A Personal Polio Pilgrimage
Karen A. O’Brien, DNP, RN

The grounds of the Roosevelt Warm Springs Institute for Rehabilitation were lovely in late April, covered in lush southern springtime vegetation of pink and white azaleas, budding magnolia trees and fountains. The brick buildings that formed the quadrangle seemed alive with the history of polio treatment, water therapy, surgery, and inpatient rooms filled with physical and emotional spirits. It took me two days to gather the courage to take the self-guided tour. I was afraid of the emotions that the buildings might pull from my memory. I watched as people walked the grounds, many of whom had a personal experience within these walls during their early days of polio. They told both humorous and painful stories that brought us together as we listened intently with respect and empathy to their struggles. Walking and wheeling the black and white checkered floor in Georgia Hall with kindred spirits of polio-inflicted bodies and their supportive caregivers brought a sense of courage, pride and conviction. We, the fortunate, have survived this disease.

The 2009 Post Polio Health International Conference was a life changing experience for me and could be described as a personal pilgrimage. Travel to Roosevelt’s Warm Springs, Georgia and the “little White House” had been on my “bucket list”, i.e., things to do before I die. My personal journey was one of discovery to a significant national landmark created to give hope for polio survivors. This journey had a purpose and I sought to pay homage to a place, town, and people who honored the experience of polio.

My most memorable presentation at the conference was given by the final plenary author (Continued on page 5)
In My Opinion . . .

Roosevelt Warms Springs Institute for Rehabilitation is an active rehabilitation center, administered by the Georgia Department of Labor. Although it no longer treats polio survivors, it provides a variety of programs for both physical and emotional rehabilitation. During our stay there, the staff of RWSIR was cheerful, positive, always helpful with foresight into what persons with disabilities might need and responsive to those needs. Thank you, RWSIR!

My visit to Roosevelt Warm Springs Institute for Rehabilitation was to attend the Post-Polio Health International’s 10th Conference, entitled “Living with Polio in the 21st Century.” While there, I met a young man from Nigeria, a polio survivor in a wheel chair, who is manufacturing wheel chairs for polio survivors in his country. I also met a group of Japanese polio survivors who could not speak English but knew how to take pictures of the exhibits and of the durable medical equipment, such as my brace, to take back to Japan with them, and a member of the government health establishment from Australia who was there to take back information to the survivors in his country. I also got to know three delegates from the Post-Polio Awareness and Support Society of British Columbia (PPASS), a thriving post-polio organization that sponsors innovative projects to help support their population, which is spread over the large area that is British Columbia.

I highlight these people because they are a sampling of the upbeat survivors that were in attendance at the conference, people who were there to connect with old friends, meet new friends, to learn about the research and the methods of living with polio as we age, and for some, to come back to the place where they were treated for their polio many years ago. The campus of Roosevelt Warm Spring Institute for Rehabilitation buzzed with the energy, the positive feelings, and the openness of the presenters, the participants and the staff of RWSIR.

At lunch in the cafeteria one day, three adolescents in manual wheel chairs went through the line and got their lunches. In addition to being in wheel chairs, their right hands were bound to the arm of the chair, rendering them unable to use them. This meant learning how to navigate and eat with the use of only one arm and hand. I assume that these young men were engaged in an awareness/sensitivity exercise, navigating in a wheel chair with one hand and one foot, trying to feed themselves and doing it in a cafeteria full of obviously disabled persons.

At first glance, they appeared to also be physically disabled. So, when the young men found a table, two polio survivors immediate got up, moved chairs and made the table accessible. Upon grasping the situation, my first response was to decry the fact that these young men were denied the opportunity to really feel the frustrations of having a disability by the thoughtfulness of the polio survivors. With further thought, I came to the conclusion that, if those teens were able to be aware of what had happened, they may have learned not only what it was like to not have the use of a limb, but that people with disabilities are able to be helpful and extend themselves to others. And also, that polio survivors have learned how to not only get along and overcome their frustrations, but also to thrive, in spite of their disabilities. If those young men learned any part of that reality, their sensitivity training was indeed a success.

(Continued on page 3)
In My Opinion . . . (From page 2)

By the way, the kids learned how to open a bottle of catsup by cooperating, one holding
the bottle and one unscrewing the cap, and they learned how to open sealed condiment packets
by using one hand and their teeth!

This minor incident, which lasted less than a minute, is part of the legacy of “Living with
Polio in the 21st Century” and is indicative of the “Spirit of Warm Springs” that was the heart of
the 10th International Conference!

I came away from the conference with a veritable treasure trove of articles and lecture
notes from the presenters. Over the next several issues of the Connections, I will be sharing
some of them with you. In this issue, Pam Duryea from the John P. Murtha Neuroscience and
Pain Institute in Johnstown, Pennsylvania, outlines the resources available for us to use in
seeking medical treatment, so we can be informed as we navigate the health care system.

On a more personal note, Karen O’Brien has shared her impressions of the Conference.
And Betty Mann’s personal story tells us about her time as a patient at Warm Springs and why
she did not go back for the conference.

Our book review, written by Annette Beck, is about the aging mind. The book not only
tries to dispel myths about our aging minds, it provides concrete suggestions on how to keep
our minds active and healthy.      Margaret Hinman, editor.

Betty Mann, Warm Springs Alumna
By Margaret Hinman

Betty Mann planned to go back to the Roosevelt Warm Springs for Post-Polio
Health International’s 10th Conference. She
would have travelled to visit relatives in
Atlanta, Georgia, where she lived as a child,
and then travelled the seventy or so miles
south to Warm Springs to revisit the place
where she received treatment as a five-year-
old child in the 1930’s. However, as time
grew closer to the conference, Betty recalled
her memories of Roosevelt Warm Springs
and could not go.

She remembered her mother taking
her to the center and leaving her there for
three months. As her mother could not
drive, that was the last time Betty saw her
until she came to pick her up. She
remembered her mother leaving her as she
was wheeled off to a ward. She is sure that
her mother told her what was going to
happen and that she would be back for Betty
but Betty does not remember that.

She also remembered the lonely
children in the beds in the ward, missing
their families and crying themselves to sleep
at night, and the children who were wheeled
out of the ward to return later in huge casts,
after having surgery. As the medical
profession did not believe in “coddling”
children they expected the children be strong
and not show any emotion. Therefore, those
children crying at night had to do it quietly,
so as to not draw attention to themselves.

As Betty has gotten in touch with
those memories, she sees them as part of her
lifelong relationship with her polio. For her,
having polio and the  (Continued on page 4)
Betty Mann (Continued from page 3) subsequent paralysis was a personal and family secret, one that she did not acknowledge until after a psychiatrist released her from his two years of treatment with the message that she really did not have any deep, dark secret to be revealed and that she should go home and get on with her life.

But Betty did have her secret, the stigma of being crippled, which she covered up by stuffing her shoes to fill the uneven sizes and by working hard at never getting tired because that was when her walking showed her disability. After high school, she went to Agnes Scott College in Decatur, Georgia, to study pre-med. One of her jobs in college was that of lab assistant, so she was on her feet for several hours each day. Only while in the lab, did she wear a brace. Also, while in college, she worked in the strep lab at the Centers for Disease Control in Atlanta, when the Centers were Quonset huts on an old U.S. Army base. The irony of her job was that she helped identify strep infections, the disease that killed her father while she was at Warm Springs.

She transferred to Georgia State University her last year, but did not get her degree because she met and married her husband, Wes, all in six weeks time. He was in the Navy so she moved to Mississippi to live with his parents when, after 10 days of marriage, he went to the Korean War. In the ensuing years, she had four sons and followed her husband with her family to eleven states. They ended up in California where he worked in the aerospace industry.

In 1982, when her sons were almost grown, Betty started teaching for Bible Studies Fellowship International. She still mentors young women in Christian studies. Now living in Colorado, in her seventies and widowed, Betty keeps busy by painting, sewing, shopping for shoes, and practicing in her three year old brace, and visiting her sons in California, Colorado and Arizona.

Betty credits her mother for her polio rehabilitation. She never had surgery at Warm Springs because her mother heard about the Sister Kenney treatment, withdrew Betty from the hospital, and took her home where she treated her with hot packs and massaged her legs until she recovered well enough to walk, although with a limp when she was tired.

Betty admits that there are difficult adjustments to make as one gets older. It took two years after seeing Dr. Eulberg for her to finally be willing to get a brace. She still has difficulty allowing others to see her disability. However, she has become an assertive advocate for the disabled, calling management’s attention to doors in public places that are difficult to open, and/or that are without automatic, electronic openers.

Her brace has made her buy different shoes than she has been used to wearing and she still is looking for the perfect pair that will fit her brace and match with her sense of style. She pointed out during this interview that she had made more progress. She was wearing Capri pants, a change from full-length pants that she usually wears. She has “come out of the closet,” letting others see that she wears a brace.

Betty has a message to polio survivors—do not deny the difficulties that come with the disease. Care for yourselves.

On a final note, she plans to be at the next Post-Polio conference in Warm Springs. She is now ready to go there!
**Pilgrimage (Continued from page 1)**

David Oshinsky, who won the 2006 Pulitzer Prize in History for his book *Polio, An American Story,*

He spoke to us about the ramifications of polio with expanded medical research, fundraising and the impact of polio on families and communities. He made our history come alive with insight from his thorough research and gift for storytelling. The Roosevelt Hall auditorium in which he spoke had seating accommodations for the 436 conference participants. The first three large front rows were reserved solely for those of us using wheeled assistance. When I “pulled in” the gentleman beside me said, “pull up close so our wheels touch.” We laughed so hard and were so grateful that we were in a place where we were the norm and could get around easily and independently.

Before the end of the conference, I took time to visit the “little White House” where President Franklin D. Roosevelt spent part of his fourth and final term. In the museum on the grounds was his portrait painting, unfinished on the day he died. Beneath the painting was the following quote, “The only limit to our realization of to-morrow will be our doubts of to-day. Let us move forward with strong and active faith.” This quote from Franklin D. Roosevelt stands true today and challenges each of us to not focus on our disability but rather on our abilities.

A pilgrimage is a journey for personal growth to a destination and the return home with a new appreciation. It can be one of sacrifice and involves a longing to understand something larger than ourselves. Let us move forward in anticipating polio eradication worldwide in our lifetime. Perhaps the next International Post Polio Health Conference will be a celebration in which we can all participate with tears and cheers of gratitude.


Karen O’Brien is a polio survivor of 55 years and a public health nurse of 35 years. She lives in Denver with her husband of 37 years, two grown and married children and two grandchildren. A life blessed with challenge and opportunity.

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**“We’re Still Here!” Campaign—Post-Polio Health International is sponsoring a “We’re Still Here!” campaign the week of October 11-18, 2009.** This week has been set aside for polio survivors to let the rest of the world to know that there are still polio survivors in society and that we not only have needs, we are contributors to the country, that many of us have had an impact on mankind.

We will be reminding you of “We’re Still Here!” in October and providing you with a suggestion of how you can help your community take note of us. The campaign will be low cost and require little effort on your part, but, if each of us makes an effort to talk to someone about polio during that week, there will be increased awareness that we are truly still here.

The Colorado Post-Polio Clinic is now 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. To make an appointment, call 303-899-5369. The purpose of the clinic is to evaluate and make recommendations for polio survivors.
Forever Mind, Eight Ways to Unleash the powers of Your Mature Mind

By Priscilla Donovan & Jacquelyn Wonder

Reviewed by Annette Beck

These authors attempt to dispel the beliefs about aging. Through scientific research, they have arrived at the conclusion that our brain does change over our life span. However, they believe that the natural changes in the brain complement the physical and emotional development that is normal for each stage of our lives. The reality is that you can actually be sharper as you age if you take steps to make use of your brain’s greatest strengths!

As we age, although we may be a bit slower, the mellowing process seems to accompany these physical changes. Our frustration level is generally lower and we take things more in stride. Short-term memory does change: in some ways, it is actually better! While we may not remember the specifics about an issue, we remember the big picture.

Interviews with mature adults in their 60’s, 70’s and 80’s revealed a strong correlation between “attitudes towards aging and how often you challenge your thinking skills.” Those who grew up with fairy tales like Cinderella and the Emperor’s New Clothes often believe many myths about aging in our society, e.g. a poor memory is part of growing old, you can’t teach an old dog new tricks, and life, like chewing gum, loses it flavor with age. They also cite other cultures where older people are not derided but are valued for their experience and wisdom. They state that it is truly important to think about our attitudes because “if you believe that you’re bound to ‘lose it’ after the fifty mark, then you’ll do little or nothing about staying healthy and mentally stimulated.” When we hear and believe negative myths about aging, they become real to us. And what we believe powerfully affects how we view and live our lives.

Conversely, when we change a belief, we change our reality. So, instead of decrying the fact that we’re in our elder years, the authors encourage us to value our experiences and build on them. To do this, they offer many ways of increasing our zest and love of life, some of which are: quell the negative self-talk—change negative statements into positive ones, know what you want and ask for it, get good feedback from others. Reward yourself for succeeding and even the effort put forth, give yourself complements and accept them from others (how many times, instead of saying “Thank you [and really getting the complement],” do we say, “Oh, this old thing? It must be xxxx years old!” We really need to listen to our bodies and see what works for us as an individual. What works for you? For instance, think about what you ate just prior to feeling sluggish or not being able to go to sleep. Or do you feel alive and energized?

The authors state that feeling good about yourself will not lead to feeling superior and righteous. In fact, you will develop an attitude of gratitude and an ability to appreciate others and become more helpful when you do. When we open our minds to change, we can fuel our passions in life and empower ourselves to pursue and enjoy them. As one 73 year old stated, “I never knew life could have such variety. It’s like I’ve suddenly discovered Baskin-Robbins options to aging.”
Although I had a difficult time in the first few chapters when it seemed these authors spoke endlessly about how much physical exercise contributed to health (a consideration that polio survivors must evaluate for themselves), I ended up with a great appreciation for this book! It contains a wealth of information, most of which is not covered in this short review, and is well worth reading and utilizing the many suggestions and methods put forth.

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**Tools to Use in Evaluating Treatment Choices**

*Barbara Duryea, MSN, RN, CPHQ*

*John P. Murtha Neuroscience and Pain Institute (JPMNPI)*

*Johnstown, Pennsylvania*

**Five Basic Steps**

Following are five basic steps to help you cope with your diagnosis, make decisions, and get on with your life.

**Step 1: Take the time you need.**

Do not rush important decisions about your health. In most cases, you will have time to carefully examine your options and decide what is best for you.

**Step 2: Get the support you need**

Look for support from family and friends, people who are going through the same thing you are, and those who have “been there.” They can help you cope with your situation and make informed decisions.

**Step 3: Talk to your doctor.**

Good communication with your doctor can help you feel more satisfied with the care you receive. Research shows it can even have a positive effect on things such as symptoms and pain. Getting a “second opinion” may help you feel more confident about your care.

**Step 4: Seek out information.**

When learning about your health problem and its treatment, look for information that is based on a careful review of the latest scientific findings published in medical journals.

**Step 5: Decide on a treatment plan.**

Work with your doctor to decide on a treatment plan that best meets your needs.

As you take each step, remember this: Research shows that patients who are more involved in their health care tend to get better results and be more satisfied.

**Ten Important Questions to Ask Your Doctor After a Diagnosis**

These 10 basic questions can help you understand your disease or condition, how it might be treated, and what you need to know and do before making treatment decisions.

1. What is the technical name of my disease or condition, and what does it mean in plain English?
2. What is my prognosis (outlook for the future)?
3. How soon do I need to make a decision about treatment?
4. Will I need any additional tests, and if so what kind and when?
5. What are my treatment options?
6. What are the pros and cons of my treatment options?
7. Is there a clinical trial (research study) that is right for me?
8. Now that I have this diagnosis, what changes will I need to make in my daily life?
9. What organizations do you recommend for support and information?
10. What resources (booklets, web sites, audiotapes, videos, DVDs, etc.) do you recommend for further information?

Now that you know your treatment options, you can learn which ones are backed up by the best scientific evidence. “Evidence-based” information—that is, information that is based on a careful review of the latest scientific findings in medical journals—can help you make decisions about the best possible treatment for you.

**Evidence-based information comes from research on people like you.**

Evidenced-based information about treatments generally comes from two major types of scientific studies:

- **Clinical trials** are research studies on human volunteers to test new drugs or other treatments. Participants are randomly assigned to different treatment groups. Some get the research treatment, and others get a standard treatment or may be given a placebo (a medicine that has no effect), or no treatment. The results are compared to learn whether the new treatment is safe and effective.
- **Outcomes research** looks at the impact of treatments and other health care on health outcomes (and results) for patients and populations. End results include effects that people care about, such as changes in their quality of life.

**Take advantage of the evidence-based information that is available.**

Health information is everywhere—in books, newspapers, and magazines, and on the Internet, television, and radio. However, not all information is good information. Your best bets for sources of evidence-based information include the Federal Government, national nonprofit organizations, medical specialty groups, medical schools, and university medical centers.

Some resources are listed below, grouped by type of information. The on-line version of *Next Steps After Your Diagnosis* lists many more, and includes links to Internet sites.

**Information.**

Information about your disease or condition and its treatment is available from many sources. Here are some of the most reliable:

- **Post-Polio Health International:** [www.post-polio.org/index.html](http://www.post-polio.org/index.html). Post-Polio Health International’s mission is to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.
- **healthfinder®:** [www.healthfinder.gov/findservices/default.aspx](http://www.healthfinder.gov/findservices/default.aspx). The healthfinder® site—sponsored by the U.S. Department of Health and Human
Services—offers carefully selected health information web sites from government agencies, clearinghouses, nonprofit groups, and universities.

- **Health Information Resource Database:** [www.health.gov/nhic/#Referrals](http://www.health.gov/nhic/#Referrals). Sponsored by the National Health Information Center, this database includes 1,400 organizations and government offices that provide health information upon request. Information is also available over the telephone at 800-336-4797.

- **MEDLINEplus®:** [www.nlm.nih.gov/medlineplus](http://www.nlm.nih.gov/medlineplus). MedlinePlus® has extensive information from the National Institutes of Health and other trusted sources on over 750 diseases and conditions. The site includes many additional features.

- **National nonprofit groups** such as the American Heart Association, American Cancer Society, and American Diabetes Association can be valuable sources of reliable information. Many have chapters nationwide. Check your phone book for a local chapter in your community. The Health Information Resource Database ([www.health.gov/nhic/#Referrals](http://www.health.gov/nhic/#Referrals)) can help you find national offices of nonprofit groups.

- **Health or medical libraries** run by government, hospitals, professional groups, and other reliable organizations often welcome consumers. For a list of libraries in your area, go to the MedlinePlus® “Find a Library” page at [http://www.nim.nih.gov/medlineplus/libraries/html](http://www.nim.nih.gov/medlineplus/libraries/html).

### Current medical research.

You can find the latest medical research in medical journals at your local health or medical library, and in some cases, on the Internet. Here are two major online sources of medical articles:

- **MEDLINE/PubMed®:** [http://www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed) PubMed® is the National Library of Medicine’s database of references to more than 14 million articles published in 4,800 medical and scientific journals. All of the listings have information to help you find the articles at a health or medical library. Many listings also have short summaries of the article (abstracts), and some have links to the full article. The article might be free, or it might require a fee charged by the publisher.

- **PubMed Central:** [http://www.pubmedcentral.nih.gov/](http://www.pubmedcentral.nih.gov/) PubMed Central is the National Library of Medicine’s database of journal articles that are available free of charge.

### Clinical Trials.

Perhaps you wonder whether there is a clinical trial that is right for you. Or you may want to learn about results from previous clinical trials that might be relevant to your situation. Here are two reliable sources:

- **ClinicalTrials.gov:** [http://clinicaltrials.gov/ct2/search](http://clinicaltrials.gov/ct2/search). ClinicalTrials.gov provides regularly updated information about federally and privately supported clinical research on
people who volunteer to participate. The site has information about a trial’s purpose, who may participate, locations, and phone numbers for more details. The site also describes the clinical trial process and includes news about recent clinical trial results.

- **Cochrane Collaboration:** [www.cochrane.org](http://www.cochrane.org) The Cochrane Collaboration writes summaries (“reviews”) about evidence from clinical trials to help people make informed decisions. You can search and read the review abstracts free of charge at [http://www.cochrane.org/reviews/index.htm](http://www.cochrane.org/reviews/index.htm). Or you can read plain-English consumer summaries of the reviews at [www.informedhealthonline.org](http://www.informedhealthonline.org).

The full Cochrane reviews are available only by subscription. Check with your local medical or health library to see whether you can access the full reviews there.

**Outcomes research:**

Outcomes research provides research about benefits, risks, and outcomes (end results) of treatments so that patients and their doctors can make better informed decisions. The U.S. Agency for Healthcare Research and Quality (AHRQ) supports improvements in health outcomes through research, and sponsors products that result from research such as:

- **National Guideline Clearinghouse™:** [www.guideline.gov](http://www.guideline.gov). The National Guideline Clearinghouse™ is a database of evidence-based clinical practice guidelines and related documents. Clinical practice guidelines are documents designed to help doctors and patients make decisions about appropriate health care for specific diseases or conditions. The clearinghouse was originally created by AHRQ in partnership with the American Medical Association and America’s Health Insurance plans.

**Steer clear of deceptive ads and information.**

While searching for information either on or off the Internet, beware of “miracle” treatments and cures. They can cost you money and your health, especially if you delay or refuse proper treatment. Here are some tip-offs that a product truly is too good to be true.

- Phrases such as “scientific breakthrough,” miraculous cure,” “exclusive product,” “secret formula,” or “ancient ingredient.”
- Claims that the product treats a wide range of ailments.
- Use of impressive-sounding medical terms. These often cover up a lack of good science behind the product.
- Case histories from consumers claiming “amazing” results.
- Claims that the product is available from only one source, and for a limited time only.
- Claims of a “money-back guarantee.”
- Claims that others are trying to keep the product off the market.
- Ads that fail to list the company’s name, address, or other contact information.
Where to Find More Information

Get the support you need.

- American Self-Help Group Clearinghouse
  http://mentalhelp.net/net/selfhelp/
  National Board of Certified Counselors (NBCC) 3 Terrace Way, Suite D
  Greensboro, NC 27403-3660  336-547-0607.  www.nbcc.org
- National Institute of Mental Health
  Public Information and Communications Branch 6001 Executive Boulevard, room
  8184, MSC
  9663 Bethesda, MD 20892-9663
  Phone:  866-615-6464 (toll free) TTY: 301-443-8431

Talk to your doctor.

- Be an Active Member of your Health Care Team.  Food and Drug Administration.
  FDA (888-463-6332).
- Be Informed:  Questions to Ask Your Doctor Before You Have Surgery.  Agency for
  800-358-9295.
- Getting a Second Opinion Before Surgery.  Centers for Medicare & Medicaid
  MEDICARE (800-633-4227).
  http://www.4woman.gov/pub/second-opinion.htm.  Phone 1-800-994-WOMAN.
- Quick Tips—When Planning for Surgery.  Agency for Healthcare Research and
  358-9295.
- Quick Tips—When Talking with Your Doctor.  Agency for Healthcare Research and
  358-9295.

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*Presenter’s notes from Post-Polio Health International’s 10th International Conference,
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 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 provide more information from the Post-Polio 10th International Conference, “Living with Polio in the 21st Century,” & the “We’re Still Here!” Campaign.

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

FREE MATTER FOR THE BLIND OR HANDICAPPED