can either help loosen those lids or ones that do it for you.

There are the traditional solutions such as the rubber square that grips the lid, the canning jar opener, that is, a gripping pair of pilers that has a hinged, rounded pliers that fit jars and a long pair of handles and there is an antique style opener with gripping teeth that tighten on the lid and a handle on the top of the gripper that can be grasped in one's fist and turned.



However, a better device is a batteryoperated opener that one sets on the lid and pushes the start button and lets the opener grasp the jar, tightens around the lid and rotates the lid to open the jar. And shuts off when it is done. It is rather compact and fits into a kitchen drawer.





Solutions (Continued)

Also, when it comes to can openers, there are battery operated or electric ones, similar to the jar opener, that again sit on the top of the can and rotate around the top to open the can. Again, they are compact, lightweight and fit into a kitchen drawer. They are not your old electric can opener that was huge and cluttered your countertop because of it size.



Items, equipment, or strategies listed have been discovered by polio survivors, are not intended or used as advertisements and are not endorsed by Colorado Post-Polio Organization or Easterseals Colorado. If you have any great discoveries that you would like to share, send them to Mitzi Tolman at

mtolman@eastersealscolorado.org and she will pass them on to the authors.

*This item may be eligible for Colorado Post-Polio Organization supplemental grant money to assist in the purchase by polio survivors who are residents of Colorado. Contact Mitzi Tolman for an application form.



Just for Fun - New Year's Resolutions

Every January we are thrust into the mindset of how to make the best of the year ahead. Setting goals and making resolutions is common practice. Let's take a look at the most common resolutions for 2025!

Save more money - 21%



Eat healthier - 19%



Exercise more - 17%



Lose weight - 15%

Spend more time with friends/family - 12%



Quit smoking - 9%



Reduce spending on living expenses - 9%



Resolutions can also include prioritizing self-care, staying active within our abilities, connecting with fellow members for support, or exploring new ways to enrich our lives. Are you making any resolutions this year?



2025 Advisory Council Members

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2025 Advisory Council Meetings

Advisory Council Meetings are when planning takes place. You are welcome to attend. Meetings are held quarterly, the 4th Wednesday of the month at 4:30 p.m. via Zoom. If you are interested in attending, please let Mitzi know.

2025 dates: January 22, April 23, July 23, October 22



Need more info? Check out CPPO's Resource Book of Articles Related to Polio and Post-Polio Syndrome. <u>https://www.easterseals.com/co/shared-components/document-library/post-polio/july-22-resource-book.pdf</u>



Colorado Post-Polio Support Group Schedules

CPPO encourages you to stay in touch with your facilitator, so you are aware of any group meeting changes.

AURORA

Meets the 4th Thursday of every month from 11:00 a.m. to 12:30 p.m. Meeting in-person at the New Hope Church, 17699 E. Hampden Ave. Facilitator: Myrna Schmidt, 608.790.5755 or <u>myrnaschmidt1@yahoo.com</u>

COLORADO SPRINGS

Meets the 1st Wednesday of every month from 10:30 a.m. to 12:30 p.m. Meeting in-person at the Colorado Springs Police Dept., 950 Academy Park Loop. Contact the facilitator for additional information.

Facilitator: Mitzi Tolman, 720.940.9291 or mtolman@eastersealscolorado.org

DENVER NORTH

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

Meeting via Zoom.

Facilitator: Jill Eelkema, LCSW, 720.675.9902 or jille@westerncarepartners.com

DENVER SOUTH

Meets the 1st Tuesday of every month from 11:00 a.m. to 12:45

Meeting via Zoom. Contact the facilitator for the link.

Facilitator: Mitzi Tolman, 720.940.9291 or mtolman@eastersealscolorado.org

GRAND JUNCTION

Contact Ron Carlson, 970.640.8052 or <u>rpcarlson2@gmail.com</u> for support and information. No group meetings at this time.

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

Contact Jill Eelkema, LCSW, 720.675.9902 or jille@westerncarepartners.com for support and information. No group meetings at this time.

ZOOM Group

Meeting via Zoom the 2nd Wednesday of every month from 2:00 p.m. to 4:00 p.m. PST / 3:00 p.m. to 5:00 p.m. MST / 4:00 p.m. to 6:00 p.m. CST and 5:00 p.m. to 7:00 p.m. EST.

Everyone is welcome to attend.

Facilitator: Jill Eelkema, LCSW, 720.675.9902 or jille@westerncarepartners.com

Join Zoom meeting at

https://us02web.zoom.us/j/89008651033?pwd=TUZhVVpPc1hKOGJRTy9Bek8rZnppdz09 Meeting ID: 890 0865 1033 Passcode: 184185 Phone number to call in: 719-359-4580



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 <u>"POST-POLIO" written in the memo line</u>. 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 <u>Memo line: POST-POLIO</u>

This Is YOUR Newsletter – *Connections* is the official news publication of the Colorado Post-Polio Program. The opinions are those of the individual contributors, and do not necessarily constitute an endorsement or approval by either the Colorado Post-Polio Council or Easterseals Colorado. (Always check with your personal physician for all medical questions and concerns.)

We invite not only your comments about this newsletter; tell us what topics you want to read about in future issues. If you have article ideas or suggestions, are willing to write a short article, tell your personal story or you'd like to review a book, please call **Mitzi Tolman** at **720.940.9291** or email her at **mtolman@eastersealscolorado.org**, or write to: Easterseals Colorado, Attn: Mitzi Tolman - Colorado Post-Polio *Connections*, 393 S Harlan St, Suite 250, Lakewood, CO 80226.

If you prefer to receive this newsletter online or need to change your mailing information, please contact Mitzi Tolman at Easterseals Colorado at 720.940.9291 or mtolman@eastersealscolorado.org.

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it doesn't mean you