

# Colorado Post-Polio *Connections*

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Winter 2012

## **Post-Polio Thoughts**

*By Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska,  
([n.carter@coxnet](mailto:n.carter@coxnet))*

### **HOME SWEET HOME?**

**FACT:** 90% of Americans polled said they definitely do not want to live in a nursing facility.

**FACT:** 80% of Americans polled want to continue living in their own homes until the end.

With the total of elderly citizens on the upswing, innovative choices are beginning to pop up, attempting to offer new ways to allow us to live where we want to as age and disability continue to do their number on us.

Now comes PACE (Programs of All-inclusive Care for the Elderly), one more entry in community-based living that may keep many of us out of institutions. PACE is a government-inspired program, decades in the making, and now individually operated by a variety of non-profit companies throughout the country. Check [www.npaonline.org](http://www.npaonline.org) to see if your state is one of the 30 currently involved.

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Winter 2012

## Council Corner:

*By Ileta Smith, Council Chairperson*

As we begin our new year, I want to thank all those who have helped Colorado Post-Polio continue through some difficult times during 2011. We have faced many challenges this past year, but have been able to quickly reorganize and move forward.

We look forward to an exciting conference to be presented in June of this year. We hope you will be able to attend and enjoy not only the variety of speakers we have for you, but also to meet one another and share ideas. This is a great opportunity to encourage one another, and to make new friends.

We will be holding elections in October for Council officers and Members-at-Large. If you are interested in serving on the council, please contact me at [CouncilChair2010@aol.com](mailto:CouncilChair2010@aol.com) or call Nancy Hanson at 303-233-1666, Ext. 237.

Our 2012 Council members are:

Chairperson: Ileta Smith

Secretary: Jeanine Ellison-Fisher

Treasurer: Gloria Aemmer

Librarian: Woody Trosper (temporary)

Mailing Coordinator: Woody Trosper

Aurora Support Group Representative: Velma Pendell

Ft. Collins Support Group Representative: Lyle Mitchell

Grand Junction Support Group Facilitator: Gail Saunders

Lakewood Support Group Facilitator: Marlene Harmon

Thornton Support Group Facilitator: Paul Puma

Member-at-Large: Margaret Hinman

Easter Seals Liaison: Nancy Hanson

Medical Advisor: Dr. Marny Eulberg

*Mission Statement: The mission of the Colorado Post-Polio Organization is to provide education, information, and support statewide to polio survivors and their support systems.*

*Colorado Post-Polio Connections* is the official news publication of the Colorado Post-Polio Organization, which is sponsored by Easter Seals Colorado, 5755 W. Alameda Ave., Lakewood, CO 80226.



The opinions expressed in this newsletter 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.

## **Bobbye Gibson's Story**

*By Jeanine Ellison-Fisher, Council Secretary*

Bobbye Dean Gibson was born July 15, 1935 @ 2 pm on a hot summer day in Oklahoma in a little town called Sasaka. She went to school with many Indians and feels sadness for how they were treated.

The oldest of 4, Bobbye was the only one in the family who had polio. Bobbye's polio came in May, 1937; she was almost two years old. "My parents were weird about doctors...I heard people talking about "what are we going to do about Bobbye," but nothing was done. My leg just didn't grow. I walked with one leg 3 inches shorter than the other. I didn't see a doctor until my 5th grade teacher, Cecelia Peck, got me into Crippled Children's Hospital in Oklahoma City in 1948. Dad had tears in his eyes begging me not to go but my teacher talked Mom into it. I stayed a month; in traction for 2 weeks after surgery...I didn't have a heel...my foot turned to the side. March of Dimes paid. Dad would cry every time I went to the hospital... people in that area believed doctors and hospitals were just for dying; Dad really believed I wouldn't come home." After many miles on crutches, she wrecked her shoulder.

She now uses a walker at night, cane and cart when shopping and after 3 braces she finally has a comfortable one!

Bobbye lived on to have 13 surgeries, staples, and fusions yet she proudly says "I've had a wonderful life." She describes adventures and her love for life. She raised 5 children (2 sons and 3 daughters), a grandson, 2 granddaughters and a lot of grandkids with tails and whiskers!

Bobbye likes to be busy, to travel, see the kids, eat out, help out, garden, fish and see ball games. She's lived in Oklahoma, Missouri, Arkansas, Arizona, Colorado, even Alaska for 4 months in the 5th wheel which she and her second husband, Clyde ("the love of my life for 37 years") bought when Clyde couldn't work anymore. They traveled in it for 10 years. Bobbye says she got along fine with polio all those years... Clyde put running boards on the truck.

She LOVES gardening. After a knee replacement at age 75, "the doctors mistook my polio fatigue for depression. I wasn't depressed, just post-polio-tired...it's taking longer

than expected to get back to gardening. Fatigue sets in but living alone now is okay because rest is whenever.” Next? A cruise with family, around the Hawaiian Islands. She’s cruised before, with the Church to Washington DC, the Rose Bowl, and the Eastern Caribbean. “Not much trouble with handicap accommodations; just put a suction cup in the showers.” Steps are scary, knees are weak. But she keeps busy - to the Rockies with the Buck Recreation Center, out for lunch, the therapeutic pool, and loving basketball “but they are turkeys this year!”

And then Bobbye says, “I would be glad to help the polio group out...just let me know!”

**Tell Your Story...** We would like to hear how you have met the challenges you faced and overcame in your personal or professional life. Was there a person or persons that encouraged you in your life’s journey? Contact Ileta Smith at [CouncilChair2010@aol.com](mailto:CouncilChair2010@aol.com) or Nancy Hanson at 303-233-1666 Ext. 237.

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*Continued from page 1*

**Who Can Join?** Those of us who are 55 or older and living in a PACE-

served area can join if we meet our state’s Medicare and Medicaid nursing home level of care guidelines. This is determined by the 11-member Interdisciplinary Team in each local PACE area.

**How Does This Work?** Participants sign a contract allowing PACE to provide services. PACE is Medicaid and/or Medicare funded on a per person basis, rather than on a fee-for-service basis. Participants not on Medicaid would have to make up the difference, paying a monthly charge, plus a hefty Part D fee. Joining PACE dis-enrolls us from other health insurance, and PACE becomes our health and Part D insurer.

PACE also provides doctors, nurse practitioners, therapists, and other participants of a health-care team to work with us, rather than using the health professionals we had before. Members are free to leave PACE at any time, and PACE social workers will help with the transition of finding a doctor, health and medicine insurance, and other care and services.

**What Do We Get?** Most of us get to live in our own homes. A large part of PACE activity centers around an

Adult Day Center, to and from which participants are regularly transported by PACE. Here we might find a chapel, TVs, a coffee bar, and a dining facility, all comfortably arranged for maximum sociability. Also at the Center is a Health Clinic, designed to provide primary care, dental and podiatry care, therapists, and all the exam rooms and equipment necessary at that facility.

Certain types of in-home care and services are provided, as determined necessary by the Interdisciplinary Team on a person-to-person basis. They decide what is needed according to the impact this has on our health. Participants requiring more care (about 7% now) go into nursing facilities, still under the auspices of PACE.

**And Others?** Family caregivers are not forgotten. At the Center, PACE offers support groups and even training in how best to deal with us in our homes. Overworked caregivers appreciate a much-needed break during the day while members are at the Center.

PACE presents an option. If we like it, it's ours. If this isn't our cup of tea, we move on to the next possibility.

Many of us who have spent a lifetime with disability might hope for more independence than I see in PACE. Personally, I'd like to be the one who decides what I do with my day—and with whom I do it. I want staying in my home to mean more than merely sleeping here—I want to *live* here. Eat here. Watch TV here. Get my laundry done here. I want my regular doctor and my usual pals. Give me my phone and my computer and let me soar. I don't want to be left to rely upon the kindness of volunteers among my family and friends to get my house cleaned or my personal needs met. There must be a way.

We have tough choices to make. You know: "Old age ain't no place for sissies."

*Nancy Baldwin Carter, B.A., M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

**Source: Post-Polio Health International**  
([www.post-polio.org](http://www.post-polio.org))

NOTE: Terry Lynch is a scheduled speaker for our June 2, 2012 conference. He will be addressing strategies for independent living.

### ***Word of Thanks to...***

- Oran V. Siler Company for printing *Connections*.
- C. H. Bernklau Charitable Trust for supporting this issue of *Connections*.
- Our wonderful "mailing crew": Gloria Aemmer, Liz Benson, Joan Kostick, Velma Pendell, Paul Puma, Ileta Smith, John Smith, Eleanor Spence and Woody Trosper.
- Peter Way, Ft. Collins Support Group Facilitator, for demonstrating the newsletter blog concept.

### **2012 Conference:**

*By Margaret Hinman, Council Member-at-Large*

**Save the Date!  
Colorado Post-Polio  
Spirited Survivors  
How to Make It Work!  
Educational Conference  
Friday & Saturday,  
June 1 & 2, 2012**

Put these dates on your calendar because we would love to see you and your families at our educational conference that will be held at the Red Lion Inn, I-70 & Quebec in Denver!

The conference is focused on issues that are part of our lives at this time: Living with a disability and how it affects a family, normal aging vs. aging with polio, the value of physical therapy, and how to live independently as long as we can. Our speakers come from around the country, including Joan Headley, Executive Director of Post-Polio Health International in St. Louis, MO.

In addition to our lineup of great topics and speakers, the conference will also include a social hour on Friday evening, a continental breakfast, a sit-down luncheon, and opportunities to talk to vendors and authors on Saturday.

The schedule takes into consideration the energy levels of many of us. The conference itself begins at 9:00 a.m. and will be over shortly after 3:30 p.m. on Saturday with many breaks and a long lunch hour.

The Red Lion Inn will have special conference rates for those of us who are coming from out of town, or who just want to spend the night and be rested for the conference.

Registration forms will be mailed the first week of April. Look for them in

your mailbox and we will see you in June!

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**CAREGIVER NOTES:** I am a caregiver of a polio survivor. At times I feel taken for granted. How can I handle this situation without hurting my partner?

**Response from Stephanie T. Machell, PsyD:** Caregivers, like parents and spouses and others we love and depend on, are often taken for granted. No matter how much someone appreciates your care, in the daily routine that caregiving becomes, the person may forget the importance of expressing appreciation and gratitude.

It's hard to be a caregiver, especially for a spouse or partner. It changes the relationship and can create inequalities and resentments. There is ambivalence for both partners about their new roles. The one receiving the care may be appreciative of what is given but fear becoming a burden and resent not being able to do what he or she once did. The one providing the care may be happy to help but resent the extra work and loss of freedom. Both may long for carefree earlier days of the relationship.

It's especially hard for polio survivors to receive care. Being taken care of may bring up memories of the original polio, which may include negative experiences of caregivers who were anything but caring. Or it may bring up feelings of helplessness and dependence that can be hard to handle for someone who has always believed it was essential to be fully in charge and independent. Expressing appreciation for care, even when it's felt, might make the polio survivor feel more vulnerable.

Can you talk with your partner about how you feel? Couples often fail to discuss such sensitive issues until they come up in indirect ways or in angry and hurtful words – or until the caregiver becomes ill and unable to carry on. Such a serious and important discussion would be best held at a calm and neutral time. You might start by asking your partner how he or she feels about the way things are going in your relationship. Or you could talk first about what you value about being able to care for your partner, or ask what it's like to receive care. You could ask your partner how he or she feels about what you are doing and if there is anything he or she especially likes or dislikes.

This may be a chance for your partner to express gratitude or appreciation for all you do. If not, you can let your partner know how you feel and see how he or she responds. If talking about it doesn't work, or if your partner can't or won't do so, there may be less direct ways he or she expresses appreciation that you can observe.

For instance, he or she might look more comfortable or smile at you when you have done something helpful. You might also notice the positive effects of what you do for your partner, like having more energy.

Feeling taken for granted could also be a sign that you need a break. It's important to care for yourself so that you can care for your partner. Find a way to take time out. If no family or friends can help, there are resources available for respite care. Use them and take the time to do something that will replenish you. You will return refreshed and revived and better able to care for your partner.

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## **Polio Survivors Ask...**

Nancy Baldwin Carter, BA, M Ed Psych,  
Omaha, Nebraska, ([n.carter@cox.net](mailto:n.carter@cox.net))

Association Members Communiqué –  
PHI, May 13, 2009 (No. 33)

**Q:** Every now and then I get a feeling of sadness over losses that I associate with my aging with polio. I was never taught to acknowledge my polio emotions, and that left me with a lump in my voiceless throat. Deep down, I think I should not express these feelings that make me feel so vulnerable. If I do, I am concerned I will be judged for expressing my feelings. How can I move through this?

**A:** No doubt we all feel hesitant about revealing our innermost selves to others in the beginning. There's that fear. Fear that someone will make fun of us, fear that our feelings will be trivialized, fear that people will think we're complaining, think we're whiners, that we're not tough enough. Whatever. It's a vulnerable spot to be in – must I always take a deep breath when I open myself up honestly, fearful that others will leap in to crush me? Fears. They can be mighty. Yet, what are the consequences of silence? Oddly, the more I stifle



myself with these fears, the more I believe they are true. Soon I have stuffed myself so full of pent-up emotion that I explode in bitterness or anger or sadness or some other expression of a person I do not want to be. I've decided this isn't the way I want to live. Much of my fear had to do with being all wrapped up in how I was viewed by others. Then one day I heard a wonderful speaker who brought me down to earth with humor: "We wouldn't worry so much about what others think of us if we realized how seldom they do." Suddenly I understood this wasn't about *them* at all – it was totally about me. Thank goodness for that- I can actually do something about *me*. First up: take a look. Over time, I had lost track of my identity. I wasn't sure who I was anymore. I started searching. What I discovered was a person who had spent a lifetime rationalizing my physical losses, pretending they meant nothing. I stayed home rather than admit I needed a chair. I even delayed getting SSDI until my time nearly ran out because I couldn't face that my considerable losses were enough to qualify me. My days had been spent "doing." As my ability to *do* diminished, I felt myself slowly disappearing, tiny pieces of physical ability falling irretrievably to the wayside until very little was left. It was time to base my perception of my self on *being*. I grieved the loss. I loved that other person – the whirlwind of

her life, the accomplishments, the fun. I had to learn to appreciate the merits of *being*. This has to be about who I am, not who I wish I were. I wasn't sure how I was supposed to act about my disability. My parents never mentioned it and seemed to think it would be better if *I* didn't. However, I needed to acknowledge it. I learned that while it usually isn't helpful to sally forth with a long catalog of my aches and pains, I *do* need to talk about what it does to me inside to be the person I am. Post-polio support group discussions can be great for this, as are loved ones and trusted friends. The important thing for me is to express myself. I become stronger each time I speak up. More free. Not every day is perfect. And of course nobody has everything. But I discovered that what I have is plenty. I take it one day at a time, and I'm still here, still intact, and still purring contentedly.

*Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association. Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))*  
<<http://www.post.polio.org/>>

NOTE: Janet Roberts is a scheduled speaker for our June 2 conference. She will be addressing family dynamics and communication strategies.

### Colorado Post-Polio Support Groups

Support groups usually have a format, a program, or an activity planned for each meeting. In bad weather, call the contact person to make sure that the meeting is still scheduled.

<b>Group</b>	<b>Frequency</b>	<b>Time</b>	<b>Location</b>	<b>Contact</b>
Colorado Post-Polio Council	January 23, 2012 3 <sup>rd</sup> Monday in, April, July, and October	10:00 AM to noon	Easter Seals Colorado, 5755 W. Alameda Ave., Lakewood	<b>Ileta Smith</b> <a href="mailto:CouncilChair2010@aol.com">CouncilChair2010@aol.com</a> <b>Nancy Hanson</b> Easter Seals Colorado 303-233-1666, ext. 237
Aurora	3 <sup>rd</sup> Wednesday April through October	10:00 AM to 11:45 AM	Spalding Hospital, 900 Potomac St., first floor	<b>Ileta Smith</b> <a href="mailto:CouncilChair2010@aol.com">CouncilChair2010@aol.com</a> <b>Nancy Hanson</b> Easter Seals Colorado 303-233-1666, ext. 237
Colorado Springs	2 <sup>nd</sup> Saturday of each month	10:00 AM to noon	Sand Creek Police Dept. meeting room, 4125 Center Park	<b>Linda Groth</b> 719-633-1497
Fort Collins	4 <sup>th</sup> Saturday of each month	10:00 AM to noon	Trinity Lutheran Church, 301 E. Stuart	<b>Peter Way</b> <a href="mailto:NOCOPolio@gmail.com">NOCOPolio@gmail.com</a> <b>Julia Hanan</b> 970-484-3822 <b>Winifred Brooks</b> 970-484-9180
Grand Junction	Call for meeting times and dates.			<b>Gail Saunders</b> 970-249-3218 <b>Millie Derksen</b> 970-434-4281
Lakewood	2 <sup>nd</sup> Wednesday in Jan., March, May, July, Sept. & Nov.	11:00 AM to 1:00 PM	Atlanta Bread Company 7740 W. Alameda Ave. In Lakewood City Commons	<b>Marlene Harmon</b> 303-689-7669
Pueblo	2 <sup>nd</sup> Saturday of each month	11:30 AM	Walking Stick Restaurant 4301 Walking Stick Blvd.	<b>Jeane Dille</b> 719-545-0162
Thornton	1 <sup>st</sup> Saturday of each month	10:00 AM to noon	Vibra Hospital, 8451 Pearl	<b>Barbara Lundstrom</b> 303-451-6241 <b>Paul Puma</b> 303-453-9552

## Please Support Our Post-Polio Efforts

Help us get the word out to others who need to know about post-polio. Every dollar that you contribute supports the Colorado Post-Polio Organization in its outreach programs, including this newsletter. Complete this form, detach it, and mail it to Nancy Hanson at the Easter Seals Colorado address. Make your check 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 \_\_\_\_\_

If you no longer want to receive this newsletter, please check here \_\_\_ and mail this form to Nancy Hanson at Easter Seals Colorado, 5755 W. Alameda Ave, Lakewood, CO 80226, email - [nhanson@eastersealscolorado.org](mailto:nhanson@eastersealscolorado.org), or call - 303-233-1666, Ext. 237.

### Easter Seals Colorado

Easter Seals Colorado, located in Lakewood, is organized to help children and adults with disabilities to gain greater independence. To learn more about the great work of Easter Seals Colorado and their mission, visit [www.eastersealscolorado.org](http://www.eastersealscolorado.org).

### Colorado Post-Polio Organization

The Colorado Post-Polio Organization, sponsored by Easter Seals Colorado, offers education and support for persons who now have, or once had, polio, as well as for those who might be experiencing the later effects of polio, called Post-Polio Syndrome (PPS). Information for polio survivors is available through educational meetings, this quarterly newsletter, and support groups. An informational packet and other resources on polio and PPS are available.

### Post-Polio Library

The Post-Polio Library contains a collection of books, plus audio and video tapes. The library is located at the Easter Seals Colorado office. To view this newsletter online, or to see a partial list of library books, go to [www.eastersealscolorado.org](http://www.eastersealscolorado.org) (click **Services**, then click **Post-Polio Support Group**). To check material out from the library, contact either Nancy Hanson at the Easter Seals Colorado office, or the librarian, Woody Trosper, at [wtrosper@aol.com](mailto:wtrosper@aol.com).

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

**FREE MATTER FOR THE  
BLIND OR HANDICAPPED**

**This Is YOUR Newsletter—**

The *Colorado Post-Polio Connections* is a newsletter for polio survivors, their families, friends, and those who care. We invite not only your comments about this newsletter, but also your personal stories, story ideas, and contributions. Tell us what topics you want to read about in future issues. If you have article ideas, suggestions, or are willing to write a short article or tell your personal story, please send an e-mail to [CouncilChair2010@aol.com](mailto:CouncilChair2010@aol.com), or write to:

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

When writing, please include your name, mailing address, telephone number, and e-mail address.

To change your mailing label information, please contact Nancy Hanson at Easter Seals Colorado at the above address; call her at 303-233-1666, ext. 237; or send an e-mail to her at [nhanson@eastersealscolorado.org](mailto:nhanson@eastersealscolorado.org).