Whatever Happened to Polio?

What We Were Thinking

Katherine Ott, Smithsonian Institution, Washington, DC.

Ott is the project director and lead curator for the exhibition, “Whatever Happened to Polio?”

After three plus years of development, Whatever Happened to Polio? has opened at the Smithsonian's National Museum of American History and on the web (www.americanhistory.si.edu/polio).

For many people who lived through the epidemic years, polio inhabits a place in the imagination – a mythic, anxious or nostalgic place – a complicated place that the museum had no possibility of re-creating. The hundreds of possible story lines made it frustrating to accept that the exhibition could never be comprehensive, so the reliance upon objects helped us winnow the topics. We did not want to simply repeat what was available in books, because until this year with Wilson and Shell's books (See pages 4 & 5.), most histories of polio concentrate on Salk, Sabin and the vaccines. People who had polio only make cameo appearances for dramatic effect, usually as children and cautionary reminders.

Over time and after many conversations with friends and colleagues in disability studies, it became clear that the people who had had polio would be the counter-weight to the story of the medical breakthrough of the Salk vaccine. The vaccine was the occasion for producing the exhibit, but it was only a piece of history. Our plan was to encourage people who had strong memories of polio to step back and re-frame what they know and, secondly, to hook those less than 55 years old on the history of the vaccines, the facts about the disease and on the people who had it.

We wanted to capture the idea that polio was not the worst thing that could happen to a person – people still had to get an education, have a family, a job, and do what everyone else does. Numerous photographs are located along two walls of the gallery, displayed like a family photo album, so their presence is always apparent, wherever you move. (See top of page 3.)

continued on page 2
Presenting topics for which there is a living constituency always adds intensity and heightens the meaning of everything related to a project. This project had urgency to it because of the health of many of the people with whom we worked. In fact, three people who had polio died before the exhibition opened, and they never saw the final product.

We knew people who had lived the history would minutely scrutinize the exhibit to see if we "got it right," so we decided to use first-person quotations rather than the dispassionate curatorial point-of-view to carry the history. In addition, we had to navigate the intricate politics of polio — the many points of view and competing interests — to show how they all influenced the history of polio.

For curators, gallery behavior is always critical in judging the success of a project. Audience testing early in the polio project revealed that only thirty percent of visitors had an interest in an exhibition on the history of polio. Consequently, we have worked hard to make the exhibit enticing and have put extra money into effective advertising. (See ad at left.)

Because we hired an educator to work in the gallery, lead activities and coordinate the docents, we receive constant feedback. The gallery hands report that many visitors are multi-generational groups. The parents and grandparents can be seen pointing to an object or photograph and leaning over to tell a child about it. Some visitors are talking about personal experiences with their families for the first time. Other visitors are so affected by some aspect of the history that they make a beeline to the educator and spill out the story of their parents or their own childhood or a neighbor. The comment cards are filled with the polio stories of visitors. Needless to say, it is personally gratifying to see how visitors have taken to the exhibit.

The online exhibit is at www.americanhistory.si.edu/polio.

The website includes more information than the exhibit, including additional photos and activities for children, e.g., a section called "Got Ramps," an architectural barriers game that demonstrates the changes in accessibility over the years.
The *Whatever Happened to Polio?* exhibit would not have been possible without the many archival photographs from past issues of the Toomey J. Gazette and Rehabilitation Gazette that Gini Laurie, the founder of Post-Polio Health International, had published over the years. Or at the very least, the exhibit would have ended up very differently without them.

A year and a half ago, Joan L. Headley, the current executive director, invited me to the Post-Polio Health International office in Saint Louis, Missouri, where polio survivor Cyndi Jones, San Diego, California, and I poured over a cache of images from the 1950s and 1960s.

I was stunned by both the number and content of the photographs and quickly begged Joan to allow the museum to borrow many of them. She agreed, and I selected a hundred or so, not quite knowing how we'd use them. I was convinced of their value in capturing people's lives, such as going to parties and picnics, hanging out with family, getting married, etc. A keepsake album, compiled by her friends at Toomey Pavilion and given to Gini Laurie when she left Cleveland for Saint Louis in 1971, contained many everyday snapshots and informal pictures and planted the seed of the idea for the gallery photo album.

-Katherine Ott, Smithsonian Institution, Washington, DC

**Whatever Happened to Polio?**

The triangular kiosks and wall displays in the 2,900-square-foot exhibition asks and answers, with memorabilia and pertinent and poignant quotes, the following questions.

- What Is Polio?
- What Happened in the Epidemics?
- What Do These Devices Do?
- What Is an Iron Lung?
- What Happened after Polio?
- What Did a Dime Do?
- Would a Vaccine Work?
- Will There Always Be Polio?
- How Did Polio Change Us?

The exhibit is located at the Smithsonian National Museum of American History Behring Center and will be on display for the coming year.
Review of Living with Polio

Joan L. Headley, Executive Director, Post-Polio Health International, Saint Louis, Missouri

Daniel J. Wilson, a polio survivor, is professor of history at Muhlenberg College, Allentown, Pennsylvania. The simple title of his most recent book, *Living with Polio*, foretells the content of the book but belies its thoroughness. And, his book is not difficult to read.

Wilson explores living with polio from the dreaded phrase “I’m Afraid It’s Polio” to “An Old Foe Returns: Post-Polio Syndrome.”

The content of the book is compiled from Wilson’s research of over 150 polio narratives. In the introduction, he explains the value and limitations of these narratives. Throughout the text, he describes each phase of living with polio, based on the words of specific narratives while drawing conclusions without overgeneralizing or making the polio experience fit a preconceived mold.

Polio survivors who read the book will “find themselves” and will gain a better understanding of their fellow survivors’ experiences. Busy health professionals will be able to read specific chapters, e.g., about medical treatment during the acute phase and polio rehabilitation, and, because of its thoroughness and minor repetition, gain useful insights for treating polio survivors today.

Wilson’s book contains photographs from the March of Dimes collection, which, in combination with the text, creates a book that fills a gap in the literature. Because it is a compilation and is well documented, readers of *Living with Polio* will learn about the breadth of the American polio experience.

I read the majority of Wilson’s book in Parc de La Tête d’Or in Lyon, France, while there to speak at the 10th International Conference on Home Mechanical Ventilation, and agreed with him as he pointed out that many, if not most, polio survivors never put polio in the past, but live with its consequences every day.

As I sat under a rose trellis in the same park writing my reaction to this book, I observed three gray-haired ladies coming towards me on the path. One had a left arm hanging limply to her side. On this beautiful clear sunny April morning she was strolling with her friends, clutching her handbag with her “good” arm and pointing out flowers with her feet. Now, that’s “Living with Polio.”

OTHER TIMELY BOOKS FOR THE 50TH ANNIVERSARY COMMEMORATION

*Splendid Solution: Jonas Salk and the Conquest of Polio* by Jeffrey Kluger, a senior writer for *TIME*, is a 373-page, illustrated book published by G.P. Putnam’s Sons ($25.95). Kluger tells the story of Jonas Salk’s quest to conquer polio in a “medical adventure full of rivalries and last minute reversals that culminated in one of the greatest accomplishments of the 20th century.”
Jerome Groopman of The New York Times describes the book as a "colorful and fast-paced narrative (that) brings Salk to life as a brilliant and determined man who, above all, believed in the probity of his ideas. His precocity was apparent to all, and made him both a leader and a target at every stage of his career."

Polio: An American Story by David M. Oshinsky, a University of Texas history professor and polio survivor, is an illustrated 342-page book published by Oxford University Press ($30).

According to Jerome Groopman of The New York Times, the book "frames the conquest of polio within the cultural upheavals of the time. Polio: An American Story is a rich and illuminating analysis that convincingly grounds the ways and means of modern American research in the response to polio."

Oshinsky's book, based on the Salk and March of Dimes archives, covers the bureaucracy behind the fight against polio and the development of modern philanthropy.

Polio and Its Aftermath: The Paralysis of Culture by Marc Shell, the Irving Babbitt Professor of Comparative Literature and Professor of English at Harvard University, will be available soon. Written by Shell, a polio survivor, the book is described on the publisher's website (Harvard University Press, www.hup.harvard.edu) as conveying "the widespread panic that struck as the disease swept the world in the mid-fifties" and revealing "why, in spite of the worldwide relief that greeted Jonas Salk's vaccine as a miracle of modern science, we have much more to fear from polio now than we know." The hardback will retail for $35.00.

Other Not-so-Light-but-Useful Summer Reading


Silver reviews the causes and characteristics of chronic pain and explores its impact on individual family relationships and on the extended family, covering such issues as employment, parenting, childbearing and inheritance, and emotional health. She treats aspects of chronic pain not covered in a typical office visit: how men and women differ in their experience of chronic pain; the effect of chronic pain on a toddler's behavior or an older child's performance in school; the risks of dependence on and addiction to pain medications; and practical ways for relatives beyond the immediate family circle to offer help and support to the person in pain.

Silver is the Medical Director of International Rehabilitation Center for Polio at Spaulding-Framingham Outpatient Center, and Assistant Professor of Physical Medicine and Rehabilitation at Harvard University.

Recent books by polio survivors

The Red Brick Birdcage by Michael Creurer; August 2004; ISBN 0-9683489-6-3; $18.00 Canadian; SFC Inc., Box 5664, Victoria, BC, V8R 6S4, Canada (250-598-7914 fax)

The Little Red Chair by Alan M. Malizia; September 2004; ISBN 1-4140-2837-7; $12.50; AuthorHouse™, 1663 Liberty Drive, Suite 200, Bloomington, IN 47403 (800-839-8640, www.authorhouse.com)
In Search of the Perfect Mini-Van
Pat Novak, Oak Harbor, Ohio, patngene@nwonline.net

Recently, my husband and I decided to purchase a new mini-van that would accommodate my Lark three-wheeled electric scooter that is 24” wide and 43” long. Our priorities for our search included buying a product made in America, as well as a vehicle that would allow some use of the third piece of plywood, or even a piano, as we once did with our former vehicle, a 1996 Dodge Grand Caravan.

What we discovered was that almost every mini-van now has some form of seating that folds into the floor. This type of seating severely hampers the flexibility for mounting a scooter lift at the rear and for moving the seats. With Chrysler’s “Stow-n-Go,” the 40% side of the split third seat would either have to be permanently “stowed,” or the lift installed partially in the well preventing the seat from ever going flat. The scooter would then go length-wise onto the stowed 60% side, thus either no use of the third row, or at best only the 40% side.

The Ford Freestar has a bench seat that doesn’t move forward or split, and folds down into a well. However, there’s no room for a scooter with the seat up. The new Ford Freestyle third row seat splits 50/50 and folds down, but the opening with one seat down wasn’t wide enough for the scooter.

General Motors has a new line of mini-vans: Chevy Uplander, Pontiac Montana SV6 and the Buick Terraza. On these vehicles, the third row does not move forward to allow space for a scooter. Also, the seats that split 50/50 fold forward and flat, but then leave an awkward raised floor, which makes it impractical to place a scooter on this split-level floor.

Finally, after looking at many vehicles, we found one that suited our needs.

Wheelchair Getaways provides short-term and long-term rentals of vans equipped with raised roofs or lowered floors, wheelchair lifts or ramps, plus interiors and tie-down systems. Some vehicles are equipped with power doors, outside-entry controls, six-way power seats in the driver’s position, and hand controls to maximize independence. For more information on renting a van from the Wheelchair Getaways nearest you, call 800-642-2042 or visit www.wheelchairgetaways.com.
We purchased a late 2004 model Pontiac Montana (not the newer SV6 model). The 50/50 third row seats “tumble” forward (no wells), and we had our Ranger Atlas lift installed. With both seats tumbled forward, the scooter easily fits behind the seats. If desired, one of the tumbled seats can be raised back up after the scooter is placed in the van. While it is awkward to do, after the scooter is in, the lift can be removed, placed elsewhere in the van, and, with some jockeying of the scooter, both seats can be raised. This is not easy, and we would only do it under extreme need. But, at least using half of the third row is reasonable. Also, the seats and the lift can be removed for full use of the van, when not needing the scooter. The Uplander Chevy Venture has this same arrangement, but none of the other amenities.

It is a shame that American car manufacturers don’t have persons with disabilities in mind when designing vehicles. If you’re searching for a mini-van to accommodate a scooter, we hope the story of our quest will be of help to you.

Fish such as mackerel, lake trout, herring, sardines, albacore tuna and salmon contain two omega-3 fatty acids – eicosapentaenoic and docosahexaenoic acids (EPA and DHA). A third kind, alpha-linolenic acid, is less potent. It comes from soybeans, canola, walnut and flaxseed, and oils made from those beans, nuts and seeds.

Flaxseed oil and flaxseeds (which need to be ground into flaxseed meal to be properly utilized by your body) each provide omega-3 fatty acids. Research shows that the omega-3 fatty acids, especially those in fish, have cardioprotective benefits, but that all omega-3 fatty acids, including alpha-linolenic acid, the one in flaxseed, are needed for good health.

Flaxseeds are also a great source of soluble fiber as well as providing thiamin, riboflavin, niacin, trace minerals and even some high quality protein. You must consume them because your body cannot manufacture them.

To add this supplement to your diet, you can either use the flaxseeds whole or use the flaxseed oil. Practically, it is easier to use the oil and not have to bother with grinding the seeds. Remember, the oil must be refrigerated so that it does turn rancid.

Nutritionally, flaxseeds will give you more bang for the buck. They have a pleasant, nut-like flavor and taste good sprinkled on a variety of foods. You must either chew the seeds very well or grind them, because whole seeds pass through the body without their essential nutrients being absorbed. You can purchase ground seeds, but they are much more perishable than the whole seeds. Either way, they need to be kept in the refrigerator, too. The seeds can also be bought in bulk and kept in the freezer for even longer storage.

The recommendation for adults is to use one or two tablespoons of flaxseed meal or oil daily. You can stir it into hot cereal or into your juice. It can also be used as a replacement for an egg in some recipes such as muffins or pancakes. To replace one egg, use one tablespoon flaxseed meal plus three tablespoons water (or other liquid). You can also mix one to three teaspoons of flaxseed oil with a little ketchup as a condiment. Be careful not to exceed recommended amounts as flax can have a laxative effect.

The bottom line is that flax, in either form, promotes heart and colon health, healthy skin, and helps to stabilize blood sugar. However, as any dietary supplement can have the potential for side effects and interactions with medications (both prescribed and over the counter), please check with your health care provider before adding this or any supplement to your diet. The Food and Drug Administration (FDA) recommends that consumers not exceed more than a total of three grams per day of omega-3 fatty acids, with no more than two grams per day from a dietary supplement.

Jann Hartman, a polio survivor, has a degree in Home Economics and Nutrition and has written and lectured on nutrition for the past 20 years.
FOOD GROUPS TO ENCOURAGE

♦ Consume a sufficient amount of fruits and vegetables while staying within energy needs. Two cups of fruit and 2 1/2 cups of vegetables per day are recommended for a reference 2,000-calorie intake, with higher or lower amounts depending on the calorie level.

♦ Choose a variety of fruits and vegetables each day. In particular, select from all five vegetable subgroups (dark green, orange, legumes, starchy vegetables and other vegetables) several times a week.

♦ Consume three or more ounce-equivalents of whole-grain products per day, with the rest of the recommended grains coming from enriched or whole-grain products. In general, at least half the grains should come from whole grains.

♦ Consume three cups per day of fat-free or low-fat milk or equivalent milk products.

FATS

♦ Consume less than 10 percent of calories from saturated fatty acids and less than 300 mg/day of cholesterol, and keep trans fatty acid consumption as low as possible.

♦ Keep total fat intake between 20 to 35 percent of calories, with most fats coming from sources of polyunsaturated and monounsaturated fatty acids, such as fish, nuts and vegetable oils.

♦ When selecting and preparing meat, poultry, dry beans and milk or milk products, make choices that are lean, low-fat or fat-free.

♦ Limit intake of fats and oils high in saturated and/or trans fatty acids, and choose products low in such fats and oils.

CARBOHYDRATES

♦ Choose fiber-rich fruits, vegetables and whole grains often.

♦ Choose and prepare foods and beverages with little added sugars or caloric sweeteners, such as amounts suggested by the USDA Food Guide and the DASH Eating Plan.

♦ Reduce the incidence of dental caries by practicing good oral hygiene and consuming sugar- and starch-containing foods and beverages less frequently.

SODIUM AND POTASSIUM

♦ Consume less than 2,300 mg (approximately one teaspoon of salt) of sodium per day.

♦ Choose and prepare foods with little salt. At the same time, consume potassium-rich foods, such as fruits and vegetables.

ALCOHOLIC BEVERAGES

♦ Those who choose to drink alcoholic beverages should do so sensibly and in moderation – defined as the consumption of up to one drink per day for women and up to two drinks per day for men.

♦ Alcoholic beverages should not be consumed by some individuals, including those who cannot restrict their alcohol intake, women of childbearing age who may become pregnant, pregnant and lactating women, children and adolescents, individuals taking medications that can interact with alcohol, and those with specific medical conditions.

♦ Alcoholic beverages should be avoided by individuals engaging in activities that require attention, skill or coordination, such as driving or operating machinery.
In Appreciation

We thank our supporters for their contributions to our work ...

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We thank our supporters for their contributions to The Research Fund ...

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Stephen J. Ellen, MD
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Special Thanks

Michelle Guevin, PT, MTC, Clinical Director and owner of Bay Area Physical Therapy and polio survivor Marge Torre of Bradenton, Florida, hosted an informational meeting about the late effects of polio on February 19, 2005, at Manatee Community College.

Approximately 55 people had the opportunity to hear and question the guest speaker, Frederick Maynard, MD, Upper Peninsula Medicine Associates, Marquette, Michigan. The donation collected to attend the meeting was given to Post-Polio Health International in honor of Dr. Maynard, President of its Board of Directors. Guevin has treated polio survivors in her private practice located at 3651 Cortez Road West, Suite 100 in Bradenton (941-739-7828) for several years.

Information available

The next issue of *Post-Polio Health* (Vol. 21, No. 3), scheduled for August 2005 will contain details on how to receive audiotapes, program booklets, etc. from the Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: STRATEGIES FOR LIVING WELL (June 2-4, 2005). The same information will be posted on our website – www.post-polio.org – by late June.

The Research Fund

We want to thank the Members of Post-Polio Health International who responded immediately to our annual appeal letter for funds earmarked for research. The fund continues to grow and provides much-needed support to qualified researchers exploring important questions of concern to polio survivors. As Dr. Kalpakjian stated in the letter, “no donation is too small.”

Letter to the Editor

“I got a laugh out of the article, ‘Transition from a Metal/Leather Leg Brace to a Plastic/Metal Hybrid’ in the last *Post-Polio Health*. Let me share my experience.

“I had polio in 1939 at age 13. After I learned to walk on crutches, dragging my left leg, the doctor decided I needed a long leg brace. This was about 1940 in El Paso, Texas. He gave us an address that turned out to be the Iron Salvage Yard. The owner searched until he found something he thought he could make a brace out of. He lifted me up onto his desk and made a drawing around my leg and took measurements. The finished brace, made of iron and leather, was very heavy and was attached to a ‘stout’ shoe. It had two locks on each side of the knee, so I had to use both hands to unlock and lock it. Wherever the metal touched my leg, it left a red rash. Today, I also have a plastic brace. It is amazing what has happened in the polio field since I had it sixty-six years ago.”

-Eleanor H. Heisler, Moultrie, Georgia
Note Cards Available!
Post-Polio Health International remembers the survivors of polio...

To commemorate the 50th anniversary of the development of the Salk vaccine, Post-Polio Health International chose to honor those for whom the vaccine was too late. Since its inception in 1958, the organization has focused its resources and efforts on improving the health and independence of polio survivors and ventilator users and is committed to continuing this practice.

Artist Deborah Goodwin and polio survivor Mickie McGraw teamed up to create a visual reminder that millions of polio survivors are citizens of the world community who are in need of information, advocacy and research. (The artwork is in shades of blue and yellow with green accents.)

The nautilus shell represents an external stillness and static mobility. Contained and protected within is a rich and active life force that radiates outward from the central creation point of its spiral to reach beyond the limits of its boundaries.

The butterfly depicts the ephemeral, unique beauty of each life that begins encased within a cocoon and emerges in its time, transformed, to color the world and give wings to the future.

Together they celebrate our human potential to transcend limitations. They commemorate the 50th anniversary of the development of the Salk polio vaccine, which forever changed our lives and our future.

Please send _____ sets of the 50th Anniversary Commemorative Note Cards.
For larger orders or international orders, please contact 314-534-0475 or info@post-polio.org.

TOTAL AMOUNT FOR ORDER: $___________

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THE MISSION OF POST-POLIO HEALTH INTERNATIONAL, including International Ventilator Users Network ... is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

Did you know?

Of the active ingredients in mosquito repellents registered with the Environmental Protection Agency, products containing these ingredients typically provide longer-lasting protection than others:

- DEET (N,N-diethyl-m-toluamide)
- Picaridin (KBR 3023)

In two recent scientific studies, oil of lemon eucalyptus [p-menthane 3,8-diol (PMD)], a plant based repellent, was tested against mosquitoes found in the US and it provided protection similar to repellents with low concentrations of DEET.

Information about Ventilator-Assisted Living

(Second Edition) is a 16-page brochure available in print. Single copies are free; bulk pricing is available. Contact International Ventilator Users Network (IVUN), an affiliate of PHI, at 314-534-0475 or ventinfo@post-polio.org.

The Spring 2005 issue of Post-Polio Health features ...

Polio Exhibit Opens at the Smithsonian ... In Search of the Perfect Mini-Van ... What About Flax Seed? ... and more!

POST-POLIO HEALTH

POST-POLIO HEALTH INTERNATIONAL
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