

connections

colorado post-polio • since 1981

January, 2017

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COCOONING IN THE WINTER CAN BE BORING!

Let the better-weather days provide a Post-Polio respite. Here are some suggestions to get you up and going. Some helpful ways to connect are:

WE'RE STILL ON THE MOVE!

EXECUTIVE COMMITTEE meetings are when our planning takes place. **Members are always valued to comment** on our future goals and activities. Meetings are scheduled for **Mondays, March 20, June 19, September 18** and

December 18. Meetings begin at **4:00p.m at Easter Seals Office on Alameda.** If **you** can't come, please contact one of our Committee members (see page 10) with your suggestions. Please make a note of these dates and come!

Attend a SUPPORT GROUP. See page 10 for one in your neighborhood. If none fits your bill, maybe you can start one. We give plenty of help and encouragement if you do so. Support Groups are the BEST way to receive encouragement and education about Post-Polio and its effects. Everyone's Polio story has details of the same condition, including different ideas for coping. **Contact Sue Brandon if you'd like to volunteer** for a group.

Watch for and be a guest at the **VOLUNTEER RECOGNITION LUNCH in June 2017.** We value and honor ALL our volunteers once a year. At the lovely lunch, we always provide a suitable speaker whose inspiration, vitality and information is worth taking home with you. This LUNCH is a way Colorado Post-Polio lets those who volunteer know how much their time and efforts matter in keeping this organization alive and thriving.

Take part in the **TRAVELING CLINIC and MINI-EDUCATIONAL MEETING.** The Colorado Post-Polio Traveling Clinic will visit Colorado Springs for two weeks this summer. Tentative dates are the **week of June 19 and the week of August 14.** Information about the location and scheduling an appointment will be sent to polio survivors in the area early this spring. Patients receive a written Post-Polio evaluation, including a muscle test and a list of recommendations to help you preserve or improve your quality of life.

The clinic is conducted by Dr. Marny Eulberg, a polio survivor and polio specialist and her team, including a Physical Therapist.

The **MINI-EDUCATIONAL MEETING and LUNCH** will be on a Saturday of those weeks. Patients who attended the clinic and other polio survivors in the area are invited

Polio survivors in the Denver Metro area can contact Dr. Eulberg at 303-829-1538, to schedule an appointment for an evaluation and recommendations.

Watch for and join us at the **FALL EDUCATIONAL CONFERENCE probably in September**. Final dates, time and location aren't settled yet. The tentative program highlights hands-on experiences in a safe environment to help you preserve independence, improve your health and keep you connected. **Three areas of concentration** include: **Physical choices** that fit your needs and abilities. **Tools to keep you mobile and safe** in your daily living and **Connectivity** through electronics. These include how to use tablets, smart phones monitors that help you keep track of your daily events and the Internet for exploring Web sites about Polio.

VOLUNTEER TO HELP set up the FALL EDUCATIONAL CONFERENCE. The Council needs a few good volunteers to help arrange the presenters for the conference. The work is easy, and there are some resources already known that need to be contacted. Most of the work can be done on the phone or through the Internet. **Contact Jan Hamilton at 720-341-2879 for more information.**

Be sure to attend the ANNUAL MEETING in the fall. Enjoy a free lunch with your Polio friends to celebrate what we have achieved through the year and what is planned for 2018. We usually have a short program with a worthwhile speaker.

Expect another wellness retreat in 2018. We hope to see you there!

From Rancho Los Amigos Post-Polio Support Group Newsletter – August 2016

Editor's note: We polio survivors are a unique group. I believe this is especially true for those who had major pulmonary involvement. These polio survivors often spent very long periods in specialized rehabilitation facilities, similar to Rancho Los Amigos, and developed life-long



friendships. I believe the girls were better at maintaining these friendships than were the boys. I remember Becky, Bea, Alice, Bonnie, Laura, Emma, Alicia, and so many more.

Besides life-long friendships, these polio survivors developed very strong emotional ties and a very personal support network. The story below is an illustration of this personal support that often goes beyond words.

My Third Child

By Rebecca Coyne

In six days my third child will turn 29. It's hard to believe it's been 29 years since his birth, and the death of a friend that I had known for 26 years. Today I sat holding my son's own little son, who is twelve weeks old. How time has passed! I will never forget that day in March of 1985 when Bea called me saying, "Becky, I'm pregnant."

For the first time in my life I was without words. I was stunned. I stood, holding the phone to my ear with a million simultaneous thoughts racing through my mind: Pictures of Bea in her iron lung next to my bed, then Bea on the bed with another respirator pumping air in and out of her lungs, and Bea, when I brushed her hair, or put her first contact lenses in her eyes. Finally I replied with the only words that I could find, "Bea, I don't know whether to say congratulations or 'you fool.'"

Bea, being Bea, replied, "I guess you had best say both," and then she gave her respirator a clicking-tongue laugh.

I said, "Ok, congratulations, you fool!" My words came fast then. "Bea, I know that doctors are advising you to abort. What were you thinking!? Haven't you heard of birth control? Lord, girl!"

Bea responded calmly with, "Yes, all the doctors are advising me to abort."

You have to understand that Bea was paralyzed from the neck down. She had the body size of an eight year old because paralyzed bodies don't tend to grow normally. She had not breathed on her own since the onset of polio when she was three years old. A baby!

I had two children when Bea called. For some reason the paralysis had regressed in my body. I went from not being able to move or breathe on my own to walking with one brace and crutches. I knew how hard it was on me to carry a baby inside my body. I knew Bea would never make it. "Ok, Bea, so what have you decided to do?"

Her response was short, brief, and blunt, "I'm going to run it!" Oh God, she had to pull that old phrase out of our past. Whenever we were facing another operation, or transition from iron lung to another respirator, or back fusions, or a cold or flu, we were "running it." We were fighting for our very lives. Everyone on the ward would join in the struggle. Those of us not enduring the treatment would cheer, cajole, and kick ass to help each other get through those times. She decided to "run it!"

"Ok," I said after taking a deep breath, "I'm running it with you."

Bea's response was to give a respirator click-tongue sound that was her way of laughing, and say, "I knew you would. When I die you have to take the baby."

Planning for the Baby

Talk about taking the life and breath out of me. She succeeded! My tears were silent, because when we are "running it" there is no room for sympathy, fear, or weakness. Our heads are down and shoulders hunched into the wind of the storm.

Bea managed to carry that baby six months. I was amazed. I threw her a baby shower at the six month mark just for good luck, and because if there was ever a mother who deserved a baby shower, it was Bea. She wanted to be a mother so much!

On the afternoon of September 2, 1985, three days after the baby shower, another phone call came. It was Bea, "I'm in the hospital at White Memorial, Beck. I need you!"

I yelled into the phone, "Why? What's going on? I'm coming!" Bea said in a rush, "Respiratory distress. They have to take the baby" I said, "Ok, I'll get there fast."

At that time there was a contractor in my house repairing things that didn't work in the one-hundred year old house we had just bought, in case we ended up with baby number three. Three babies would never have fit in the little house we had lived in for the last five years. My two babies, Libby, who was three, and Jimmy, who was one, were in front of me, and the contractor was staring at me. I guess I turned white or something.

I hung up the phone, and the big, burly contractor guy was standing in front of me. I said, "I have to go. I have to go now. You'll just have to do the best you can do. I won't be here."

He stood still, facing me and said quietly, but firmly, "What is going on?"

"My friend is in the hospital going to give birth to my third child ... maybe ... if she dies. I have to get over there. You do whatever needs doing. You just make the decisions, please. I can't be here!"

The man still stood, blocking my movement. He said, "Ma'am, my wife would be hysterical right now. I have to ask you, do you trust me? I mean really trust me?"

I responded, "I don't have a choice right now. I trust you. Just fix these problems. I have to go." - and he stepped aside.

I grabbed the diaper bag and took Libby and Jimmy to my friend Diane's house. Then I drove as fast as I could to White Memorial Hospital, where I met with the doctor and Bea. They were going to pump Bea full of steroids for three days to help mature the baby's lungs. Meanwhile they would run oxygen through her respirator to bring up her oxygen levels in her blood. I said, "No!"

Bea interrupted, "Yes! Becky, listen to me. I can face God and say quite bluntly that I got pregnant out of wedlock. I feel fine about that. But I cannot face Him and say, 'Oh, by the way, I killed the baby to protect myself.' Do you understand me?"

I had to think a second, then said, "Yeah. I hear you. You do know what oxygen does to lung tissue, and your right lung is worthless already. You're taking a chance of burning up some of the left lung."

Bea clicked her tongue in a laugh again. "Have you ever thought we know far too much about medicine, Becky? Look at my doctor's face. He's never heard patients talk like this. We're giving him a whole new life experience."

Birth

Bea hung on for the three days of steroids dripping into her arm through the IV tube. Diane took care of my kids each day. I took them at 6:00 a.m. and picked them up about 6:00 p.m. When my husband came home for the night, I returned to the hospital to sit and take care of Bea. I knew how to suction her. I knew how she liked the catheter to be cut so it wouldn't hurt her lungs when I suctioned her. I knew how to be quiet when she slept and I knew how to make small talk when distraction was very much needed. How well my life had trained me for such occasions as this. The nurses from all over White Memorial knew I was pulling round the clock nursing care, and they knew which nurses made coffee. They came regularly with big mugs of the dark brew. I never drink coffee, don't like it, but I drank it because I needed the caffeine like crazy.

On September 6, 1985 we prepared for surgery. They would take the baby by caesarean section. I would be with her in the operating room, because I could hear when she needed suctioning and I could make her feel safe. I had done direct line transfusion several times growing up because my blood type is O positive, so being in the operating room didn't bother me. I did it. I saw when the doctors pulled Jacob through the incision site, the tiniest baby I had ever seen.

Through the afternoon, Bea was feeling fine. She told me I should go home and get some sleep. I gave in. I hired a one-on-one nurse for her and stayed long enough to teach the nurse how to suction her, how to hear when she needed suctioning in case Bea was asleep.

I didn't leave until I was sure the nurse could handle it. Then I left, picked up my babies and went home.

After dinner and putting Jimmy and Libby to bed, I crashed. I slept like the dead! The next morning, I took Libby and Jimmy back over to Diane's. I had renewed energy and was happy. Bea had made it through the delivery! My relief was euphoric! I went up to the OB-GYN ward, walked to the door of Bea's room, started to step in then I heard it. Bea had pneumonia. Bea was awake, staring at me. I said, "Bea, please tell me that it is in your right lung, not your left lung!" A tear fell from Bea's right eye as she nodded, "No!"

I returned to automatic. As children, the hospital staff was aware that we knew as much about our conditions as they did. They didn't argue with us. They listened and took our word on medical issues as fact. We did know. We lived it! So, I went to the nurses' station and said, "Get Dr. Bounds, the respiratory doctor, up here stat, also get x-ray up here stat, and notify ICU they will be getting a patient as soon as it can be arranged."

The little nurse on the other side of the high desk said, "And who do you think you are?"

I leaned over the counter and said, "I am your worst nightmare or your best friend. Which one you see depends on your ability to follow my orders now! Your patient has pneumonia. You must act quickly since you missed it when you came on duty this morning. You do not want to take me on!" I hadn't been raised by Dr. Jacquelin Perry* for nothing! I knew how to make hospital staff move. **Pioneering polio surgeon and Post-Polio mentor to thousands*

I returned to Bea, paid the nurse I had hired, and began suctioning and rolling Bea onto her side to pound on her back and then suction again. I was clearing as much mucous as possible when Dr. Bounds walked in with a stethoscope around his neck. He said, "Does someone think there is pneumonia in this room?" The little nurse from the nurses' station was standing behind him smirking.

I said, "I don't think, I know. I've heard it before in respirator breathing. It's in her left lung." He moved to the side of the bed, removing the stethoscope from around his neck. He listened for a second, then said in a voice that tolerated no argument, "Get x-ray here stat, and notify ICU they will be getting another patient immediately." The nurse took off running.

Continuing Struggle

Bea fought for a solid week to live. She wanted to raise that baby. She finally had someone who wouldn't abandon her as her family did when she contracted polio. She fought hard. I did round the clock nursing care in the ICU. I knew more about tracheotomy care, suctioning, and respirator care than the nurses knew. Diane took my two beautiful babies and made sure they were loved and well cared for.

In the evening of September 12, a woman walked into the room in the ICU. She introduced herself and said, "I work in the NICU. The entire hospital is talking about you. We're worried! You need to go home and get some rest. I'm here to learn what you know so I can take care of Bea tonight and you can get some sleep." The nurse pushed up her long white sleeves and said, "So, start teaching!"

After a few hours, this nurse could suction, and could hear when suctioning was needed, because Bea was no longer conscious very often. I told her, "Don't get upset if she stares at you. She has always slept with her eyes wide open. It looks freaky, but it is just Bea."

The nurse shooed me out of the room and I drove home in a fog. When I got home, Diane had brought Libby and Jimmy home for Jeff to take care of during the night, so I got to give my healthy babies a hug, sing them to sleep and then I fell into bed exhausted.

At 2:08 a.m. the phone rang. It was White Memorial Hospital. Bea had gone through cardiac arrest. I was needed back at the hospital. By that time I could drive over in my sleep, thank God, because I don't think I really woke up until after I was in her room in the ICU. I looked at her lying on the bed, and knew that Bea was no longer with us. Yes, the respirator was pumping, and yes the IV was dripping, but Bea had left to go home. She had given me power of attorney over Jacob, and her body, but had refused to give me power of attorney over her life. So, I sat down for another long battle.

About thirty minutes later she had another cardiac arrest. They got her heart beating again. Then four phlebotomists descended on the room. One on each extremity, trying to find a vein that was not collapsed. I sat quietly through the next hour as they poked needles over and over again. I prayed silently, "Please dear Lord, don't let them find an open vein." After an hour they stood up, and apologized, "We're so sorry. We can't find a vein that isn't collapsed. We're so sorry."

I said, "I'm not. She is not here. We need to let her go."

A few minutes later Dr. Bounds came into the room. "Becky, we are going to have to put a shunt into the chest cavity to issue medication to keep her heart pumping."

I said, "Dr. Bounds, is there another doctor in this hospital that can join you in here and make the determination that she is brain dead?" I do know hospital politics and some law. If it was determined that she was brain dead, then she would be a "no code" and could simply pass away quietly without more torture.

He asked, "Are you sure you will be alright with that?"

I replied, "I think I just suggested it."

Dr. Bounds left and, in about 30 minutes, came back with a neurologist. I went to see the nurse who made my good coffee. When I got back, both doctors stood in front of me at the nurses' station and said, "We have determined that Beatrice Marin is brain dead. There is nothing else we can do. If she has another cardiac arrest she will be a 'no code'. Do you understand what we are saying?"

With sadness and firmness I said, "Yes. My friend will finally fully pass into the arms of her Heavenly Father. I understand."

It only took about fifteen minutes before Bea had another cardiac arrest. I held her hand as even the respirator could no longer force air into her chest. I sat and cried.

When I went to the nurses' station, I picked up the phone and called my husband. "She's gone," is all I said.

Life Goes On

Jeff came and took me out to a breakfast in downtown Los Angeles. They served mimosas. Now, I'm a person who cannot hold her liquor. I downed twelve mimosas and didn't feel a thing. I ate whatever it was they set in front of me, and to this day I cannot tell you what the food was. Then Jeff drove me back over to White Memorial Hospital.

We entered the hospital and I automatically turned to the right to take the elevator up to the ICU. Jeff grabbed me from behind, turned me in his arms and said, "Becky, I'm going upstairs to take care of the body. You are going to NICU to take care of our son."

I finally cried. I didn't stop all the way down the hall to NICU. I didn't stop while washing up, robing up, and walking to the back of the room where Jacob's incubator was placed. There was a nurse holding him in her arms with the wires and tubes hanging off him. There was the rocking chair and the warming light ready for me to sit and just hold my new son. I bawled all over that tiny little person, and no one said a word. They were all running it with me.

EDITOR'S NOTE: Jacob is now a healthy adult, with two children of his own. This sad, but also uplifting, story illustrates the commitment that many of us have to each other. We share so many life experiences. We know, and we care.

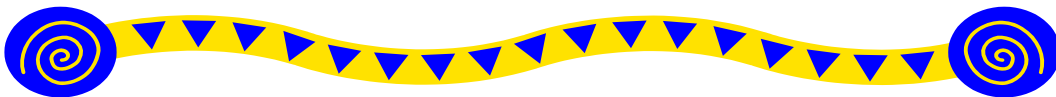


REMINDERS.....



Our DME (Durable Medical Equipment) fund offers help to individuals who have a gap between their insurance coverage and their financial assets to cover durable medical equipment. The applicant must be a **POLIO SURVIVOR** who **RESIDES IN COLORADO**, with **LIMITED FINANCIAL RESOURCES**.

THE \$650 GRANT can be used IN ADDITION TO YOUR INSURANCE. The recipient PAYS SOME OF THE COST THEMSELVES and IF ABLE, may be asked TO VOLUNTEER IN SOME WAY TO SUPPORT POST-POLIO. Nancy Hanson 303-233-1666 Ext. 237 has the application and will send it to the applicant.



Already hundreds of Zika sufferers are arriving at our shores; most have traveled here from other countries. While Colorado only has few cases, this is vacation season in our South, primarily California, Texas, Florida, Georgia and many cases in New York. The Center for Disease Control hasn't an idea yet about how to cure or treat them. The virus can be transmitted through mosquito bites, pregnant mothers to their babies, and sex between partners. Imagine having a new baby with a less than normal size head!

This all reminds the Editor about the continuing need for regular vaccinations. Since Polio is a life-long danger, thank heaven that vaccinations have stopped it in the US; but Post-Polio is still with us and will be here for years. Three other countries are still dangerous because of insufficient Polio vaccinations there yet.



Mumps, Measles and Whooping Cough (Pertussis) are back in this country, too, again. Even adults are getting some of these old diseases!

Certainly, we should encourage that all school children should be vaccinated, because so many parents don't know about the danger of Post-Polio striking years later!

OUR EXECUTIVE COMMITTEE MEMBERS

Sandy Abbott	303-646-7346	Sandya65@outlook.com
Sue Brandon, Chairperson	763-377-2287	Sue.Brandon@q.com
Marny Eulberg, MD, Medical Advisor	303-829-1538	marnyeul@me.com
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Nancy Hanson, Easter Seals Liaison	303-233-1666 x237	Nhanson@eastersealscolorado.org
Pat Jenni	303-880-3581	patjenni@gmail.com
Janet Thompson	303-937-5052	janetandjere@SoftHome.net

Executive Committee dates for 2017 are **Mondays, March 20, June 19, September 18 and December 18**. Meetings are at **4:00pm**. **Everyone is invited**.

Colorado Post-Polio Support Group 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 informally these days

Contact: Linda Groth - 719-633-1497 – (Call for time and location)

Grand Junction – Please call for date, time and place.

Contact: Loran Dake - 970-241-7825 - lorandake@msn.com

Lakewood - Meets the 2nd Tuesday of each month, 11:00am to 1:00pm in Golden, bring a brown bag lunch. **Contact: - Annette Beck - 303-427-1789 - annette.beck242@outlook.com**

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

Contact: Peter Way - 870-460-6164 - NOCOPolio@gmail.com

Pueblo – Looking for new time and meeting place. Call for details.

Contacts: 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.

*As long as you are breathing
it's never too late to do some good. - Maya Angelou*



Because of effective vaccination efforts in the US since the 50's, we no longer have new polio cases here. However, many immigrants in their 30's to 60's who contracted the disease abroad travel here or become residents. Native-born survivors are now in their 30's - 80's. Support for these new survivors will be needed for the next 4 decades!

Because we are blessed with the help of some serious major donors, we are building reserves for the future. Our valued regular donors support our overhead and special programs. Our many valuable Volunteers are the icing on our cake.

Please complete this form, detach it, and mail it to Nancy Hanson at Easter Seals Colorado.

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 again!

Name: _____

Address: _____

**City, State,
Zip:** _____

Phone: _____

E-Mail _____

Mail to: Easter Seals Colorado, 5755 West Alameda Ave, Lakewood, CO 80226

Memo line: Post-Polio

**FREE MATTER FOR
BLIND OR DISABLED**

**Colorado Post Polio
5755 W. Alameda Avenue
C/o Easter Seals Colorado
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