

PHI's mission is supported by its Membership.

## Michigan Support Group Collaborates with OUWB School of Medicine

Tim Brown, Southeast Michigan Post-Polio Support Group

Typically, when one joins a support group, he or she might expect to share similar experiences with others, to find solutions to problems from others, to be able to listen and learn from speakers on related topics, perhaps even to occasionally meet at a restaurant with others from the group for lunch or dinner. The Southeast Michigan Post-Polio Support Group (SEMiPPSG) has indeed been providing all those benefits to its members for nearly 30 years. In addition to what is usually expected, we have also found a way to add yet a new dimension to the support group.

A common remark from polio survivors at group meetings is that they feel their doctors or medical service providers having little or no knowledge of polio or post-polio issues. Knowing this, several individuals who were both leaders of the support group as well as board members of the Michigan Polio Network (MPN), the Michigan statewide network of polio survivors, were determined to find a way to use its resources to address this problem. Bonnie Levitan, who also sits on the PHI board, and I took the lead on this effort. We reached out to the Oakland University William Beaumont School of Medicine (OUWB), a partnership between one of Michigan's top universities (Oakland University) and the state's largest health system (Beaumont Health).

We contacted the dean's office and scheduled an appointment to discuss what we viewed as an opportunity to raise awareness of polio survivors' issues among their medical students and perhaps even the teaching staff.

OUWB was founded upon the principal of providing a unique teaching experience to its medical students,

which includes such values as kindness, awareness and consideration of the human experience, as opposed to simply viewing the patient as a bundle of facts. A committee of very highly placed school administrators and professors scheduled a meeting with us to listen to our presentation. It was an impressive group who responded positively to what was said and indicated that they were receptive to adding issues surrounding polio to their program. As a result of this meeting, MPN was soon named a "Community Partner" in their COMPASS community engagement mentor program.

Following that initial meeting, we were put in touch with a first-year medical student who asked if MPN would participate in her three-year Capstone Research Project. MPN agreed and soon after mailed questionnaires to 700 polio survivors from our membership list. The four-page questionnaire was entitled, "An Assessment of (Michigan) Polio Survivors to Identify Longterm Sequelae of Polio: Educational Tool for Medical Students."

This turned out to be a highly successful venture between MPN and the student, with well over 50% of those polio survivors responding. The final results highlighting the lifelong experiences of this large group of polio survivors were summarized and shared with the student's classmates and made available to all future incoming students.

MPN was also invited to speak at an OUWB scheduled "Lunch 'n' Learn," an educational seminar at which lunch is provided to students while they listen to speakers discuss medical topics. The focus of this particular Lunch 'n' Learn was "Caring for Unique Populations: The Case of Polio," hosted by the school's chief of neurology. Bonnie and I were also invited to speak to the large auditorium full of students, staff and faculty, and answer their questions about polio and living with the after-effects.

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When the class was dismissed, a small group gathered with even more questions. Among them was Dr. Tracey Taylor, Associate Professor of Microbiology in the Department of Foundational Medical Studies and current Assistant Dean for Diversity and Inclusion. She was interested in learning more about the post-polio support group, so we invited her to attend several SEMiPPSG meetings and speak with the group. Since then, an ongoing relationship with Dr. Taylor has developed, resulting in involvement in a second student's Capstone Research Project, currently in its final stages.

During her first and second year of school, the medical student with whom SEMiPPSG is currently involved, Marlin Amy Halder, interviewed a number of volunteers from the support group—some in focus groups and some individually—to gather facts and information for her project, “Post-Polio Syndrome and Polio Survivor Biographies.” Amy was mentored by Dr. Taylor, and her research team included another medical student peer, Lucas Nelson, as well as a qualitative research expert, Dr. Tracy Wunderlich.

Amy, now a third-year medical student, has been working with the research team to identify common trends and experiences derived from living with the

effects of having been infected with polio early in life. Nearing the conclusion of her efforts, Amy created a poster which summarized the methodology and the results of her research and submitted it as part of the 10th Annual William Davidson Medical Education Week conference. Her poster (pg. 3) was awarded first place as the 2021 Poster Winner in the Education Research Category and displayed at the school for all to view.

Following Amy's final submission of the findings of her research, Drs. Taylor and Wunderlich plan to explore the possibilities of combining the results of the two post-polio studies with which SEMiPPSG has been involved to date with the intention of submitting for publication so that others can also benefit from the work.

In the meantime, we are discussing with Dr. Taylor a potential third post-polio project with another incoming medical student. And the members of the group are anxious to again share their experiences to further increase awareness of polio and post-polio syndrome among the staff and medical students of OUWB and beyond. ■



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*Post-Polio Health International's mission is to collect, preserve and make available research and knowledge to promote the well-being and independence of polio survivors, home ventilator users, their caregivers and families, and to support the health professionals who treat them.*

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Send us your second address and dates you will be there and we'll do our best to send you newsletter.

# Post-Polio Research Update

Aug. 28, 2021

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## 1

### INTRODUCTION

Prior to the development of vaccines in 1954 and 1960, polio virus infected over 55,000 children per year in the United States; approximately 21,000 of those infections lead to paralysis. 30-40 years following recovery from polio virus infection, many survivors suffer from post-polio syndrome (PPS) – a new weakening in muscles that were previously affected by polio, as well as in muscles that were not originally affected.

There are no studies to the authors' knowledge that explore the combination of polio experience and PPS, major experiences that polio survivors share in terms of life history, and how they managed to deal with certain disruptions in their lives, such as being taken away from school and separation from family.

## 2

### OBJECTIVE

The objective of this mixed-method study is to explore the intersection of quality of life and life course theory as it relates to a sample of polio survivors in the United States by working with the Southeast Michigan Post-Polio Support Group.

## 3

### METHODOLOGY

- Open-Ended Questions & T/F Quality-of-Life Surveys
- 3 Focus Groups & 6 One-on-One Interviews
- Developed a script for questions and used rev.com for transcription following analysis by at least 2 research personnel
- Approved by OU IRB: 1400610-1

## 4

### RESULTS

It is the tiredness that gets you down (n = 18)

True 12 (66.67%)  
Not True 6 (33.33%)

I would much rather do things by myself but I cannot (n = 18)

True 12 (66.67%)  
Not True 6 (33.33%)

I have lost friends as they do not understand my condition (n = 17)

True 2 (11.76%)  
Not True 15 (88.24%)

I worry I am not going to get better (n = 18)

True 8 (44.44%)  
Not True 10 (55.56%)

I do not want to have to ask other people do things for me (n = 16)

True 11 (68.75%)  
Not True 5 (31.25%)

## 5 RESULTS

### Poliomyelitis Survivors & Common Themes of Their Stories

01

#### Stigma

Even long after we had polio and we were, you know, fine, people said 'Oh, kids can't play at your house because that's a polio house.' ... I remember our neighbor had a Slip 'n Slide and he said 'Oh, you can't go on it because you had polio and we might get it.'"



02

#### Isolation

"The [hospital] had to have their own spinal tap, [my second one of the day]...so a few more men held me down there. They put me in a room with an iron lung, a small room. There was just a bed and the iron lung and they shut the door because I was crying so much. And I just, I mean, I remember that horror."



03

#### Acceptance

"I never learned to ask for help. It's what I have done for myself. I changed that stinkin' thinkin' that I had that I didn't need anybody and I do need people"



04

#### Positivity

"Thinking back, my life would not be as rich and full as it is today if I had not had polio"



05

#### Social support

"He [my husband] keeps encouraging me and telling me that 'hey, you're doin' good.' So I just um, I say to myself I know I'm doing good."



06

#### Determination

"We attended regular school. It was initially recommended that we attend handicapped school. [Mom] said there was nothing wrong with our minds, so off to regular school we went. We did just fine."



## 6

### CONCLUSION

**Quantitative:** The significance of having kids with worrying less about health conditions deteriorating or health not getting better shows that support systems plays a big role in health outcomes on patients living with chronic conditions. The sample questions show that survivors want to be independent.

**Qualitative:** Major themes highlighted on the left shows that chronic illness has major implications on life and physicians need to be aware of them when treating patients.