WE’RE STILL HERE! What Having a Disability Taught Me

PHI invites you to participate in its 2013 WERE STILL HERE! campaign during the week of October 6-12 by speaking to students in your local elementary, middle and high schools.

Why would they want to hear from us? What would we want to tell them? What is the purpose of telling an experience or two from our lives? How would we decide what to say?

We want to send the message to our children and youth that having a disability is part of the human experience and that the experience taught us lessons that helped make us successful. We will be reminding them that we all have more in common than we have as differences.

Think about it. Can you synthesize what having had polio taught you that would be a good and positive lesson for our youth? It would be a great time to show off your wheelchair, your brace, your ventilator and how equipment grants you independence. (Maybe you will inspire a future rehabilitation engineer!)

You could tell them about your education, and how important it was to your success in life. Was there a special experience during your school days that was a significant factor in your success? (Staying in school and graduating from high school is an important message.)

This is probably not the time to tell about that kid who picked on you all through high school … unless asked. Or about the fear you experienced while in the iron lung … unless asked.

Start with the principal. Summer is a good time to contact your local school principal to discuss a visit to one of the classrooms. Whether you choose elementary, middle or high school depends on your background and is up to you.

Here are some ideas and excellent resources for you to share with the principal and faculty.

**For lower elementary**


**For upper elementary**

*Small Steps: The Year I Got Polio* by Peg Kehret, well-known children’s book author. Kehret has won many awards and many children in grades 3-8 will have read *Earthquake Terror, Escaping the Giant Wave, Trapped* and *The Ghost’s Grave*.

Kehret has a website – www.pegkehret.com – and a Facebook page. There are reader’s guides available online for *Small Steps*. It is also available as an audio book.

*Libby and the Cape of Visitability* by Eleanor Smith and Nadeen Green (e-book). This book is the diary of Libby, a KWD (Kid with Disability). Written for children ages 8-13, this book raises awareness of the exclusion created when houses are not built with simple features that allow wheelchair users to visit or live in them. It provides not only a captivating story and relatable characters, but a reader’s guide with discussion questions and resources as well.
For middle and high school

**Polio: An American Story** by David Oshinsky “tells the gripping story of the polio terror and of the intense effort to find a cure, from the March of Dimes to the discovery of the Salk and Sabin vaccines – and beyond.”

**Paralysed with Fear: The Story of Polio** by Gareth Williams is the story of mankind’s struggle against polio that is “compelling, exciting and full of twists and paradoxes. One of the grand challenges of modern medicine, it was a battleground between good and bad science. He takes an original view of the journey to understanding and defeating polio.”

**Biographies of Disease: Polio** by Daniel Wilson “draws on recent scholarship to provide the most current portrait of polio available; written in an engaging, non-scholarly fashion to make the science of polio accessible to readers of all kinds.” *Biographies of Disease* is a series of books written specifically for high school libraries.

To find an extensive list of books about polio and the polio experience, visit PHI’s Polio Place at [www.polioplace.org/resources/books](http://www.polioplace.org/resources/books). Some books are appropriate for biology and psychology classes, in addition to history.

**Polio Place** lists a variety of DVDs at [www.polioplace.org/resources-multimedia](http://www.polioplace.org/resources-multimedia) that could be shown, including the classics *A Paralyzing Fear: The Story of Polio in America* directed by Nina Seavey and *The Polio Crusade* from *American Experience* video series by filmmaker Sarah Colt.

**What Having a Disability Taught Me**

**Learning from Wise Elders** ([www.polioplace.org/sites/default/files/files/Tenth_International_Conference.pdf](http://www.polioplace.org/sites/default/files/files/Tenth_International_Conference.pdf), pages 30-33) by Sunny Roller, MA, Mary E. Switzer Distinguished Research Fellow National Institute on Disability and Rehabilitation Research, Ann Arbor, Michigan, revealed that post-polio mentors coping strategies included having a strong social support system, enjoying life and being optimistic. Self-acceptance, assertiveness, education and spirituality also were mentioned as beneficial to living life with polio.

Roller concluded, “Over time, perception of life with a disability from polio changed for this group. Before encountering the late effects of polio at mid-life, individuals operated and worked hard using their ‘lens of difference,’ a self-perception that rejected the shame and prevalent social stigma of disability. High achievement was crucial.

“Later in life post-polio mentors became more willing to look at their lives through the ‘lens of disability,’ more fully embracing their disability as part of their overall personal identity. In so doing, they found a new freedom to be more content with this new self-perception and life in their retirement years.”

Can you identify with this? Has your perception changed? What wisdom have you acquired? Be a part of WE’RE STILL HERE! 2013 and tell a short story from your life’s “book” to the younger generation in your community.

**PHI’s Polio Place** ([www.polioplace.org](http://www.polioplace.org)) is collecting Essays and Artifacts or Memorabilia accompanied by recollections. Send your “What Having a Disability Taught Me” to info@post-polio.org, so others can learn from you.