POST-POLIO RESEARCH: WHY AND WHAT?

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www.post-polio.org    www.polioplac.org    www.ventnews.org
Myths? Half-truths?

- Donors like to fund 'cures'.
- More serious conditions to study.
- You are aging, get used to it (or dying).


PHI’s Why

PHI’s mission is to enhance the lives and independence of polio survivors and home ventilator users, i.e., independent living, disability rights, quality of life through education, networking and advocacy.

In 1995, added supporting research as the fourth part of mission.
What PHI is doing?

Research Fund (1995)

- Initiated by a bequest from a polio survivor ventilator user
- Grants funded: 10
- Amount given: $395,000
- Amount in fund: $770,000 ($50,000 committed)
- Next call in early 2017 for 2018
## Research Fund

### Awards

<table>
<thead>
<tr>
<th>Year</th>
<th>Description</th>
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<tbody>
<tr>
<td>2001</td>
<td>Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life</td>
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<td>2003</td>
<td>Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress</td>
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<tr>
<td>2005</td>
<td>Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis</td>
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<td>2007</td>
<td>Pilot Study to Identify PPS Biomarker</td>
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<tr>
<td>2009</td>
<td>Persisting Noninfectious Fragments of Poliovirus in PPS Patients: Virus Detection and Susceptibility to Antiviral Drugs</td>
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<tr>
<td>2011</td>
<td>The Role of Glutathione in Health Outcomes Among Persons with the Late Effects of Poliomyelitis</td>
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<td>Characteristics of poliomyelitis and post-polio patients among Arabs and Jews in Jerusalem</td>
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<tr>
<td>2013</td>
<td>Effects of Whole Body Vibration on People with Post-Polio Syndrome</td>
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<tr>
<td>2014-15</td>
<td>Poliovirus genome in patients with post-polio syndrome (PPS): Defining virus mutations by novel genome sequencing methods and investigating possible treatments with antiviral antibodies and drugs</td>
</tr>
<tr>
<td>2016-17</td>
<td>Cough Assist: use education needs, health service utilization and outcomes.</td>
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Research ideas

From:

Linda Bieniek
Cher Coughlin
Ann Crocker
Ruby Daugherty
Donna Dellario
Carol Elliott
Gary Elsner
Carol Ferguson

Susan Payne Gato
Peg Graham
Karen Hagrup
Jann Hartman
Fran Henke
Nickie Lancaster
Bonnie Levitan
Marvin Jech

Marge Lumchick
BJ McGough
Warren Peascoe
Karla Stromberger
Els Symonds
Joyce Ann Tepley
Agnes Wilcox
Sherry Wiley
Why?

- Knowledge can be applied to other viral illnesses.
- Research can lead to policy changes.
- Polio is still not eradicated; opting out of vaccinations; mutations.
- Survivors of the 20th century helpful to those in the 21st Century.
- People don’t know they had polio.
What?

Cause/Symptom related

- Progressive new weakness: what factor(s) contribute the most.
- Compare pre and post-surgery weakness.
- Pain in post-polio - who, why, why not, solutions, tolerance of meds.
- Fatigue, especially cognitive ability.
- Drug interactions with polio weakened muscles.
- Pursue inflammation as one cause of symptoms.
- Develop a marker for PPS and then a vaccine to prevent it.
- Explore hypnotherapy as an influence on neurological repair.
What?

Surveys

- Breathing problems of survivors before and after anesthesia.
- Immune deficiency in polio survivors (how many, causes).
- Incontinence problems; elimination problem.
What?

Living with polio

- “What helps” vs “what makes the situation worse” vs “what doesn’t make a difference.” For example, what is the best brace? Exercise? Medication?
- Best practices for managing aging with polio to manage pain, fatigue, breathing difficulties, and still remain active and engaged.
- Explore various styles of adapting to changing health needs/ways of coping.
- Examine if disabled people treated by the medical community on an equal footing with others of the same gender and age.
- Establish a standard assessment protocol for evaluating polio survivors, especially for respiratory needs.
- Establish standard treatments for diseases of aging (heart, cancer, pneumonia)
Health professional survey by PHI. 29 of 49 said they participated in studies.

Barriers to doing so:

- None in my area. Unaware of any studies.
- Time.
- PPS a diagnosis of exclusion, so research becomes difficult.
- Lack of participants. Disagree with protocol.
PHI’s What?

Treatment and management of the late effects of polio or to explore historical, social, psychological and independent living aspects of living with polio

OR

management of neuromuscular respiratory insufficiency or to explore historical, social, psychological and independent living aspects of long-term home mechanical ventilation (HMV).
PHI’s What?

Research must:

- Improve the lives of polio survivors or users of HMV,
- Quantitative or qualitative,
- Follow accepted research methodology,
- Preference to innovative or original research, which leads to new interventions, products, methods or applications.

Starting in 2013, expanded beyond basic science, offered an annual award of $50,000, up from $25,000.
Accepting myths/half-truths

- There ARE fewer polio survivors and/but many are living in emerging economies.
- There IS cancer, amyotrophic lateral sclerosis (ALS), etc.
- We ARE aging (dying), but meanwhile.
Busting myths/half-truths

- Is there a hierarchy of diseases?
- Should/are numbers (be) the determining factor?
- Do researchers (and donors) seek fame and fortune?
- Source of comments? Are they qualified to speak? Should we listen?
Concerns

- Studies struggle to get participants. (Lack of understanding of process and benefits.)
- Many faces of post-polio syndrome.
- Grants are easier to obtain than implement. (Talented people are busy.)
- Researchers apply only once.

NEED: Increase the funds available for research.