Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: STRATEGIES FOR LIVING WELL

For polio survivors, ventilator users, families and friends, health professionals, organizations and companies

WHEN? Thursday-Saturday, June 2-4, 2005

- Thursday opens with an 11:30 am luncheon, followed by afternoon and twilight sessions.
- Friday offers 24 diverse sessions.
- Saturday has 17 more presentations focusing on STRATEGIES FOR LIVING WELL, concluding at 4:30 pm.

WHERE? Marriott Saint Louis Downtown
Saint Louis, Missouri

WHY?
- To learn personal STRATEGIES FOR LIVING WELL
- To provide information and support to families and friends of polio survivors and ventilator users
- To exchange ideas with polio survivors and ventilator users
- To exchange ideas with health professionals
- To contribute to the worldwide activities supporting the improved health and independence of polio survivors and ventilator users
- To renew old acquaintances and make new friends

Interested in exhibiting? Want to be listed in the Catalogue of Resources for Post-Polio Health and Ventilator-Assisted Living? CALL 314-534-0475!

Program for Thursday, June 2, 2005
Program subject to change. www.post-polio.org for updates

9:00 am – 6:15 pm/REGISTRATION
2:30 am – 5:30 pm and
8:30 pm – 9:30 pm/EXHIBITS OPEN
11:30 am- 1:00 pm
OPENING LUNCHEON
Post-Polio Health International Board President
Frederick Maynard, MD
U.P. Rehabilitation Medical Associates,
Marquette, Michigan
Conference Co-Chairs
Audrey King
Toronto, Ontario, Canada
William Wischmeyer
Saint Louis, Missouri
1:30 pm – 2:45 pm
SESSION I (PLENARY)
THE PAST, THE PRESENT, THE FUTURE
The Vaccine Story
Christopher Rutty
Health Heritage Research Services,
Toronto, Ontario, Canada
The Rotary Story
Ray Klinginsmith
Rotary International Foundation,
Kirksville, Missouri
Ray Taylor
Polio Survivors & Associates,
Pinehurst, North Carolina
The Unfinished Story
Daniel Wilson, PhD
Muhlenberg College,
Allentown, Pennsylvania
2:45 pm – 3:15 pm/BREAK
3:15 pm – 4:30 pm
SESSION II OPTIONS
ANESTHESIA PRECAUTIONS FOR PEOPLE WITH NEUROLOGICAL CONDITIONS
Selma Calmes, MD
Olive View-UCLA Medical Center,
Sylmar, California
Erik Jacobsen, MD
Chief Anaesthetist (Retired),
Copenhagen, Denmark

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK
4207 Lindell Blvd #110, Saint Louis, MO 63108-2915 USA
314-534-0475, 314-534-5070 fax
info@post-polio.org
www.post-polio.org

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INTEGRATIVE MEDICINE APPROACH TO POST-POLIO SYNDROME MANAGEMENT IN PRACTICE
William DeMayo, MD
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain Institute, Conemaugh Health System, Johnstown, Pennsylvania
Reactor: Sue Harris
Canton, Massachusetts

TRAVEL TIPS
Taking Cruises
Linda Priest
Atlanta, Georgia
Surviving Not Driving: Getting Around without a Car
Susan Borgman
Black Coffee Creative, Wyoming, Michigan
And, If You Use a Vent
Angela King, BS, RRT, RPFT, NPS
Pulmonetic Systems, Inc., Minneapolis, Minnesota

EMOTIONAL EATING
My Story
Marge Torre
Bradenton, Florida
Robert Thayer
Clinton, Mississippi
What Is It and What to Do About It
Linda Bieniek, CEAP
La Grange, Illinois
Reactor: Stephanie Machell, PsyD
International Rehabilitation Center for Polio, Framingham, Massachusetts

DISABILITY INSURANCE: BUYING IT AND SECURING IT
Moderator: Saul Morse
Springfield, Illinois
Mark DeBofsky
Daley, DeBofsky and Bryant, Chicago, Illinois

LEAVING A LEGACY
The Polio Oral History Project
Anna Rubin
International Rehabilitation Center for Polio, Framingham, Massachusetts
Documenting Polio Stories: Learn from the Canadian Experience
Sally Aitken
Polio Québec, Québec, Canada

6:30 pm – 6:15 pm
DINNER (On Your Own)

6:15 pm – 8:30 pm
TWILIGHT SESSION OPTIONS

6:15 pm – 8:30 pm
THE LATEST IN VENTILATORY EQUIPMENT
Moderator: Larry Kohout
Edina, Minnesota
Representatives of ventilatory equipment and manufacturers

6:15 pm – 8:30 pm
SPIRITUAL HEALTH
Strategies for Living in Peace with Polio
Robert Ronald, SJ
Kuangchi Program Service, Taipei, Taiwan ROC
The Art of Making A Difference in Your Own Life
Scotty Foglesong, MA, PhD (Theology)
Marina, California

6:15 pm – 8:30 pm
GETTING TO KNOW YOU: POST-POLIO SUPPORT GROUPS
Moderator: Beth Kowall, MS, OTR
Greenfield, Wisconsin
Johan Bijttebier
PostPolio België, Antwerpen, Belgium
Harald Hasle
International Post-Polio Support Organization, Braskereidfoss, Norway
Ray Taylor
Polio Survivors & Associates, Pinehurst, North Carolina
Other support group leaders who are in attendance

6:15 – 7:15 pm and repeated at 7:30 – 8:30 pm
EXPERIENCE ACUPUNCTURE
Sue Harris
Canton, Massachusetts

6:15 – 7:15 pm and repeated at 7:30 – 8:30 pm
EXPERIENCE YOGA
David Riley, MD
Editor-in-Chief, Explore: The Journal of Science and Healing, Santa Fe, New Mexico
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain Institute, Conemaugh Health System, Johnstown, Pennsylvania

6:15 – 7:15 pm and repeated at 7:30 – 8:30 pm
EXPERIENCE REIKI
Stephanie Machell, PsyD
International Rehabilitation Center for Polio, Framingham, Massachusetts

6:15 – 7:15 pm and repeated at 7:30 – 8:30 pm
EXPERIENCE WATSU
Kathleen Christ, LMT, NCMBT
Saint Louis Aquatic Healing Center, Saint Louis, Missouri

6:15 – 7:15 pm
THERAPEUTIC USE OF MUSIC: EXPERIENCE MUSICAL ACUPUNCTURE AND MUSICAL BIOFEEDBACK
Janalea Hoffman, RMT, MA
Rhythmic Medicine, Olathe, Kansas

6:15 – 7:15 pm
SERVICE DOGS FOR PEOPLE WITH NEUROMUSCULAR CONDITIONS AND THOSE WHO USE VENTS
Joanne Kocourek, RN, CCRC, with Annalies and Kristen Worth, Illinois
Susan Borgman
Black Coffee Creative, Wyoming, Michigan

7:30 – 8:30 pm
THERAPEUTIC USES OF THE NATIVE AMERICAN CEDAR FLUTE
Janalea Hoffman, RMT, MA
Rhythmic Medicine, Olathe, Kansas

8:30 pm – 9:30 pm
MEET FOR HEALTHY TREATS
CLARIFYING CHOICES
Moderator: Lawrence Becker, PhD
Roanoke, Virginia
The Right Ventilation at the Right Time
Tony Oppenheimer, MD
Pulmonary Medicine (Retired),
Los Angeles, California
Non-Invasive Ventilation for a Tracheostomized Polio-Patient without Intubation Tube
Grethe Nyholm Olesen (RN)
Respiratory Centre East, Copenhagen University Hospital, Copenhagen, Denmark
Birgitte Brandt Lassen (RN)
Copenhagen, Denmark
Lottie Lotte Mortensen (RN)
Institutionen for Respirationspatienter, Copenhagen, Denmark
10:15 am – 10:45 pm/BREAK
10:45 am – 12:00 noon
SESSION II OPTIONS
ANALYZING YOUR GAIT: THE ROLES OF EXERCISE, BRACING OR SURGERY
Mary Ann Keenan, MD
Orthopaedic Surgery, University of Pennsylvania, Philadelphia, Pennsylvania
Alberto Esquenazi, MD
Gait & Motion Analysis Lab, Moss Rehabilitation Hospital, Philadelphia, Pennsylvania
RESULTS I: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?
Moderator: Lauro Halstead, MD
National Rehabilitation Hospital, Washington, DC
Results of a NHIS Survey: How Info Might Prompt New Research and Care
Nancy Myers, PhD, RN CPHQ
Northeastern Ohio Universities College of Medicine, Rootstown, Ohio
Update on Growth Factors Used in Mouse Model
Burk Jubelt, MD
Department of Neurology, SUNY Upstate Medical University, Syracuse, New York
Update on Modafinil Study
Col. William Campbell, MD
Chairman of the Department of Neurology, Uniformed Services University, Bethesda, Maryland
UPDATE FROM MEDICARE
Moderator: Jean Csaposs
New Jersey Polio Network, Martinsville, New Jersey
Prescription Drug Cards
Bill Hunot
Social Security Administration, Saint Louis, Missouri
Payment for Durable Medical Equipment and Staying in Your Home: What Medicare Can Do for You
Diana Brady
CLAIM, Columbia, Missouri
TRAUMA TREATMENT: WHAT IS IT AND WHAT ARE THE BENEFITS
Stephanie Machell, PsyD
International Rehabilitation Center for Polio, Framingham, Massachusetts
CAN WE TALK ABOUT IT? BEING PREPARED FOR MEDICAL CRISIS, ADVANCE DIRECTIVES, LIVING WILLS
Moderator: Lawrence Becker, PhD
Roanoke, Virginia
Allen Goldberg, MD, FRACP
Chicago, Illinois
Kristi Kirschner, MD
Rehabilitation Institute of Chicago, Chicago, Illinois
EATING BETTER FOR BETTER HEALTH WITH YOUR FAMILY AND FRIENDS
Jann and John Hartman
Baltimore, Maryland
12:15 pm – 1:15 pm/LUNCHEON
1:30 pm – 2:45 pm
SESSION III OPTIONS
SOLUTIONS FOR OVERUSE AND DISUSE WEAKNESS
Moderator: Glee O. Helms, RN, NP
Novato, California
Frans Nollet, MD, PhD
Rehabilitation Medicine, University of Amsterdam, Netherlands
Tracie Harrison, PhD, RN, MSN, FNP
University of Texas, Austin, Texas
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ANALYZING YOUR SLEEP
Moderator: Bill Stothers
San Diego, California
Is It Apnea, Hypoventilation ... or Both ... or Something Else?
Brenda Butka, MD
Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee
Sleep Hygiene
William DeMayo, MD
John P. Murtha Neuroscience & Pain Institute, Conemaugh Health System, Johnstown, Pennsylvania
SPINAL BRACING & NEW TECHNOLOGY IN LOWER EXTREMIT Y ORTHOTICS
Mark Taylor, MLS, CPO
Ammanath Peethamaran, MS, CO
University of Michigan, Ann Arbor, Michigan
Reactor: Alberto Esquenazi, MD
Gait & Motion Analysis Lab, Moss Rehabilitation Hospital, Philadelphia, Pennsylvania
SUMMARIES OF SELECT THERAPIES: YOGA, WATSU, REIKI, MYOFASCIAL RELEASE
David Riley, MD
Editor-in-Chief, Explore: The Journal of Science and Healing, Santa Fe, New Mexico
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain Institute, Conemaugh Health System, Johnstown, Pennsylvania
Kathleen Christ, LMT, NCMBT
Saint Louis Aquatic Healing Center, Saint Louis, Missouri
Stephanie Machell, PsyD
International Rehabilitation Center for Polio, Framingham, Massachusetts
Nancy Caverly, OTR/L
Cedar Ridge Wellness Center, Bland, Missouri
EXPLORING STRATEGIES: QIGONG AND ACUPUNCTURE
Tony Lu, MD
Medical Director, Integrative Medicine, La Grange Park, Illinois
Sue Harris
Canton, Massachusetts
PHI’S WEBSITE: WHAT IT CAN DO FOR YOU AND WHAT YOU CAN DO FOR IT
Sheryl Rudy
Webmaster, Post-Polio Health International, Saint Louis, Missouri

2:45 pm – 3:15 pm/BREAK
3:15 pm – 4:30 pm
SESSION IV OPTIONS
PAIN AND POLIO: PITFALLS, MYTHS AND REALITIES
Moderator: Selma Calmes, MD
Olive View-UCLA Medical Center, Sylmar, California
Julian Lo, MD, FRCP
Physical Medicine & Rehabilitation, West Park Healthcare Centre, Toronto, Ontario, Canada

FINDING TECHNOLOGY TO MAINTAIN INDEPENDENCE
David Gray, PhD
Program in Occupational Therapy, Washington University
School of Medicine, Saint Louis, Missouri
Maria Cole, OTR/L
Laura Ryan, OTR/L
Kristeen Muldoon, MSPT
International Rehabilitation Center for Polio, Framingham, Massachusetts

HOW SELF ASSESSMENT CAN HELP YOU IN OBTAINING BETTER CARE FROM HEALTH PROFESSIONALS
Hilary Hallam
Denise Carlyle, BA, MA, PhD, LRAM
Mary Kinane, BA, PGCE
Lincolnshire Post-Polio Network, Lincolnshire, United Kingdom
Reactor: Carol Vandenakker, MD
Physical Medicine & Rehabilitation, University of California Davis Medical Center

PHI SECOND RESEARCH AWARD: WOMEN WITH POLIO AND THE MENOPAUSE STUDY-PRACTICAL ADVICE BEHIND THE DATA
Claire Kalpakjian, PhD
Sunny Roller, MA
University of Michigan, Ann Arbor, Michigan

MAINTAINING PULMONARY HEALTH
Monitoring and Preventing: What You Can Do
Tony Oppenheimer, MD
Pulmonary Medicine (Retired), Los Angeles, California

The Importance of Cough
Augusta Alba, MD
Rehabilitation Medicine (Retired), Coler Goldwater Specialty Hospital and Nursing Facility, Roosevelt Island, New York

IMPROVING BALANCE AND STAMINA VIA PEDORTHIC SOLUTIONS
Edith James, C.Ped.
Michael Lukowsky
Comfort Shoe Specialists, Saint Louis, Missouri
Dennis Janisse, C.Ped.
National Pedorthic Services, Inc., Milwaukee, Wisconsin

6:30 pm – 8:45 pm
Post-Polio Health International’s Awards Dinner & Entertainment

Program for Saturday, June 4, 2005
Program subject to change.
www.post-polio.org for updates

8:00 am – 1:30 pm/REGISTRATION
8:30 am – 9:00 am/
Meetings of Medical and Consumer Advisory Committees
CONTINENTAL BREAKFAST
8:30 am – 1:30 pm/EXHIBITS OPEN
9:00 am – 10:15 am
SESSION I OPTIONS
THE TRACHEOSTOMY OPTION
What, Why and When
Tony Oppenheimer, MD
Pulmonary Medicine (Retired), Los Angeles, California

Management of Neuromuscular Breathing Problems:
The Danish Way
Jesper Qvist, MD
Respiratory Centre East, Copenhagen, Denmark

RESEARCH II: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?
Moderator: Lauro Halstead, MD
National Rehabilitation Hospital, Washington, DC

Inflammation of the Central Nervous System: A Treatable Cause of PPS?
Kristian Borg, MD
Karolinska Hospital, Stockholm, Sweden

Update on Stem Cell Research for Neuromuscular Disorders
David Gottlieb, MD
Washington University School of Medicine, Saint Louis, Missouri

Update on Research at USU
Olavo Vasconcelos, Jr., MD
Physician Research Coordinator, Uniformed Services University, Bethesda, Maryland
EXERCISE, PART 1: A DEBATE ABOUT THE DEBATE
Moderator: Frederick Maynard, MD
U.P. Rehabilitation Medical Associates, Marquette, Michigan

Clinical predictors of electromyographic findings of remote polio in "unaffected" limbs of patients with a history of acute paralytic poliomyelitis
Chanda Mayo, MD
Physical Medicine & Rehabilitation, National Rehabilitation Hospital, Washington, DC

Opinion of an Experienced PT
Holly Wise, PT, PhD
Medical University of South Carolina, Charleston, South Carolina

Opinions from Polio Survivors
Jane Atkey
Toronto Peel Post-Polio Community, Toronto, Ontario, Canada
David Kelly
South Lake Tahoe, California

SCOOTERS AND POWER CHAIRS
The Care and Feeding of a Scooter or Power Chair
John and Jann Hartman
Baltimore, Maryland

Choosing and Funding a Scooter or Power Chair
Jean Csapos
New Jersey Polio Network, Maywood, New Jersey

PREVENTING AND MANAGING SECONDARY CONDITIONS FOR POST-POLIO HEALTH
Alexa Stuifbergen, PhD, RN, FAAN
Tracie Harrison, PhD, RN, MSN, FNP
University of Texas, Austin, Texas

NEW BRACING: THE CHALLENGE AND THE PAYOFF
Marny Eulberg, MD
St. Anthony's Family Medical Center
West, Denver, Colorado

Marmaduke Loke
Dynamic Bracing, Encinitas, California

Reactor: Mark Taylor, MLS, CPO
University of Michigan, Ann Arbor, Michigan

10:15 am – 10:45 am/BREAK

SESSION II OPTIONS

OPTIONS FOR MANAGING THE MULTIPLE CAUSES OF FATIGUE
Martin Wice, MD
Physical Medicine & Rehabilitation, St. John's Mercy Medical Center, Saint Louis, Missouri
Alexa Stuifbergen, PhD, RN, FAAN
University of Texas, Austin, Texas

EXERCISE, PART 2: WHAT STEPS TO TAKE
Moderator: Frederick Maynard, MD
U.P. Rehabilitation Medical Associates, Marquette, Michigan

Suggestions from …
Mary Klein, PhD
Director, Post-Polio Project, Moss Rehab Research Institute, Philadelphia, Pennsylvania

Barbara Duryea, RN
John P Murtha Neuroscience & Pain Institute, Conemaugh Health System, Johnstown, Pennsylvania

Holly Wise, PT, PhD
Medical University of South Carolina, Charleston, South Carolina

Reactions from Polio Survivors
Jane Atkey
Toronto Peel Post-Polio Community, Toronto, Ontario, Canada
David Kelly
South Lake Tahoe, California

VENTILATOR USERS: GETTING YOUR ACT TOGETHER AND TAKING IT ON THE ROAD
Audrey King
Toronto, Ontario, Canada

Barbara Rogers
Respiratory Resources, Inc., New York, New York

Sponsored by Pulmonetic Systems, Inc.

CHOOSING TO FLOURISH: WHAT WORKS FOR ME
Linda Wheeler Donahue
The Polio Outreach of Connecticut, Southbury, Connecticut

Dorothy Woods Smith, PhD, RN
Houses of Healing, Portland, Maine

LONG-TERM CARE: BUYING IT AND SECURING IT
Moderator: Saul Morse
Springfield, Illinois

Matt McCann
Darien, Illinois

12:15 pm – 1:15 pm/LUNCHEON

SESSION III OPTIONS

OPTION IF A POST-POLIO CLINIC IS NOT AN OPTION
Moderator: Mary Louise Dickson
Toronto, Canada

Carol Vandenhakker, MD
Physical Medicine & Rehabilitation, University of California Davis Medical Center, Sacramento, California

Reactor: Armand Zilioli, MD
Bay Pines VA Medical Center, Saint Petersburg, Florida

EXPRESSING SEXUALITY: WHAT WORKS FOR ME
Moderator: Linda Bieniek, CEAP
La Grange, Illinois

Panel: TBA

INTERFACES: NEW, TRIED AND TRUE, AND CUSTOM
Barbara Rogers
Respiratory Resources, Inc., New York, New York

Sponsored by Pulmonetic Systems, Inc.

Diana Guth RRT
Home Respiratory Care, Los Angeles, California

COLLABORATION WITH PHI AND WITH EACH OTHER
Moderators:
Beth Kowall, MS, OTR
Greenfield, Wisconsin

Joan Headley
Post-Polio Health International, Saint Louis, Missouri

Representatives of post-polio organizations

BREATHEING TRAINING: DEVELOPING A USER-FRIENDLY BODY
Betsy Thomason, RRT
Park Ridge, New Jersey

2:45 pm – 3:15 pm/BREAK

3:15 pm – 4:15 pm

SESSION IV (PLENARY)
TRANSLATING GOOD IDEAS INTO PRACTICE, WHAT ABOUT TOMORROW?
Kristi Kirschner, MD
Rehabilitation Institute of Chicago, Chicago, Illinois

4:15 pm – 4:30 pm

CLOSING SESSION
Hotel Information
Space is reserved at the Marriott Saint Louis Downtown, 1 Broadway, Saint Louis, MO (Missouri) 63102 (314-421-1776). The Marriott Saint Louis Downtown is located just north of Busch Stadium on Broadway (one-way, southbound) between Market Street (two-way with median) and Walnut Street (one-way, eastbound, between the Marriott and Busch Stadium).

If you are interested in sharing a room, contact PHI for a list of potential roommates.

Make reservations online at https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=18966, or call 800-266-9432.

Shower benches and commode units will be made available as modifications in regular rooms. If you have need of either modification or an accessible room, you should call 314-421-1776 and ask for Sandy or Kay to make a reservation.

Some accessible rooms have been reserved at the Adam’s Mark Hotel, Fourth & Chestnut (www.adamsmark.com/stlouis). Call 800-444-ADAM (2326) for reservations. Ask for the Post-Polio Health International meeting. A credit card number is required. The Adam’s Mark Hotel is two blocks from the Marriott Saint Louis Downtown.

Information about Saint Louis and Other Hotels
Contact the Saint Louis Convention & Visitors Bureau at 800-888-3861 or visit www.explorestlouis.com. (Note: The Saint Louis Cardinals will not be in town.)

Parking
At the Marriott, valet parking is available at the Broadway entrance ($21/day). Parking is also available in the Stadium Park East garage, across Broadway, for $19/day.

Transportation from the Airport
www.lambert-stlouis.com/index/ground.html

METROLINK: MetroLink is Saint Louis’ light rail system. It is located on the upper level of the Main Terminal at Exit MT1 and the East Terminal through the parking garage on all levels. Operating daily from 5 am until midnight, with tickets priced at $3 for an adult one-way trip from the airport, less for seniors and children under 12. There is no charge to ride between the East and Main Terminals. Disembark at Busch Stadium, the closest station to Marriott Saint Louis Downtown (about two blocks).

TAXIS: Board at Main Terminal, Exit MT14 (yellow level of garage) or East Terminal, Exit ET12. Approximate cost one-way $32.00. Harris & Eagle Paralift Service, 314-535-5087, $49 one-way, recommends at least one day’s notice in advance.

GEM SHUTTLE/TRANS EXPRESS TRANSPORTATION: Provides shared van service to downtown hotels (including Marriott Saint Louis Downtown). Purchase tickets and board at: Main Terminal, Exit MT12; East Terminal, Exit ET12. Tickets are $13.00 one way, $21.00 round trip.

For their lift-equipped van service, call 800-844-1985 a few days in advance.

Advanced reservation limousine/van services are available for transportation to your destination in Saint Louis and surrounding Missouri/Illinois locations. Phone 314-427-3311.

Scooter and Wheelchair Rental
Individuals wanting to rent a scooter should contact Scootaround, Mobility Product Rentals (www.scootaround.com/rentals/postpolio or call 888-441-7575).

Personal Assistance Services
Individuals wanting personal assistance services may contact Lari Calder, Assistant Director of Independent Living and Housing, Paraquad (314-567-1558).

NOTE: Smoking will not be permitted in the conference meeting rooms.