SET YOUR CALENDAR FOR ANOTHER RETREAT!
AUGUST 14 to 19, 2016
For Information ----- Anita Vedi (303) 587-8412
Spring, 2016

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Having Fun, Making Friends, Mastering Skills, Expanding Knowledge and Independence is what We’ll offer you.

Do you remember the good-ole-days meeting and laughing with roommates, sleeping on the bottom bunk and sharing the bathroom? Well, here’s another chance to revisit that memorable time. You’ll be surprised and enjoy all the joyful comradeship!

After 800 kids frolick at Easter Seals’ Rocky Mountain Village Summer Camp, Colorado Post Polio is moving in for a second Retreat there. The dates are Sunday through Friday, August 14 to 19, 2016.
Over 50 survivors and caregivers from many states attended in 2014, and their helpful suggestions are incorporated this time.

All Camp facilities are handicap accessible and paths are also. Savor the clean air as you meet new friends and fill up with new Post-Polio knowledge.

The plan calls for many Learning Sessions, Entertainment and Fun events indoors and out. And we will have various experts available to help and challenge you to try something you’ve never done! SEVERAL OF OUR PREVIOUS PRESENTERS ARE COMING AGAIN!

If you are over 85, you might just qualify for the oldest zip-liner or wall-climber!

There will be several LODGING CHOICES, since the historic 220-acre camp with new improvements, dates from years ago. Most buildings are log, though renovated.

HOMEBUILDER’S LODGE is our new 3 story lodge accommodating up to 50 people. Besides an elevator, it has a conference room, a cozy lounge area with a gas fire place, a fully equipped kitchen, 2 kitchenettes, an apartment with a private entrance, other rooms with bunks or queen size beds and 11 restrooms. This Lodge is not “roughing it.” Relax on the covered deck to savor the beautiful mountain views and natural surroundings and maybe inhale an afternoon sprinkle. Reservations are first-come, first-serve for this beauty.

FRONTIER LODGE has 5 rooms with a combination of bunk and single beds accommodating up to 30 people. With two restrooms, this lodge is conveniently attached to the main lodge, allowing for your easiest access to our dining hall, recreation room, conference room and Genesee Hall, the lovely up-to-date conference room.

6 NEWLY REMODELED CABINS comfortably sleep up to 15 people. Restrooms in these are fully accessible.

Off-site lodging options are available for those folks uncomfortable without upscale creature comforts. – Just ask for suggestions.

The year-round and cross-trained camp staffers are youthful and have lived at the Camp for years. You will be delighted being around such peppy and thoughtful folks.

The 3 meals a day are delicious. A flexible casual and fine dining menu allows for special dietary needs. Water and snacks are always available.

Call Nancy Hanson for a brochure: 303-233-1666 x237 – Nhanson@eastersealscolorado.org

If you are computer savvy, here’s how you can find more information and see pictures of the Camp itself: http://www.easterseals.com/co/shared-components/document-library/rocky-mountain-village.pdf
How the Brain Works

For about 6 months, your editor has suffered from what’s wrong in this cartoon.
Surviving more than one acute episode of depression has taught me some valuable helps I’d like to share them with readers:

Seek professional help
Treasure your faithful friends
Try to enjoy eating and sleeping
Get dressed; (even same clothes every day)

Stay away from doubters
Helpful ideas come from many sources
Try to laugh and sing
Don’t give up

Sandy Stoler is returning for our August Retreat to give us wise and clever information about our brains..... Do yourself a favor; come see and hear her!

RECOGNIZING TYPICAL COPING STYLES OF POLIO SURVIVORS CAN IMPROVE RE-REHABILITATION


Post-Polio Syndrome is diagnosed by excluding it from other conditions or symptoms. During the past ten years many polio survivors in the U.S. have actively been seeking professional help for a wide range of new physical problems, commonly referred to as the late effects of polio. (Post-Polio Syndrome). Often, these people need Re-rehabilitation to continue their usual social roles. The Post-Polio Research and Training Program of the University of Michigan Medical Center found three patterns of emotional reaction to the need for Re-rehabilitation among polio survivors. These formulas may result from characteristic styles of living with a chronic disability. We suggest a model for classifying polio survivors based on these observations. At many Post-Polio conferences, (although limited by over-generalization,) we found polio survivors themselves have confirmed our proposed categories. In 1963, a
study of children with polio and their families also describe early coping behaviors that are compatible with our model.

**Passers, Minimizers and Identifiers each adopted typical coping styles in the past** that worked to create some of our generation's most successful and resilient survivors of physically disabling illness. The onset of new post-polio problems (previously long-term mild, moderate, or severe disability) can present a challenge to their previously successful coping methods and create significant new emotional distress and pain. Health care professionals need to be aware of polio survivors' distinctive past coping styles and of their need for different coping tactics during the re-rehabilitation process. They can point out to polio survivors how it is possible to find opportunity in their new changes.

**Passers** had a disability that was so mild it could be easily hidden in casual social interactions. They could pass for nondisabled. **Passers** worked diligently to hide their long-term disability. Many of their acquaintances probably did not know they were disabled in any way. Although intimate family members and friends may have known, on the whole **Passers** became psychologically invested in hiding their disability from other people. Even today, they don’t like to have to explain it or to talk about it. They don't want to think of themselves as having a disability. By using denial, they have been able to put their disability out of existence mentally and physically and create an image that fools the casual onlooker. **Passers** may hide a paralyzed hand by keeping it constantly in a pants pocket or cover slightly imperfect body parts with stylistically camouflaging clothing. **Passers** is a coping style requiring constant vigilance and attention to the nondisabled disguise. Good **Passers** believe they cannot "blow their cover" or they might be branded as part of society's disabled minority.

We administered an attitude survey to 100 polio survivors and discovered that **Passers** were the group most distressed by having to adjust to the late effects of polio. They were more likely to be emotionally overwhelmed by the physical changes from the late effects than any of their post-polio counterparts. Helping professionals need to know that among Post-Polio people, **Passers** may have the greatest resistance and emotional difficulty making and accepting, some of the fairly minor lifestyle adaptations needed to cope with the late effects of polio. **Passers** confronted with Post-Polio Sequelae often have their self-image threatened because they can’t pass any longer. Their disability has become undeniable and suddenly they must give in to it. They may become frightened because they don’t know how far it will progress. Typical thoughts may include: "Wearing a brace could lead to using two crutches, and a year later to a wheelchair, or who knows what after that... And now the disability is obvious, what will other people think ...?"

When confronted with polio's late effects, **Passers** often must alter
their self-perceptions and life-style to continue successful coping. Their former coping style might not be effective and they must learn new attitudes and behaviors. Clinically, Passers can often be fully Re-rehabilitated because their new disabilities are less severe. They can be reassured that modern orthotics, such as plastic braces, can be worn nicely under clothing and hidden under shoes. Passers may require an unexpected amount of understanding, patience and empathetic support from health care professionals. Memories of past polio-related experiences and strong emotional reactions are triggered by the impending public nature of their new disability. When Passers' disability progresses from mild to moderate, they become undeniably disabled for the first time. This can be a harsh reality for them to face, accept, and adapt to. Passers can "come out of the closet", relax and enjoy a little more freedom with their acceptable natural physiques and identities.

Minimizers had a moderate disability that was readily clear to themselves and to others. They often used visible adaptive equipment or had to do physical tasks differently to operate optimally. They typically minimized the importance of their physical difference. They coped with polio's first effects by minimizing the negative and accentuating the positive importance of their physical changes. Minimizers may say, "So what, if I use braces and crutches and I can't walk in a normal fashion, look at all the other things I can do." Minimizers have adapted by de-emphasizing physical pain, deformity, and operational faults. Many have sought intellectual vocations and hobbies in place of more physical or athletic activities. They often have been high achievers who pushed themselves to their limits. Minimizers have learned how to tune out their bodies to ignore physical faults, called "devaluing physique." This practical approach to living with an obvious physical disability has often been effective for coping in a society which stresses physical beauty and skill. However, Minimizers are often so adept at this form of denial that they recognize polio's late effects only when physical symptoms become unbearable and insurmountable. To survive and operate at peak capacity they maybe used minimizing as a defense mechanism to such an extent that they are numb to their own pain, sadness, weakness, and anger. This could have led to becoming insensitive to similar conditions and feelings in other people, including people with a more severe disability.

When asked to respond to the survey statement, "I feel uncomfortable around other disabled people," Minimizers backed it more than the other groups. We found they often had negative attitudes about severely disabled individuals as a group, particularly wheelchair-users. Therefore, they may feel that starting to use a wheelchair
means associating with a social group they have previously devalued. Or it implies defeat, helplessness, and not having fought vigorously enough against polio's disabling effects.

It is useful for professionals to recognize these phobic-like reactions when they occur and employ techniques for helping **Minimizers** change their views of wheelchairs and users. Indeed, these post-polio patients are the most likely to physically benefit from using a wheelchair. **Minimizers** may have difficulty describing new physical symptoms because they are skilled at ignoring or denying such problems. They need coaching and encouragement to fully focus on their body sensations and reactions and to become what might be called "wise hypochondriacs." Health care providers must listen closely to **Minimizers** for the slightest mention of new medical problems and give them permission to elaborate. **Minimizers** most commonly feel guilty about causing others inconvenience (including health care professionals) related to their new disabilities. Additionally, they are likely to have intense angry feelings about having to deal with new disabilities and Re-rehabilitation.

Despite many negative emotional reactions, **Minimizers** know how to set goals and achieve them with persistence and determination. The astute health care professional will encourage and help empower the **Minimizer** to use these qualities to refocus on what is important in life; to take another look at how to be successful; to set new goals and achieve them in new ways. Health care professionals must be patient in helping **Minimizers** work through understandable resistance, fears, and anger with Re-rehabilitation. They must respect, remember, and sometimes remind **Minimizers** that they are experienced copers who have a well-proven capacity to adapt effectively. By surrendering their struggle for physical independence and accepting new personal and technological help, **Minimizers** can also be empowered to live life with a greater sense of wholeness through more fully recognizing, accepting, and integrating all facets of their bodies.

**Identifiers** are post-polio people who have usually been disabled enough since their acute polio to require wheelchairs for independent mobility. Some also used respiratory equipment. They needed to fully identify with their disability to make the major lifestyle adaptations and cope successfully. They needed to more fully integrate their disability into their self-image to create successful and purposeful lives. Through identifying with others having physical disabilities, they have gained the strength to tolerate social prejudices and architectural barriers. Not surprisingly, many became disabled rights activists and helped start the independent living movement. Among the three groups sampled through the attitudes survey, **Identifiers** most strongly support the statement, "high achievement is a requirement for survival as a disabled person." They also most intensely believed that taking an active role in the disabled rights movement was necessary to their future well-being in society, and that fully recognizing their disability will help them cope with it more effectively.
With the onset of polio's late effects many **Identifiers** confront the loss of their independence. The smallest loss of routine can be distressing to a person who has been chronically severely disabled. If breathing becomes significantly impaired, death may be a realistic threat. **Identifiers** have had to work diligently to learn to feed themselves and perform other simple self-care. Any independence in daily living pursuits may have been one of the most important accomplishments of their lives. Therefore, if Post-Polio Sequelae threatens a further decline in strength, they can be expected to appear extremely distressed.

Effective-helping professionals need to expect the **Identifier's** concerns and recognize that their intense interest in autonomy and control of their environment is not pathologic. **Identifiers** have needed to develop a heightened concern about physical independence and about how adding necessary help they can reach high self-esteem and survive with their severe disability. Freedom to control their life activities is threatened by new physical limits or even by temporary dependency imposed by a hospital setting. **Identifiers** may experience a threat to their whole life and purpose for living. This reaction often leaves **Identifiers** vulnerable to others false views of them as being excessively controlling, difficult, and demanding people. In reality, they simply know what they need and are not too timid to ask for it. The aware health care professional will accept this and will do everything possible to let them continue feel and be in charge of what happens to them. **Identifiers** can gain the time and energy to develop new pursuits and cultivate other realms of interest. It is in this honest and encouraging spirit of healthy transition that successful Re-rehabilitation can occur for this ever-adapting group of polio survivors.

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Bless your uneasiness as a sign that there is still life in you. – Dag Hammarskjold - Author. Swedish diplomat, Second Secretary-General of the United Nations
Colorado Post-Polio is coming to Greeley and Fort Collins in 2016! (THIS IS OUR NEW PROGRAM – WE BELIEVE OTHER POST-POLIO GROUPS DON’T DO IT)

Dr. Marny Eulberg, M.D. and Ann Hueter, Physical Therapist, founded The Colorado Post-Polio Clinic in 1985 to provide evaluations and make recommendations about issues specifically related to polio survivors and those experiencing post-polio syndrome. In the Denver area since its founding, Dr. Eulberg has seen over 1,600 polio survivors during her 30 years of practice.

Colorado Post-Polio Council and Easter Seals Colorado sponsor the Clinic, with generous financial support from the Bernklau Family Charitable Trust and Bob Watenpaugh, a Colorado polio survivor.

Dr. Eulberg and her volunteer staff plan to bring this unique Clinic to various cities and towns in Colorado over the next few years.

These 3-day events follow the successful ones we held earlier in Grand Junction and Pueblo.

The Post-Polio Clinics – Tentative dates:

Greeley:  Tuesday, May 17 - Friday, May 20, 2016

Fort Collins:  Tuesday, June 20 - Friday, June 24, 2016

Each Clinic appointment includes:

a. Individual Polio evaluation by Dr. Marny Eulberg, M. D. and her staff
b. Evaluation by appointment only
c. As there is no set fee for the clinic, donations are encouraged and appreciated. Dr. Eulberg and her team donate their time but their expenses are paid for by Colorado Post-Polio.

Post-Polio Educational Meeting (to wrap up the appointments)

Greeley:  9:30 a.m. to 1 p.m. Saturday, May 21, 2016

Fort Collins:  9:30 a.m. to 1 p.m. Saturday, June 25, 2016

Lunch, water and coffee provided. – Attendees may bring a friend or caregiver.

Tentative Agenda – Introductions, video lecture by post-polio experts (possible topics – Personal Philosophy about Disability, Polio and Anesthesia, or Components of Comprehensive Post-Polio Management, Ask the Polio Doctor.)
Educational Meeting Cost - $15.00 per person, with cash or check to Easter Seals Colorado (Post-Polio on the memo line) at the door.

Applications went to the area in February. To sign up, reserve your space or get more information on both these events in Greeley and Fort Collins, please contact Dr. Eulberg by April 15, 2015 to:

Dr. Marny Eulberg, M. D. - 9461 W. 37th Place, Wheatridge CO 80033, Phone: 303-829-1538 - marnyeul@me.com

Can You Help Colorado Post-Polio find a Used Golf Cart?

Colorado Post-Polio wants to donate a used 6-passenger golf cart to the Rocky Mountain Village Easter Seals Camp in Empire, Colorado, and we need your help!

As many polio survivors have aged, they need help getting from place to place, especially if the distance is more than a few steps and over uneven ground. This is the challenge that campers at the 2016 Post-Polio Wellness Retreat will face in August. The camp is in the mountains and lodging and event sites are some distance from each other. Some can walk between the sites but many appreciate the boost of a ride. Also, the lack of transportation can make a difference to some in terms of their participation in the Retreat.

As many as 60 retreat attendees may descend on the Village, and Colorado Post-Polio would like to add to the camp’s fleet of one 6-passenger golf cart by permanently donating a second cart for use during the Retreat and then have it available for the next summer disabled children’s camps that Easter Seals sponsors. Colorado Post-Polio sees this gift as a thank you to Easter Seals Colorado and Rocky Mountain Village for all of the support and help that the Camp has provided, both for the 2014 retreat and for the one in August.

A good used 6-passenger golf cart costs between $5000 and $6000. Your donation of any amount for this cause will be greatly appreciated. If you would like to help with this, please send a check in any amount, payable to Easter Seals Colorado. Put “Post-Polio Golf Cart” in the memo line to insure it goes to the correct account. Mail your donation to: Nancy Hanson:

Easter Seals Colorado
5755 West Alameda Avenue
Lakewood, CO 80226-3500

Thank you for your generosity and do join us at the Retreat, August 14-19, 2016 in Empire, Colorado.

P.S., Colorado Post-Polio also wouldn’t turn away the outright donation of a still workable 4 or 8 passenger golf cart!
OUR EXECUTIVE COMMITTEE MEMBERS

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Colorado Post-Polio Support Groups Schedules

Support groups usually have a plan, 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: Sandy Abbott – 303-646-7346 - sandya65@outlook.com

Colorado Springs - Meets 2nd Saturday of each month, 10:00am to Noon
Contact: Linda Groth - 719-633-1497 – (Call for location)

Grand Junction – Please call either of these members for date, time and place.
Contact: Loran Dake - 970-241-7825 - lorandake@msn.com or Chuck Langan - 970-270-0654

Lakewood - Meets the 2nd Tuesday of each month, 11:00am to 1:00pm in Golden, bring a bag lunch.
Contact: - Annette Beck - 303-427-1789 - annette.beck@hotmail.com

Northern Colorado (Fort Collins) - Meets 4th Saturday of each month, 10:00am to Noon -
Contact: Peter Way - NOCOPolio@gmail.com – 870-460-6164

Pueblo – Looking for new time and meeting place. Call for details.
Contact: Maureen Sullivan - 719- 561-3182 - msmosul2005@yahoo.com – or Mary Agnes Leonard – 719-544-4789 – maryagnesleonard@gmail.com

Survivors South —Due to health reasons, this group is regrouping. Someone will contact you.

Thornton – (now North-Metro) this group is reorganizing. Someone will contact you.

“The friend who holds your hand and says the wrong thing is made of dearer stuff than the one who stays away”.

Barbara Kingsolver – Novelist, Essayist and Poet
Because of vaccination efforts in the US in the 50’s, no longer do we have new polio cases here. However, we find many immigrants who contracted the disease in other countries now living with us. Many are still in their 30’s to 60’s. We’re finding many native-born survivors are now in their 70’s - 80’s. Obviously, for the next 4 decades there will be a continuing need for support for the new survivors.

We are grateful, with the help of some serious major donors; we are building reserves for the future. We call them our “Angel” donors because they aren’t seeking publicity and we are blessed for them.

However, we still are thankful to receive help from our many regular donors, since it is they who support our overhead, leaving funds for our outreach and special programs.

Likewise, we are grateful to have so many willing in-kind and volunteer help.

Every dollar you contribute supports our outreach efforts, support groups, education and this newsletter. Please complete this form, detach it, and mail it to Nancy Hanson at Easter Seals Colorado, address below. Your contribution will be gratefully acknowledged.

Remember, many supporters donate in memory of a loved one by including Colorado Post-Polio in their wills or trusts.

To insure that we receive 100% of your donation, any contributions should be payable to Easter Seals Colorado and PLEASE WRITE "POST-POLIO" IN THE MEMO LINE. Your contribution will be gratefully acknowledged.

Thank you!

Name:________________________________________________________

Address:_____________________________________________________

City, State, Zip:_______________________________________________

Phone:_______________________________________________________

E-Mail_______________________________________________________

Mail to: Easter Seals Colorado, 5755 West Alameda Ave, 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 Easter Seals Colorado. (Always check with your personal physician for all medical questions and concerns.)

We invite not only your comments about this newsletter, but your personal stories, other story ideas, and contributions. 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 Janet Thompson at 303-937-5052 or send an e-mail to her at janetandjere@SoftHome.net, or write to:

Colorado Post-Polio Connections
c/o Easter Seals Colorado
5755 W. Alameda Ave.
Lakewood, CO 80226

If you prefer to receive this newsletter online or change your mailing label information, please notify Nancy Hanson at Easter Seals Colorado, at 303-233-1666, ext. 237 or email her at: Nhanson@eastersealscolorado.org