



10th International Conference

Living with Polio in the 21st Century

April 23-25, 2009

Thursday, April 23, 2009

**Session T1, 1:00–2:00 pm
through
Session T4, 6:15–8:30 pm**

This book belongs to



POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

ROOSEVELT
WARM SPRINGS



POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 Lindell Boulevard, #110
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314-534-5070 fax

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director@post-polio.org

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QUESTIONS from the audience will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Post-Polio Health International (PHI) thanks the presenters for providing the excellent information contained in the daily program books.

If you share this information, we respectfully ask that you acknowledge the presenter and that the information was disseminated at PHI's 10th International Conference: Living with Polio in the 21st Century (April 2009). PHI will incorporate additional information presented at the conference and make it available to attendees and others at a later date. Details will be published in *Post-Polio Health* and on www.post-polio.org.

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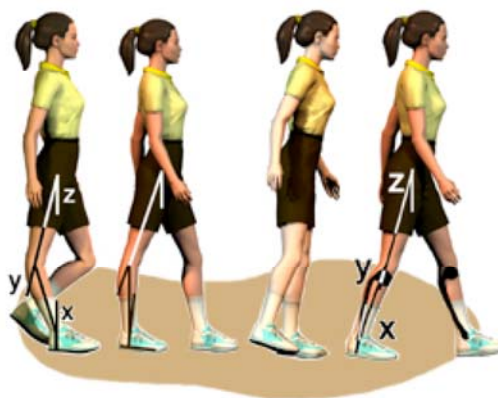
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Visit the following companies in Georgia Hall during these hours:

Friday, April 24 from 11:30 am–7:00 pm

Saturday, April 25 from 8:30 am–1:30 pm



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Welcome to the Roosevelt Warm Springs Institute for Rehabilitation.

Whether you have been here before or this is your very first time on our campus, we are thrilled to have you here as our guests. As you may know, we are the “living legacy” of FDR’s vision for healing, so as you enjoy your symposium you will notice patients and students coming and going, and that we are very much a living and breathing rehabilitation center. We have been providing rehabilitation for 81 years, and you will also note that parts of our campus show our age.

We are not a modern conference center like you may find in downtown Atlanta, but we have something that they don’t. My hope for you during your visit is that you experience what we call the “Spirit of Warm Springs,” which refers to our caring and compassion. We are very proud of our historic legacy, and I encourage you to reflect on that as you travel around and across our campus. Franklin D. Roosevelt never learned to walk by coming here, but I believe it made him a better man and a much better President. So on behalf of all of us who come to work here every day in pursuit of the same mission “to empower individuals with disabilities to achieve personal independence” as FDR did, welcome to this place of healing. May you enjoy your conference and fully enjoy your stay with us.

Greg Schmieg
Executive Director, RWSIR

From Post-Polio Health International (PHI):

Welcome to the tenth in our series of international conferences.

PHI's goal for these conferences has always been threefold: First, we aim to promote the face-to-face exchange of authoritative, up-to-date information about the late effects of polio and independent living with its consequences. Second, we aim to sustain a productive network of active polio survivors and healthcare professionals with relevant expertise – by providing a forum in which these two groups can inform each other and interact. Third, we aim to disseminate the results of our conferences to all those interested polio survivors and medical professionals who are unable to attend.

We are honored to have this conference at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR). RWSIR's place in the history of physical medicine and rehabilitation is a prominent one indeed. It began with Franklin Delano Roosevelt, and with the idea of rehabilitation as a cooperative venture between medical professionals and polio survivors. From its beginnings, like PHI, it has also been dedicated to helping people develop and sustain the functional abilities necessary for independent living with a physical disability.

This event was made possible by the dedicated labors of many staff members at RWSIR. To all of them, we owe our thanks. We also thank Carolyn Raville, founder of the North Central Florida Post-Polio Support Group, for suggesting a post-polio conference at RWSIR.

Thank you for joining us to learn about "Living with Polio in the 21st Century."

Lawrence C. Becker
Chair, Board of Directors, Post-Polio Health International

Acknowledgements

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Carolyn Raville, Founder, North Central Florida Post-Polio Support Group, Ocala, Florida
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Special Acknowledgement

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Program / Thursday, April 23, 2009

9:00 am – 6:15 pm

Registration in GEORGIA HALL

1:00–2:00 pm

SESSION T1 – OPENING PLENARY

Location & Legacy – Purpose & Possibilities

ROOSEVELT HALL AUDITORIUM

Representatives of Roosevelt Warm Springs
Institute for Rehabilitation and Post-Polio
Health International

2:30–3:45 pm

SESSION T2 OPTIONS

First Things First: Understanding Poliomyelitis

SCHOOLHOUSE 105

John Fitzsimmons, Centers for Disease
Control and Prevention, Atlanta, Georgia

Tools to Use in Evaluating Treatment Choices

VRU AUDITORIUM

Barbara Duryea, MSN, RN, CPHQ, John P.
Murtha Neuroscience and Pain Institute
(JPMNPI), Johnstown, Pennsylvania

Polio: The Legacy of Warm Springs

ROOSEVELT HALL AUDITORIUM

Edith Powell, Ed.D, MT(ASCP)SBB,
Tuskegee University, Tuskegee, Alabama

Naomi Rogers, PhD, Yale University,
New Haven, Connecticut

Daniel J. Wilson, PhD, Muhlenberg College,
Allentown, Pennsylvania

Modifying ADL Techniques to Accommodate New Weakness

MEADOWS CLASSROOM

Carolyn Podolski, OT,
Peachtree City, Georgia

4:15–5:30 pm

SESSION T3 OPTIONS

Demonstration and Discussion of a Post-Polio Examination: Sorting Out Secondary Conditions, Part 1

ROOSEVELT HALL AUDITORIUM

Frederick Maynard, MD, UP Rehabilitation
Medical Associates, Marquette, Michigan

Brenda Butka, MD, Vanderbilt Stallworth
Rehabilitation Hospital, Nashville,
Tennessee

William DeMayo, MD, John P. Murtha
Neuroscience and Pain Institute (JPMNPI),
Johnstown, Pennsylvania

Martin Wice, MD, Medical Director,
St. John's Mercy Rehabilitation Hospital,
St. Louis, Missouri

Feel Good Food: Boosting Energy, Maintaining Weight

SCHOOLHOUSE 105

Kathryn Bussey, RD, LD,
St. Francis Hospital/Sodexo,
Columbus, Georgia

Meeting Other Users of Home Mechanical Ventilation

MEADOWS CLASSROOM

Moderator and Attendees

**Finding and Disseminating
Information through Support Groups**
SCHOOLHOUSE 111

Moderator: Margaret Hinman, editor,
Colorado Post-Polio Connections,
Westminster, Colorado

Using the Internet

Barbara Gratzke, International Post-Polio
Support Group, Miami, Florida

Developing Special Projects

David Holland, Post-Polio Awareness and
Support Society of British Columbia (PPASS
BC), Langley, British Columbia, Canada

Suggestions for Increasing Advocacy

Linda Priest, CTRS/L, Atlanta Post-Polio
Association, Decatur, Georgia

Sharing Newsletters

Attendees

DINNER AND SESSION T4 OPTIONS

5:30–7:30 pm *Dinner*

6:15–8:30 pm *Sessions*

(6:15–7:15 pm; Repeat 7:30–8:30 pm)

**Improving Your Mobility Device:
*Move Forward***

CTR GYMNASIUM

Michelle Guevin, PT, MTC, Bay Area
Physical Therapy, Bradenton, Florida

(6:15–7:15 pm; Repeat 7:30–8:30 pm)

Water Can Still Benefit Survivors
CTR POOL

Mary Essert, BA, ATRIC, Conway,
Arkansas

Cynthia Henley, PT, Miami, Florida

Kathryn Wollam, PT, Coral Springs, Florida

(6:00–8:15 pm; Stop in anytime.)

Yes, You Can Bowl

CTR BOWLING

Rosanna Borders, CTRS, RWSIR,
Warm Springs, Georgia

(6:45–8:15 pm)

**Polio Narratives: Readings and
Discussion of the Writing Process**

CTR 201

Jacqueline Foertsch, PhD, University
of North Texas, Denton, Texas

Joyce Tepley, LMSW, Dallas, Texas

(6:15–7:15 pm; Repeat 7:30–8:30 pm)

Learn About Acupuncture

CTR GAME ROOM

Susan Harris, Lic Ac, Kingman, KS

(6:15–7:15 pm; Repeat 7:30–8:30 pm)

Yes, You Can Practice Yoga

CTR 202

Barbara Duryea, MSN, RN, CPHQ,

John P. Murtha Neuroscience and Pain

Institute (JPMNPI), Johnstown, Pennsylvania

SESSION T1

Opening Plenary

Location & Legacy – Purpose & Possibilities

**Representatives of Roosevelt Warm Springs Institute for Rehabilitation
and Post-Polio Health International**

SESSION T2

First Things First: Understanding Poliomyelitis

**John Fitzsimmons,
Centers for Disease Control and Prevention, Atlanta, Georgia**

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 with 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 treatments for you.

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

Evidence-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 (end 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
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/organizations/OrgListing.asp
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
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
MedlinePlus® has extensive information from the National Institutes of Health and other trusted sources on over 650 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) 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.nlm.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/entrez/query.fcgi> 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/> PubMed Central is the National Library of Medicine's database of journal articles that are available free of charge to users.

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 resources:

- **ClinicalTrials.gov:** <http://clinicaltrials.gov/ct/g> 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 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>. Or you can read plain-English consumer summaries of the reviews at 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 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/selfhelp/>

National Board for 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

<http://www.nimh.nih.gov/HealthInformation/GettingHelp.cfm>

Talk to your doctor.

Be an Active Member of Your Health Care Team. Food and Drug Administration. 2004.

http://www.fda.gov/cder/consumerinfo/active_member.htm. Phone: 888-INFO-FDA (888-463-6332).

Be Informed: Questions to Ask Your Doctor Before You Have Surgery. Agency for Healthcare Quality and Research. 1995. <http://www.ahrq.gov/consumer/surgery.htm>. Phone: 800-358-9295.

Five Steps to Safer Health Care. Agency for Healthcare Research and Quality. 2003.

<http://www.ahrq.gov/consumer/5steps.htm>. Phone: 800-358-9295.

Getting a Second Opinion Before Surgery. Centers for Medicare & Medicaid Services. 2004.

www.medicare.gov/Publications/Pubs/pdf/02173.pdf. Phone: 800-MEDICARE (800-633-4227).

How to Get a Second Opinion. National Women's Health Information Center. 2003.

<http://www.4woman.gov/pub/secondopinion.htm>. Phone: 1-800-994-WOMAN.

Quick Tips – When Planning for Surgery. Agency for Healthcare Research and Quality. 2002.
<http://www.ahrq.gov/consumer/quicktips/tipsurgery.htm>. Phone: 800-358-9295.

Quick Tips – When Talking with Your Doctor. Agency for Healthcare Research and Quality. 2002.
<http://www.ahrq.gov/consumer/quicktips/doctalk.htm>. Phone: 800-358-9295.

Talking with Your Doctor: A Guide for Older People. National Institute on Aging. 2002.
www.niapublications.org/pubs/talking/index.asp.
Phone: 800-222-2225. |

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Polio: The Legacy of Warm Springs

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A Black Oasis: Tuskegee Institute's Fight Against Infantile Paralysis, 1941-1965

**Edith Powell, Ed.D, MPA, MT(ASCP)SBB,
Tuskegee University, Tuskegee, Alabama**

Note: This presentation is based on original research funded by a Basic Research Grant #1-1046 with the same title, co-authored with John F. Hume M.D.

Purpose: To share the knowledge about the Infantile Paralysis Centre at Tuskegee Institute, it's mission, work and relationship to the National

Introduction

At a time in our history when the country was in a great depression, in the rural South there was much ignorance, poverty and desolation. The land was not productive anymore, having been used up by many years of growing cotton. Segregation still required separate water fountains, eating places and entrances to health care facilities. Blacks had no money, clothes and little food. They were living in dilapidated houses with no electricity, outdoor toilets, appalling morbidity, and high mortality.

Yet, in the midst of this rural Alabama bleakness of the 1930's, lay a beautiful little town known as Tuskegee. It occupied the site of the Indian village known as Tuskigi, and on its outskirts was the most noted institution in the United States for the education of blacks—Tuskegee Institute. Within the tree-lined, immaculately groomed grounds of this famous educational facility, were streams of happy, laughing black students whose education was carefully tended by many of the outstanding black educators of this decade---truly a black oasis ---where the thirst for learning, described by Dr. Washington in 1881, was satisfied by those who carried on the philosophy of excellence and quality of the education put forth by the Institute's founder, the same Booker T. Washington.

Because of the commitment and dedication of the people who made up the Institute and due to their mission to teach, to guide, to encourage and to serve the blacks of the rural South, a program began at Tuskegee which became one of the most outstanding health care services available for blacks anywhere in the country---the Tuskegee Infantile Paralysis Centre.

(A Black Oasis: Tuskegee Institute's Fight Against Infantile Paralysis, 1941-1975, pp.xiv-xv.)

This Center was made possible by the first grant from the National Foundation for Infantile Paralysis (1938) newly established by President Franklin D. Roosevelt; and, was announced at Commencement Exercises at Tuskegee Institute by Foundation President, Basil O'Connor in May, 1939.

In Tuskegee, there were two hospitals: one for whites and one for blacks. Macon County Hospital, a small 30-bed, ill-equipped facility admitted only whites. The John A. Andrew Memorial Hospital, located on the campus of Tuskegee Institute and provided quality health care for Negroes plus all the other amenities that insured a wholesome and pleasant environment for the sick. While John A. Andrew Memorial Hospital was an excellent health care facility for blacks, a poliomyelitis epidemic which swept through the South in 1936, crippling black children and adults, was beyond its scope. Those institutions capable of treating poliomyelitis effectively were either too far away to permit travel for poor rural blacks or were open to whites only. Therefore, blacks really had nowhere to turn for the critically needed specialized care.

Also, at Tuskegee Institute, there was a nurses' training program begun in 1921, graduates were working all over the country as public health nurses, private practice, and at smaller institutions. This expanded to include an additional 4-month intensive course in midwifery. This further expanded in 1941 to a graduate nurse training course in midwifery culminating in a certificate.

Additionally, at Tuskegee Institute, there was the world-famous scientist, Dr. George Washington Carver, who had training as a mass-use for the Ames, Iowa football team. He continued his "research" using his peanut oil, in conjunction with rubbing sore muscles, on people who came to him daily, seeking relief. Although not a medical doctor, he did report positive results. In 1933, an article published by an AP writer was carried by papers all over the country, describing the tremendous improvement of two polio patients. This generated much publicity, letters, and future patients. Dr. Carver, personally, never claimed a cure: that was the spin put by the reporter in the press release. Dr. Carver later sent a sample of his peanut oil and directions for use to President Roosevelt, saying that it might offer him some relief. The President responded with a letter of thanks.

In 1936, Dr. John Watson Chenault, a young black man who was a junior attending orthopedic surgeon from Provident Hospital in Chicago, attended the 25th Annual John A. Andrew Clinic. He presented a paper on "The Crippled Child." While making rounds during the Clinic in the crippled children's wing, he noted that many of the little patients had infantile paralysis, an observation which was directly contradictory to the generally accepted statistics showing that Negro children did not contract this disease. Further, they required a much different type

of medical care than those children routinely admitted to the pediatric ward. To this end, Dr. Chenault began a crusade for specialized treatment facilities for all children suffering from polio, and especially those at Tuskegee. Dr. Chenault returned to Tuskegee in 1937 as Director of Orthopedic Surgery at the John A. Andrew Memorial Hospital.

There was also a shoe and brace making curriculum at Tuskegee Institute whereby a student could study orthopedic shoe and brace making, either as a two-year vocational diploma or a 4-year B.S. degree. Interns of Dr. Chenault, and later, Dr. John F. Hume, could also rotate through this program.

This then describes the environment of health care that met the criteria for the establishment of the Infantile Paralysis Center at Tuskegee Institute in 1941.

The National Foundation for Infantile Paralysis was founded in 1938, as you know, by President Franklin D. Roosevelt to raise money for finding a cure and treatment of polio. One of the fund raisers was the Presidential Ball held all over the country in January on the President's birthday. Separate balls were held for blacks and whites, with each of the groups' contributions added to the total. The Warm Springs Foundation had already been established, however, blacks were not admitted, and their care was confined to inadequately equipped and staffed facilities in various local hospitals. The onus to "do something for blacks" thus fell upon the National Foundation and its President, Mr. Basil O'Connor.

My comments today will be divided into five topic and related sub-topic areas, and will be very brief due to time constraints : 1) Poliomyelitis Among Blacks:1936-1941, President Roosevelt's trip to Tuskegee, Role of Basil O'Connor; 2) The Infantile Paralysis Center at Tuskegee Institute, Warm Springs Contribution; 3) Educational Activities, Nursing Education, Liaison with National Foundation for Infantile Paralysis; 4) New Missions, Tuskegee Rehabilitation Center, Carver Research Foundation and HeLa Cell Cultures.

The Polio Crusaders: Disability Activism at Warm Springs in the 1930s

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During the 1930s, disabled adults at Warm Springs initiated a public disability rights campaign. So effective was this campaign that President Franklin Roosevelt's able-bodied advisors considered it a political threat, and sought to displace the articulate adult polio survivor in the public mind with the image of the poster child, vulnerable, silent and grateful. At the core of this disability rights movement were polio patients who wanted more than a healing refuge. They saw the Warm Springs' high profile as a potent weapon in a cultural war to challenge discrimination against the disabled. Their eight-page newsletter, the *Polio Chronicle*, its slogan "Every Patient, a Polio Crusader," boldly protested the narrow, medicalized definition of rehabilitation and provocatively suggested "rehabilitating" prejudiced, able-bodied employers and health professionals. And they consciously redesigned Warm Springs to function as an exemplar of the way polio survivors and other disabled people deserved to live. To make what seemed like a special interest demand into a public right, these Polio Crusaders built a feisty and hedonist community filled with poker games, vaudeville shows and romance.

The community of activists at Warm Springs was part of a broader, nascent disability rights movement. In 1935 the League of the Physically Handicapped protested discriminatory government policies and marched with signs that read "We Don't Want Tin Cups We Want Jobs," mocking the piteous images of the disabled typically promoted by charities and New Deal agencies. But the class allegiances of most Warm Springs patients were worlds away from the League, an organization never discussed in the *Polio Chronicle*. In the 1930s this community was made up of wealthy adults, and from the beginning Warm Springs patients, administrators and medical staff were all white, with, as was typical of other Southern institutions, African Americans working as maids, waiters, body servants, gardeners and janitors.

By the end of the 1930s, with the founding of the March of Dimes, the *Polio Chronicle* had ceased publication, the League for the Physically Handicapped had dissolved, and disabled activism was in retreat. The March of Dimes developed no policies for employing the disabled or battling discrimination. Despite increasing numbers of adolescents and adults disabled by polio, March of Dimes publicity campaigns remade the polio survivor into a hopeful, young child, attractive and eager to walk again, silent and smiling. Now, rehabilitation meant an adjustment to physical limitations and not integration into society, a striving for normality and not an open realism about physical difference. Children were good for fund-raising, but they also signaled the shift back to the treatment of the disabled as the objects of sentimental publicity, and a renewed disregard for the disabled as agents of policy and change. Polio survivors continued to fight social and economic discrimination at their homes, schools and workplaces. The emergence of the Independent Living Movement in the 1960s was spearheaded by a new generation of adult polio survivors, who were children just as Warm Springs oriented its rehabilitative efforts around child patients. Perhaps the legacy of activism can be traced to the inspiring example of Warm Springs as a "Polio's Paradise."

Polio: The Legacy of Warm Springs

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Seventy years ago the Georgia Warm Springs Foundation was the most famous rehabilitation facility in the nation. Part of that fame, of course, derived from its founder and frequent visitor, President Franklin D. Roosevelt. But by the late 1930s Warm Springs had also garnered national attention for the rehabilitating survivors for the annual polio epidemics. Beginning in 1934, millions of Americans contributed to the President's Birthday Balls to help support the work at Warm Springs. But now, some eighty years after Roosevelt established Warm Springs as a polio rehabilitation facility, much of that fame has faded. Most of my history students have no sense of what Warm Springs was or what it accomplished. It good to recall why Warm Springs was so important to people with polio, and to explore its legacy for polio survivors, for rehabilitation, and for the history of disabilities in the United States.

- I want to explore briefly this afternoon several important legacies of Warm Springs and I hope that at the end of the presentations we can have a good conversation about this place that meant so much to so many polio survivors. Let me just note the legacies I want to discuss:
- Perhaps more than any other rehabilitation facility at the time, Warm Springs never forgot that patients in rehabilitation are people first. The doctors and the staff seemed to recognize the individuality of the boys and girls, men and women, they treated even as they pushed them to achieve maximum possible recovery.

- Warm Springs was one of the first, perhaps the first, rehabilitation facility to emphasize the psycho-social element of rehabilitation. For individuals who had experienced a devastating disease and the paralysis of their body rebuilding their self esteem and social skills was no less important than rebuilding their bodies.
- Warm Springs demonstrated the importance of a powerful role model-FDR.
- Warm Springs created a temporary haven for people with serious disabilities, in which disability was the norm-in which polio survivors were the normals.
- Warm Springs and the need to put it on a solid financial footing gave rise not only to the President's Birthday Balls, but also to the National Foundation for Infantile Paralysis, the March of Dimes, and the development of the polio vaccines of Salk and Sabin.

Modifying ADL Techniques to Accommodate New Weakness

Carolyn Podolski, OT, Peachtree City, Georgia

SESSION T3

Demonstration and Discussion of a Post-Polio Examination: Sorting Out Secondary Conditions, Part 1

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

**William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNI),
Johnstown, Pennsylvania**

Martin Wice, MD, Medical Director, St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri

Post-Polio Patient Assessment

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

I. History

A. Chief Concerns: eg. Pain, fatigue, new weakness, change in function

B. Polio History

1. Age and severity during first month; historical year
2. Early rehabilitation highlights and timeframes of recovery
3. Residual disability at maximum recovery or after 2 years
4. Any rehabilitative surgeries and/or History of device/brace use
5. More recent or later(>15 years) changes in strength or function
6. Current motor functional capacity

C. Past General Medical History

1. Chronic conditions
2. Injuries
3. Surgeries
4. Timing of above in relation to PPS symptoms

D. Current Health

1. Review of Systems: pain, fatigue, new weakness, breathing or swallowing problems, sleep, weight change
2. Current medications

E. Family & Social History

1. Lifestyle Assessment relative to health & wellness
2. Psychological & social stressors

F. Review Relevant Medical, Laboratory & Imaging Reports

II. Examination

A. Observe Function: seating/standing/walking postures and capacities— do fully clothed and with usual devices/methods

B. Formal Range of Motion assessment of joints & muscles

C. Strength assessment of key functional muscle groups(modified MMT)

D. General and/or focused Orthopedic Exam

1. Structural deformities of neck, back, chest, limbs
2. Joint Instability
3. Leg Length Discrepancy

E. General and/or focused Neurologic Exam

1. Muscle tone and bulk(?atrophy)
2. Reflexes
3. Sensation
4. Co-ordination
5. Mental status & affect

F. Provocative Pain Examination

1. Can pain be reproduced during the exam?
2. Does pain occur with active and/or passive movements, or with pressure?

G. Focused Evaluation of Gait or other Functions

1. With and without devices
2. Challenged

III. Planning

A. Is More Information Needed?

1. Lab Studies: eg. CBC, thyroid, blood sugar, etc.
2. Further X-Rays or Imaging Studies
3. Electrodiagnostics: EMG, Conduction studies
4. Pulmonary Function Studies and Arterial Blood Gases
5. Sleep Studies
6. Rehab.Team Evaluations: PT, OT, CR, Psych/social work, orthotics, dietician
7. Medical evaluations: Orthopedist, Neurologist, Internist (pulmonologist, cardiologist), ENT, Psychiatrist, Surgeon
8. Medical Records/Reports: eg. Primary Care Physician, original polio care, reconstructive surgery operative reports, etc.

B. Preliminary Goals Presented and Discussed with Patient (and family)

C. Short-term and Long-term Goals Agreed to by Patient & Physician

D. Treatment Plan Outlined and Agreed To

For Example:

1. Weight Loss Plan
2. Use Bi-PAP at night
3. Obtain orthosis (brace) and follow with PT to learn correct use & adjust
4. PT for Individualized Exercise Program
5. Pain Management Plan
6. Counseling & anti-depressant use
7. OT for energy conservation plan

How does one assess an individual for the post-polio syndrome?

**Martin Wice, MD, Medical Director
St. John's Mercy Rehabilitation Hospital, St. Louis, Missouri**

The first thing I do when I examine polio survivors is to get a very detailed medical history from the time they had polio through their entire recovery process and then their new decline. I conduct a detailed physical examination, including a neuromuscular and functional evaluation. Tests are performed not so much to prove one has the post-polio syndrome (no test can do this), but to rule out other problems which can masquerade for it. Tests include blood work (including a CBC, chemistry profile, thyroid screen, CPK, and ANA), and a vital capacity (a breathing screen).

If I have cause for concern about breathing, I request a blood gas, which checks for oxygenation and for CO₂ retention. I may request a sleep study I may also do a special barium "cookie" swallowing study if swallowing is a problem. I may do electrodiagnostic testing of the arms and legs, not to prove that someone has the post-polio syndrome, but to look for other problems -- carpal tunnel syndrome, radiculopathy -- which may explain someone's symptoms. I also may request appropriate radiological testing such as x-rays of joints that are hurting to look for arthritis or for fractures. I may request an MRI scan of the spine to make sure nothing else is masquerading for the post-polio syndrome.

Other tests can be requested depending on what is found during the physical examination. Depending on the results of the above-mentioned tests, I will arrange appropriate referrals.

It is important that the patient and his/her family get the most out of the evaluation. It is to bring in all relevant information including a completed patient profile, if sent, records of past evaluations, test results, treatments and treatment results and to have their questions in writing with someone to help record the answers.

Feel Good Food: Boosting Energy, Maintaining Weight

Kathryn Bussey, RD, RWSIR, Warm Springs, Georgia

Meeting Other Users of Home Mechanical Ventilation

What is currently known as Post-Polio Health International (PHI) was incorporated in 1960 as the International Iron Lung Polio Assistance, Inc. The organization's original focus was to provide information to polio survivors and their families who had spent time in an iron lung. In 1987, International Ventilator Users Network (IVUN) was formed to enhance the lives and independence of home ventilator users through education, advocacy, research and networking. Its work mirrors that of PHI in that it has a unique newsletter (*Ventilator-Assisted Living*), directory (*Resource Directory for Ventilator-Assisted Living*), and website (www.ventusers.org).

Problems and solutions for users of home mechanical ventilation are also unique. Ventilator users and their families and attendants will gather at this early session to discuss issues and to meet each other to instigate networking throughout the conference. Health professionals, representatives of ventilatory manufacturers and those who have post-polio related breathing problems are encouraged to attend.

Finding and Disseminating Information through Support Groups

Moderator: Margaret Hinman, editor, *Colorado Post-Polio Connections*,
Westminster, Colorado

Using the Internet

Barbara Gratzke, International Post-Polio Support Group, Miami, Florida

Developing Special Projects

**David Holland, Post-Polio Awareness and Support Society of British Columbia (PPASS BC)
Langley, British Columbia, Canada**

Suggestions for Increasing Advocacy

Linda Priest, CTRS/L, Atlanta Post-Polio Association, Decatur, Georgia

Sharing Newsletters

Attendees

Use the Internet to Expand Your Knowledge, Meet Friends, Join PPS Groups, Play Your Favorite Games, Read Articles, Shop, Take Classes and More.

Barbara Gratzke

President, International Post Polio Support Organization (IPPSO)

www.ippso-world.org

President, Post Polio Assn. of South Florida

2660 SE 7th Place, Homestead, FL 33033

Email: blgratzke@aol.com or telephone: 305-230-0687

**The International Post Polio Support Organization (IPPSO) is an
Internet-based nonprofit organization.**

IPPSO's mission is to provide Internet forums for communication so polio survivors can support each other and share information. IPPSO also strives to advocate for polio survivors to have the best quality of life possible.

IPPSO currently:

- Hosts a Yahoo group bulletin board and supports real-time voice and type chat for its members. We plan to solicit prominent people to be guests to answer questions on various topics of interest to polio survivors. To join go to: <http://groups.yahoo.com/group/ipsobulletinboardchat>
- Hosts a Yahoo group "Polio World" with a bulletin board and chat forum which is restricted to PPS support group leaders and PPS advocates so they can share creative ideas, successes, failures and strive to gain credibility by joining forces to speak as "one loud voice." The goal is to organize the PPS community to be a powerful force for change – politically, economically, medically and socially. To join go to: <http://groups.yahoo.com/group/polio-world>

- Maintains a website with a list of recommended PPS medical professionals, PPS groups, articles related to PPS, and links to other pertinent web sites. If you would like your web site linked via our web site, please contact us.
- Emails medical updates, a monthly IPPSO Magazine, and other PPS-related articles to its members that have completed an application for membership at www.ippso-world.org.
- Responds to questions and offers support via individual emails.

For the Computer Novice

Be sure to start out very slowly so you are not over-whelmed. A good way to begin is to play a game like Solitaire which teaches you mouse operations and selecting icons on the screen. Next, you should obtain an email box and email address (many go to www.yahoo.com or www.msn.com to do this). Then, you can learn to type key words into the search field in your Internet browser in order to navigate to what you want to find.

Check with a senior citizen center, library, school or Center for Independent Living near you for free computer lessons. Best Buy stores in the US now offer computer services (called their “Geek Squad”) and will come to your home to assist you with set up, installing programs, or instructions on how to use your computer.

Due to mobility impairments, many seniors and persons with disabilities, spend the majority of their time at home, isolated from social interaction and the Internet can reduce feelings of loneliness and depression.

Reasons to Utilize the Internet:

Keep in touch with family and friends easily

- Emails can take the place of postal mail to send greetings quickly without the cost of stamps.
- Pictures and short movies can be shared easily.
- Type or voice chat real-time. (*Especially the youngsters love to communicate this way.*)
- Use a webcam for live viewing. It’s a great way to watch the little one’s grow up.

Make new friends all over the world without leaving your home

- Internet chat rooms are the source of new friendships and possible new relationships.
- Listservs, blogs and newsgroups can be sources for interesting group conversations.

Enjoy online games – solitary games or play with other people real-time

- Get on the Internet and play online mind games when you’re bored. An active mind is especially vital as age catches up with us.
- Play word, card or board games with real people or against the computer. (www.yahoo.com has free games)
- Can’t sleep – go to the Internet. (www.pogo.com has many games at a cost of about \$30 a year)

Gain knowledge and perform tasks required in your everyday activities such as:

- Banking and paying bills
- New recipes for meals
- Maps and directions for travel
- Yellow pages and white pages (*You no longer have to use heavy telephone books.*)
- Local TV and Movie Listings
- Order products and services including:
 - * Compare prices * Look up product ratings & best buys for your money. * Discounts and coupons * Newspapers available online from many locations * Fix things around the house by learning how to at web sites such as www.fixya.com * Encyclopedia-type information at such web sites as www.en.wikipedia.org. * Online seminars are available from colleges, museums and libraries. * Take travel tours, learn about sculpture, or discuss poetry or history without ever having to leave your home.

Research to get articles to improve your medical health and well-being

* Review drug information and interaction of drugs, herbs, and vitamins. * Search for assistive devices. *(pictures, specifications, prices and testimonials)* * Look up medical symptoms and information. * Check ratings of doctors, hospitals, and nursing homes. * Get tips and products to make your home more accessible. * Find various online government services and often you can fill out questionnaires to find out what benefits are available to you. * Contact organizations that support your conditions or interests.

Internet web sites that many find useful

- *Note that the list below is not all inclusive.*
- *Please contact us to share more websites that you find helpful to add to this list.*
- *This list will soon be posted on our web site (www.ippso-world.org) with hyperlinks to click on which will take you directly to the sites. Please contact us to have our web site linked to yours.*

Government Information in US

Nat'l Institute of Neurological Disorders & Stroke (NINDS) - www.ninds.nih.gov.

Post Polio Information Page is http://www.ninds.nih.gov/disorders/post_polio/post_polio.htm

Social Security Regulation for PPS used to determine eligibility for disability income (SSDI) and also Supplemental Security Income (SSI) which provides payments for individuals who are disabled and qualify. In most states, individuals who qualify for SSI also receive Medicaid health care benefits right away. - <http://www.post-polio.org/edu/di245801.html>

Navigate the world of disability benefits - www.disabilitybenefits101.org

Disability-related government resources - www.disabilityinfo.gov

Magazines & Newsletters Geared to People with Disabilities

- **World of Possibilities** is a magazine that offers disability-related information about equipment, products and goods. It features articles on health, employment, technology, education, sports, travel, universal design, mental health and much more. - www.caringcommunities.org
- **DisabilityWorld** is the online international periodical of news and views by World Disability Resources. - www.disabilityworld.org
- **Disabled On Line** provides a newsletter, web directories, forums, chat rooms, shopping and classifieds. - www.disabledonline.com
- **New Mobility Magazine** is a monthly magazine with all types of disability information. They distribute an annual guide to use to review and purchase assistive devices. - www.newmobility.com
- **Disabled Dealer** is a US Magazine online or by postal mail of new and used accessible vans, power chairs, and RV's - www.disableddealer.com

Medical Professionals Familiar with PPS & Post Polio Support Group Directories by Locale

- www.ippso-world.org
- www.post-polio.org
- www.ott.zynet.co.uk/polio/lincolnshire/directory/org.html

Organizations for People with Disabilities

Global:

Centers for Independent Living –location closest to you - www.ilru.org/html/publications/directory/index.html

Rotary International Polio Survivors & Associates (PSA) Action Group - www.rotarypoliosurvivors.com

US:

- **The Alliance of Technology Access for people with disabilities** - www.ataccess.org
- **Families USA** (“the voice for Health Care consumers”) provides advocacy tools, resources, information, and easy to understand explanations of current healthcare coverage issues. – www.familiesusa.org
- **The National Council on Disability (NCD)** examines employment, housing, education, transportation and other federal policies that affect people with disabilities. - www.ncd.gov
- **The American Association for People with Disabilities (AAPD)** is the largest nonprofit cross-disability member organization in the US, dedicated to ensuring economic self-sufficiency and political empowerment for the more than 56 million Americans with disabilities. - www.aapd.com
- **The Medicare Rights Center** works to ensure access to affordable health care for older adults and people with disabilities through counseling, educational programs and public policy initiatives – www.medicarerights.org
- **The US Clearing house for home and community based services** - www.hcbs.org

PPS-related Chats, Bulletin Boards & Email Listservs

- **IPPSO Yahoo group bulletin board and chat availability for members** to support each other by discussing meeting the challenges of everyday life and making friends. To join go to: <http://groups.yahoo.com/group/ippsobulletinboardchat>
- **IPPSO Yahoo group bulletin board and chat availability for the major PPS support group leaders and advocates.** To join go to: <http://groups.yahoo.com/group/polio-world>
- **POST-POLIO-MED** is a forum for PPS researchers & medical professionals, polio survivors and others interested in PPS. Posts are limited to the topics of PPS research, clinical issues, clinical trials, current treatment practices, and support group newsletters. Get Information at: www.skally.net/ppsc/ppsc-l.htm. Subscribe via e-mail to: Post-Polio-Med-subscribe-request@listserv.icors.org.
- **Justice For All (JFA) Email** is a free service of the American Association of People with Disabilities (AAPD) that shares disability news (legislation and policy, popular culture, etc.) and issues calls to action to advocates across the country. To join go to - <http://www.aapd.com/Advocacy/JFA.html>
- **Dear Marci** is a weekly e-newsletter that features Medicare coverage advice, health tips and links to health care resources. Tel# is (800) 333-4114 or sign up to receive emails at - www.medicarerights.org
- **The Boulevard** is a disability resource directory of products and services for the physically challenged and healthcare professionals. It has a message board and a newsletter to subscribe too. – www.blvd.com

Products for Independent Living

- **Apparel for those in wheel chairs** - www.agapparel.com/shop.php
- **Daily living aides, personal care, orthopedic and fitness supplies** - www.goallegro.com
- **Disability resource directory of products and services** - The Boulevard - www.blvd.com
- **Exhibits of Assistive Devices in the US**
 - Abilities Expo - independent and assisted living products and services from retailers and seminars on topics of interest to people with disabilities - www.abilitiesexpo.com
 - Medtrade Show –the largest exhibition of assistive devices from the leading manufacturers of home medical equipment. Also seminars offered for retailers of HME. - www.medtrade.com
- **Mobility challenges** - The Institute for Rehab Research and Development gives you basic guides on choosing ambulatory devices, basic principles of wheel chair seating, etc. - <http://www.irrd.ca/education/default.asp>
- **Seating International Symposium** - the University of Pittsburg sponsors a conference each year that covers topics for people with disabilities that have seating and mobility issues. - www.iss.pitt.edu
- **Wheelchairs, scooters and other home care needs** – www.Spinlife.com
- **Wheel chairs, scooters, lifts, ramps, bathroom products.** They are starting a free classified ad section where you can list free and purchase used power chairs, accessible vehicles etc. – www.planetmobility.com
- **Wheelchairs & scooters-** assists in determining what will work for you - www.wheelchairjunkie.com

PPS Support Group Newsletters on the Internet

International PPS Organization Newsletters

Post-Polio Health International (PPHI) - www.post-polio.org

International Post Polio Support Organization (IPPSO) - www.ippso-world.org

European Polio Union (EPU) - www.postpolio.eu

Global PPS Support Groups (excluding the US - see below):

Africa	Post-Polio Network RSA - www.postpolio.co.za
Australia	Post-Polio Network NSW, Inc. - www.post-polionetwork.org.au Australia PP NETWORK OF WA INC) - www.upnaway.com/~poliowa/
Brazil	www.abraspp.org.br
Britain	Lincolnshire Post-Polio Network (Cornwall United Kingdom) www.zynet.co.uk/ott/polio/lincolnshire or www.lincolnshirepostpolio.org.uk British Polio Fellowship - www.britishpolio.org.uk
Canada	Victoria - PPASS of BC - www.ppass.bc.ca Canadian March of Dimes - PPS group - www.poliocanada.com Saskatchewan Polio Regina Inc - http://nonprofits.accesscomm.ca/polio/
Ireland	PPS Group - www.ppsg.ie/index.htm
Italy	Erba - www.postpolio.it/convegno_post_polio
Mexico	Asociación Post Polio Litaff - www.postpoliolitaff.org
New Zealand	The Post Polio Support Society of NZ – www.nzordgroups.org.nz/postpolio

US PPS Support Group Newsletters

Arizona	Tucson - www.aztecfreenet.org/polioecho/org06.htm
California	Los Angeles area - Los Ranchos Amigos – http://www.polioassociation.org/Rancho.html Los Angeles area - The Southern California PPS Manager Newsletter

	www.ppsmanager.com
	Sacramento & Auburn - www.poliosurvivors.com
	San Diego - http://polio.home.mindspring.com/
Colorado	Colorado Post Polio Connections - www.co.easterseals.com and select "Post-Polio Support Group"
Connecticut	Norwalk - Polio Outreach of Connecticut - www.the-polio-outreach-of-ct.com
Florida	Boca Raton – Boca Area Post Polio Support Group – www.postpolio.wordpress.com Ocala - North Central Florida Post-Polio Support Group – www.postpoliosupport.com Orlando (eastside) - Post-Polio Resource Group of Central Florida - http://homepage.mac.com/j.annsingleton Ormond Beach - Florida East Coast Post-Polio Support Group – http://home.iag.net/~bgold/polio.htm
Massachusetts	Greater Boston Post-Polio Assn. - www.gbppa.org
Michigan	Michigan Polio Network Inc - http://www.geocities.com/mi_polio_net/index.html
Missouri	St. Louis - Post-Polio Health International (PHI) - www.post-polio.org Branson - http://www.postpoliobransongoers.com
New Jersey	Northern New Jersey - www.njpolio.org Ocean County - http://tomsrivernjpolio.org/
New York	Polio Connection of America - http://www.geocities.com/w1066w/
Pennsylvania	Conemaugh Health Systems - http://postpolio.conemaugh.org
Texas	San Antonio - http://sapsa.mu.nu/
Washington	Spokane - http://polionet.org/
Wisconsin	Milwaukee - www.pprg.org

Recreational Activities for People with Disabilities

Access Anything encourages people living with disabilities around the world to enjoy life to its fullest through the sense of freedom provided by travel and adventure. - www.AccessAnything.net

Access to Recreation - catalog of adaptive equipment for recreation i.e. bowling, cycling, hunting and fishing, swimming, travel, exercise equipment, pool lifts, portable shower, & ramps - www.accesstr.com

Adaptive Adventures is a nonprofit organization dedicated to improving the lives of people with disabilities through outdoor sports & recreation. - www.adaptiveadventures.org

US Air Travelers with Disabilities - Hotline # 800-778-4838 to obtain information about the rights of persons with disabilities during air travel, or report a disability-related air travel service problems. File a complaint to airconsumer@ost.dot.gov or mail to: US Department of Transportation, 400 7th St SW, Washington, DC 20590.

Disaboom is a community forum where people with disabilities can share lifestyle articles, blogs, forums, and health information and a special interest in exploring adaptive sports. - www.Disaboom.com

US National Sports Center for the Disabled - www.nscd.org

US Northeast Passage provides therapeutic recreation services. They deliver disability-related health promotion and adapted sports programs throughout New England. - <http://www.nepassage.org/>

RV rallies and travel club – RV Tips and newsletter, plus used accessible RVs for sale by owners – www.handicappedtravelclub.com

The Society for Accessible Travel & Hospitality (SATH) raises awareness of the needs of travelers in order to remove physical and attitudinal barriers and expand travel opportunities globally. Members include travel professionals, consumers with disabilities and other individuals and corporations that support this mission. Conferences are hosted and are a great place to exchange travel tips to make travel less stressful. - www.sath.org

Post-Polio Health International including International Ventilator Users Network www.post-polio.org

Research References for Post Polio Syndrome (PPS)

National Library of Medicine & the National Institute for Health – see research and clinical trials as well as all types of information on polio and PPS - www.nlm.nih.gov/medlineplus/polioandpostpoliosyndrome.html

Post-Polio Central archives web site for research and clinical trials - <http://i-sites.net/ppsrl/reslarc.html>

Post-Polio Central - PPS recently published medical articles – <http://i-sites.net/ppsma/medindx.html>

Online Health Forum – (put “Post Polio” in the search field) - www.medicalnewstoday.com

PubMed is the world’s largest medical library and is a service of the U.S. National Library of Medicine and the National Institutes of Health (put “Post Polio” in the search field) - <http://www.ncbi.nlm.nih.gov/pubmed/>

Vent-User & Respiratory Resources

Vent Users Mailing List provides a forum for people who require a ventilator (respirator) to breathe to communicate with others with like issues. Send questions to vent-users@eskimo.com. To subscribe send an email to: vent-users-request@eskimo.com - in the Subject line type: “subscribe”

International Ventilator Users Network, an affiliate of (PHI) - www.ventusers.org

The Institute for Rehabilitation Research and Development’s web site section on “Respiratory Protocols for SCI and neuromuscular diseases” teaches you about frog breathing, assisted cough using an ambu bag and abdominal thrust to expand your lungs and many other issues - <http://www.irrd.ca/education/default.asp>

Progressive Medical in Carlsbad, California USA has an organization that specializes in sleep apnea and respiratory function tests geared to people with neurological conditions- www.progressivemed.org

Developing Special Projects

A presentation by:

David Holland, Vice-President Mainland, (PPASS BC) Post Polio Awareness and Support Society of British Columbia, Canada

Introduction:

PPASS came into being in 1986, as a result of a number of Polio Survivors who live in Victoria, the capital of British Columbia, finding out about Post Polio Syndrome. The society has 30 Area Support Groups throughout the Province – some of which are very active, having monthly or bi-monthly coffee / lunch meetings with speakers.

Our mandate is to provide resource information for our members, increase awareness of the existence of PPS to the general public, the medical profession and most importantly, Polio Survivors.

While we don’t solicit members outside of our own Province, we welcome anyone who wishes to join PPASS BC, resulting in our membership stretching from as far a-field as Scotland to New Zealand, and of course many states within the USA, with of course the vast majority of our members being located in our own Province of British Columbia.

British Columbia is situated between the Rockies and the Pacific Ocean, the 49th parallel (U.S. / Canada border) to the south and the Yukon Territory, located over 1,000 miles to the north. With a population of only 4.1 million scattered over this vast area of 365,000 square miles, our population density is low, resulting in large distances between towns and cities. This has necessitated us bringing events to the population centres, rather than expecting

our members to travel to these events under their own steam, when in many instances their “steam” is diminishing and their energy levels are falling fast.

The PPASS Water Exercise Programme:

PPASS established its water exercise programme for polio survivors in the Greater Victoria area in 1995 under the supervision and guidance of a Dr. Alan Bass, a physiatrist working at the Gorge Road Hospital in Victoria. Dr. Bass was associated with a rehabilitation aquatics programme at the Esquimalt Recreation Centre and although several polio survivors had participated in this programme, both they and Dr. Bass realized that it did not meet the needs of polio survivors, resulting in the development of a specific programme together with an exercise regime that would suit the needs of polio survivors.

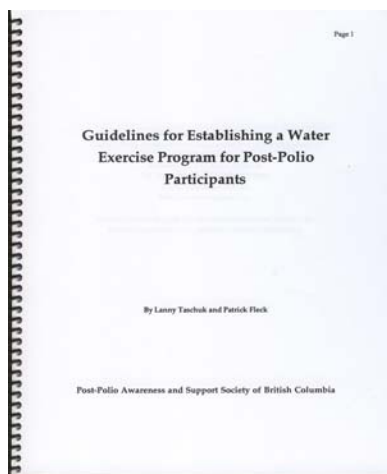


Qualified kinesiologists were trained as instructors for the programme by Dr. Bass and funding to support the programme was secured from the British Columbia Provincial Employees Community Services Fund. This funding continues to this day for which we are very grateful. The 1 ½ hour sessions are held every Monday and Friday now on a year round basis apart from the time when the pool is shut down for annual maintenance. Attendance ranges from 6 to 12 participants at every session. Generally there is a ratio of 10

participants to one kinesiologist, resulting in a high level of personal supervision and instruction. Participants have their own specialized exercise programmes, dependent upon their individual level of motor skills. These exercises may range from simply walking back and forth along the bottom of the pool with the water level at chest height to stretching and rotating arms and / or legs in specified patterns and for a predetermined number of cycles.

PPASS BC Members at George Pearson Rehabilitation Centre.

Of the six pools in the Victoria and Vancouver areas that have suitable facilities and sufficient instruction to undertake exercise programmes for Polio Survivors, it has been found that the water temperatures range should be from 30 Celsius (86 Fahrenheit) to 34 Celsius (93.2 Fahrenheit). This temperature range is higher than the usual public pool temperatures of 28 Celsius (82.4 Fahrenheit) due to Polio Survivors' intolerance to the cold, coupled with their limited exercise regime that Polio Survivors are capable of undertaking.



It is interesting

to note that the Esquimalt pool in Victoria is a salt water pool with a limited amount of chlorine which provides greater buoyancy for the participants – a helpful feature.

Even though the PPASS WEP programme is partially funded by the B.C. Provincial Employees Community Services Fund our members still have to pay a nominal monthly fee for the sessions. These fees help to cover the pool lane rental (see photo showing sign) and the exclusive use of the kinesiologists.

The other pool of note that has specialized facilities and supervisors is located at the George Pearson Rehabilitation Centre in Vancouver, which is part of the Vancouver General Hospital. This pool's water temperature is at the high end of the range, possibly on account of the fact that the facility deals with many stroke and trauma cases. As a result of this facility being part of a hospital both

kinesiologists and physiotherapists are available for advice.

At Pearson participants pay \$3.00 for each session. This fee also covers equipment and assistance from the kinesiologist and physiotherapist. At the West Vancouver Aquatic Centre the fee is \$6.00 per person per session, again covering equipment use and supervision from medically trained staff. It must be noted that none of the pool facilities or the Water Exercise Programmes that take place, other than the Victoria (Esquimalt) pool are supported by outside funding. These facilities have WEP programmes that follow some of the guidelines as set out in the WEP programme but are not necessarily endorsed by PPASS BC.

The PPASS BC Brochure:

Our tri-fold brochure has been developed by various members of PPASS during the past few years,

Membership Benefits:

Resource Information - research articles; assistance that may be available to you and where you might find it. Also creating resources such as water exercise programs in your community.

Group Meetings - An opportunity to meet with those who cope with the same or similar problems. Groups may have speakers and presentation of interest.

Assistance with applications - where to obtain forms and assistance in their completion.

Information - answers to questions for members, family and friends of those with PPS.

Support - please know that you are not alone in your struggle with Post Polio Syndrome.

If you or someone you know had polio be assured that PPASS BC is here to help you. PPASS BC is a registered charitable organization and all gifts over \$10.00 are tax deductible.

Official Registration No: 0732883-11

PPASS BC endorses the work of Rotary International, WHO (the World Health Organization), CDC (Centres for Disease Control) and UNICEF to immunize the children of the world against polio.

Immunization is still our only protection against Polio and Post Polio Syndrome. Without immunization it is estimated that 10 million children will be paralyzed during the next 40 years

For more information, contact.....

Post Polio Awareness and Support Society of British Columbia

Phone: (250) 655 - 8849
Fax: (250) 655 - 8859
Email: ppass@ppass.bc.ca
Website: www.ppass.bc.ca

To Contact The Society - Please Leave A Message By Phone, Fax or E-mail At The Office And It Will Be Answered As Soon As Possible.

The Post Polio Awareness and Support Society of British Columbia would like to thank the patrons and staff of Bingo Bingo in Victoria BC and the British Columbia Lotteries Corporation for their generous support since 1986.

Post Polio



Syndrome

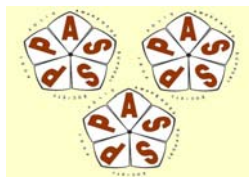
Post Polio Awareness and Support Society of British Columbia

#102 - 9775 - 4th Street,
Sidney, BC
V8L 2Z8

E-mail: ppass@ppass.bc.ca
Website: www.ppass.bc.ca

resulting in the version as you see here. We have attempted to provide a publication that is both helpful to potential members as well as the medical profession. These brochures are distributed by PPASS members to Health Centres, doctors and other medical professional's offices, together with medical laboratories throughout the Province. Distribution is specifically concentrated during Polio Awareness month, but when recipients request copies of the brochure of course we are pleased to make sure that an inventory of brochures is always available for distribution.

The PPASS BC Website Home Page – go to www.ppass.bc.ca for more information.



Polio:

Polio is a highly contagious viral disease that has infected humans for more than 3,500 years. Industrialization saw polio turn from a virtually unknown disease to epidemics that terrorized the world. Polio damaged and destroyed motor neurons leaving countless numbers of children and young adults paralyzed....unable to breathe...or worse...they died. The introduction of the Salk (1955) and Sabin (1961) vaccines signaled the end of epidemics in North America.

Post Polio Syndrome (PPS):

PPS occurs about 35 years past the onset of polio. It is caused by the failure of motor neurons that have carried orphaned muscles, but can no longer activate their muscle fibers. Anyone who had polio can be susceptible to PPS. Symptoms may vary, but may include:

- **Excessive** fatigue not related to activity or relieved by rest.
- **Increased** weakness in unaffected and previously affected areas.
- **Muscle** and joint pain.
- **Reduced** endurance.
- **Cold** intolerance.
- **Difficulty** sleeping
- **Problems** with breathing and swallowing
- **Sensitivity** to anesthetics and medication.

These symptoms may necessitate people to reduce their activities...rest more frequently...perhaps leave their jobs. Polio survivors **MUST** be prepared to accept lifestyle changes and perhaps a return to assistive devices in order to be successful in their lives.

---PPASS BC---

The Post Polio Awareness and Support Society of British Columbia (PPASS BC) is a non-profit registered society that links 30 Area Groups throughout BC via Area Group Contacts who are the liaison between our members and the provincial office

PPASS BC assures polio survivors who are now facing the many challenges of Post Polio Syndrome that they are not alone in their struggles.

PPASS BC brings awareness about PPS to communities through information and presentations. PPASS provides a source for education and dissemination of information about the facts research and treatments available for those with Post Polio.

PPASS publishes a bi-monthly newsletter - *PPASS NEWS* - which contains information on Polio and Post Polio Syndrome.

Our website (www.ppass.bc.ca) has articles of interest and information on as well as links to worldwide websites relating to PPS.

We at PPASS work to provide information about the recent medical findings lifestyle alternatives resources and assistive devices that can help to maintain quality in people's lives.



---Application Form---

I would like to:

- ☐ Become a member
- ☐ Receive more information
- ☐ Become a volunteer
- ☐ Support PPASS BC with a donation of \$ _____

(Tax Deductible Receipt issued for amount over \$10:00)

Name: _____

Address: _____

City: _____

Province/State: _____

Postal/Zip Code: _____

Phone: _____

E-mail: _____

Signature: _____

Date: _____



Post Polio Awareness and Support Society of British Columbia
Phone: (250) 655-8849 Fax: (250) 655-8859
E-mail: ppass@ppass.bc.ca

I

The PPASS BC Flyer:

An inexpensive and easily produced flyer meant to bring people's attention to "Polio" and in turn make people aware of the possible future problems associated with Post Polio Syndrome.

This flyer was developed by the PPASS BC office and is distributed to our members, who in turn arrange to leave the materials in various health and doctor's offices. You will note that very little technical and medical wording is used – the reason being is that we intend for this document to be used to prompt people to visit their doctor if they suspect that they have suffered with Polio in the passed.

We are in the throws of translating this document into Mandarin and Punjabi – they being two of the languages spoken by many members of the immigrant population in British Columbia. The various ministries within the Provincial Government, associated with multiculturalism are delighted to learn of our initiative and in turn propose to assist us with the printing costs.

The PPASS News:

Our bi-monthly newsletter is mailed out to all members along with a considerable number of medical professionals. We also make sure that copies of the newsletter are exchanged with other PPS groups throughout the world.

Did You Have Polio?

Are you experiencing symptoms such as:

- **excessive fatigue** not related to activity or relieved by rest
- **increased weakness** in unaffected and/or previously affected or paralysed areas
- **muscle and joint pain**
- **reduced endurance**
- **sensitivity to cold**
- **difficulty sleeping**
- **problems with breathing and swallowing**
- **sensitivity to anaesthetics and medication**

If you are having difficulty with one or more of these symptoms and you had polio previously, you may have Post Polio Syndrome.

It is important to inform yourself about this condition. **Tell your doctor.**



For more information
please contact our office at:

**Post Polio Awareness and Support Society
of British Columbia**
Phone: 1-250-477-8244
Fax: 1-250-477-8287
Email: ppass@ppass.bc.ca

Visit our web site at: ppass.bc.ca

Mini Conferences and Trade Shows:

We have found that for the amount of man-hours spent in setting up a one day mini conference and trade show generates a greater return than organizing a multi-day event. Generally, the plan is for the Trade Show (with say 6

A BIG "Thank You" Goes to Our Supporters

We wish to extend our thanks to the following organizations, companies, and individuals who have helped make this event possible:

PPASS BC

Langley Central Rotary Club

The Langley Times

Dundee Securities - The Timms Investment Team

5 Star Catering

Our Volunteers

Our Exhibitors:

A-1 Wheelchairs Unlimited (Chilliwack),

CMHC

Motion Specialties BC Limited

Regional Disabled Persons Association.

Sam Sullivan Disabilities Foundation.

Shoppers Home Health Care,

Tetra Society of North America

Travel Only

Our Registrants:

Without you, an event such as this would not be possible - thank you for attending. We hope you find it enjoyable and beneficial.

And finally, our Guest Speakers:

Ramesh Ferris - Cycle to Walk Society

Dr. Simon Mai

Dr. Saul Pressman

The Post-Polio Awareness Support Society of BC

PPASS is a non-profit support organization designed specifically for people who have survived the onslaught of the Polio virus many years ago, and are now suffering from its after-effects - commonly known as Post-Polio Syndrome (PPS).

PPASS BC

Langley AG-37

Coordinators & Contacts:

**David - (604) 530-5739
Zosia - (604) 530-9342**

**PPASS BC
#214-10114 McDonald Park Road,
Sidney, BC
V8L 5X8**

**Phone: (250) 655-8849
Fax: (250) 655-8859**

Email: ppass@ppass.bc.ca



Post Polio Awareness & Support Society of BC

Langley (AG-37)

**March 6, 2008
Symposium & Trade Show
At**

**5 Star Catering at the
Sunrise Golf Centre
5640 - 188th St.
Surrey, BC V3S 4N5**



PPASS BC

Langley AG-37

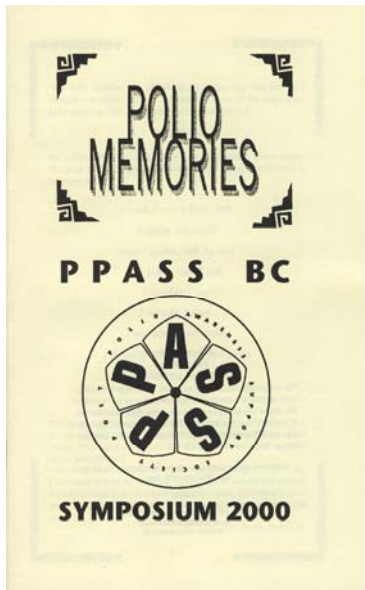
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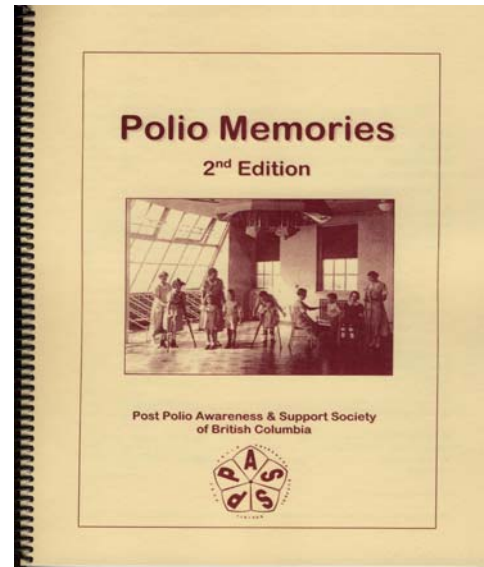
to 10 exhibitors) takes place up until lunchtime, by so doing the attendees are able to speak one on one with equipment suppliers and have their questions answered. This has resulted in many orders for the suppliers, coupled with our members feeling at ease when trying to get help with either a medical or equipment problem. Lunch is served following the Trade Show, with the exhibitors joining the attendees and the speakers – again promoting a relaxed atmosphere. Exhibitors are more than willing to pay a nominal fee for a 10' x 10' booth space, with this fee also covering up to two lunches for the company representatives. The registration fee for attendees is normally \$25, which covers their lunch, coffee breaks and facility rental. We have managed to run these events at a profit, with all net profits being used to financially help those members wishing to attend but are living on a restricted budget – a win-win situation.

The success of the Mini Conferences has resulted in the trade show / speaker meeting structure being used for the PPASS BC Annual General Meetings, which has ended up with the media and general public being made more aware of the scourges of Polio, and its lifelong effects in the form of Post Polio Syndrome. The difference between the mini trade shows and the AGM being that exhibitors are not expected to pay any fees at the AGM, nor are they allowed to sell products, however we encourage them to make appointments to meet potential clients at a later date.

Polio Memories:

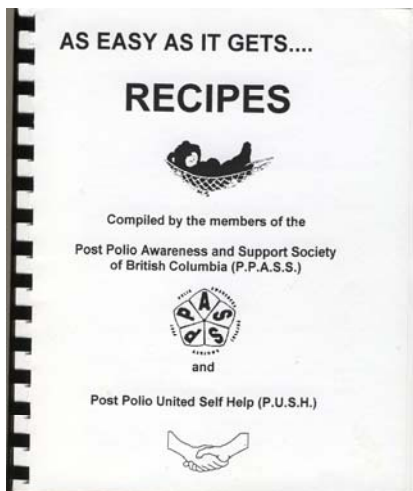


Two editions of “Polio Memories” have been published – these consisting of articles written by our members about their own experiences both during their fight with Polio and the years that followed, with in many cases the Polio Survivor ending up with Post Polio Syndrome. There are many examples of courage, funny situations and some sad instances. The popularity of this publication first resulted in a second edition being published and this edition has had two printings to date. There is a possibility of a third edition being created in the future.



PPASS Recipe Book:

“As Easy as it Gets” A recipe book specifically designed for people with disabilities in mind, using recipes with only a few ingredients.



PPASS Poster:

A group of members located in the Metro Vancouver area are currently working on designing a new poster for PPASS BC that is intended for display during Polio Awareness Month in October. We understand that the poster has illustrations of assistive devices along with children and adults.

Polio Scrapbook:

The most recent PPASS project is one that has been assembled by our President, Joan Toone as an aid to help her illustrate the importance of immunization against Polio whilst speaking to Rotary International Clubs in

British Columbia and the United States. If we are able to encourage Rotary International to keep their PolioPlus programme going, more immunization will occur worldwide thus reducing the likelihood of Polio infections and in turn one day eliminate **Post Polio Syndrome**.

All PPASS publications are available for sale, either through our website www.ppass.bc.ca or by contacting the office at 1-250-655-8849. All monies generated are used to promote awareness and education about PPS both to the general public, members of the medical profession, polio survivors their family members and friends.

Advocating for Yourself and Others

Presenter, Linda L. Priest, CTRS/L
Atlanta Post-Polio Association, Decatur, Georgia

Many people who had polio find advocacy uncomfortable and difficult. My struggle to become an advocate will sound familiar to most of you. By its very nature, being an advocate for one's civil rights brings unwanted attention to our disability. After a lifetime of ignoring our disability and discounting its impact in our lives, how can we turn our attitude around? Learning how to advocate is a personal right and privilege. We will discuss effective advocacy strategies that can change "How Things Work" in order to change "How Things Are."

This presentation will provide a brief overview of disability rights law in the United States, how to find resources and how to put it to good use. It is time to "take it personally." Many of the disability rights movers and shakers in the early days were polio survivors themselves. We will discuss their accomplishments and how we can use them as role models.

In order to survive the larger society, members of oppressed groups are forced to come to terms with a potent force that constantly, and in many ways, says they are no good. This is truly an impossible dilemma, and it is not surprising that people react with rage and fear, turning inward against themselves or outward against others. One of the less constructive ways people may use to cope with their situation is Learned Helplessness, which may consciously or unconsciously be adopted as a mechanism of defense.

N.I. Brill, 1990

Disability Rights Laws

Americans with Disabilities Act - prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress.

Telecommunications Act - require manufacturers of telecommunications equipment and providers of telecommunications services to ensure that such equipment and services are accessible to and usable by persons with disabilities, if readily achievable. These amendments ensure that people with disabilities will have access to a broad range of products and services such as telephones, cell phones, pagers, call-waiting, and operator services, that were often inaccessible to many users with disabilities.

Fair Housing Act - prohibits housing discrimination and covers private housing, housing that receives Federal financial assistance, and State and local government housing. It is unlawful to discriminate in any aspect of selling or renting housing or to deny a dwelling to a buyer or renter because of the disability of that individual, an individual associated with the buyer or renter, or an individual who intends to live in the residence. Other covered activities include, for example, financing, zoning practices, new construction design, and advertising.

Air Carriers Access Act - The Air Carrier Access Act prohibits discrimination in air transportation by domestic and foreign air carriers against qualified individuals with physical or mental impairments. It applies only to air carriers that provide regularly scheduled services for hire to the public. Requirements address a wide range of issues including boarding assistance and certain accessibility features in newly built aircraft and new or altered airport facilities.

Voting Accessibility for the Elderly and Handicapped Act - The Voting Accessibility for the Elderly and Handicapped Act of 1984 generally requires polling places across the United States to be physically accessible to people with disabilities for federal elections. Where no accessible location is available to serve as a polling place, a political subdivision must provide an alternate means of casting a ballot on the day of the election. This law also requires states to make available registration and voting aids for disabled and elderly voters, including information by telecommunications devices for the deaf (TDDs) which are also known as teletypewriters (TTYs).

National Voter Registration Act - The National Voter Registration Act of 1993, also known as the "Motor Voter Act," makes it easier for all Americans to exercise their fundamental right to vote. One of the basic purposes of the Act is to increase the historically low registration rates of minorities and persons with disabilities that have resulted from discrimination. The Motor Voter Act requires all offices of State-funded programs that are primarily engaged in providing services to persons with disabilities to provide all program applicants with voter registration forms, to assist them in completing the forms, and to transmit completed forms to the appropriate State official.

Civil Rights of Institutionalized Persons Act - The Civil Rights of Institutionalized Persons Act (CRIPA) authorizes the U.S. Attorney General to investigate conditions of confinement at State and local government institutions such as prisons, jails, pretrial detention centers, juvenile correctional facilities, publicly operated nursing homes, and institutions for people with psychiatric or developmental disabilities. Its purpose is to allow the Attorney General to uncover and correct widespread deficiencies that seriously jeopardize the health and safety of residents of institutions.

Individuals with Disabilities Education Act - The Individuals with Disabilities Education Act (IDEA) (formerly called P.L. 94-142 or the Education for all Handicapped Children Act of 1975) requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs. IDEA requires public school systems to develop appropriate Individualized Education Programs (IEP's) for each child. The specific special education and related services outlined in each IEP reflect the individualized needs of each student.

Rehabilitation Act - The Rehabilitation Act prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors. The standards for determining employment discrimination under the Rehabilitation Act are the same as those used in title I of the Americans with Disabilities Act. **Section 501** requires affirmative action and nondiscrimination in employment by Federal agencies of the executive branch. **Section 503** requires affirmative action and prohibits employment discrimination by Federal government contractors and subcontractors with contracts of more than \$10,000. **Section 504** states that "no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under" any program or activity that either receives Federal financial assistance or is conducted by any Executive agency or the United States Postal Service. **Section 508** establishes requirements for electronic and information technology developed, maintained, procured, or used by the Federal government. Section 508 requires Federal electronic and information technology to be accessible to people with disabilities, including employees and members of the public

Architectural Barriers Act - The Architectural Barriers Act (ABA) requires that buildings and facilities that are designed, constructed, or altered with Federal funds, or leased by a Federal agency, comply with Federal standards for physical accessibility. ABA requirements are limited to architectural standards in new and altered buildings and in newly leased facilities. They do not address the activities conducted in those buildings and facilities. Facilities of the U.S. Postal Service are covered by the ABA.

Resources for Disability Rights Information

US Department of Justice

Civil Rights Division
950 Pennsylvania Avenue, NW
Disability Rights Section – NYAV
Washington, DC 20530
www.ada.gov
Toll-free ADA Information Line 1-800-514-0301

Equal Employment Opportunity Commission offers technical assistance to the public concerning the employment provisions of title I of the ADA.

ADA publications
800-669-3362 (voice)
800-800-3302 (TTY)
ADA questions
800-669-4000 (voice)
800-669-6820 (TTY)
www.eeoc.gov

Federal Communications Commission offers technical assistance to the public concerning the communication provisions of title IV of the ADA.

ADA publications and questions
888-225-5322 (voice)
888-835-5322 (TTY)
www.fcc.gov/cgb/dro

U.S. Department of Transportation, Federal Transit Administration provides information about the transportation provisions of title II of the ADA.

ADA Assistance Line for regulations and complaints
888-446-4511 (voice/relay)
www.fta.dot.gov/ad

U.S. Architectural and Transportation Barriers Compliance Board, or Access Board, offers technical assistance to the public on the ADA Accessibility Guidelines.

ADA publications and questions
800-872-2253 (voice)
800-993-2822 (TTY)
www.access-board.gov

DBTAC: ADA Centers are funded by the US Department of Education through the National Institute on Disability and Rehabilitation Research (NIDRR) in ten regions of the country to provide resources and technical assistance on the ADA.

800-949-4232 (voice & TTY)
www.adata.org

Project ACTION is funded by the U.S. Department of Transportation to provide ADA information and publications on making transportation accessible.

Information on accessible transportation
800-659-6428 (voice/relay)
<http://projectaction.easterseals.com>

The **Job Accommodation Network (JAN)** is a free telephone consulting service funded by the U.S. Department of Labor. It provides information and advice to employers and people with disabilities on reasonable accommodation in the workplace.

Information on workplace accommodation

800-526-7234 (voice)

877-781-9403 (TTY)

www.jan.wvu.edu

Americans with Disabilities Act: Assistance at Self-Serve Gas Stations

People with disabilities may find it difficult or impossible to use the controls, hose, or nozzle of a self-serve gas pump. As a result, at stations that offer both self and full service, people with disabilities might have no choice but to purchase the more expensive gas from a full-serve pump. At locations with only self-serve pumps, they might be unable to purchase gas at all.

The Americans with Disabilities Act (ADA) requires self-serve gas stations to provide equal access to their customers with disabilities. If necessary to provide access, gas stations must -

- Provide refueling assistance upon the request of an individual with a disability. A service station or convenience store is not required to provide such service at any time that it is operating on a remote control basis with a single employee, but is encouraged to do so, if feasible.
- Let patrons know (e.g., through appropriate signs) that customers with disabilities can obtain refueling assistance by either honking or otherwise signaling an employee.
- Provide the refueling assistance without any charge beyond the self-serve price.

Fair Housing Law

The Fair Housing Act covers most housing. In some circumstances, the Act exempts owner-occupied buildings with no more than four units, single-family housing sold or rented without the use of a broker, and housing operated by organizations and private clubs that limit occupancy to members.

What Is Prohibited?

In the Sale and Rental of Housing: No one may take any of the following actions based on race, color, national origin, religion, sex, familial status or handicap:

Refuse to rent or sell housing

Refuse to negotiate for housing

Make housing unavailable

Deny a dwelling

Set different terms, conditions or privileges for sale or rental of a dwelling

Provide different housing services or facilities

Falsely deny that housing is available for inspection, sale, or rental

For profit, persuade owners to sell or rent (blockbusting) or

Deny anyone access to or membership in a facility or service (such as a multiple listing service) related to the sale or rental of housing.

In Mortgage Lending: No one may take any of the following actions based on race, color, national origin, religion, sex, familial status or handicap (disability):

Refuse to make a mortgage loan

Refuse to provide information regarding loans

Impose different terms or conditions on a loan, such as different interest rates, points, or fees

Discriminate in appraising property

Refuse to purchase a loan or

Set different terms or conditions for purchasing a loan

Air Carrier Access Act

* Carriers may not refuse transportation to people on the basis of disability. Airlines may exclude anyone from a flight if carrying the person would be inimical to the safety of the flight. If a carrier excludes a handicapped person on safety grounds, the carrier must provide the person a written explanation of the decision.

* Airlines may not require advance notice that a person with a disability is traveling. Carriers may require up to 48 hours' advance notice for certain accommodations that require preparation time (e.g., respirator hook-up, transportation of an electric wheelchair on an aircraft with less than 60 seats).

* Carriers may not limit the number of handicapped persons on a flight.

* Carriers may not require a person with a disability to travel with an attendant, except in certain limited circumstances specified in the rule. If the person with the disability and the carrier disagree about the need for an attendant, the airline can require the attendant, but cannot charge for the transportation of the attendant.

Airlines are required to provide assistance with boarding, deplaning and making connections. (They need not hand-carry a person on board a plane with less than 30 seats whose physical limitations preclude the use of existing lifts, boarding chairs, or other devices. DOT is continuing to seek additional data about lifts for small aircraft.) Assistance within the cabin is also required, but not extensive personal services.

* Disabled passengers' items stored in the cabin must conform to FAA rules on the stowage of carry-on baggage. Assistive devices do not count against any limit on the number of pieces of carry-on baggage. Wheelchairs and other assistive devices have priority for in-cabin storage space over other passengers' items brought on board at the same airport, if the disabled passenger chooses to preboard.

* Wheelchairs and other assistive devices have priority over other items for storage in the baggage compartment. * Carriers must accept battery-powered wheelchairs, including the batteries, packaging the batteries in hazardous materials packages when necessary. The carrier provides the packaging.

* Carriers may not charge for providing accommodations required by the rule, such as hazardous materials packaging for batteries. However, they may charge for optional services such as oxygen.

* Other provisions concerning services and accommodations address treatment of mobility aids and assistive devices, passenger information, accommodations for persons with hearing impairments, security screening, communicable diseases and medical certificates, and service animals.

How to File ADA Complaints

Title I

Complaints about violations of title I (employment) by units of State and local government or by private employers should be filed with the Equal Employment Opportunity Commission.

Call 800-669-4000 (voice) or 800-669-6820 (TTY) to reach the field office in your area.

Titles II and III

Complaints about violations of title II by units of State and local government or violations of title III by public accommodations and commercial facilities should be filed with --

U.S. Department of Justice
Civil Rights Division

950 Pennsylvania Avenue, N.W.
Disability Rights Section - NYAV
Washington, D.C. 20530

If you wish your complaint to be considered for referral to the Department's ADA Mediation Program, please mark "Attention: Mediation" on the outside of the envelope.

If you have additional questions concerning the ADA, you may call the Department of Justice's ADA Information Line at (800) 514-0301 (voice) or (800) 514-0383 (TDD) or access the ADA Home Page at: (www.usdoj.gov/crt/ada/adahom1.htm).

Newsletters

Margaret C. Hinman, editor
Colorado Post-Polio Connections, Westminster, Colorado

Often times, dedicated newsletters for polio survivors, their families and their support system are the only means of remaining connected and keeping informed about current information related to polio and post-polio syndrome. This is particularly the case when people are spread over a large geographical area and are not concentrated in an urban area where they can potentially access support groups. Also, as polio survivors age and their mobility becomes more restricted this medium can be one of the windows to the larger world of other polio survivors.

The continued production of newsletters becomes more difficult as the polio/post-polio population ages, becomes less mobile and they find it harder to meet and put out a newsletter. An added factor is that, in some cases, staff members burn out after many years of putting out newsletters and there is no one to take up the task.

Some of the issues and considerations for the production of a newsletter are:

1. Content

- a. The content of the newsletter depends its purpose and on the audience for which the newsletter is produced. This is a decision that needs to be made and communicated at the onset, and can and will be modified over time. Having a clearly stated vision helps determine what to include and what not to include in the newsletter. It also is a safety net for the editor in that limits can be set, thus allowing for the rationale needed when requests for inclusion of articles must be denied.
- b. Information gleaned from samples of post-polio newsletters across the country show that many newsletters include at least some of the following: articles on health related issues, personal stories, book reviews, announcements of upcoming events, news about members of support groups, helpful hints, inspirational sayings, photos, artwork, contact persons and other information that is tailored to the specific audience that the newsletter serves.
- c. Finding sources of information can be an issue. Again, by using other newsletters as examples, one can uncover a variety of resources, including articles from magazines, the Internet, books, other newsletters, and especially the Post-Polio Health International publications. Also, original articles written by members of the newsletter staff or by the editor of the specific newsletter are great resources and add a personal touch to the newsletter.

2. Copyright laws and acknowledgements

- a. Copyright laws protect the writer, the organization and/or the original publication. Therefore, it is important to get permission from the information source and to cite sources and references, both when copying an article and when copying part of an article. It is also important to cite the variety of sources if an original article is based on research from several sources. In the long run, this protects the newsletter and its writers from legal problems.
- b. It appears that many newsletters borrow information and articles from each other. This seems to be an acceptable practice among those of us who are in the post-polio newsletter business. However, it is a courtesy to ask permission and/or to at least cite the post-polio newsletter source when articles and features are shared. This courtesy also makes those of us who volunteer to put out the newsletter feel a sense of pride because something we produced was good enough to be copied and reprinted.

3. Staffing

- a. Again, looking at samples of post-polio newsletters, the production staff of the newsletters covers a spectrum from one person working alone to having any combination of volunteers, including having a full staff to help with the task. The workload on individuals is lightened if there is more than one person involved, helping with everything from researching information, to writing articles, to proofreading, to distribution. If the staff is large enough, then the same people are not called upon each time and burnout is reduced.

Because the staff members of most newsletters are volunteers, the opportunity to have professionally trained journalists is limited. This need not be a problem because anyone with reasonable writing skills and a desire to contribute can be of help to a newsletter. On the other hand, those contributing must be assured that any editing of their work is not a personal slight but is needed to make the newsletter work. At the same time, as in any group endeavor, leadership is needed to coordinate every step of the production and distribution in order to insure that the content is consistent with the purpose of the newsletter and that the issues get out regularly.

- b. Communication among staff is vital. Face-to-face planning meetings offer an opportunity to interact with each other, allow people to bounce ideas off each other and provide inspiration and motivation that can help keep a newsletter vital. On the other hand, in this day of the Internet and easy phone communication, editors can call upon the remote resources of the readership to help produce a newsletter. Even as people become less mobile, they can do research, write, interview and communicate without leaving home and can submit their work over the Internet to the editor. Also, the editor can e-mail finished documents to be checked over for errors and to be proofread.

4. Finances and costs

- a. A newsletter cannot be produced without some financial resources. These can come from subscriptions, donations, fundraisers and grants when and where available. Sometimes, if working through non-profit organizations such as Easter Seals, printing companies may be willing to cover part of the cost of printing. To cover mailing costs, some newsletters use the "Free Matter for the Blind and Handicapped" stamp from the U.S. Postal Service. Others use bulk mailing, or cover the cost of stamps through donations. If funding is unavailable at startup, then the support group will need to put forth effort and energy to find funding resources. If funding dwindles or dries up, then the newsletter is no longer viable and ceases to exist.

- b. Included in production costs, however the revenue is generated, is the issue of who receives the newsletter. If the purpose of the newsletter is to be all-inclusive, that is, to provide information for anyone in the post-polio community who wants the newsletter, regardless of the ability to help pay for it, then the cost factors are different than if it is limited to paying subscribers/donors only.
- c. The re-printing articles from magazines can be a potential added expense as some charge for the right to re-print. It is wise to check the re-print and/or copy policies of the specific magazine when considering copying an article.

Producing and printing a newsletter takes time, effort, leadership and money but the result of such efforts is that polio survivors, those with post-polio syndrome, their families and those in the survivor's community can keep in touch with current information, and can connect with others who are having similar experiences in their lives.

SESSION T4

Improving Your Mobility ***Move Forward***

Michelle Guevin, PT, MTC, Bay Area Physical Therapy, Bradenton, Florida

Presenter: Michelle Guevin PT, MHSc, MTC is a physical therapist and owner of Bay Area Physical Therapy & Wellness in Bradenton and Palmetto, Florida. She has been treating patients with the late effects of polio since 1997. Michelle has been in practicing therapy for 25 years. She received her Associates of Arts degree in 1982 and Associates of Science in 1984 from St. Petersburg College, her Bachelor of Science degree in Physical Therapy from Florida A&M University in 1991, Manual Therapy certification in 1995, and her Masters of Health Science specializing in orthopedics in 1997 from The university of St. Augustine. Michelle is currently seeking certification in Pelvic health from The American Physical Therapy Association.

The 2 hour presentation will present options for your mobility needs.

The course will contain both didactic lecture and audience participation for problem solving and/or trying new skills. Volunteers will be called on from the audience to participate. Be prepared with questions to seek answers for your mobility needs.

Water Can Still Benefit Survivors

Mary Essert, BA, ATRIC, Conway, Arkansas

Cynthia Henley, PT, Miami, Florida

Kathryn Wollam, PT, Coral Springs, Florida

Post Polio WaterWork Management & Techniques

Mary Essert B.A., ATRIC
www.maryessert.com

HISTORY: Post Polio Syndrome

- PPS is a condition which may develop several decades after a person has polio
- Affects muscles & nerves
- Causes weakness, fatigue, pain etc.
- Polio vaccine: 51 yr.
- 1,630,000 Americans had polio in middle of 20th century
- 70% develop PPS

Criteria for Diagnosing PPS

- Confirmed case history of bulbar, spinal or bulbar-spinal polio
- Changes on EMS compatible with prior polio
- Onset of weakness in affected or seemingly unaffected muscles
- May experience fatigue, muscle or joint pain, decreased endurance & function
- Atrophy
- Exclusion of other conditions with similar symptoms

Common Symptoms

- Unaccustomed fatigue
- New weakness in muscles
- Pain in muscles & joints
- Sleeping problems
- Breathing problems
- Decreased ability to tolerate cold
- Functional decline in ADL's
- Voice difficulties
- Depression or anxiety

Benefits of an Aquatic Exercise Program as Related To PPS

- Increased cardiovascular & respiratory effect
- Weight management, reduced energy expenditure
- Socialization & support group
- Sleep enhancement, reduced spasticity
- Increased function & independence through strength & conditioning
- Development of lifetime wellness principles

Post Polio Exercise

Why Water?

- Non fatiguing
- Conserve to preserve"

Water Provides:

- PREPARATION FOR LAND
- CROSS TRAINING
- SAFETY & COMFORT

Preparation for Living

- **Water is kind**
- **Conditioning can occur during simple waterwork such as walking**
- **Adherence to any exercise program is vital**
- **Comfort makes this possible**

Temperature

- Warmer temperature decreases postural tone
- Encourages relaxation
- Decreases fear
- Cooler stimulates tone & alertness
- Avoid hot water with edema

More Benefits of Water

- Buoyancy reduces weight bearing
- Pain reduction (warm water)
- Viscosity utilized in resistance Work for strengthening & endurance
- Range of motion easily attained with water's assistance/support
- Balance improved w/o danger of falls - decrease fear & guarding

Hydrodynamic Principles

- Effects of immersion:
- Research shows increased venous return due to hydrostatic pressure
- More effective cardiac output
- Heart rate lowered

Effects of Immersion

Walking/running in water requires 1/2 to 1/3 speed of land to reach same metabolic intensity
Because heart works more efficiently in water, we use target H-R 10-17 BPM below land targets
Dr Borg perceived exertion scale

Renal Effects

- Immersion affects renal system mechanically & hormonally
- Increases central blood volume, Increases renal BP, results in more urine output
- Increases with depth
- Faster/greater for elders

Respiratory Effects

- Makes breathing more difficult: hydrostatic pressure on chest & abdomen
- Total work of breathing for a tidal volume of 1 liter increases by 60% with immersion to neck

Skeletal System

- Tsukahara et al. in 1994 found bone density of veteran water exercisers (35 Mo.) was greater than that of beg. exercisers or controls
- Prevents bone loss
- Can comfortably provide strength and conditioning to participate in land work
- Other studies: Becker, Bravo, Goldstein, Sinaki, Rostein, Harush and Vaisman corroborate above result
- NOF suggests resistive exercise

Muscular System

- Hydrostatic pressure promotes return of venous blood and lymph
- Soft tissue compression promotes fluid transport and reduces edema
- Increased blood supply to muscles
- Muscles relax in warm water

Other Effects

- Reduced spasticity
- Reduction of joint compression
- Energy expenditure: aerobic energy expenditure may be less than, greater than or same as land depending on buoyant forces, effect of water's viscosity & thermal conduction - body size, shape, position, angle of movement, speed, water depth & temp. all affect total energy expenditure (Becker, Cole, Kinnaird)

Exercise:

- What is right for you?
- Energy conservation: motto: "conserve to preserve."
- Recognize fatigue
- Assess amt. of muscle damage
- Other contributing conditions?
- Pay attention
- Consider doing half of that you think you can do for each limb, ask?
- What is the most severely involved muscle in this limb? Is it weak? Do I notice increasing weakness?
- Other reasons?

A Limb with No Weakness

- Classified non clinical polio; use like any other
- Cardio vascular workout 3-4 x week for 20 min. hr-80% Mild/moderately weak
- No sign of increasing weakness

Clinically Stable Polio

- Exercise with care; do not fatigue
- 3 x week 10-20 min. with rests
- Progressive resistance work
- Monitor for increased weakness

Severely Weak

- Severely atrophic polio
- Active exercise likely impossible
- Passive ROM will maintain Flexibility, weak & increasing
- Ask "Am I Doing Too Much Or Too Little?"
- Do not fatigue
- Do stretch
- Try carefully graduated program of non fatiguing exercises
- Monitor yourself carefully, make change to conserve energy
- Pay attention to fatigue & rest before exhaustion
- If overweight, lose weight
- Listen to your body, you know it best....

Cross Training

- Pool/aquatic exercise
- Gym
- Considerations Re: Chair Ex
- Walking
- Use of assistive devices
- Other?
- Adherence?

Safety

- Safety... pool, gym, locker rooms, entry, exit, supervision
- Guidelines Re: Posture...
- Promote strength & conditioning and avoid falls
- Promote education/understanding
- If in doubt, think twice or don't

Program Hints

- Walking : choose depth, waist to mid chest - all directions
- Gentle stretches
- Attention to postural alignment & breathing
- Range of motion
- Strengthening (Model AFYAP)
- Replicate ADL & functional skills
- Trunk stability work
- Gait training
- Balance & agility
- Build confidence
- Provide challenges with position and direction changes
- Teach fall prevention pool, deck/locker
- Discuss safety issues
- Improve trunk, shoulder, lower extremity strength
- Avoid overuse of affected muscles
- Avoid exercises which
- Compromise your posture or cause discomfort
- Strengthen trunk muscles and back extensors
- Practice trunk stability and balance work - at wall, with a buddy
- Independent
- Using board or noodle
- Conclude with extension, deep breathing, postural awareness
- May introduce recreational Exercise or ADL replication in water
- Transition to gravity based environment when possible
- Include general conditioning
- Always stretch warm muscles

Awareness of Polio's Late Effects

- Polio survivors need a complete general medical evaluation by a primary care physician & a specialized neuromuscular evaluation by a knowledgeable polio specialist such as a physiatrist or rehabilitation specialist.

Post Polio WaterWork

- Consider water work as one tool in the tool chest of coping techniques
- Remember ... "conserve to preserve."
- Enjoy your adventures in the water!

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http://www.aquaticsintl.com/2007.jun/0706_healing.html
- *Post Polio WaterWork DVD*: Essert & Ramsey 2005 www.maryessert.com
- Central Arkansas Polio Survivors: pdsphd@suddenlink.net.
- San Francisco Bay Area Polio Survivors: www.hometown.aol.com/sfbaps
- Post Polio Health Newsletter: www.post-polio.org
- Jubelt B., *Post Polio Syndrome* Current Treatment Options of Neurology, Dept. of Neurology, SUNY Upstate Medical University, Mar. 2004 jubeltb@upstate.edu

- Wise, Holly H., PT, PHD; *Effective intervention strategies for management of impaired posture and fatigue with post-polio syndrome: a case report*; Physiotherapy Theory and Practice; Sept.9, 2005
- Aquatic Resources Network: www.aquaticnet.com
- Aquatic Therapy and Rehab Institute: atri@atri.org
- www.fmpartnership.com (Fibromyalgia Partnership)

Books

- *Post Polio Syndrome: A guide for Polio Survivors*/Julie Silver/Yale University, 2002/ISBN 0300088086
- *The Polio Paradox* /Richard L. Bruno/Warner Books 2003/ISBN 0446690694
- *Managing Post Polio*/Lauro S. Halstead/ABI Prof. Pub, 1998 /ISBN 1886276178
- *Comprehensive Aquatic Therapy*/A. Cole & B. Becker/Butterworth Heinemann (2nd ed.)
- Vargas. L, *Aquatic Therapy, Interventions & Applications*, Idyll Arbor.

Email: messert@mindspring.com

SAMPLE POOL SESSION

Mary Essert B.A., ATRIC
www.maryessert.com

Posture; breathing

Know your own comfort level, never work thru new pain

Understand safety issues; entry, exit, sculling, recovery

WALKING WARM UP: fwd, backwd, sideways

CIRCLE, GROUP FORMATION:

BREATHING, POSTURE -AI CHI

UE-UPPER EXTREMITY: NECK; LOOK OVER SHOULDERS, RETRACTION, RIB CAGE, SHOULDER LIFT, ROLL BACK & FORWARD, SHRUGS, HOLD, CIRCLES, DOORKNOBS, FOLLOW SHARK, TRUNK ROTATION, SIDE STRETCH, TRICEP STRETCH, CROSSOVER SHOULDER STRETCH

STANDING AT WALL; RUNNERS
STRETCH

ACHILLES TENDON

HAMSTRING QUAD, WALL CURL

FACING WALL: PEDAL
 TIPTOES. HEELS, OUTSIDE, INSIDE

BALANCING BY WALL ONE SIDE & THEN OTHER
 OUTSIDE LEG, KNEE LIFT & EXTENSION
 CIRCLE FROM HIP

HIP ROM

SWEEP

ENDURANCE ACTIVITIES: USE BORG PERCEIVED EXERTION SCALE

INTERVALS : COMBO JOG, SCULL, MARCH, HALF JACKS, CROSS CO., ROCKING HORSE, SKI, ELBOW KNEE, ETC...TO TOLERANCE
(UTILIZE HYDRODYNAMIC PRINC. OF WATER, BEGIN PROXIMAL, SMALL MOVES, SHORT LEVER, SLOW, PROGRESS TO MORE DISTAL, LARGE ROM, SPEED, TURBULANCE, LONG LEVER
(May walk instead of intervals)

ADD EQUIPT. ONLY WELL CONDIT. 6 WK. OR MORE (may never use additional equipment if not comfortable)

REPEAT STRETCHES AS ABOVE

CORE EXERCISES FOR TRUNK STABILITY

STANDING PELVIC WORK
BALANCE SELF, THREATEN STABILITY WITH SCULLING, DIAGONALS,
DIF. STANCE, SUDDEN CHANGE OF DIRECTION
SIT ON NOODLE OR KICKBOARD, CONT.
ALTER SHAPE, TRAVEL, W & W/O HANDS

BALANCE & AGILITY
DUI WALK ON LINE, W & W/O HANDS
PINK FLAMINGO
DOWNHILL SKI-USE LINE
SUDDEN DIRECTION SHIFTS
CHANGE ANGLE OF MOVEMENT.
WITH AND W/O HANDS
USE CLOCK IMAGE FOR CHALLENGE
RE-VISIT COORD....CROSS COUNTRY. ETC.

GAIT TRAINING:
USE ASSISTANCE, WALL, HANDS, LONG BAR, KICKBOARD, AND NOODLE.ETC.

REVIEW SCULLING & RECOVERY
REVISIT WALKING, POSTURE, BREATH
3 PT. LANDING
CHANGE BODY SHAPE, SURFACE
AVOID FWD. FLEXION

ABDOMINAL WORK/TONING

NOODLE, FRONT, STRETCH, ABS, CRUNCHES, OBLIQUES
NOODLE BEHIND SHOULDERS, EXTEND LEGS, ABDUCTION, ADDUCTION, CHANGE FOOT POSITION
ROTATION
ANKLE, WRIST CIRCLE,
FLEXION, EXTENSION

REPEAT STRETCHES END WITH HUGS & AFFIRMATION....

AI-CHI

CONSIDER WARM WATER BODYWORK (WATSU®) WITH PRACTITIONER OR PARTNERS FOR FURTHER PAIN REDUCTION.

~Remember: "Conserve to preserve!"~

Yes, You Can Bowl

Rosanne Borders, CTRS, RWSIR, Warm Springs, Georgia

Polio Narratives: Readings and Discussion of the Writing Process

Jacqueline Foertsch, PhD, University of North Texas, Denton, Texas

Joyce Tepley, LMSW, Dallas, Texas

In this session, moderators Joyce Tepley (retired social worker and author of her own in-progress polio memoir) and Jacqueline Foertsch (University of North Texas English professor and author of *Bracing Accounts: The Literature and Culture of Polio in Postwar America*) will provide a forum for aspiring polio memoirists to share their ideas regarding the whys and hows of polio narrative-making.

There are many reasons why one might wish to write a memoir of the polio experience – to help oneself better understand the experience, to leave a legacy to family and friends, to reach out to others who had polio in electronic and print venues, to inform or inspire a general audience through publication in the literary marketplace, and to add one's voice to the history of an era.

The moderators will provide some brief opening remarks then lead a discussion with the audience, guided by key questions and favorite passages from early and recent polio memoirs. The goals of the session are to encourage participants in the telling of their unique stories and to offer suggestions regarding the writing process for publication.

Contact the moderators at thrival@ix.netcom.com for Joyce Tepley and foertsch@unt.edu for Jacqueline Foertsch.

Suggested reading:

- Writing Life Stories: How to Make Memories Into Memoirs, Ideas Into Essays, And Life Into Literature (1998) by Bill Roorbach (The author covers all the elements of good narrative and offers practice exercises with a list of creative non-fiction readings in the appendix.)
- Writing For Story: Craft Secrets Of Dramatic Nonfiction By A Two-Time Pulitzer Prize Winner (1994) by Jon Franklin (The author gives in-depth analysis of the structure of good story telling.)
- Warm Springs: Traces Of A Childhood At FDR's Polio Haven (2007) by Susan Richards Shreve (Detailed account of the author's two years at Warm Springs Rehabilitation Hospital from 1950, when she was eleven, to 1952 showing the relationships that shaped her life and encouraged her undaunted spirit.)
- Polio: A Dose of the Refiner's Fire: Surviving Polio (2005) by Jeane L. Curey Dille (The self-published memoir covering the years from 1952, when at twenty-eight and mother of two young children, she was diagnosed with bulbar polio. She leads the reader through her remarkable journey to reestablish her life after rehabilitation, divorce, remarriage, creating a career, and earning her doctorate in education.)
- In The Shadow Of Polio: A Personal And Social History (1996) by Kathryn Black (When the author was four years old her mother got polio, was in an iron lung, and sent out of state for care and treatment. She

did not see her mother again and her father withdrew from the family. This memoir is the authors search to recover the story of her mother and the era that profoundly impacted her family.

- As I Live And Breathe (1996) by Kenneth Kingery (The narrator of this memoir of survival in and out of a respirator effectively focuses on the issue of a marriage challenged – and in many ways ruined – by intensive polio involvement. A “vintage” story from many decades ago, it is available in public libraries and for sale used on-line.)
- View from the Seesaw (1986) by Louis and Dorothy Sternberg (Another memoir from an iron-lung using polio survivor honestly told. Sternberg bravely describes his own moments of weakness and his less-than-admirable behavior as a demanding, frustrated husband.)

Suggested websites:

- www.post-polio.org (The premier website for all things polio including a comprehensive list of polio memoirs.)
- www.iowacenterforthebook.org/ips-home (This is the All Iowa Reads 2007 website for the Iowa Polio History Project. On it are links to Iowan polio survivors telling their stories. A good example of what can be done to encourage polio memoir literature and preserve polio history.)

Learn About Acupuncture

Susan Harris, Lic Ac, Kingman, Kansas

Yes, You Can Practice Yoga

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The John P. Murtha Neuroscience and Pain Institute has completed a preliminary outcome study evaluating the benefits of Hatha yoga and meditation in patients with post-polio syndrome (PPS). This research integrates clinical trials investigating the application of Hatha yoga with ongoing patient care and education. The results showed significant improvements in a patient population where a lack of deterioration is often viewed as success. These patients improved and at the end of 12 weeks they were actively involved in self-care.

Yoga is a mind-body practice in complementary and alternative medicine (CAM) with origins in ancient Indian philosophy. The various styles of yoga that people use for health purposes typically combine physical postures, breathing techniques, and meditation or relaxation. This Backgrounder provides a general overview of yoga and suggests sources for more information.

Key Points

People use yoga for a variety of health conditions and to achieve fitness and relaxation.

It is not fully known what changes occur in the body during yoga; whether they influence health; and if so, how. There is, however, growing evidence to suggest that yoga works to enhance stress-coping mechanisms and mind-body awareness. Research is under way to find out more about yoga's effects, and the diseases and conditions for which it may be most helpful.

Tell your health care providers about any complementary and alternative practices you use. Give them a full picture of what you do to manage your health. This will help ensure coordinated and safe care.

Overview

Yoga in its full form combines physical postures, breathing exercises, meditation, and a distinct philosophy. Yoga is intended to increase relaxation and balance the mind, body, and the spirit.

Early written descriptions of yoga are in Sanskrit, the classical language of India. The word "yoga" comes from the Sanskrit word *yuj*, which means "yoke or union." It is believed that this describes the union between the mind and the body. The first known text, *The Yoga Sutras*, was written more than 2,000 years ago, although yoga may have been practiced as early as 5,000 years ago. Yoga was originally developed as a method of discipline and attitudes to help people reach spiritual enlightenment. The *Sutras* outline eight limbs or foundations of yoga practice that serve as spiritual guidelines:

1. *yama* (moral behavior)
2. *niyama* (healthy habits)
3. *asana* (physical postures)
4. *pranayama* (breathing exercises)
5. *pratyahara* (sense withdrawal)
6. *dharana* (concentration)
7. *dhyana* (contemplation)
8. *samadhi* (higher consciousness)

The numerous schools of yoga incorporate these eight limbs in varying proportions. Hatha yoga, the most commonly practiced in the United States and Europe, emphasizes two of the eight limbs: postures (*asanas*) and breathing exercises (*pranayama*). Some of the major styles of hatha yoga include Ananda, Anusara, Ashtanga, Bikram, Iyengar, Kripalu, Kundalini, and Viniyoga.

Use of Yoga for Health in the United States

A 2002 survey by the National Center for Health Statistics and the National Center for Complementary and Alternative Medicine (NCCAM) on adult Americans' use of CAM found that yoga is one of the top 10 CAM modalities used. Nearly 8 percent of the more than 31,000 survey participants had ever used yoga for health; adjusted to nationally representative numbers, this means more than 15.2 million adults.

People use yoga for a variety of health conditions including anxiety disorders or stress, asthma, high blood pressure, and depression. People also use yoga as part of a general health regimen—to achieve physical fitness and to relax.

The Status of Yoga Research

Research suggests that yoga might:

- Improve mood and sense of well-being
- Counteract stress
- Reduce heart rate and blood pressure
- Increase lung capacity
- Improve muscle relaxation and body composition
- Help with conditions such as anxiety, depression, and insomnia
- Improve overall physical fitness, strength, and flexibility
- Positively affect levels of certain brain or blood chemicals.

More well-designed studies are needed before definitive conclusions can be drawn about yoga's use for specific health conditions.

Side Effects and Risks

Yoga is generally considered to be safe in healthy people when practiced appropriately. Studies have found it to be well tolerated, with few side effects.

People with certain medical conditions should not use some yoga practices. For example, people with disc disease of the spine, extremely high or low blood pressure, glaucoma, retinal detachment, fragile or atherosclerotic arteries, a risk of blood clots, ear problems, severe osteoporosis, or cervical spondylitis should avoid some inverted poses.

Although yoga during pregnancy is safe if practiced under expert guidance, pregnant women should avoid certain poses that may be problematic.

Training, Licensing, and Certification

There are many training programs for yoga teachers throughout the country. These programs range from a few days to more than 2 years. Standards for teacher training and certification differ depending on the style of yoga.

There are organizations that register yoga teachers and training programs that have complied with minimum educational standards. For example, one nonprofit group requires at least 200 hours of training, with a specified number of hours in areas including techniques, teaching methodology, anatomy, physiology, and philosophy. However, there are currently no official or well-accepted licensing requirements for yoga teachers in the United States.

If You Are Thinking About Yoga

Do not use yoga as a replacement for conventional care or to postpone seeing a doctor about a medical problem.

If you have a medical condition, consult with your health care provider before starting yoga.

Ask about the physical demands of the type of yoga in which you are interested, as well as the training and experience of the yoga teacher you are considering.

Look for published research studies on yoga for the health condition you are interested in.

Tell your health care providers about any complementary and alternative practices you use. Give them a full picture of what you do to manage your health. This will help ensure coordinated and safe care.

NCCAM-Funded Research

Recent studies supported by NCCAM have been investigating yoga's effects on:

- Blood pressure
- Chronic low-back pain
- Chronic obstructive pulmonary disease
- Depression
- Diabetes risk
- HIV
- Immune function
- Inflammatory arthritis and knee osteoarthritis
- Insomnia
- Multiple sclerosis
- Smoking cessation.

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For More Information

NCCAM Clearinghouse

The NCCAM Clearinghouse provides information on CAM and NCCAM, including publications and searches of Federal databases of scientific and medical literature. The Clearinghouse does not provide medical advice, treatment recommendations, or referrals to practitioners.

Toll-free in the U.S.: 1-888-644-6226

TTY (for deaf and hard-of-hearing callers): 1-866-464-3615

Web site: nccam.nih.gov E-mail: info@nccam.nih.gov

PubMed®

A service of the National Library of Medicine (NLM), PubMed contains publication information and (in most cases) brief summaries of articles from scientific and medical journals. CAM on PubMed, developed jointly by NCCAM and NLM, is a subset of the PubMed system and focuses on the topic of CAM.

Web site: www.ncbi.nlm.nih.gov/sites/entrez

CAM on PubMed: nccam.nih.gov/camonpubmed/

ClinicalTrials.gov

ClinicalTrials.gov is a database of information on federally and privately supported clinical trials (research studies in people) for a wide range of diseases and conditions. It is sponsored by the National Institutes of Health and the U.S. Food and Drug Administration.

Web site: www.clinicaltrials.gov

NIH National Library of Medicine's MedlinePlus

To provide resources that help answer health questions, MedlinePlus brings together authoritative information from the National Institutes of Health as well as other Government agencies and health-related organizations.

Web site: www.medlineplus.gov

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