



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."

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Bea, being Bea, replied, “I guess you had best say both,” and then she gave her respirator 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

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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?”

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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!”

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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 her 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,

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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 shoed 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

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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 sat 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.



Support Group Meetings

Rancho Los Amigos Post-Polio Support Group

Saturday, August 27, 2016 - Show and Tell - Bring photographs of your polio experiences. These can be from your hospital experiences, your school years, or any period you think others would enjoy seeing. Our stories are all unique, and these photographs illustrate this. So find those old photo albums and share.

Saturday, September 24, 2016 - Fun at Café La Reina - Café La Reina is actually Richard Daggett's backyard. We will enjoy food, games (no running or jumping), and the company of some extraordinary people. A map with directions will be mailed to our Southern California readers a few days before the meeting.

For meeting information, please call Diane at (562) 861-8128

For newsletter comments, please send an e-mail to: ranchoppsg@hotmail.com



Post-Polio Support Group of Orange County

Saturday, September 10, 2016 - Planning for the Future - Putting your affairs in order to facilitate the disposition of your estate, be it through an Executor or your Trustee. Make it easy to find estate information and necessary keys policies and other objects of importance for your heirs. Inform, Organize, and Identify, but most importantly, plan ahead.

For meeting information, please call Aleta at 949-559-7102 or send an e-mail to Priscilla at prisofoc@aol.com



The Rancho Los Amigos Post-Polio Support Group and the Post-Polio Support Group of Orange County share a mailing list and publish newsletters on alternate months. All of our meetings are open to polio survivors, family, and friends. Our meetings are relaxed, informal, and provide a supportive atmosphere for the exchange of ideas and concerns.