



# Colorado Post-Polio **Connections**

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## **Polio in Our Family: The First Years**

*By Martha Heilman*

**August: 1953**

There is blue wall paper on the wall of Mom's bedroom. A door separates the room from the kitchen with the coal burning stove, linoleum floor and metal heat registers. A little bed is tucked in the corner behind the door. I sleep there at night and sometimes go there for an afternoon nap after dinner in the summer time. I will be in fourth grade when school starts and turn nine years old in November.

I'm on that bed and hear Daddy talking to Mom. "You don't suppose she has it too."

Sometime before that he had taken Jim to the hospital for a check up and Jim didn't come home. Now he is talking about Margaret. "I better take her in to be checked."

I feel my heart beating. Jim has polio. It couldn't be that Margaret has it too. I don't know what polio is, but I know it's bad and you can die from it and you can be crippled from it too. You can catch it in a swimming pool. I know that everything will be all right. Bad things like this happen in the other families. But Jim has polio.

Margaret didn't come home from the hospital either.

I feel their absence. Before then, I had never noticed their presence. Things just were as they were. Today was like yesterday. Mom in the kitchen. Daddy coming in from outside. Kids in the family. A big play table in the living room with little stools Daddy had made.

*(Continued on page 8)*

## **In My Opinion. . .**

Last October, I took the initiative and talked with my sister and two of my brothers, one of whom also had polio at the same time I did, about our polio experience. It only took me 54 years to do that and the results were wonderful. We shared our memories of that time, how we saw things, what we understood, and how we felt. I had talked with my youngest brother many years ago. He was a baby at the time and I naively asked him about my polio. His response was that he never knew me to be any different than I am. In hindsight, what else would he say?

However, my sister and my brothers who are closer to me in age had never talked about our experiences. The result of our sharing was in itself interesting, a sharing of forgotten memories and details and perspectives, leaving us with some holes in the story that probably will never be filled. As we tried to piece together our shared information, I realized that my greatest adult resources about that time, my parents, who are no longer living, are no longer available to talk about what happened.

Out of our time together, I received perhaps my greatest gift, a written memoir by my sister, who was eight years old when I had polio. I am now at an age when family history is important to me and so her story is a treasure. Her memoir paints a bigger picture of the impact that my polio had on my family and provides pieces of the picture that have been missing. It has opened up for me a new, broader perspective on my experience. I hope that by sharing her story, some of you might want to copy my experience and talk to members of your family about your experiences.

This leads into the focus of the rest of the newsletter, the value of keeping our own medical records, with an article written by Jim Oxley. Some sort of system for doing so makes our navigation through the health care world much easier for us. It is also part of our personal history. Included in this issue is also a two page summary of polio entitled "Post-Polio 101" from Polio Epic, Inc. in Tucson, Arizona which can be clipped from the newsletter and kept with your medical records. It is a comprehensive and efficient means of communicating with your health care professionals on the issues facing polio survivors.

Another related article is the book review on Warm Springs by Susan Richards Shreve, a memoir of her polio experience. In the review, Ileta Smith shares her personal response to the author's experience, which has as much impact as her summary of part of the book.

On another note for those of you who want to keep up with the latest information on polio and post-polio syndrome and who like to travel, Post-Polio Health International will be hosting their conference at Warm Springs, Georgia in April or May of 2009. The location provides attendees an opportunity to see where Franklin D. Roosevelt spent his time and where many polio survivors were treated over the years. It will also be an opportunity to meet other survivors and learn something about our shared experiences. More information to follow as it becomes available.

*Margaret C. Hinman, editor*

# POST-POLIO 101

## WHAT YOU NEED TO KNOW

### 1. DID YOU HAVE POLIO?

- Spinal tap?
- Unexplained fever?
- Flu like symptoms?
- Paralysis?
- Severe neck pain and/or headache?
- A disease that severely affected the nervous and muscular systems?

### 2. WHAT IS POST-POLIO SYNDROME? (PPS) (late effects of polio)

#### TRUTHS:

- A secondary condition to having had polio
- New symptoms approximately 10-40 years after recovery from polio
- Not everyone who had polio develops PPS
- Other conditions have been ruled out including normal aging

#### MYTHS:

- It doesn't exist
- The virus has returned
- You can't do anything about it
- Everyone gets the same symptoms
- PPS is life threatening
- All polio survivors have atrophied limbs

### 3. WHAT CAUSES POST-POLIO SYNDROME? (PPS)

- Decades of "overuse and abuse" of the body
- Polio damaged the nervous system, including the brain
- Motor neurons, that move muscles, weakened by polio are beginning to fail
- Triggered by a trauma (surgery, accident, immobilization, death of a loved one, etc.)

### 4. WHAT ARE SOME OF THE SYMPTOMS?

- Unaccustomed fatigue – either rapid muscle tiring or feeling of total body exhaustion
- New weakness in muscles – both those originally affected and those unaffected by the virus
- Pain/burning sensations in muscle and/or joints
- Breathing difficulties and/or sleep problems
- Swallowing problems
- Functional decline
- Depression and/or anxiety
- Weakness and muscle atrophy
- Muscle spasms, twitching and tingling
- Nerve compression problems, (carpal tunnel, tendonitis, etc.)
- Hypoglycemia
- Hypothyroidism

### 5. WHAT CAN BE DONE?

To **PREVENT** new symptoms from occurring

- Awareness of type "A" behavior
- Plan frequent rest periods
- Pace daily activities
- Limit exposure to cold
- Increase protein and decrease added sugars in diet.
- Gentle exercise program as prescribed by a professional familiar with PPS

To **PRESERVE** remaining strength

- Conserve energy, "Conserve to Preserve"
- Stop overusing and abusing
- Be active, but STOP short of fatigue and pain
- Use assistive devices (braces, canes, wheelchairs etc.)
- Use quality nutritional supplements as advised by a nutritionist
- Control your weight
- Maintain a positive attitude
- Join a post-polio support group

### 6. WHAT ABOUT BREATHING PROBLEMS?

Polio survivors may experience new breathing problems; even though the lungs were not originally thought to be affected by the acute polio virus.

#### SYMPTOMS:

- The need to sleep sitting up
- Insomnia
- Morning headaches\*
- Excessive daytime fatigue/sleepiness
- Night sweats and interrupted sleep
- Unproductive cough and increase in respiratory infections

#### APPROPRIATE ACTIONS:

- See your Healthcare provider and/or a pulmonologist immediately
- Be wary of oxygen therapy if your lungs are not damaged. (You cannot assume that polio damages the lungs)
- Tracheostomy tubes should be avoided
- Possible need for sleep study

### 7. WHAT TO DO WHEN SURGERY IS REQUIRED.

- Talk to your healthcare provider about the planned procedure and post-polio concerns
- Set up a consultation with the anesthesiologist during the pre-admission process about concerns with post-polio and curare types of anesthesia
- Review your previous medication reactions with surgeon
- Assess with Healthcare provider your need for in-patient vs. out-patient surgery:
  - Body positioning during procedure

- Cold intolerance
- Additional post-operative recovery time may be required
- Additional anesthesia and/or pain medicine may be required
- Assess level of fatigue to determine your ability to tolerate out-patient or in-patient procedures

## 8. WHAT TO DO ABOUT PAIN?

### Tips that have worked

- Use moist heat and/or ice packs to the painful area
- Get light massages
- Try warm water therapy
- Get tested for sleeping and/or breathing problems  
Use assistive and adaptive aids, as necessary to reduce stress to muscles and joints
- Check into need for anti-depressant prescription drugs
- Use pain medication (ibuprofen, Celebrex, Vicodin, Percocet, Oxycontin, etc.) as prescribed by your Healthcare provider
- Try alternative type treatments (acupuncture, yoga, myofascial release, Reiki, Watsu, etc.)

## 9. WHAT ABOUT MEDICATION?

It is your responsibility to know all your prescriptions, over-the-counter (OTC) drugs, and supplements. Inform your health care provider with:

- Name
- Purpose
- Dosage
- Interaction with other medications
- Side effects and risks
- Previous medication reactions
- Change your lifestyle before turning to pain medications
- Avoid stimulants that cause increased fatigue

## 10. HOW IS PPS DIAGNOSED?

Having a Healthcare provider exclude all other possible causes for new symptoms, (normal aging, ALS, MS, MD, Guillen-Barre, etc.)

## 11. HOW TO COMMUNICATE WITH YOUR HEALTHCARE PROVIDER?

**BEFORE** you visit your Healthcare provider

- Keep a journal of progression of symptoms, making simple entries concerning:
  - Daily living
  - Physical
  - Emotional
  - Time of day most affected
  - Positive and negative changes
- Note current symptoms, (tiredness, fatigue, exhaustion, etc.)
- From journal, make a list of questions and concerns to present to your Healthcare provider

**DURING** the visit with your Healthcare Provider

- Describe all current symptoms and when/how they have changed over time
- Be specific about what you need, if known
- Avoid giving “Yes” and “No” answers
- Describe HOW: (i.e. much, long, in what way). (“I can climb 3 steps in 5 minutes with assistance.”)
- Clarify what you hear by asking, “Did you say...?”
- Bring written post-polio information
- Build a relationship with your Healthcare provider
- REMEMBER, some symptoms are not PPS related, (normal aging, heart disease, diabetes, etc.)

**AFTER** your Health care provider’s visit

- Request copies of all reports and test results
- Call if you have further questions

## 12. DID YOU KNOW?

- There are Post-polio Clinics and support groups all over the world
- Rotary International goals are to:
  1. Eradicate polio worldwide
  2. Develop programs to assist polio survivors
- People still get polio
- Polio survivors are likely to develop post-polio symptoms
- “No Pain – No Gain” DOES NOT apply to post-polio syndrome
- Many resources are available

## 13. WHERE DO YOU FIND MORE INFORMATION?

- **Polio Epic, Inc.**  
P.O. Box 17556  
Tucson, AZ 85731-7556  
(520) 750-8608 (message)  
[www.polioepic.org](http://www.polioepic.org)
- **Polio Echo, Inc.**  
P.O. BOX 61024  
Phoenix, AZ 85082-1024  
(480) 545-1147  
[www.polioecho.org](http://www.polioecho.org)
- **Post-polio Health International (PHI)** including International Ventilator Users Network  
St. Louis, MO  
(314) 534-0475  
[www.post-polio.org](http://www.post-polio.org)



**TAKE CHARGE OF YOUR MEDICAL CARE. YOU KNOW YOUR OWN BODY BEST!**

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## Developing and Maintaining Our Own Health Record

*By Jim Oxley*

Why on earth do we need to have medical records? Doctors, therapists, hospitals and clinics keep records of us. There are paper and computer trails out there that we can access. But, if we don't keep track of our own medical information, such as list of pills, last physical, blood pressure, cholesterol, inoculations, phone numbers and weight how can we recall these details when we need them? After all, our aging memories aren't always reliable either. A Special Report from In Motion, by Dupes and Mathis, states that complete medical information is needed should we move or change doctors. They add that the records ensure accuracy and save time.

A self-kept record of important medical information (a medical diary, if you will) becomes a necessity and is useful to us for the above reasons and more. It is particularly important for some of us to have our records available for use by our caregivers, spouses and family members. Another good reason to keep an account of our health is to have questions or comments ready for our next doctor's visit. (Leave space for noting the major points that your doctor makes during every visit.) As most of us have experienced, referrals made by our doctor, therapist or other care providers always preface the visit with questions about our medications, last physical, and symptoms of note. If we have our records with us, we won't be embarrassed by saying we don't know or remember.

With doctors asking more and more questions about our family history, we should record that information where it can

be accessed easily. And why not put that in your medical journal? Then when the question is raised "Is there any cancer in your family?" we can refer to our journal and accurately relate that information to our doctor. Certainly our polio history should be in a place where family or caregiver can find it. We should list our concerns and cautions about anesthesia, fatigue, food allergies, postoperative recovery time and more. Also one can list insurance carriers and appropriate medical card numbers. We may wish to list the location of our living will, medical power of attorney and organ donor wishes.

So, is there a right or wrong way to keep records? With access to computers now, our records can be kept on a computer disc, on a portable USB drive or "memory stick" for immediate access, or filed in some other form. A recent book by Laura Casey, How to Get the Health Care You Want, has a chapter on "Creating and Maintaining Your Own Health Record." She goes into detail on all kinds of records one can keep and the software available to do it. Her website is: [www.howtogetthehealthcareyouwant.com](http://www.howtogetthehealthcareyouwant.com). The American Hospital Information Management Association (AHIMA) has made available to anyone a set of forms for recording all appropriate personal health information. Logging on to [http://myphr.com/your\\_record/record\\_contents.asp](http://myphr.com/your_record/record_contents.asp) can access it. These forms can be filled out on the computer or by longhand and made part of our health journal, notebook, a computer disc or other form for filing. Hospitals and doctors are using this means for their files. Of course, we have to update these as changes *(Continued on page 6)*

## Developing and Maintaining Our Own Health Records

*(Continued from page 5)*

occur in our personal information. AHIMA has created forms for both adults and children. Share this website with your children and grandchildren to “kick start” their own record keeping!

My comment with respect to both of these sources, which are very useful, is that if keeping our health information becomes too detailed or complicated, we are liable to give up and not keep any records at all.

I have been keeping my medical records for a number of years after the topic was discussed at a support-group meeting. I chose to use a bound journal or ledger for writing things down after any medical intervention in my life. This technique has helped me to acquire the habit of jotting notes down, much like keeping up with a diary. It is easily carried to your appointments and especially useful when one sees a different or new provider.

In summary, the most important step is to begin the process and use whatever form of recording that is easy. Keeping it simple prompts one to develop the habit of “just doing it.” Dates of treatments and appointments, doctor’s visits, hospital stays and so forth, followed by a few notes or computer printouts fastened in the notebook can be a beginning point. Remember that your medical records are available to you by law and that you can have them duplicated for your own use, usually without cost. Beyond that, more detail can be added and notes of historical importance incorporated in your record as part of your health journal. You may want to ask a caregiver or friend

not only to accompany you to your appointments but also to help you record the most salient information from your visit.

### *References:*

Casey, Laura L. 2007 “How To Get the Health Care You Want,” 1 Life Press. P.O. Box 26644, Austin. TX 78755

American Health Information Management Association, 233 North Michigan Ave., Chicago, IL 60601-5800. 2007.

Dupes, Bill and Lee Mathis, “The Importance of Keeping Copies of Medical Records,” *In Motion*, Vol. 17 Issue 4, July/August 2007, pp.18-20.

11/19/07

## Warm Springs: Traces of a Childhood at FDR’s Polio Haven By Susan Richards Shreve

*Reviewed by Ileta Smith*

Susan contracted polio at the age of one, and entered the sanitarium at Warm Springs, Georgia when she was eleven. Prior to her arrival at Warm Springs, her mother had devised her own regimen of exercises for Susan. All through her childhood, Susan and her mother spent their days “on the floor, on the bed, standing against the wall, doing a long series of exercises.” Her mother was always developing new games, stories, and fun things to do to make the exercises seem more like games than work. Susan developed a *storytelling* attitude about life. Always changing situations to have a *happy ever after* ending. By the time she was three, she could walk with braces, holding her mother’s hand or swinging back and forth in a kind of jump step, moving forward by throwing her hips ahead of her. *(See page 7)*

## Book Review: Warm Springs

*(Continued from page 6)*

It was around this time that Susan's doctor had arranged for her to be the subject of a lecture by Sister Kenny at Washington's Doctors Hospital. Sister Kenny was a physical therapist with no formal medical training. She had decided instinctively that the paralysis and stiffness associated with Polio were due to muscle spasms and devised a treatment of hot packs which she used to help the muscles relax.

Sister Kenny was already on stage, and looking at the audience as Susan was wheeled out on a stretcher wearing an oversized gown and covered by a sheet. Susan introduced herself. Sister Kenny's response was to look down and with a "grand gesture" tear the sheet from Susan. She began reciting factual information; the child's name, age, type of polio, when it was contracted, physical deformities, etc. She continued by telling the audience that "the patient has been treated by methods devised by her mother. These methods have never included the application of hot cloths or muscle stretching or reeducation of the damaged muscles." And so she swooped Susan off the stretcher, stood her on the floor, and told her to walk. After Susan took five or six unsteady steps, Sister Kenny lifted her back to the stretcher, raised her hands in a gesture of defeat, and replied, "By the time she is twelve years old, this child will not be able to walk any longer." With that, Susan's doctor rushed up to the stage, gathered Susan in her arms, left the stage, dressed her, and gave her to her mother. Susan felt she had let her mother down. Her mother apologized to her for what Sister Kenny had said.

This experience was one of many harsh and confusing interactions Susan experienced during her childhood. Her story has an underlying sense of sadness, of not being worthy, of being a trouble maker. At age eighteen, Susan had written an unpublished novel about a girl with mild paralysis who went to Warm Springs. After rereading the manuscript some forty years later, she was surprised at how different her present memory of her time at Warm Springs was from that of her youth. People thought she was blessed with a sunny disposition. Susan didn't realize until she was in her twenties that the image of her as a happy-go-lucky, fearless girl was in fact an invention for both she and her mother.

Susan's Warm Spring journey began the night before she was to be admitted. Her mother, father, and brother all slept in the same double bed in a small hotel. Susan slept on the floor, afraid to test her own emotional strength by giving in to the comfort of her family. The next morning at Warm Springs, as she waited to be admitted, she noticed Joey Buckley and immediately included him in her vision for her life. Joey was thirteen, and dreamed of playing football for Alabama. They spent a lot of time together during their stay at Warm Springs sharing words of encouragement, and companionship. She loved him and considered him hers. They both had several stabilization surgeries and painful muscle transplants while at Warm Springs.

Susan's ward was arranged with beds on each side. The girls who were to have surgery within a day or two were closest to the door. As their surgery was completed, they would be rotated *(See page 8)*

## **Book Review: Warm Springs**

*(From page 7)*

farther into the room. She recounts how she spent her days at Warm Springs; experimenting with different religions, helping in the baby ward, helping with bed pans and food trays, befriending a young mentally disabled child of a staff member, and of course, spending time with Joey.

One Thanksgiving, after being disappointed that she would not be going home for the holiday, Susan felt subdued, as if some of her former self had vanished and she was left with the shell of the girl she had been. She was getting more positive comments from the staff, since she no longer had the drive to exert herself with the exuberance she had displayed previously. Joey was getting ready for reconstructive surgery and was supposed to put on weight, so on the days Susan passed out the food trays she would bring him Clark bars and extra ice cream.

As Susan and Joey were going to the movies, they had to move their wheelchairs very slowly down a hill. "There was a long, steep dip of cement walk from the level ground of the first floor of the hospital to the movie theater room on the basement level." Susan suggested that they might race down the hill when Joey got out of surgery. About two weeks after his surgery, Joey was scheduled to go home. They decided to do something special to celebrate . . . racing the hill.

Susan had always been told that no one left Warm Springs until they were as well as possible. The next morning, after the race, her Warm Springs journey was ending. She was told she was going home.

She protested saying she wasn't that well, that she could hardly walk, and was in much pain. She was told she was well enough to go home. Her roommates avoided eye contact, and conversation. Her father arrived wearing a suit. He wasn't angry. "He wasn't anything at all, simply a father who had come to pick up his daughter, dismissed in disgrace." He was told that if Susan continued to work hard, there was no reason she couldn't be better than when she arrived, but it would take time, years even.

Joey had broken both his legs in the race. She never saw or heard from him again.

I found the book to be interesting, but not always flowing chronologically. It was a series of memories of her childhood. The book was written similarly to how we might recount our own memories. You know, how we remember things, but not necessarily in the order in which they happened. I felt she was still trying to come to terms with her own feelings. How her experiences, and her perception of those experiences, has influenced her outlook today. I wouldn't say this was a "feel good" book, but very real. I could relate and remembered very similar experiences in my own childhood. I did not find it to be uplifting, but it did remind me that I am not alone in the unpleasant memories of growing up with polio, spending a lot of time away from my family, and at the mercy of those around me.

## **Polio in Our Family** *(From page 1)*

Doing dishes with Margaret. Cleaning the house with Margaret on Saturday to get ready for church on Sunday. Walking to the mailbox to take the bus to school. Going barefoot on hot summer days. *(See page 9)*



## **Polio in Our Family** *(From page 8)*

Twinkle Time, Bobby Benson and Sergeant Preston on the radio. All the family in the green Chrysler. Sometimes comic books for a treat after Mass.

Time passes. It's Sunday after Mass and we're in Thompson's drugstore. It's the first time I remember all of us going in. Usually Mom waits with us in the car while Daddy goes in to buy something. Us kids went in that day because Mom and Daddy are looking for something for Margaret and Jim to have in the hospital and they wouldn't leave us alone in the car. They agree that they should get something for the other kids too. I look around carefully. I know what I choose shouldn't cost too much money. On the shelf I see a package holding a little toy oven that bakes small cakes. Everything you need to do it is there. I've always wanted one. I show Mom. She said it would be a waste of money because you could only use it once. She sees the longing in my eyes and says, "OK." I know she's right; I feel guilty and sorry I asked for it, but take it anyway because I haven't the courage to choose something else. I know I got it because Margaret and Jim have polio.

We're home from church in the kitchen. Mom walks in the door, quiet and sad. She turns to Daddy and bursts into tears. He puts his arm around her waist and walks her to the couch in the living room. She is sobbing. She is my life. I am terrified. He talks to her in a low voice and she continues to weep. "She just lays there," Mom sobs. "She doesn't say anything or look at you." Daddy holds her and talks. She cries.

I wrap my arms around myself to quiet my fear. I get an idea. I will bake the little cakes in my oven and give them to her. It will make her feel better. She will like them and like me for giving them to her.

I carefully read the directions. The oven is powered by a light bulb. I mix the powder with water and pour it into two little pans. It takes a long time for them the bake. Finally they are done. I wait for her to come out of the living room.

A long time goes by. She's not crying any more, just sitting there with Daddy.

More time. I think she must be able to eat a cake now. I carefully take one to the door with the tiny fork. "I made this for you." I say. There is a pause. She looks at me sadly. "Oh Martha, I'm sorry, I just don't feel like eating now. You should go ahead and eat it." She doesn't hug me. I walk away.

I sit the cake on the counter and wait. She doesn't come out of the room. She stays with Daddy. More time passes. And more. Finally I take the little cakes and eat them. They don't taste very good. She was right.

.....

We're all going to the hospital to get shots because Margaret and Jim have polio. They are in the hospital but we can't see them because they are in isolation. That means they're too sick to have visitors and could get sicker if people visited them and brought germs in. They show us the doors to the part of the hospital where they are.

Lenny and David and Ray get their shots. The baby Jerry is too small. I notice Ray stands up afterward *(See page 10)*

**Polio in Our Family** (From page 9)

and I see his peeper. I think he should be more modest. Then I get the shot. It feels like the shots we got during the school year except it's in our bottoms, not our arms. It's less scary because you can't smell the alcohol or hear other kids crying. I don't cry and can't remember if the boys did.

School starts. Mrs. Salverson is my teacher. She tells the class that some of the students got polio during the summer. She says my sister and brother got it and so did Paul Schulte. We'll write letters to them, she says. And we do. Margaret is still in the hospital. Jim will come home soon.

Margaret is very sick. She needs to go the hospital in Helena to get better treatment. Daddy puts a piece of plywood in the back seat of the car and makes a bed for her there. We don't see her before she leaves.

Mom says we should write letters to her. I write her often and hope people will notice how good I am. Once I write her all the parts of a story I've read. It doesn't sound good to me, not as interesting as the book, but I'm proud I wrote so much. Nobody notices. I hope she likes it, but secretly think it will be boring for her.

Jim is home from the hospital and the same as he was before.

Margaret gets to come home for Christmas on the train. She walks into the house with metal crutches wearing a dress

and a heavy brace connected to brown shoes. I didn't expect that. She talks about making leather purses at the hospital and going swimming. She has a friend whose name is Delores. She isn't sad. She's still smart and seems really grown up.

**Spring and Winter: 1954**

Things change when Margaret comes home for good. It takes a long time to walk with her because she has to go slow, but she can climb stairs and stand up good enough to take a shower. Daddy takes her and me to see Brigadoon at night at Custer High School. We'd never seen a play before and this one had songs in it to help tell the story. She and Daddy take a class in tooling leather and making leather belts. A man we met when we went on a family car ride sent her a rock collection in the mail because she had polio.

Margaret's leg gets really cold and that changes some things. We used to walk up to the mailbox to catch the bus and walk home at night even when it was freezing cold. Now when it's cold Mom drives the car up to get us. Pretty soon she comes in the car even when the weather is nice. I miss not being able to run home and sometimes I don't go in the car. I walk home by myself.

Hanging clothes on the clothesline in the winter and taking them down is the worst. We used to have to do it together. Now I have to do it by myself because she might slip and her leg gets cold. I hate it. It's freezing, freezing cold. I also have to be the one to always go downstairs to get cans of vegetables and it's my job to keep the fire going in the hot water heater. If I forget to put coal in and the

(Continued on page 11)

## **Polio in Our Family** (From page 10)

fire goes out, I have to make a new fire, which I hate. Your hands get dirty with coal dust from putting the kindling in. When I first started doing the down stairs jobs it was kind of scary because sometimes snakes get in. I got used to it though and wasn't afraid anymore. Anyway, the point is that Margaret can go up stairs to get to the bedroom, but she never has to go downstairs. I have to do it all. It's not fair.

There's one more change. They're giving everybody shots now so no one will get polio anymore. The main thing is that Margaret really hasn't changed. She has trouble walking, that's all.

.....

## **And By the Way. . .**

Polio survivors want their health care professionals to know up front:

- All prescription medications, including dosage
- All non-prescription medications and supplements used
- Family history
- Allergies
- Surgeries
- Where x-rays are
- **Physical limitations and needs**, i.e., help getting on the examination table, and/or inability to use one or more of their limbs
- Presence of arthritis
- Oxygen levels
- Ventilator information—Liters of Oxygen
- Breathing problems
- Swallowing problems

- Polio, post-polio and **potential anesthesia complications**
- Contact numbers—who to call in an emergency
- Living will and medical durable power of attorney
- “Do Not Resuscitate” instructions

Some polio survivors share that information by organizing and using:

- A 3-ring binder of all medical information, which is taken to each medical appointment
- A diabetic diary
- A notebook, divided by medical problem and treatment done
- A medical journal
- Information stored on a computer disc
- A reduced print size of medical information printed from the computer so that it can be kept in a wallet or a small plastic case
- A Medical Alert Bracelet
- The File of Life or Vial of Life, fire department or government sponsored safety alert programs
- A fireproof box to store the information at home

## **Meetings and Conferences**

**Easter Seals Colorado and Colorado Post-Polio Connections will hold an educational meeting** at the Lakewood Holiday Inn, Hampden and Wadsworth on Saturday, May 10, 2008. Info to be mailed.

**The 2009 Post-Polio Health International Conference** will be held at Warm Springs, Georgia in April or May 2009. Information will be available on the Post-Polio Health International web site at [www.post-polio.org](http://www.post-polio.org).

## **This Is Your Newsletter-----**

Colorado Post-Polio Connections is a newsletter by and for polio survivors, their friends and others who are interested in being part of our network. The editors and staff invite your contributions to the newsletter. If you have comments, articles, or suggestions for topics for future issues, please email us at [post-poliocolo@comcast.net](mailto:post-poliocolo@comcast.net) or write to us:

### **Colorado Post-Polio Connections**

Easter Seals Colorado  
5755 West Alameda Avenue  
Lakewood, Colorado 80226

Please include your name, address, phone number and email address in any correspondence. To change mailing information, contact Nancy Hanson at 303-233-1666, ext. 237 or email her at [www.nhanson@eastersealscolorado.org](mailto:www.nhanson@eastersealscolorado.org).

**Our next issue will focus on keeping control of our lives—Preventing falls.** We need suggestions from you as to what you do or have done to prevent falling as we age for our “And By the Way. . .” column.

### **Disclaimer**

The opinions expressed in this newsletter are those of the individual writers and do not necessarily constitute an endorsement or approval by Easter Seals Colorado or the Post-Polio Advisory Council. If you have personal medical problems, consult your own physician.

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