

VOLUME 25 NUMBER 3

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Anesthesia Update: Separating Fact from Fear

Summer 2010

Selma Harrison Calmes, M.D. Retired Clinical Professor of Anesthesiology, UCLA School of Medicine Sylmar, California

INTRODUCTION:

This talk will briefly review the process of anesthesia care, current anesthesia practice, and how these might relate to post-polio syndrome (PPS) patients having surgery. The goal is to make clear that proper pre-op planning allows postpolio patients to have surgery and anesthesia with a minimum of risk. Indeed, the risk of anesthesia is much, much less than the risk of death from an error while hospitalized. It also emphasizes that it is not necessary for post-polio patients to keep up with drugs and practices in anesthesia. Anesthesia, like every medical specialty, is rapidly changing, as legions of dedicated researchers and clinicians work to make what we do more effective and safer. It is extremely difficult for anesthesiologists to keep up with all the new drugs and practices; patients can not possibly keep up.

This talk will <u>NOT</u> address pain management, except pain immediately post-op. Research has—and is still finding numerous, complex mechanisms that cause pain, and pain treatment is becoming more and more complicated. Continuing research on pain mechanisms will probably lead to better therapies for PPS patients with pain problems.

(Continued on page 3)

In My Opinion . . .

Over the years, many of us have heard about the risks related to anesthesia for polio survivors. If we have not experienced adverse effects ourselves we often know of someone who has. When I attended the 10th International Conference of Post-Polio Health International I was excited to hear Dr. Selma Calmes, a noted anesthesiologist and a polio survivor, talk about the latest research and her conclusions about the risks of anesthesia on polio survivors, and I was pleased at what she had to say. The notes from her talk are quite extensive and will take both this issue of the <u>Connections</u> and the next one to provide you with the complete talk.

On another note, this issue celebrates transition. There have been some major changes in the Colorado Post-Polio organization, sponsored by Easter Seals Colorado. Over the years the organization has been kept alive by a stalwart group of polio survivors who have given of their time and energy to make available support groups, conferences and educational meetings, grants and this newsletter to polio survivors and their support systems in Colorado, as well as throughout the country. Many of these "old guard" are becoming more limited in their mobility and their ability to commit their time to the organization.

In an attempt to revitalize the organization, the Colorado Post-Polio Council has generated a mission statement and goals, and after four years as chairperson for the Council, Marlene Harmon has turned over the gavel and the leadership to Ileta Smith. Her objective is to keep the organization alive and hopefully not only keep the "old guard" involved but also generate a new group of volunteers who will also be committed to keeping the group going.

There are a lot of us polio survivors still here. In Colorado alone we have over 800 subscribers to this newsletter. So, each of us who depend on Colorado Post-Polio for information and support is not alone. Therefore, the Council is inviting people who see the value of the organization and have some time and energy to give to contact Ileta to see how they might be of help to the organization. Your involvement need not necessarily be on-going but can be limited to special projects and events, and much of the work to be done can be done by phone and/or the Internet, so you don't have to live in the Denver area to participate.

Another transition will occur with the Fall (November) issue of the <u>Connections</u>. That will be the last issue of the newsletter that I will edit. For personal reasons, I am stepping down from a volunteer job that has been fun, a challenge, an opportunity to learn so much about polio and polio survivors, an opportunity to meet and become friends with some great people, and an opportunity, I hope, to have made a difference in some of your lives. So, Colorado Post-Polio needs someone to do the newsletter from that time on, if there is to be a newsletter. A new editor need not do things the way I have, can make the newsletter their own, and I will help with the transition, having set up the newsletter in such a way that someone can fill in the blanks on a lot of it.

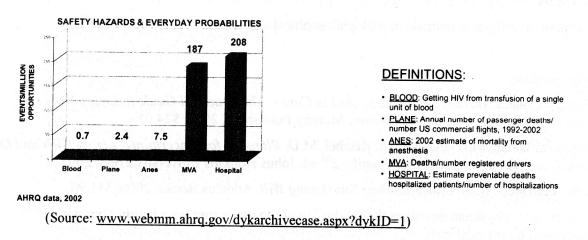
Our other features include a book review, <u>Twin Voices</u>, about a polio survivor and her twin brother, reviewed by Barbara Lundstrom, and Marlene Harmon's story by Woody Trosper. *Margaret Hinman, Editor*

Anesthesia Update (Continued from

page 1)

THE RISK OF ANESTHESIA

What is the risk of anyone having anesthesia, and how does this compare it to other risks in our daily lives? The government's Agency for Healthcare Research and Quality looked at this in 2002



It should be clear where the real risk is: just being in the hospital! The risk of dving from anesthesia is much, much smaller. The focus for worry should move from anesthesia to being hospitalized. Fortunately, a nation-wide effort to improve hospital safety is developing, but safety still varies markedly by individual hospital.

ANESTHESIA RISKS FOR PPS PATIENTS:

What do we know about how PPS patients do during anesthesia? Very little! Medical knowledge like this can be measured by looking at the number and type of medical journal publications over time, something easily done on the National Library of Medicine's PubMed data base. (This lists all articles in standard medical journals over time.) Searching for "postpolio Syndrome AND anesthesia," 11 articles were found. The first was in 1990. Ten more articles were published in the next 12 years. Not all were significant/focused only on PPS. There were 3 case reports, 3 letters-to-the-editor on the cases, 1 was a theoretical article with no cases, 1 was on dental issues, 1 mentioned PPS as part of a larger study of a new drug and 1 was on indications for modafinil (Provigil), not about anesthesia. This is a very small amount of information, really only 8 articles.

Contrast this meager number of articles with those on PPS itself. 946 articles were published since 1990, when the first article on anesthesia was published! So researchers were focused on the bigger problem of what is PPS and what should therapy be. Additionally, few hospitals have many PPS patients coming for surgery, so a significant study of anesthesia complications would be very difficult.

Fortunately, we will get some real data in the next few years. The Mayo Clinic has had an electronic medical record since 1980, and it is often used to study (Continued on page 4)

Anesthesia Update (Continued from page 3)

anesthesia complications. So, I convinced my anesthesia friends there to study this. The question is, "How many and what type of anesthesia complications occur in PPS patients having anesthesia and how does that compare to other patients with a neuromuscular disease and also how do they compare to normal patients?"

Data gathering is finished and they are halfway through data analysis. They gave me permission to give you some early, preliminary results, as of March 6, 2009. The study covers 1986-2008 and includes all PPS patients having surgery (excludes sedation cases and patients less than 18 years old). There are 779 patients, a very generous sample size, which will make the results very powerful. Data analysis is complete on the first 300/779 patients. No anesthesia complications occurred. It will take another 6-plus months to finish the data analysis, write this up and get it published, so we won't get the final results for a while. But, I think this is a most hopeful study, and it supports my clinical impression that if a good pre-op evaluation is done and if surgical, aesthesia and hospital care are competent, PPS patients can have surgery without problems.

PPS patients have asked numerous questions about anesthesia since 1996, when I gave the first talk on this. Many questions have been about normal things that can happen, for example a drop in blood pressure after a spinal anesthetic was placed. This is due to the effect of the spinal anesthetic on nerves controlling blood vessels and is actually not a complication. Well-trained anesthesiologists look for these "complications" and treat them appropriately and promptly. And, some of the most significant "anesthesia complication" questions were actually about complications from surgery and had nothing to do with anesthesia. We have to use great care about what we call "anesthesia complications."

THE PROCESS OF ANESTHESIA CARE:

Because each patient's anesthesia needs differ, and differ over time as new problems show up, this talk will focus less on specific anesthesia techniques and drugs and discuss how you can hopefully communicate with anesthesiologists about your problems. This is an area of confusion, so the usual process is reviewed here.

Most PPS patients will have surgery in a hospital or an out patient surgery facility attached to a hospital. (PPS patients should not have anesthesia in physicians' offices, for safety reasons, and that situation will not be discussed.) The anesthesia process is essentially the same, but varies by elective and emergency surgery.

A. FOR ELECTIVE SURGERY:

 The surgeon and you decide on surgery. You should state your special problems for anesthesia (sleep apnea or whatever). If you have a request for a particular anesthesiologist, tell the surgeon. *Continued on page 5*)

Anesthesia Update (Continued from page 4)

- 2) The surgeon's office calls the hospital's scheduling office and schedules time, date and the operation. The special medical problems related to anesthesia should be stated to the scheduling secretary. If there is an anesthesia request, the office secretary should give the information to the office. (Many hospitals do this process on the web now.)
- 3) Anesthesia pre-op evaluation varies in different institutions. Many hospitals now run a daily clinic for upcoming surgery patients. These are at the hospital; blood work, EKG and chest X-ray can be done at the same time. You receive an appointment usually from the pre-op clinic's scheduling office. These clinics are often staffed by specially trained nurses, who follow protocols. Anesthesia residents are also used. An anesthesiologist is always available to the nurse/resident, who would call him/her for complicated patients. The anesthesiologist might suggest special tests or even come to the clinic to examine you. The data on each patient is recorded and reviewed at the end of the day to see if anything is missing. These forms are passed along to the scheduled anesthesiologist, usually the night before. If there is no pre-op clinic, trained nurses will usually call before surgery to check on your medical history and medications. The answers to those questions are given to an anesthesiologist.

Often, you don't physically see the anesthesiologist until the day of surgery. If your problems are very difficult, for example you need assisted ventilation, appointments can be made ahead of time for the Anesthesia Pre-op Clinic or to see an anesthesiologist. The surgeon's office would facilitate that. Patients with these difficult problems should get evaluations by your pulmonary and post-polio physicians before that pre-op clinic visit, and you should come with all those records (a pulmonary function test, at least!), so the anesthesiologist has maximum information about you. Be sure you are well organized and precise when you speak with them ("I've had polio and need or have ---- whatever."); they are usually extremely busy and pressed for time.

- 4) Hospital operating rooms are chaotic and always in flux, due to emergencies incoming at all hours and also problems possibly occurring in the scheduled operations. As a result, anesthesia staffing is always in flux. The department should do their best to get you your desired staff, but there are times when it just isn't possible. In that case, all the pre-op information is passed along to the new physician, who should have all the needed information on you.
- 5) After surgery, you should get a visit from an anesthesia person, usually a specially trained nurse and/or anesthesia resident. They should ask about your anesthesia experience and if you note any possible complications on the first post-op day. Be frank in your responses. They need to know what YOU experienced. This information is typically put into a database so the department can see how they are doing and compare themselves to national figures.

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Anesthesia Update (Continued from page 5)

B. FOR EMERGENCY SURGERY: In a true emergency such as a car accident, there is little choice of hospital or anesthesiologist. The Emergency Room physician will assess you and decide how urgent surgery is. There may be time for your own physician to get involved. The anesthesiologist will talk with you, often in the OR.

You can help by having a MedicAlert bracelet or some other way to identify your health problems and needs. Because of the wide recognition of the MedicAleart program, that is probably the best to use. Also, your companion/spouse should be aware of your needs. Simple wallet cards can provide them with the needed information. This could save your life! It's also helpful to know which are the best hospitals in your geographic area and discuss this with your companions/spouse.

This paper will be concluded in the Fall 2010 (November) issues of the <u>Connections.</u> <i>This paper was presented at Post-Polio Health International's 10th International Conference: Living with Polio in the 21st Century (April 2009).

The Colorado Post-Polio Council

I am so excited about the changes that are taking place with Colorado Post-Polio (CPP), and the opportunity I have to lead you in this process. My goal for my term in office is to clarify our structure, organize our procedures, and enhance communication throughout our organization so that Colorado Post-Polio can become a vibrant, active organization.

We have eagerly begun the process of developing our guidelines by reviewing, defining, and determining our mission, goals, and procedures. These guidelines will provide continuity and clarity for future officers, Council members, and CPP participants.

We recently elected our new Vice-Chair, June Blanchard, and Treasurer, Gloria Aemmer. We still ARE IN NEED OF A SECRETARY. Do you have typing and clerical skills, time to attend meetings, and an interest in helping our organization grow? If so, contact me . . . let's talk.

keep Colorado То Post-Polio energized, we need to have more people step forward and support the organization by giving of their abilities, talents, and ideas. With your help, we can continue to build Colorado Post-Polio into a vibrant and productive organization, an organization that will continue to meet, if not exceed, the needs and expectations of polio survivors, their families and friends. The determination and strength that has brought us through the challenges of living with the effects of polio will also guide us as we find creative ways to meet our needs as we age. This past year survey was conducted asking for a volunteers. I so appreciate those of you who responded to help, and I apologize for our inability to fully follow up with you at that time.

(Continued on page 7)

TheColoradoPost-PolioCouncil(From page 6)

I assure you that if you contact me about volunteering, your ideas will be given serious consideration, and if at all possible, your talents will be put to use.

We have renewed enthusiasm about organizing Colorado Post-Polio, and are in need of others to join us in this endeavor. We serve the state of Colorado, and are asking for help from those of you not only in the Denver metro area, but also throughout the state. Your help is essential if we are to continue to not only maintain Colorado Post-Polio, but also to expand our outreach. Your input on how we may creatively meet our needs is crucial. I encourage you to join us in this exciting process. If you are unable to attend our Council meetings, perhaps you could contribute from home via email, telephone, writing articles for the newsletter, helping with special projects, fundraising, reviewing cassettes and videos to determine if they are a viable resource. etc. The possibilities are only limited to your imagination.

In just a few short months, we have re-established the official name of our organization, the role of the Council, determined the mission statement and goals for Colorado Post-Polio, established the Expectations of Council Officers, Officers' Terms-of-Office, and the election process. If you would like to receive a copy of our guidelines, contact me and I will see that you receive a copy upon completion.

Again your help is needed. Please contact me if you are interested in becoming involved in our wonderful organization. No contribution is too small. I look forward to getting to know you, and serving you as the Colorado Post-Polio Council Chair.

Ileta Smith, CPP Council Chair Telephone: 303-755-7491 Email: CouncilChair2010@aol.com

About Ileta Smith

Ileta contracted polio in July, 1949 in McAlister, Oklahoma when she was 2 $\frac{1}{2}$ years old. She moved from McAlister to Bennett, Colorado when she was 13 years old and lived there until she graduated from high school. After she was married and became a mom she went to college and studied management and psychology. She worked for fifteen years at the Community College of Aurora until she retired.

Ileta has been active in the post-polio community since 1991, attending the Aurora support group and acting as secretary of the Colorado Post-Polio Council until she was elected president of the council this year.

<u>COLORADO POST-POLIO</u> MISSION STATEMENT

The mission of Colorado Post-Polio is to provide education, information, and support statewide for polio survivors and their support systems.

<u>COLORADO POST-POLIO</u> <u>GOALS</u>

-- To grow, sustain and maintain the organization -- To enhance, continue support groups statewide -- To provide information via packets, newsletters and the library -- To utilize the Internet -- To develop a Speakers' **Bureau with resources** -- To continue/enhance the financial viability of our organization -- To assess our needs and skills -- To continue to hold conferences and educational programs -- To develop a plan for our legacy

And By the Way ...

When Colorado Post-Polio met to craft a mission statement and set some goals, they talked about some of their wishes that the organization could do for polio survivors, wishes that could be reality in a world with no financial and personnel restrictions. Here are some of them:

- Stop the movement against vaccination.
- Increase help for polio survivors when they buy durable medical equipment—braces, crutches, wheel chairs, and home improvements to

help make their homes more accessible.

- Provide help with transportation assistance.
- Provide resources to encourage and fund training and education about polio and post-polio syndrome for our medical support systems—doctors, physical therapists, orthotists and others.
- Develop a resource center that polio survivors can access—information on medical service providers, funding for equipment, emotional support personnel, new and tried and true devices and interventions that are medically sound.
- Use the resources of the Internet to help connect polio survivors, especially those who are increasingly homebound or experiencing limited mobility, with each other.
- Record our stories—travel the state with media equipment and record the polio stories of the survivors in our state and produce a book or video of those stories.
- Create an outreach program to let the world know that "WE ARE STILL HERE," targeting the media, schools, Rotary International and philanthropic organizations.
- HAVE A HUGE CELEBRATION WHEN POLIO IS ERADICATED IN THE WORLD . . . IN OUR LIFETIME.

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Marlene Harmon, Polio Survivor and Denver Post-Polio Leader

By Woody Trosper

The year that she was five years old, Marlene Kay Catlett, later Harmon, was living in Omaha, NE and that was also the year Marlene and her sister contracted polio. Her sister, a baby, became ill with polio first. Marlene also had an older brother but he was not affected by polio, however he died about 4 years later of other causes. How he lived with his disabilities, however, was an inspiration for how Marlene would lead her life.

After attending first grade for oneand-one half days. Marlene came home for lunch and could not walk so her parents the doctor's office and they called misdiagnosed her problem. After she became totally paralyzed she was finally taken to Dodge County Hospital, but the epidemic was so bad that she had to wait for several days to get a bed! She fell into a 6week long coma, so she does not remember what was done for her in the beginning. She does remember being on a ventilator, not in an iron lung. She also remembers receiving hot packs every day – she still has a burn scar on her right hand from a hot pack that was too hot!

Since she could not swallow well, she had to eat baby food. Her voice was so weak that she could barely whisper. She was placed in casts at night, with straps used to hold up her toes in the daytime. Later she was fitted with a long leg brace and was given crutches. Both of her parents had difficulty with Marlene's illness, however her mother coped better than her father, who withdrew from Marlene. Marlene had further problems when she broke her leg three times after being released from Dodge County Hospital, and she recalls some bad experiences in the convalescent homes she went to over her lifetime.

To help get treatment for Marlene, the family moved to Lincoln, NE. Later they moved to Denver so Marlene could attend the Boettcher School, where she was a student throughout grade school and high school. After high school, Marlene went to college at Denver University (she broke an ankle while there), then to Opportunity School, then to Metropolitan State College (she broke a shoulder while there). Her original desire was to be a speech therapist, but polio led her to a different area of emphasis, studying architectural design, and several of her designs were actually built. After college she also went to Patricia Stephens Finishing School with her sister!

By the time Marlene was in her twenties, she was doing well using one full leg brace and crutches. Her family did not see her as very handicapped. Although her polio involvement meant that her family always helped her in and out of the bathtub as she was growing up, she did many regular things and had a good social life. She married when she was 25. They later had a daughter, Anna. Her husband seemed to be okay with her handicap until she began to become weaker. This led to a later divorce.

Using the skills she learned in college, she worked in architectural design and at the U.S. Geological Survey. After she had a car (*Continued on page 10*)

Marlene Harmon (From page 9)

accident about 30 years ago, she became a collector for the Internal Revenue Service. She later worked from home and is now retired. Otherwise, the effects of polio had limited effect on her professional life.

Since Marlene developed post-polio syndrome, she has fatigue and must use a power wheel chair. She uses oxygen plus a ventilator at night. About twelve years ago, she developed diabetes. When she was no longer able to drive, the loss of mobility was very stressful, although she enjoyed the freedom of movement after she began to use a power wheel chair and still gets around town with the services of RTD's Access-a-Ride and her family.

In time, she had to move from her own home to an accessible residence, a move which has led to frequent feelings of isolation. For years she was able to exercise by swimming regularly, which helped her to keep active.

Her faith is also important in helping her to live with the progress of her postpolio symptoms. She credits the Reverend Leroy King with helping her cope with postpolio problems, and feels that prayers, especially the Lord's Prayer, have helped tremendously.

Marlene has felt thankful for the wonderful help from some of the medical professionals during her "polio life." These include Dr. Tipton, who treated her when she first became ill, and physical therapists, Alice Wiggins and Mary Carpenter. In recent years she gives credit to Marny Eulberg and Ann Heuter for helping her live with her polio and related problems. Also, she feels blessed to have so many post-polio friends, especially the late Mary Ann Hamilton, as well as a supportive family, including her daughter and grand children.

Marlene has not let polio stop her contributing to the post-polio from community in the Denver area. In the early 1980's when she was in rehabilitation at Spalding Hospital and the first information about post-polio syndrome was coming out, she was involved in the support groups that were formed. In the late 1980's she was a paid facilitator for support groups in Aurora and Englewood. When the Colorado Post-Polio organization started having board meetings early in the 80's, they were held at her house. Over the years, she has been a support group facilitator and has been actively involved in setting up and running post-polio educational meetings and conferences. Since 2004, Marlene has be the chairperson of the Colorado Post-Polio Council, a position she turned over to Ileta Smith in May.

She insists that sharing with others through laughter and faith has helped her face life. She has learned that others are often worse off than she is, is determined to never give up, and believes that she needs strong determination in order to reach her goals.

Book Review: Twin Voices: A Memoir of Polio, the Forgotten Killer

By Janice Flood Nichols, Reviewed by Barbara Lundstrom

<u>Twin Voices</u> is a very emotional book by Janice Flood Nichols. The worst polio epidemics in the United States took place in the 1950's. One particular area was in DeWitt, New York in 1953. DeWitt is a suburb of Syracuse, New York.

Published in 2007, <u>Twin Voices</u> is a beautiful and interesting memoir of her life with her twin brother. At the age of six years old, Janice's twin, Frankie, died within 61 hours of his onset of polio. Tragically, the night of Frankie's burial, Janice was diagnosed and hospitalized with polio. Many other children in DeWitt also died from polio that year. Janice suffered temporary paralysis and underwent months of intensive therapy, but maintained a strong religious faith, and was determined to walk again.

Being a very inquisitive and serious youngster, Janice insisted that her parents, friends and relatives tell her stories of her young life with her twin brother with whom she bonded since birth. She wished to display photos of them together and continued celebrations of holidays and family customs over the years. After high school, she earned a B.A. degree in psychology from Hill University and a Masters Degree in rehabilitation counseling from the University of Pittsburgh. She married an orthopedic surgeon, Dave, and has one son, Kevin.

Janice always believed polio was eradicated throughout the world due to the Sabin and Salk vaccines. After becoming aware that polio was still prevalent in many parts of the world, especially in third world countries, Janice became a woman on a mission, campaigning for the complete eradication of the disease worldwide.

Fortunately, medical advances have greatly improved the quality of life. The iron lung was the only treatment available for respiratory (bulbar) patients during the epidemic years but that alone was not enough to save Janice's brother.

Janice was finally approached in 2003 to write her own story that resulted in this book. She chose to write her personal story of recovery and that of her short life with her twin brother before he died. As she still maintains a close bond with her dead brother, she insists that he watches over her She wished also to include both family. educational and human-interest stories from parents, relatives and friends. Several chapters by Dr. Alice (Janos) Turek, M.D., M.P.H., who signed Frankie's death certificate, wrote her own story of her involvement in the 1953 epidemic. She devoted several pages to a concise medical primer on polio, which the reader should find very interesting.

The book also contains many statistics and historical information about polio. Janice's husband, Dave, is an orthopedic surgeon who has written of surgical procedures for some polio survivors. A chapter entitled Dave's Medical Care Update includes the late effects of polio, known as Post-Polio Syndrome. *(Continued on page 12)*

Twin Voices: A Memoir

(From page 11)

Since tragedy oftentimes bonds families, wrote many acquaintances of their involvement in their mission to help eradicate this devastating disease, their involvement in the March of Dimes. participating in clinical trials of both the Sabin and Salk vaccines, and the continuing endeavors to create a polio free world. I found the book, which contained many voices, extremely interesting. The book is worth the time for anyone to be informed of what was then and what is now by the amazing research in Mrs. Nichols' collection of appendices and notes at the end of her book.

Post-PolioDurableMedicalEquipment(DME)AssistanceFund

The Colorado Post-Polio Advisory Council has established an assistance fund to help those polio survivors who are in financial need by assisting with the purchase or rental of durable medical equipment needed for a polio-related condition. Established in 2009, this fund has been continued into 2010. Eligible persons must be residents of Colorado who are polio survivors and who need assistance with copayment for such items as crutches, canes, braces, wheel chairs, and other equipment needed to maintain or improve their quality of life.

This assistance will be based on financial need as determined by a DME Fund Committee and based on information from an application form that can be obtained from Nancy Hanson at Easter Seals Colorado, phone--303-233-1666, ext. 237, <u>nhanson@eastersealscolorado.org</u>.

Grants for <u>up to</u> \$500 will be awarded on a first come, first serve basis and will be issued on a sliding scale until the fund is exhausted. Renewal for future years will depend on the amount of funds in the Colorado Post-Polio budget.

Persons can also donate to the fund either directly or as a memorial. To do this make checks payable to Easter Seals Colorado and then designate that the funds are to go to the Post-Polio DME Assistance Fund. If donations are made to Easter Seals Colorado without designating that they go to this fund, they are put into the regular Post-Polio restricted fund and the DME Assistance Fund will not receive the benefit of your generosity.

The <u>Colorado Post-Polio Connections</u> thanks the following volunteers who help with the writing, proofreading and mailing and have made this newsletter possible:

Gloria Aemmer, Liz, Benton, Vada Carey, Jeanine Ellison-Fisher, Marlene Harmon, Richard Johns, Barbara Lundstrom, Margaret Ann McCarthy, Mary McWilliams, Velma Pendell, Paul Puma, Ileta Smith, Eleanor Spence and Woody Trosper.

Thanks also to Marny Eulberg, M.D., Medical Advisor; Nancy Hanson, Easter Seals Colorado; Marlene Harmon, Retiring Chairperson, Post-Polio Council; Ileta Smith, Chairperson Elect, Post-Polio Council; and Margaret Hinman, Editor

Additional books in the Post-Polio Connections Library

The Colorado Post-Polio Library is located at Easter Seals Colorado. It is being maintained for the use of the subscribers of the <u>Colorado Post-Polio Connections</u>. It contains a small collection of books, audio and videotapes that may be checked out for a limited period of time and they will be mailed with a return mailer enclosed. Below is a list of the books that have been added to the library since the Winter 2010 master list was published. In the future, as books are reviewed in the <u>Connections</u> they will become available for loan.

For further information about the library and/or to request a book, contact Nancy Hanson at Easter Seals Colorado, 303-233-1666, ext. 237, email-- <u>nhanson@eastersealscolorado.org</u>.

Black, Kathryn. **In the Shadow of Polio, A Personal and Social History**, 1996. Ms. Black writes of her mother's struggles with polio within the context of the history of America in the 1940's and 1950's.

Bruno, Richard H.D, Ph. D. <u>The Polio Paradox</u>, 2002. A popular book on all aspects of polio and post-polio syndrome and Dr. Bruno's interpretation on how to treat the symptoms.

Casey, Laura L. <u>How to get the Health Care You Want</u>, 2007. Help in making confident, informed choices about health care and its costs. Reviewed in the <u>Connections</u> Spring 2008.

Carter, Rosalynn with Susan K. Golent. <u>Helping Yourself--Helping Others, A Book for</u> <u>Caregivers,</u> 1994. An emotionally supportive guidebook for family caregivers from the Rosalynn Carter Institute for Human Development.

Gould, Tony. <u>A Summer Plague, Polio and its Survivors</u>, 1995. A history of polio from its first appearance in New York in 1916 through FDR's work at Warm Springs to the vaccine developments of Salk and Sabin and to the discovery of post-polio syndrome.

Harrington, Candy, B. **Barrier Free Travel**, 3rd ed., 2009. A guide to national and international travel by all modes of transportation and how to assess accessibility in lodging when a disabled person travels.

Hostetter, Joyce Moyer. <u>Blue</u>, 2006. <u>Blue</u> is a fictional story of a young girl who got polio in the 1940's. However, it is based on research of the disease and how it was treated at the time.

Kennedy, Craig P. <u>Access Anything: Colorado</u>, 2005. A guide to recreation and travel in Colorado for persons with disabilities.

Silver, Julie, M.D. and Daniel Wilson, Ph. D. <u>Polio Voices</u>, 2007. A combination of historical perspective and testimonials from polio survivors, both historically and regarding polio today. Reviewed in the <u>Connections</u> Fall 2008.

Youdath, Raymond. <u>50 Years of Miracles: and Adventures</u>, 2006. A personal story of one man's ability to deal with having polio and the challenges he faced.

COLORADO POST-POLIO MEETINGS

In bad weather, check with person(s) listed with each group.

The Post-Polio support groups listed usually have a format, a program or an activity planned for each of their meetings. <u>Before showing up for the meetings</u>, <u>please call any contact person listed for each group to get specific information about their upcoming events and any changes that may occur.</u>

<u>The Colorado Post-Polio Council</u> meets quarterly at Easter Seals Colorado, 5755 W. Alameda Ave. All polio survivors are invited to attend; each group should send a representative. Call Ileta Smith (303-755-7491) for the date and time of the next meeting.

Aurora group: third Wednesday of each month, 10 AM to 11:45 AM, at Spalding Hospital, 900 Potomac St., first floor. Lisa Haft Robison (303-360-6887).

Colorado Springs group: second Saturday of each month, 10 AM to 12 noon, Sand Creek Police Department meeting room, 4125 Center Park. Linda Groth (719-633-1497).

Fort Collins/Loveland group: third Saturday of each month, 10 AM to 12 Noon, at Trinity Lutheran Church, 301 E. Stuart. Jim Oxley (970-377-0117) or Romola Fritz (970-225-9573).

Grand Junction group: for meeting information contact Gail Saunders (970-249-3218) or Millie Derksen (970-434-4281).

Lakewood group: The second Wednesday, every other month, contact Marlene Harmon (303-689-7669).

Pueblo group: second Saturday of each month, 2 PM to 4 PM, at the barkman Branch Library.

Thornton group: first Saturday of each month, 10 AM to 12 Noon, at North Valley Hospital, 8451 Pearl. Barbara Lundstrom (303-451-6241) or Paul Puma (303-453-9552).

Anyone who would like to talk to someone experiencing the late effects of polio can contact any of the group leaders listed above. Others to talk to include Marlene Harmon (303-689-7669), Richard Johns (303-477-5564), Velma Pendell (303-340-4348), and Barb Rubenstein (719-269-7316).

F.Y.I--The Colorado Post-Polio Clinic--evaluates and makes recommendations for polio survivors. It is located at the St. Anthony's North Family Medicine Center at 8510 Bryant St., Suite 200, on the northwest side of St. Anthony's North Hospital in Westminster. Call Dr. Marny Eulberg, M.D. at 303-899-5369 to make an appointment.

COLORADO POST-POLIO AT EASTER SEALS COLORADO

COLORADO POST-POLIO is a program sponsored by Easter Seals Colorado to offer education and support for persons experiencing the late effects of polio. Information for polio survivors is available through educational meetings, a quarterly newsletter and through support groups in Colorado that are facilitated by knowledgeable polio survivors. The office at Easter Seals Colorado also offers an introductory packet and other resources on polio and postpolio syndrome from its center in Lakewood, Colorado, as well as a telephone contact person Nancy Hanson, (303-233-1666, extension 237). For additional articles and information, and to view the newsletter online, go to <u>www.eastersealscolorado.org</u>.

Our post-polio program needs the support of the people it serves. The educational meetings and the quarterly newsletters cost money and your financial support is appreciated. Our newsletter contains articles and news about all aspects of polio and post-polio syndrome and its treatment, plus personal stories of polio survivors. It is mailed to over 1000 in-state and out-of-state addresses. We do not charge a subscription fee for any publication or most of our other services, as we believe these services should be free for those in need.

SUPPORT FOR OUR POST-POLIO ACTIVITIES
Mail your voluntary contribution for Colorado Post-Polio programs, including the newsletter, with this coupon. Make check payable to EASTER SEALS COLORADO (address on other side), and enter POST-POLIO on the memo line. Suggested yearly donation is \$20.00. Thank you! You will receive an acknowledgement of your donation.
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If you want this subscription stopped, check hereand return or contact Nancy Hanson, 303-233-1666, ext. 327, <u>nhanson@eastersealscolorado.org</u> .

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 <u>post-poliocolo@comcast.net</u> 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 nhanson@eastersealscolorado.org.

Our next issue will again feature an article presented at the 2008 Post-Polio Health International Tenth International Conference by Selma Calmes, M.D. entitled "Anesthesia Update: Separating Fact from Fear."

Read and share the Connections on line at www.eastersealscolorado.org

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.

Colorado Post-Polio Connections Easter Seals Colorado 5755 West Alameda Ave. Lakewood, CO 80226

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