

# Promoting Healthy Ideas



PHI's 11th International Conference

## Program Schedule and Presenters

Saturday, May 31<sup>st</sup>, 2014  
Through Tuesday, June 3<sup>rd</sup>, 2014  
Hyatt Regency St. Louis at The Arch

**POST-POLIO HEALTH**  
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

## Location of sessions on the Second Floor

- The Saturday afternoon Pre-Conference Session will be held in Regency A.
- The Saturday evening dinner will be held in Regency D. *Ticket is required.* Sunday and Monday dinner are not included. Join your friends for dinner in the hotel or area. See [www.explorestlouis.com](http://www.explorestlouis.com).
- The Sunday, Monday, Tuesday sessions will be held in Regency A, B, C, D, E and the specific room for each session is identified in this Program Schedule along with an abstract. An exception is “Exploring Exercise” which will be held in the Fitness Center and Room F.

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

Lunch, included in the registration fee (one per guest), is a box lunch which will be picked up in the prefunction area. Lunch, which is 1¼ hours, may be eaten in Regency C/D or in your room if you choose.

Restrooms are on the second floor, near the top of the escalators. See map. The breaks are ½ hour, which allows time to go to hotel rooms

Post-Polio Health International thanks the presenters for providing the content of this book. If you share this information, you *must* acknowledge the authors of the material and state the following: *Prepared for Post-Polio Health International's 11<sup>th</sup> Conference: Promoting Healthy Ideas, May 31-June 3, 2014.*

**EMERGENCIES:** Call 911 and then call 55 in the hotel so they are alerted and can direct the emergency crew to you.

Saint Louis University Hospital is a Level One Trauma Center located at 3635 Vista at Grand Blvd., St. Louis, MO 63110, 3635 Vista at Grand Blvd, 314- 577-8000. To contact the Emergency Department directly, please call 314-577-8777. (3.8 miles; 6 minutes depending on traffic)

Barnes-Jewish Hospital Emergency Room, a Level One Trauma Center, is located at 400 S. Kingshighway Blvd., St. Louis, MO 63110, 314- 362 – 9123. (5 miles; 6-7 minutes depending on traffic)



POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

Welcome to St. Louis in 2014! Over the span of the past 33 years, PHI has coordinated 11 educational conferences for the post-polio community.

Each conference has been instrumental in identifying, articulating and solving problems and instigating action. PHI has always encouraged the involvement of survivors in their own communities. We are proud to welcome representatives from groups who can trace their beginnings to us, and we are proud that we have served the survivors of polio for almost 55 years.

I have always resisted the common practice of saying “all polio survivors,” because the over-generalization can unfairly stereotype survivors and prevent us from transcending our limitations.

Undoubtedly though, we are bound by a common and unique experience and spending time with others has long-lasting effects.

Our theme, *Promoting Healthy Ideas*, asserts PHI’s view that we individually can, and must, be part of the solution as we age with a disability. For this reason, PHI’s goal at this conference is to arm each participant, including survivors, family members and health professionals with information and connections.

Thank you for coming. You are why we organize these meetings and why so many dedicated individuals volunteer their time and expertise.

Lastly, a message from our Board of Directors: Post-polio -- what does the future hold? We want your suggestions regarding the future of Post-Polio Health International. What kinds of programs would you find most helpful? To what extent should we rely on electronic means of disseminating information to our members and the wider world? Should PHI focus its efforts on polio survivors in the United States, Canada and the developed world or on the younger polio survivors in places like Africa, Asia and Latin America? Are you aware of the activities of International Ventilator Users Network (IVUN)? Should the organization continue and/or expand its activities related to survivors' breathing problems? Should IVUN continue and /or expand its activities to all medical conditions where home mechanical ventilation is an option? (e.g. SCI, ALS, etc.).

We will be providing various avenues for you to let us know what directions you think PHI should take going forward. The first opportunity is the closing session on Tuesday, June 3, which will be led by Dan Wilson and Bill Stothers, Members of the PHI Board. We invite you to join the conversation.

Joan L. Headley, Executive Director

## **Board of Directors of Post-Polio Health International**

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**Daniel J. Wilson**, PhD, Allentown, Pennsylvania

**Mohammed Yousuf**, Chantilly, Virginia

\* Members of the 11<sup>th</sup> International Conference Committee. Lawrence C Becker also served on the committee.

# CONFERENCE PROGRAM SCHEDULE

## SATURDAY, MAY 31

**12:00 – 4:00 pm**

**Registration**

**5:30 – 6:00 pm**

**Cash Bar**

**3:00 – 4:15 pm**

**Regency A**

**Pre-Conference Session: Orientation  
for participants attending their first  
PHI conference**

**Welcome**

William G. Stothers

**Maximizing Your Conference Experience**

Joan L. Headley

**Review: Late Effects of Polio & Your  
Health**

Frederick M. Maynard, MD

**6:00 – 7:30 pm**

**Regency D**

**Dinner** (ticket required)

**7:45 – 8:30 pm**

**Regency D**

**“One World,” performed by the  
DisAbility Project of That Uppity  
Theatre Company and Common  
Threads Dance Company**

*Supported by Rehabilitation Foundation for  
Disabled Persons, Inc.*

## SUNDAY, JUNE 1

**8:00 – 9:00 am**

**Registration**

**Regency B**

**Help with Healing: Humor,  
Breathing, Stretching, Yoga ■**

**Presenters:** Melissa Gatlin, Hannah Hedrick,  
PhD, Millie Lill

**9:00 – 10:15 am**

**Regency A**

**Changing Relationships through a  
Life Span ■**

**Presenters:** Sandra Loyer, LMSW, Stephanie  
T. Machell, PsyD

**Regency C**

**Polio's Effects on Breathing ■**

**Moderator:** Bonnie Jo Grieve, MD

**Presenter:** John R. Bach, MD

### THEME

■ Medical Matters

■ Wellness Practices

■ Recreating Ourselves

■ Minding Our Relationships

■ Conditions of Aging

■ Life Decisions of Aging

## SUNDAY, JUNE 1 (cont'd)

### Regency D

#### Managing More Meds ■

**Presenters:** Marny K. Eulberg, MD, Alicia B. Forinash, PharmD

### Regency E

#### Advice on Solo Aging ■

**Presenters:** Jann Hartman, Alison (Sunny) Roller, MA, Susy Stark, PhD, OTR/L, FAOTA

**10:15 – 10:45 am ■ Break**

**10:45 am – 12:00 pm**

### Regency B

#### Being Spiritual ■

**Presenters:** Allison (Sunny) Roller, MA, Ann Williams, AdvCBP, BAT

### Regency C

#### Travel Opportunities ■

**Presenters:** Barbara Gratzke, Jean Hartley, Mary Gordon

### Regency D

#### Assessment: Our Home ■

**Presenters:** Gina Hilberry, AIA, Cyndi Jones

### Regency E

#### Pain: It Gets Our Attention ■

**Moderator:** Ann Crocker

**Presenters:** William M. DeMayo, MD, Frederick M. Maynard, MD

**12:00 – 1:15 pm**

### Regency C or D

#### Lunch

**12:30 – 12:50 pm**

### Regency C

#### Support Dog Demonstration

Nadine Wenig, Lead Assistance Dog Trainer, Support Dogs, Inc.

**1:15 – 2:30 pm**

### Regency B

#### Assessment: Our Abilities ■

**Presenter:** Hilary Boone

**Reactors:** Beth Kowall, MS, OTR, Carol Vandenakker-Albanese, MD

### Regency C

#### Managing Polio's Effect on Breathing ■

**Moderator:** Bonnie Jo Grieve, MD

**Presenter:** John R. Bach, MD

### Regency D

#### Cardiovascular Aging ■

**Presenters:** Michael W. Rich, MD, Martin B. Wice, MD

### Regency E

#### Relatives of Survivors: Three Perspectives ■

**Moderator:** Stephanie T. Machell, PsyD

**Presenters:** Mary Navarre, OP, EdD, Willard (Bill) Smith, PhD

**2:30 – 3:00 pm ■ Break**

**3:00 – 5:00 pm**

### Regency B

#### Beyond Eradication: The Forgotten Polio Survivors of India

**Presenter:** Neena Bhandari

■ Medical Matters  
■ Wellness Practices

■ Recreating Ourselves  
■ Minding Our Relationships

■ Conditions of Aging  
■ Life Decisions of Aging

## SUNDAY, JUNE 1 (cont'd)

### Regency C

**Passing in the Shadow of FDR:  
Polio Survivors, Passing, and the  
Negotiation of Disability ■**

**Presenter:** Daniel J. Wilson, PhD

**5:00 – 7:00 pm**

**Dinner on your own**

**7:00 – 8:30 pm**

### Regency D

**Roundtable on Post-Polio Bracing ■**

**Moderator:** William M. DeMayo, MD

**Presenters:** Marny Eulberg, MD; Marmaduke  
Loke, CPO, Dynamic Bracing Solutions;  
Dennis Richards, CO, Townsend Design

### Regency C

**Reflections on Being a Polio  
Survivor**

**Moderators:** Frederick M. Maynard, MD,  
Allison (Sunny) Roller, MA

## MONDAY, JUNE 2

**8:00 – 9:00 am ■ Registration**

**9:00 – 10:15 am**

### Regency A

**Pause – Relax – Attend: the Mindful  
Way to Stress Relief ■**

**Presenter:** Bridget Rolens, MA, BSOT

### Regency B

**Staying Active: Mind & Body ■**

**Presenters:** Mark D. Peterson, PhD, MS,  
Beverly Schmittgen, EdD, William G.  
Stothers

### Regency C

**Refining Our Castle ■**

**Presenters:** Frank Frisina, Karen Hagrup

### Regency D

**Let's Talk about the Spine ■**

**Presenters:** Cynthia Henley, PT, Carol  
Vandenakker-Albanese, MD, Kathryn  
Wollam, PT

### Regency E

**A Good Night's Sleep ■**

**Moderator:** Ann Crocker

**Presenter:** William M. DeMayo, MD

**10:15 – 10:45 am ■ Break**

**10:45 am – 12:00 pm**

### Regency A

**Moving You to Better Health with  
the Lebed Method ■**

**Presenters:** Laura Dowell, PT, CLMT

### Regency B

**Legal Concerns for Polio Survivors:  
A Benefits Primer ■**

**Presenter:** Martha C. Brown, JD

### Regency C

**Weight Management ■**

**Moderator:** Jann Hartman

**Presenter:** Kathy Davis, MSW, LCSW,

**Reactor:** Mark D. Peterson, PhD, MS

■ Medical Matters

■ Wellness Practices

■ Recreating Ourselves

■ Minding Our Relationships

■ Conditions of Aging

■ Life Decisions of Aging

## MONDAY, JUNE 2 (cont'd)

### Regency D

#### Maintaining Posture ■

**Presenters:** Holly Wise, PT, PhD, Carol Vandenakker-Albanese, MD

### Regency E

#### Communicating for Understanding ■

**Presenters:** Stephanie T. Machell, PsyD, Rhoda Olkin, PhD

**12:00 – 1:15 pm**

Regency C or D

Lunch

**12:30 – 12:45 pm**

Regency C

#### Adventures on Cruises

Maureen Sinkule

**1:15 – 2:30 pm**

### Regency A

#### Exploration of Faith & Disability ■

**Presenter:** Cyndi Jones

### Regency B

#### Finding a Pair of Hands and Legs ■

**Presenter:** Ann Ford

### Regency C

#### Support Groups: What Works ■

**Presenters:** Mary Gordon, Jean Graber, Beth Kowall, MS, OTR, Mary-ann Liethof, Micki Minner

### Regency D

#### Why Worry? Stop Coping and Start Living ■

**Presenter:** Kathryn Tristan

### Regency E

#### Update on Anesthesia ■

**Presenter:** Selma Calmes, MD

**2:30 – 3:00 pm ■ Break**

**3:00 -5:00 pm**

### Regency C

#### My New Reality ■

**Moderator:** Rhoda Olkin, PhD

**Presenters:** Neena Bhandari, Mark Mallinger, PhD, Joyce Tepley

### Regency D

#### Roundtable on RADs, Vents & Interfaces ■

**Moderator:** Betsy Thomason, RRT

**Presenters:** Ronda Bradley, MS, RRT, FAARC, CareFusion – Alternate Care, Tony Mengwasser, RRT, Philips Respironics, Michael Madison, RRT, Bob Richardson, RRT, ResMed

#### Regency F – Two Forms of T'ai Chi & Yoga

**Fitness Center (Lobby Level) – Machines, Weights, Bands**

#### Exploring Exercise ■

**Facilitators:** William M. DeMayo, MD, Melissa Gatlin, Hannah Hedrick, PhD, Mark D. Peterson, PhD, MS, Frederick M. Maynard, MD, Ann Williams, AdvCBP, BAT, Holly Wise, PT, PhD

■ Medical Matters

■ Wellness Practices

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## TUESDAY, JUNE 3

**8:00 – 9:00 am ■ Registration**

**9:00 – 10:15 am**

**Regency B**

**Proven Energy Boosts ■**

**Presenters:** Betsy Thomason, RRT

**Regency A**

**A Discussion for Significant Others ■**

**Presenter:** Willard (Bill) Smith, PhD

**Regency C/D**

**Lessons from The Rehabilitation Research & Training Center on Aging with a Physical Disability ■**

**Presenter:** Alexandra Terrill, PhD, Aimee Verrall, MPH

**Regency E**

**End of Life: The Practical & The Experiential ■**

**Presenters:** Maria Miskovic, LCSW, William G. Stothers

**10:15 – 10:45 am ■ Break**

**10:45 am – 12:00 pm**

**Regency C/D**

**Post-Polio Research – Plenary Session**

**Moderators:** Selma Calmes, MD, Daniel J. Wilson, PhD

**Summary from Brazil & South America**

**Presenter:** Sheila Jean McNeill Ingham, MD, PhD

**Genetic Predisposition to Polio: New Research from Canada**

**Presenter:** Mark Loeb, MD, MSc, FRCPC

**Update on PHI-funded Research**

**Presenter:** Antonio Toniolo, MD

**12:00 – 1:15 pm**

**Regency C/D**

**Lunch**

**12:30 – 1:00 pm**

**Regency C/D**

**Disabilities Treaty (CRPD)**

Judith E. Heumann, MPH, Special Advisor for International Disability Rights at the U.S. Department of State

**1:15 – 2:30 pm**

**Regency C/D**

**Post-Polio Research (cont'd)**

**Endurance Training: How to target intensity?**

**Presenter:** Eric Voorn, MSc

**Update on PHI-funded Research**

**Presenters:** Carolyn (Kelley) Da Silva, PT, DSc, NCS, Claire Kalpakjian, PhD

**2:30 – 3:00 pm**

**Regency C/D**

**Discussion of Future Needs of Polio Survivors**

**Facilitators:** William G. Stothers, Daniel J. Wilson, PhD

■ Medical Matters

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# CONFERENCE ABSTRACTS

## SATURDAY, MAY 31

### 3:00 – 4:15 pm

Pre-Conference Session	Regency A
Welcome	
William G. Stothers	
Maximizing Your Conference Experience	
Joan L. Headley	
<p>PHI's activities are grounded in the independent living philosophy, the idea that polio survivors can and should be involved in life, that they have the same opportunities as those without disabilities. Its conferences cover a broad range of topics in numerous sessions presented by a variety of experts, combining the opinions of professionals and the experiences of polio survivors and family members. As the principal organizer and recipient of feedback from six previous conferences, Joan Headley will offer hints to maximizing the opportunities of the next three days.</p>	
Late Effects of Polio & Your Health	
Frederick M. Maynard, MD	
<p>This talk explores concepts of holistic health and categories of changes resulting from aging with paralytic polio sequelae that affect health and function. One change is loss of muscle strength resulting from motor nerve losses that defines post-polio syndrome, a late complication of polio. Other common complications result from years of living with initial polio sequelae (weakness and deformities). Most relate to accelerated age-related "wearing out" of joints, ligaments, muscles and tendons, resulting in musculoskeletal pain problems. Also, many common medical conditions known as "co-morbidities of aging" may develop at increased frequency. These include heart disease, diabetes and obesity and commonly produce fatigue and weakness. Other changes occur in the psychosocial and environmental dimensions of health.</p> <p>Five key strategies for achieving lifetime wellness as a polio survivor will be discussed at length: 1) optimize activity and exercise; 2) optimize nutrition, sleep and reduce stress; 3) prevent complications and/or recognize and treat early; 4) educate yourself, family and friends; 5) empower yourself by taking control and involving others.</p>	

# SUNDAY, JUNE 1

**9:00 – 10:15 am**

<b>Changing Relationships through a Life Span</b>	<b>Regency A</b>
<b>Sandra Loyer, LMSW, Stephanie T. Machell, PsyD</b>	
<p>As life changes so do our relationships. We suddenly find ourselves widowed or close family members have moved a distance away. Having to adapt to these changes is not unique among polio survivors and their families, but it does bring about challenges that may be unique. If the late effects of polio has increased disability, isolation may become a problem. Keeping and maintaining relationships can become more difficult. This session will discuss the ways that survivors and family members can take a realistic approach to maintaining important relationships and thus increasing satisfaction with life.</p>	

<b>Help with Healing: Humor, Breathing, Stretching, Yoga</b>	<b>Regency B</b>
<b>Melissa Gatlin</b>	
<p>The benefits of yoga for polio survivors will be discussed and moves will be demonstrated. Wear comfortable clothes and join an instructor experienced in Recuperative Yoga, Yoga for the Core, and Yoga for Breast Cancer. (See Monday afternoon's "Exploring Exercise.")</p>	
<b>Hannah Hedrick, PhD</b>	
<p>Experienced teacher of self-care/peer support classes will follow her idea that the best way to "do" something is to "share" it. Learn about breathing to nurture self by learning SELF breathing.</p>	
<b>Millie Lill</b>	
<p>Laughter is good medicine and a sense of humor will get you through some very difficult times.</p>	

<b>Polio's Effects on Breathing</b>	<b>Regency C</b>
<b>John R. Bach, MD, Bonnie Jo Grieve, MD</b>	
<p>People with post-polio syndrome and most other neuromuscular disorders can experience respiratory complications. Learn about the respiratory muscle groups, symptoms of breathing problems, patient evaluation and intervention objectives.</p>	

<b>Managing More Meds</b>	<b>Regency D</b>
<b>Marny K. Eulberg, MD, Alicia B. Forinash, PharmD</b>	
Learn more about safe medication usage. Topics discussed in this presentation will include the risk for drug and food interactions, storage and disposal of medications, use to help prevent problems, use of over the counter and herbal medications, importance of medication compliance and talking with your healthcare professionals.	

<b>Advice on Solo Aging</b>	<b>Regency E</b>
<b>Jann Hartman</b>	
Restructuring of my life after my husband's premature death continues to be a challenge, but the transition has brought with it the realization that I am not truly alone. Faith, friends and family are what get me through one day to the next.	
<b>Susy Stark, PhD, OTR/L, FAOTA</b>	
Aging in place alone with a disability can be easier with “environmental support.” Support can be formal or informal personal support or changes to the physical environment. Strategies to enhance daily activity performance and community participation will be discussed.	

## 10:45 am – 12:00 pm

<b>Being Spiritual</b>	<b>Regency B</b>
<b>Allison (Sunny) Roller, MA</b>	
Someone once said that we are all spirits on earth who just happen to have a body. We each have a spirit. Spirit animates human life. Capacities of the spirit enable one to transcend any experience at hand and seek meaning and purpose; to have faith, to love, to forgive, to pray, to meditate and to see beyond the here and now. I believe that each of us has deep inside of us a divine spark. It is a glimmer of God that affirms us and keeps us strong. Affirming that spark every day has the power to fill us with enthusiasm and strength in new and meaningful ways as we grow older with a disability from polio.	
<b>Ann Williams, AdvCBP, BAT</b>	
Are you missing the most beneficial 15 minutes of your day? Connecting to your Spirit daily is one of the most powerful tools you have to prevent dis-ease in the body and mind. Learn and experience simple and effective techniques to still the mind, calm the body and engage the spirit. Heal from the inside. With each beautiful breath, the Spirit reminds the physical body to be at-ease.	

<b>Travel Opportunities</b>	<b>Regency C</b>
<b>Mary Gordon, Barbara Gratzke, Jean Hartley</b>	
<p>Have a "Bucket List?" Want to "Get out and Live?" Hear about resources and first-hand accounts that will assist you to make good, accessible travel plans that insure a less stressful experience. Discover benefits of leisurely traveling in an accessible RV and full-timing to live more economically. Find out how "Accessible Hawaii" can assist you to fully enjoy Hawaii. Hear experiences of flying alone, with a scooter, to 34 different countries. Understand how to travel with Polio Canada, with attendant care provided, tours and cruises available to anyone with a disability, and their friends or family... and much, much more.</p>	

<b>Assessment: Our Home</b>	<b>Regency D</b>
<b>Gina Hilberry, AIA</b>	
<b>Cyndi Jones</b>	
<p>As we get older, many of us need more accessible housing features. In 1978, I became a real estate agent to find a home that would work for us, and I helped many others find homes as well. In the 1980s, Eleanor Smith developed the concept of Visitability - the idea that all new residential units could, and should, be "visitabile" by everyone. There are ways for us to modify own homes to meet our needs and we can advocate for more global changes that can benefit everyone.</p>	

<b>Pain: It Gets Our Attention</b>	<b>Regency E</b>
<b>Ann Crocker, William M. DeMayo, MD, Frederick M. Maynard, MD</b>	
<p>Pain is one of the most common and distressing symptoms experienced among aging polio survivors, reported by 80-100% of those diagnosed with post-polio syndrome and occurring at an average of 9.5 locations.</p> <p>This session will discuss the different types of pain that are most frequent and will introduce the concept of 'pain generators.' Using the example of disabling low back pain in the sacroiliac area, the process of doctor and patient working together to identify pain generators and how this leads to effective treatment strategies will be illustrated.</p> <p>The roles for medications, injections, therapy, exercise, assistive devices and orthotics, and activity change will be discussed, particularly as they apply to the most common post-polio pain syndromes, including shoulder pain, wrist/hand pain, hip/knee/leg pain and back pain.</p>	

SUNDAY

## 12:30 – 12:50 pm

Support Dog Demonstration	Regency C
<p>Watch a demonstration of a support dog in action by an experienced assistance dog trainer. Nadine Wenig represents Support Dogs, Inc., a St. Louis-based not-for-profit that was started in 1983 to provide highly skilled assistance dogs to people with disabilities and uniquely trained therapy dogs for the community.</p>	

## 1:15 – 2:30 pm

Assessment: Our Abilities	Regency B
<b>Hilary Boone, Beth Kowall, MS, OTR, Carol Vandenakker-Albanese, MD</b>	
<p>“My Polio Life” developed by the United Kingdom-based Polio Survivors Network is designed to help survivors understand their polio and post-polio experience or “life.” One of its authors will introduce the self-assessment tool that provides insight to polio survivors and their families. An experienced post-polio clinic physician and an occupational therapist who has post-polio syndrome will add their perspective to the self-assessment document. There will be time for questions and perspectives from the audience.</p>	

Managing Polio's Effect on Breathing	Regency C
<b>John R. Bach, MD, Bonnie Jo Grieve, MD</b>	
<p>Respiratory complications are preventable for people with weak respiratory muscles. Noninvasive intermittent positive pressure ventilation (not "BiPAP") can provide up to full inspiratory muscle rest during sleep and total ventilatory support. Learn about devices and methods that can provide effective cough flows to prevent pneumonias and eliminate need to resort to indwelling tracheostomy tubes. Also, learn about what does not help manage post-polio respiratory problems.</p>	

Cardiovascular Aging	Regency D
<b>Michael W. Rich, MD, Martin B. Wice, MD</b>	
<p>According to the CDC, about 600,000 people die of heart disease in the United States every year—that's 1 in every 4 deaths. Heart disease is the leading cause of death for both men and women. Cardiovascular issues related to aging will be discussed with added insights about cardiovascular aging with a disability.</p>	

<b>Relatives of Survivors: Three Perspectives</b>	<b>Regency E</b>
<b>Stephanie T. Machell, PsyD, Mary Navarre, OP, EdD, Willard (Bill) Smith, PhD</b>	
<p>It has been observed that when one member of a family has a disability the entire family is affected. In this presentation family members of polio survivors will speak about their experiences as spouse, sibling, and child of a polio survivor. The diversity of our experiences and those of all who have lived in polio-affected families is reflected in the different styles that will be used by each presenter, including storytelling, a meditation on marriage vows, and a consideration of how personal experience can create and be integrated into professional life. At the end of the presentation the moderator will engage the audience in dialog with the presenters about how what we have presented might help polio survivors and their families better support one another by opening up communication and sharing our experiences</p>	

## 3:00 – 5:00 pm

<b>Beyond Eradication: The Forgotten Polio Survivors of India</b>	<b>Regency B</b>
<b>Neena Bhandari</b>	
<p>India, which has been certified polio-free by the WHO on 27 March 2014, was the epicentre of polio with nearly 200,000 reported cases a year until 1978. While data abounds on number of children vaccinated and the number of reported polio cases, there is no count of polio survivors, many of whom are battling with PPS. There are few doctors, who recognise and understand PPS, and there are no polio support groups. Despite the odds, stories of endurance and resilience unfold as I meet polio patients in villages, towns and bustling cities. The Government, NGOs and the larger community now needs to invest in polio survivors facing new physical, social, cultural and economic challenges.</p>	

<b>Passing in the Shadow of FDR: Polio Survivors, Passing, and the Negotiation of Disability</b>	<b>Regency C</b>
<b>Daniel J. Wilson, PhD</b>	
<p>Many polio survivors sought to emulate President Franklin D. Roosevelt who passed with the aid of his wealth and the Secret Service as someone who had completely recovered from polio. Many developed strategies to “pass,” even though evidence of their disability was obvious. This presentation will explore those strategies and the physical and psychological costs that they entailed, including what happened to passing strategies when post-polio syndrome and its new disabilities forced many polio survivors to renegotiate their disability. The presentation will be the prelude to a discussion among those attending about passing in their own lives.</p>	

SUNDAY

Roundtable on Post-Polio Bracing	Regency D
<b>Marny Eulberg, MD; William M. DeMayo, MD; Marmaduke Loke, CPO, Dynamic Bracing Solutions; Dennis Richards, CO, Townsend Design</b>	
Considering a new brace? Learn about the basics of post-polio bracing and some options of design from orthotic professionals. Bring your questions and join the discussion.	

**7:00 – 8:30 pm**

Reflections on Being a Polio Survivor	Regency C
<b>Frederick M. Maynard, MD, Allison (Sunny) Roller, MA</b>	
After dinner, Sunny Roller and Fred Maynard, MD, will lead a time for reflection on being a polio survivor. Then it will be your turn to share a short story. What's one of the smartest things you have ever done as a polio survivor? What are your current and future goals?	



# MONDAY, JUNE 2

9:00 – 10:15 am

Pause – Relax - Attend: the Mindful Way to Stress Relief	Regency A
<b>Bridget Rolens, MA, BSOT</b>	
<p>Mindfulness meditation is a spiritual practice and a tool for stress reduction. Learn about it from an experienced teacher in traditional healthcare and a variety of spiritual practices rooted in the Christian, Buddhist and Twelve-Step Recovery traditions; a teacher who has a strong understanding of the connection between body, mind and spirit in promoting health and well-being.</p>	

Staying Active: Mind & Body	Regency B
<b>Mark D. Peterson, PhD, MS</b>	
<p>Using activity monitors in our recent study of glutathione and health, we found that most of our participants were very sedentary. There is considerable evidence for the positive impact of exercise and physical activity on health and well-being. Given what we learned in this study and our growing understanding of how important exercise is in people with mobility limitations, this is an exciting area to explore new ways to reduce sedentariness and increasing physical activity safely and effectively to improve health and well-being.</p>	
<b>Beverly Schmittgen, EdD</b>	
<p>For the past three years, I've been enjoying life more and doing less physically taxing work. My husband and I downsized and moved into a more manageable house within an active seniors' community. I'm now enjoying socializing with new neighbors, keeping my mind active and expanding my horizons. My passion for travel has not changed, but my methods for doing it have. I'm feeling better on so many levels by successfully adapting to a new lifestyle.</p>	
<b>William G. Stothers</b>	
<p>I spent a lot of time outdoors as a youngster – before polio. Afterward, my life moved indoors – hospital, rehab, then school and into employment as an adult. Yet, the outdoors continued to resonate in my heart and soul. I've always had “a good eye,” and eventually an interest in photography took hold and dragged me back outside more and more. Surprisingly, life became more colorful and energetic – I met more people and got increasingly involved in community activities, and disability rights activism. It continues to be a great adventure.</p>	

<b>Refining Our Castle</b>	<b>Regency C</b>
<b>Frank Frisina, Karen Hagrup</b>	
<p>President of Welcome Home, Inc., a non-profit Arizona corporation, and polio survivor son of a builder/developer, who redesigned his personal living area before 10 years old of age will share his knowledge about many aspects of design. And, take a photographic tour of the newly-renovated condominium of a wheelchair user and collect ideas for your home.</p>	

<b>Let's Talk about the Spine</b>	<b>Regency D</b>
<b>Cynthia Henley, PT, Carol Vandenakker-Albanese, MD, Kathryn Wollam, PT</b>	
<p>The spine and supporting muscles are the support system for all movement. Polio survivors may experience spinal problems directly related to residual muscle weakness or secondary problems related to aging. Some of the symptoms of spine problems can be confused with post-polio syndrome. This session will include information on how acute polio affects the spine, spine problems that can develop later in life, and how to differentiate spine conditions from post-polio syndrome. We will discuss medical treatment options and physical therapy interventions, including the use of modalities, therapeutic exercise, body mechanics and ADL modifications to decrease stress on the spine.</p>	

<b>A Good Night's Sleep</b>	<b>Regency E</b>
<b>Ann Crocker, William M. DeMayo, MD</b>	
<p>Why is sleep important? What are reasons for poor sleep? What is insomnia? What factors influence poor and "good" sleep? Join the exploration of sleep and its effect on pain and the whole person.</p>	

## 10:45 am – 12:00 pm

<b>Moving You to Better Health with the Lebed Method</b>	<b>Regency A</b>
<b>Laura Dowell, PT, CLMT</b>	
<p><i>Healthy-Steps</i>, Moving You to Better Health with the Lebed Method, is a therapeutic dance and movement program done to great music. <i>Healthy-Steps</i> improves overall wellness, range-of-motion, balance, strength and endurance. Try a movement program, that can be done seated, that has been proven to help enhance the well-being of those with cancer or other chronic illnesses or medical conditions. Learn a new and healthy method of movement from a certified and experienced instructor.</p>	

<b>Legal Concerns for Polio Survivors: A Benefits Primer</b>	<b>Regency B</b>
<b>Martha C. Brown, JD</b>	
<p>As an elder law and special needs attorney, Ms. Brown will discuss recent changes and developing trends in Social Security benefits, the Affordable Care Act, Medicaid benefits, Medicare and Veteran's Administration benefits. This session will alert the audience to the intricacies of these benefit programs. Special attention will be made to the Medicare Part D Drug Plans and the Affordable Care Act impact on drug formularies. With regard to the Affordable Care Act, this program will discuss its various provisions and the time table for the provisions to become effective.</p>	

<b>Weight Management</b>	<b>Regency C</b>
<b>Kathy Davis, MSW, LCSW, Jann Hartman, Mark D. Peterson, PhD, MS</b>	
<p>Learn about the issues of nutrition and weight loss from a knowledgeable clinician who is also experienced in cognitive/behavioral and reality-based techniques.</p>	

<b>Maintaining Posture</b>	<b>Regency D</b>
<b>Carol Vandenakker-Albanese, MD, Holly Wise, PT, PhD</b>	
<p>This interactive presentation will provide the participant an overview of the basic mechanics associated with postural alignment. The physical, cognitive and psychological benefits associated with achieving best postures at rest and with movement will be discussed. Effective strategies including the use of assistive devices, bracing, exercise, seating assessment, etc., will be presented through the use of case studies. Audience members will be invited to participate in "mini-consults" with the presenters.</p>	

<b>Communicating for Understanding</b>	<b>Regency E</b>
<b>Stephanie T. Machell, PsyD</b>	
<p>Aging and PPS affect all relationships, not just those with family members. It can be difficult to know how to discuss the changes that have occurred or are occurring, even with close friends. It can be even more difficult to know how (or if, or when) to present this information to new friends or potential relationship partners. Learn some ideas for how (or if, or when) to talk about disability and PPS with friends and others.</p>	
<b>Rhoda Olkin, PhD</b>	
<p>An experienced mom, partner, and psychology professor, and author with polio, the presentation will introduce ideas about living and aging with a disability. These include models of disability and polio within a family context and suggestions for polio survivors and their families based on new data about falling, depression and well-being.</p>	

MONDAY

**12:30 – 12:50 pm**

**Adventures on Cruises**

**Regency C**

Hear about Adventures on Cruises from Maureen Sinkule, who has been the force behind numerous cruises organized for polio survivors and families. Learn how you can join them.

**1:15 – 2:30 pm**

**Exploration of Faith & Disability**

**Regency A**

**Cyndi Jones**

Can we have a disability and also have faith? What is it about disability that prompts total strangers to approach you to “lay hands on you,” or to tell you, “If you had faith, you would be healed”? There are many scriptures that talk about healing a person with a disability, but seldom in the context of living as a person of faith with a disability. From the pews to the pulpits to academia, there is an emerging movement for a contextual theology of disability to be heard. Join this conversation on people with disabilities as people of faith.

**Finding a Pair of Hands and Legs**

**Regency B**

**Ann Ford**

This session will be a detailed conversation exploring possible avenues of assistance when we can no longer do those things we always could, including dealing with that loss in order to move on.

**Support Groups: What Works**

**Regency C**

**Jean Graber**

**Leaving a Legacy --- The Traveling Trunk**

Polio’s story at a personal level? Today’s children need to know. Why? The cornerstones: Grasping the epidemic’s impact on our nation’s history. Adapting to what life deals and choosing to move forward. Understanding those disabled with compassion. Realizing polio’s world-wide potential effects. Teaching today’s children about polio. How? Beginning with Peg Kehret’s autobiography, *Small Steps*, this hands-on learning unit provides upper elementary/middle school students with real-life experiences of polio’s history, plus hot packs, breathing restrictions, braces, personal stories, and more. All relate to curriculum: math, reading, social studies, music, writing, and physical education.

<b>Beth Kowall, MS, OTR</b>
In April 2013, the Post-Polio Resource Group of Southeastern Wisconsin began its 28th year of service to our members. To meet the changing needs of our members, we developed and sent out a survey to seek input and feedback from those on our mailing list. We will use this information to help guide us in planning future programs and services to fit the needs of our members. We were amazed at the excellent return rate and received some interesting results that we would like to share with others.
<b>Mary-ann Liethof</b>
Polio Australia's Annual (four) Health and Wellness Retreats provide an opportunity to survey participants as to whether the experience has resulted in any improvements in their Health Literacy and Health Outcomes. The results of this survey provide essential statistical data for use in reports, funding submissions, lobbying government, health-related publications and further research.
<b>Mary Gordon</b>
Sharing, caring and learning one story at a time! Success stories where survivors have the opportunity to share their "turning point" and what made it so special.
<b>Micki Minner</b>
Discussion of the safety and security methods needed if you get your support from an on-line support group. This discussion will cover Facebook, and Twitter; the safety issues apply to all internet discussion of support groups and how they function. We will be able to discuss the types of groups that will work for you as an individual. Discussion will cover different ideas about using the internet resources available to discuss your journey with being a polio survivor with other's on the same journey.

<b>Why Worry? Stop Coping and Start Living</b>	<b>Regency D</b>
<b>Kathryn Tristan</b>	
We live in an age of increasing global anxiety. Uncertainties and challenges from health, finances, relationships, etc. can leave us feeling constantly stressed out, worried, and tense. To better deal with our lives requires that we become our own mental masters by directing our psychological immune system, a protective mechanism that often goes haywire. This talk provides a mind-body-spirit focus with easy-to-learn practical tips and the latest science on how to rewire your brain and turn on your happy genes. Learn how to stress less and enjoy more using easy-to-learn strategies to better deal with the modern world.	

<b>Update on Anesthesia</b>	<b>Regency E</b>
<b>Selma Calmes, MD</b>	
Learn about topics related to anesthesia that are of concern to polio survivors: colonoscopies and bariatric surgeries and find out "What's new in anesthesia?" and "Why is it so hard to link-up ahead of time with your anesthesiologist?"	

**3:00 – 5:00 pm**

<b>My New Reality</b>	<b>Regency C</b>
<b>Rhoda Olkin, PhD (Moderator)</b>	
<b>Neena Bhandari</b>	
<p>I contracted polio in India soon after receiving the oral polio vaccine, a month short of my third birthday. Since then, I have lived and worked in three continents as a journalist and foreign correspondent, reporting on issues ranging from environment and development, human rights and gender, education and health to crime and law. Many bylines and many calipers on, as PPS poses new challenges each day, I am constantly evolving ways to live life to its fullest as a mother, a wife and above all a professional in the fast-paced, highly competitive media industry.</p>	
<b>Mark Mallinger, PhD</b>	
<p>Since being diagnosed with polio at age 8 my goal has been to respond to adversity with an optimistic perspective. Semi-retired I continue to teach part-time in the graduate business school at Pepperdine University. I proudly state that I have had and continue to participate in a fulfilling career and equally fulfilling life outside of work. Having travelled extensively world-wide, I find post-polio to be a recognized irritant rather than an obstacle to my goals. I would like to share my thoughts about ways in which we can enhance our lives even when faced with the debilitating effects of post-polio syndrome.</p>	
<b>Joyce Tepley</b>	
<p>Retired from a forty-year career as a clinical social worker, I have dedicated the rest of my life to honoring those who thrive through adversity by telling their stories. My book, <i>Thriving Through It, How They Do It: What it Takes to Transform Trauma into Triumph</i>, gives the reader insight into the lives of twenty people I interviewed who had long term physical disabilities and told me what personality traits, beliefs, and support are necessary in being a thriver. One of the people featured in the book is Joan Headley, PHI's competent executive director. As one of four panelists I will share my insights about how to create our new reality through the transformational process of thriving.</p>	

<b>Roundtable on RADs, Vents &amp; Interfaces</b>	<b>Regency D</b>
<b>Betsy Thomason, RRT; Ronda Bradley, MS, RRT, FAARC, CareFusion – Alternate Care; Michael Madison, RRT, Bob Richardson, RRT, ResMed; Tony Mengwasser, RRT, Philips Respironics</b>	
<p>Has your breathing ability changed? Is it time to consider new equipment? Learn about the devices available for survivors of polio with apnea and/or new breathing muscle weakness. Bring your questions and join the discussion.</p>	

**3:00 – 5:00 pm** (cont'd)

Exploring Exercise	Regency F/Fitness Center
<b>William M. DeMayo, MD, Melissa Gatlin, Hannah Hedrick, PhD, Mark D. Peterson, PhD, MS, Frederick M. Maynard, MD, Ann Williams, AdvCBP, BAT, Holly Wise, PT, PhD</b>	
<p>Take advantage of a two-hour time period to visit the fitness center to learn if machines, light weights, or therapeutic bands might work for you. Also, spend part of the time experiencing T'ai Chi Gong form that can be practiced sitting or standing; T'ai Chi Chih, and various types of yoga in Room F starting at 3:00 pm and 4:00 pm.</p>	

## TUESDAY, JUNE 3

**9:00 – 10:15 am**

### **A Discussion for Significant Others**

**Regency A**

**Willard (Bill) Smith, PhD**

This session will be primarily a discussion, not a presentation. First, definitions of "significant other" will be presented, both the narrow definition of a "significant other" as a single individual in a person's life, and the broader definition as one of several individuals with varying degrees of significance, as perceived by that person. This will be followed by a give-and-take discussion among audience members and presenter of the role of a "significant other" under both the narrow and broader definition, and the potential issues which may arise in each case.

### **Proven Energy Boosts**

**Regency B**

**Betsy Thomason, RRT**

Just Breathe Out! Learn how focusing on the outbreath can help you manage the effects of polio.

### **Lessons from The Rehabilitation Research & Training Center on Aging with a Physical Disability**

**Regency C/D**

**Alexandra Terrill, PhD, Aimee Verrall, MPH**

For the last five years, the University of Washington has held a Rehabilitation Research & Training Center (RRTC) on Aging with a Physical Disability. Recently, this RRTC was renewed another five years to continue our work on promoting healthy aging of people living with long-term physical disability, including post-polio syndrome (PPS). What does it take to age well with a physical disability? We'll go over what we've learned so far from our surveys and studies. We'll also talk about where our research is headed in the next five years.

### **End of Life: The Practical & The Experiential**

**Regency E**

**Maria Miskovic, LCSW**

Learn about some of the practical issues related to end-of-life issues in a safe environment with someone who has experience across the continuum of care and who has a passion for assisting elderly and people with disabilities to maintain a high quality of life, while remaining as self-sufficient and independent as possible.



**10:45 am – 12:00 pm**

<b>Post-Polio Research – Plenary Session</b>	<b>Regency C/D</b>
<b>Moderators: Selma Calmes, MD, Daniel J. Wilson, PhD</b>	
<b>Summary from Brazil &amp; South America</b>	
<b>Sheila Jean McNeill Ingham, MD, PhD</b>	
<b>Genetic Predisposition to Polio: New Research from Canada</b>	
<b>Mark Loeb, MD, MSc FRCPC</b>	
<p>Although exposure to polio was widespread in North America in the pre-vaccine era, &lt; 1% of individuals infected with poliovirus developed paralytic polio. This suggests that it is likely that human genetic factors played an important role. Surprisingly, there are no genetic studies that have examined the role of the host in susceptibility to paralytic polio. We are conducting a genetic study to determine which genetic variants in people led them to develop polio. We have received ethics approval and, through March of Dimes Canada, have already enrolled 500 older adults across Canada with paralytic polio and 200 of their spouses as controls. The data will allow polio survivors to gain insight into why they became ill and the results could point to targets for anti-virals or immune therapy. Importantly, this will be a discovery-based study that will to insights into the pathogenesis of paralytic polio that affect so many older adults.</p>	

<b>Update on PHI-funded Research</b>
<b>Antonio Toniolo, MD</b>
<p>Poliovirus genome in patients with post-polio syndrome but not in their family members. We investigated polio survivors diagnosed with PPS, their family members, and control individuals. The three poliovirus types were searched for in blood leukocytes, cerebrospinal fluid, and other tissue samples. 86% PPS patients were poliovirus-positive vs. 3.7% of controls. Type 1 poliovirus was most prevalent. Results suggest that slow-acting poliovirus can persist in PPS patients. Data show that poliovirus is not transmitted to family members of PPS patients, a finding of obvious interest. It is hoped that virology methods will allow identifying individuals at risk for PPS and treat them with antivirals preventing the disease or for blocking its progression.</p>

**12:30 – 1:00 pm**

Disabilities Treaty (CRPD)	Regency C/D
<b>Judith E. Heumann, MPH</b>	
Learn about The Disabilities Treaty (The UN Convention on the Rights of Persons with Disabilities): what is it? why is it important?	
<p>Judith E. Heumann is an internationally recognized leader in the disability community and a lifelong civil rights advocate for disadvantaged people. In June 2010, she was appointed to her current position as the Special Advisor for International Disability Rights at the U.S. Department of State. As the Special Advisor, Heumann leads the Department efforts to encourage and assist foreign governments and civil society organizations to increase their commitment and capacity to protect the rights, and ensure the inclusion and full participation of persons with disabilities.</p>	
<p>She served as the World Bank's first Advisor on Disability and Development and served in the Clinton Administration as the Assistant Secretary for the Office of Special Education and Rehabilitative Services in the Department of Education from 1993 – 2001. She previously worked with numerous disability rights organizations including co-founding the World Institute on Disability and the Center for Independent Living in Berkeley, California.</p>	

# 1:15 – 2:30 pm

<b>Post-Polio Research (cont'd)</b>	<b>Regency C/D</b>
<b>Moderators: Selma Calmes, MD, Daniel J. Wilson, PhD</b>	
<b>Endurance Training: How to target intensity?</b>	
<b>Eric Voorn, MSc</b>	
Physical therapy recommendations for polio survivors include endurance training to prevent or reverse deconditioning and preserve muscle endurance for daily life activities. Determining the desired training intensity is delicate in polio and other neuromuscular disorders because exercise levels should be sufficiently intense to stimulate a training effect; however, they should avoid muscular overload. The exercise test as applied at the department of Rehabilitation of the Academic Medical Center in Amsterdam and how this can be used to determine training intensity for individual patients in clinical practice will be explained.	
<b>Update on PHI-funded Research</b>	
<b>Carolyn (Kelley) Da Silva, PT, DSc, NCS</b>	
An update on current PHI-funded study on the effects of whole body vibration on people with post-polio syndrome will be provided. The discussion will include the benefits found in existing publications, description of typical basic vibration sessions, and description of who can and cannot participate in whole body vibration.	
<b>Claire Kalpakjian, PhD</b>	
An update on her PHI-funded study on the effectiveness of oral glutathione for improving health outcomes in persons with the late effects of poliomyelitis will be presented. Also included, will be a brief review of study findings on outcomes of physical activity, sleep, self-rated health and wellbeing.	

# 2:30 – 3:00 pm

<b>Discussion of Future Needs of Polio Survivors</b>	<b>Regency C/D</b>
<b>William G. Stothers, Daniel J. Wilson, PhD</b>	
This session is designed to enable polio survivors and conference attendees to express their views on what polio survivors need now and in the foreseeable future. The Board of PHI hopes that participants will provide suggestions that will help guide the Board as it makes decisions about PHI activities. Please come with your questions, comments, and suggestions.	

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# APPENDIX



POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK



An affiliate of Post-Polio Health International (PHI)

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. The mission of International Ventilator Users Network (IVUN) parallels that of PHI but focuses its activities on users of home mechanical ventilation.

PHI and IVUN create the following resources.

*Post-Polio Health*, quarterly printed newsletter

*Ventilator-Assisted Living*, bi-monthly e-newsletter

*Post-Polio Directory*, compilation of health professionals and support organizations

*Resource Directory for Ventilator-Assisted Living*, compilation of health professionals, respiratory home care companies, in-home care agencies, equipment and aids, etc.

Comprehensive websites include [www.post-polio.org](http://www.post-polio.org), which is divided into sections based on mission – education, advocacy, networking and research. Highlights include many articles from the *Polio Network News/ Post-Polio Health* dating back to 1993 in the Education section. The *Post-Polio Directory*, which can be downloaded for free, is in the Networking section. The Advocacy section contains information about past WE'RE STILL HERE! campaigns. The Research section includes the history of the fund and reports from eight past grant recipients awards given in the odds years between 2001-2013.

The IVUN website ([www.ventusers.org](http://www.ventusers.org)) also includes articles in *IVUN News and Ventilator-Assisted Living* dating back to 1990. The *Resource Directory for Ventilator-Assisted Living* is also available for free.

PolioPlace is the organization's third website at [www.polioplace.org](http://www.polioplace.org). Its major sections include People, History, Resources, Medical Articles, Living with Polio and Artifacts. One of its goals is to actively collect and preserve post-polio and independent living history. For example, every document published by the organization has been included. Another goal is to enhance the lives and independence of our younger fellow polio survivors in other countries by providing information to them and their health professionals. The site is a work in progress and film from this conference will be included. You are your invited to contribute your expertise. For more information on how to do so, visit the PHI table.



## Meet those behind PHI and IVUN



**Front row from left to right:** Sheryl Rudy, SherylzArt, newsletter and web designer; Joan L. Headley, Executive Director; Gayla Hoffman, Gayla Hoffman Associates, newsletter editor.  
**Back row from left to right:** Brian Tiburzi, Assistant to the Executive Director; Lucky Leong, LLC, Certified Public Accountant; Todd Harrell, AAMS, Edward Jones.



Long-time volunteer and friend, Karen Hagrup with Brian Tiburzi, Assistant to the Executive Director.

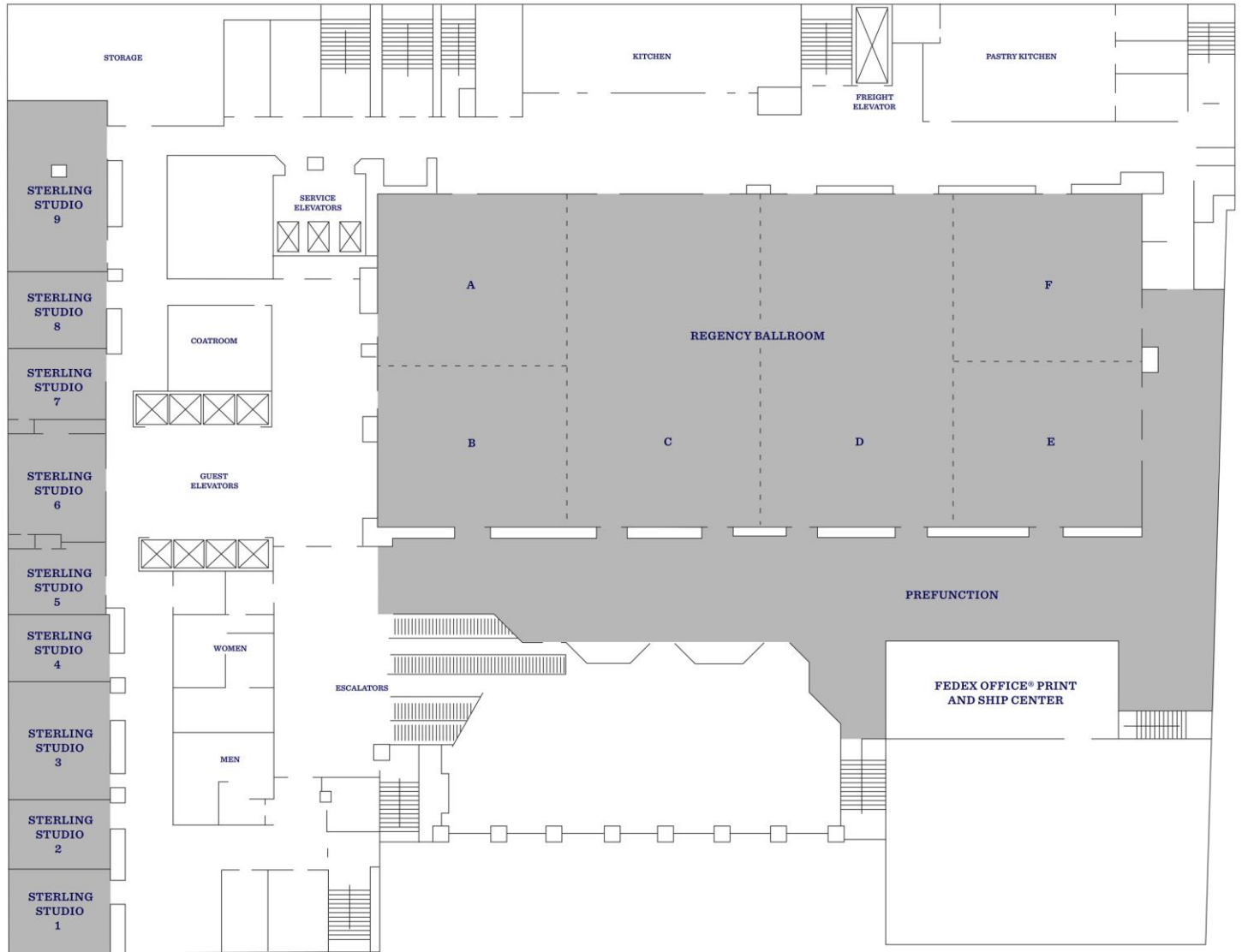
### Support PHI and IVUN

Post-Polio Health International and International Ventilator Users Network are Membership organizations. The work it accomplishes is supported by Memberships, donations and grants.

It is easy to join PHI and IVUN online at <http://shop.post-polio.org/>. Thank you!

**FLOOR PLAN**  
*Second Floor*

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**AT THE ARCH**



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