

August - Sept 2011
Southern Arizona
Post-Polio

Support Group

Est. 1985

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POLIOEPIC, INC.

Dear Members,

As my term comes to a close I have been reflecting on those members who died recently. In May we lost Charlie Minner who was an extraordinary man. When we gathered to memorialize Charlie I recognized that I only knew a fraction of his life and after hearing others speak about Charlie and the way he lived and loved and shared life, I wish I had know more about him all along.

In July we lost Ed Boyles who has been our major link to Rotary International. Part of their mission is to eradicate this disease worldwide, the disease that many members knew little about. Thru Ed we began a speakers group to present information about polio and post polio to Rotarians one group at a time and give greater dimension to their mission. Ed's life dream was to see his pre and post polio and military life story published. Shortly after his book signing event, Ed succumbed to his illness.

In July we lost Joseph Duchene who was a quiet uninvolved Polio Epic member but another extraordinary man who gave great testimony to what we can become thru our passion to rise above life's obstacles.

Sadly many lives only stand out when we hear their stories after they are gone. Look around at those still with us who lead lives that are colorful and profound and influential and emulate-able. When we see them and listen to them and absorb them we also validate them and isn't it a welcome and wonderful sensation, to be validated and respected and appreciated.

As Micki Minner enters, for her second time, into the Presidency this coming September, I see a compassionate person who has a keen sense of understanding this medical condition and we are blessed with her dynamic leadership. To know Micki is to recognize her great strength. I am pleased that even after her loss of Charlie, she will guide Polio Epic forward as she did once before.

For your support in all its forms during my time as president, thank you.

Frank Frisina



Hello again,

I only hope that I can live up to Frank's words of praise. As always, the Polio Epic group has been dynamic, powerful and supporting. Let's all continue the great work, and do not hesitate to call me with any ideas, suggestions, or questions. We are all in this together, and it's a pleasure to travel the route with all of you. Micki Minner

**Membership
Meetings
every
Second Saturday
of the Month
10:00A.M.
Education Room
HealthSouth
Rehabilitation
Hospital
2650 N. Wyatt
Road
Tucson, AZ**

July – August

Take the summer
off, have fun, enjoy
and come back
when the Tucson
Weather cools, and
see you in
September !

The next
general
membership
meeting is
September
10th.

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The Telegraph--Monday 04 July 2011

Even though there are still 120,000 people in Britain with Post Polio Syndrome, most of whom who contracted the disease in the 1950s epidemic, they have been "forgotten" and the medical community has "no real understanding" of their problems, believes the British Polio Fellowship.

It has carried out a study into the long-term effects of PPS, a devastating neurological condition which affects four in five people who get polio.

Pam Jones, chairman of the British Polio Fellowship, said: "The tens of thousands who contracted polio in the epidemics of the 1950s are still with us and are now facing years of crippling pain and fatigue without any medical support due to shockingly low awareness of PPS amongst health professionals."

POLIO – WORLD PHOTO SUBMISSION CONTEST

Polio-World is holding a photograph contest. Each photo should show the three phases of your Polio life 1) *Polio* 2) *Living with Polio* and 3) *Post Polio*. Below are some examples. We will be using the photos to demonstrate the concept "WE ARE STILL HERE". Post Polio Health International's-- WE ARE STILL HERE campaign will be the second week of October, 2011. The photos will be shown at various Post Polio conferences and educational seminars throughout the world. Send your photos to Mickiminner@msn.com, with a description of less than 50 words to describe the photographs.





What polio took away: Survivors seek the records that may fill in gaps in childhood

9:49 PM, Jun. 11, 2011 | DETROIT FREE PRESS

Bruce Sachs is shown as a boy when he fought polio.

Somewhere, someone may have the records. In some file cabinet, warehouse or

library.

For a survivor of what was once a whispered horror -- *polio* -- those documents might fill in gaps of a childhood fractured by comas and surgeries, isolation rooms and iron lungs, braces and grueling rehabilitation.

They also might provide clues for doctors trying to understand postpolio syndrome, a disorder that develops decades after the virus is gone. It happens when disease-weakened nerves and muscles -- and even their stronger counterparts -- finally give out. Many survivors are now returning to the braces and crutches they had worked so hard to leave behind.

Bruce Sachs, one of Michigan's estimated 12,000 polio survivors, said parents today can't understand the fear that seized the nation before April 12, 1955 -- the day a University of Michigan epidemiologist let the world know that Dr. Jonas Salk's vaccine was working. Six days later, the first Detroit kids lined up for shots.

Sachs, 71, of Mt. Clemens, who wears braces again, began looking for his records in 2003, about the time postpolio syndrome set in.

He's had more success than others, locating 15 pages from a northern

Michigan hospital -- documents that outline surgeries, including one in which ivory was used to even the lengths of his legs.

"I think a lot of it goes to the fact that for so many years, we denied it," he said.

"Now we all want to know more, to fill in the blanks from something that we tried to leave in our past."

Polio: When a nightmare comes back

Dianne Dych-Sachs was in denial until her ankle snapped.

For years, the medical technologist noticed her muscles weakening and her body tiring much earlier than her colleagues'. Sure, she had heard of postpolio syndrome; her sister -- also a polio survivor -- had sent her clippings and research articles.

But after all these decades, could her childhood polio still exact such damage?

"You're afraid. You're afraid to go back into braces," the 59-year-old Mt.

Clemens woman said. "You become successful, you go to college, you get married, and you have children, and you work, and you give your 100%. You don't want to go back."

But the syndrome, for which there is no cure, leaves no choice for up to half of the 440,000 polio survivors in the U.S. today.

It's unclear what triggers it. The syndrome can include new pain or weakness and daytime fatigue. It's generally diagnosed when doctors rule out other medical problems, said Dr. Ann Laidlaw, who cares for polio survivors at the University of Michigan's

Physical Medicine and Rehabilitation clinic.

The poliomyelitis virus is long gone from their bodies, of course, but once-weakened nerves and muscles are finally giving out.

Some theorize that to cope with the original disease, the body rewired some neurons to muscles that were weakened or disabled during the original infection. Those nerves served those muscles well for years, but essentially were overworked, Laidlaw said.

"It's like hooking up wires to 50 different appliances instead of three. After a time, they burn out," Laidlaw said.

As they deal with the syndrome, survivors search for medical records that are a half-century or more old. They've had limited success individually but are beginning to share stories and dig deeper through the Michigan Polio Network.

Survivors hope the records provide insight into treatment for the syndrome, though doctors are skeptical. But the records still might offer an important starting point for doctors born into a postpolio world, said Bonnie Levitan of Grosse Pointe.

When Levitan's right hand began losing its grip several years ago and her fingers began freezing in awkward directions, doctors were perplexed. Her 1951 admissions records from Children's Hospital of Michigan held the clue: Childhood polio paralysis had first settled in her right hand.

"When I went to doctors, they couldn't tell me what was going on," said Levitan, 70. "Now I could tell them." Locating the decades-old records is like the proverbial search for a needle, but

it's unclear where the haystack moved or even whether it exists anymore because of the many mergers and closings of hospitals over the years. Plus, state law allows for medical records to be destroyed after seven years.

Children's Hospital of Michigan, which was affiliated with the former Michigan Hospital School, began destroying polio patient records years ago because of space issues, officials said.

Some documents and pictures from the Sister Kenny Hospital -- part of a larger, national program that was located at the Michigan Hospital School -- were transferred to the Bentley Historical Society at the University of Michigan. Patient records were not, but it's unclear why.

Some patient records ended up in storage lockers or transferred as one doctor left his or her practice for another.

When it comes to finding records, "some are lucky, some are not," said Sue Hoyt, a staff member who fields survivor's calls at the Minnesota-based Sister Kenny Foundation.

Trying to be normal

A return of physical failings is especially difficult for survivors still haunted by childhood horrors -- they were sometimes cut off from their parents by doctors who felt the visits were disruptive.

Many remember spinal taps and hot wool soaked in boiling water and wrapped around their bodies to try to improve circulation and relax muscles. "There are survivors who, to this day, can't stand the smell of wet wool," said Levitan, who remembers her hospital isolation room and the sight of her

parents looking at her through a tiny round window in the door.

The goal as a kid with polio was clear: Be a "passer," said Levitan, a retired high school paraprofessional. "Your parents wanted you out of the hospital, to come back and become a passer. ... You wanted to become as normal-looking as possible, to pass for normal." At the St. John Providence Post-Polio Clinic in Warren, Dr. Daniel Ryan's patients are history lessons.

Some happily recall days at summer camps for disabled children, support through the national March of Dimes campaign and kind neighbors. They bring photos. Sometimes they cry. It takes a while, he said: "A lot of them are in denial. They were ostracized as children."

At last, a cure

In 1952, fear surged like never before: Reported cases peaked at 57,628 that year. In Michigan, doctors reported 3,912 new cases; 213 people died. But on April 12, 1955, in the Rackham Building on the U-M campus -- at a news conference crammed with reporters from around the country -- news broke with nine words: "The vaccine works. It is safe, effective and potent."

U-M epidemiologist Dr. Thomas Francis Jr. had been given \$7.5 million by the National Foundation for Infantile Paralysis -- money primarily collected through the March of Dimes -- to put Dr. Jonas Salk's breakthrough polio vaccine through field tests. The announcement was carefully guarded; the information was delivered by police car.

The U.S. licensed the vaccine the same day.

Later, Salks' vaccine would be replaced

by Albin Sabin's vaccine, carrying the live poliovirus and licensed in 1960. The two men would be forever credited with essentially eradicating the virus from the country and most of the world. The last case of polio reported in Michigan was in 1986.

All this was too late for Dych-Sachs and Debby Bookout, then 13-month-old twins from what is now Eastpointe. Dych-Sachs was diagnosed and hospitalized. A visiting nurse later saw her sister limping.

Both spent their childhood in braces paid for by the March of Dimes, the campaign created by another polio survivor, President Franklin D. Roosevelt.

Now Bookout is in a wheelchair and legally blind. Those and other health problems, she said, are part of tangled diagnoses of postpolio syndrome and multiple sclerosis. The latter -- she's convinced -- was brought on because of her polio-weakened body she had tried so hard to strengthen decades ago.

"Your dream as a kid is growing and being out of these braces," she said. Dan Matakas, 74, who contracted polio when he was 2 years old and later became a designer for Ford, remembers the day he ditched his crutches. He had just started at Cass Technical High School in Detroit, and the young teen left his crutches at home, opting for a slower, grueling gait so he wouldn't have to juggle crutches with heavy books.

He has always been active -- using his stronger muscles when he swam or bowled to compensate for those weakened by polio. But within the past year, he has noticed he can no longer lift his stronger, left leg to his bike pedal.

He uses crutches again.
The drive that was built into kids with polio, he said, also makes them unwilling today to give up easily on a search for medical records.
"A lot of polio survivors have a stubborn

streak or a survival streak," he said.
"Polio was a black mark on you, and so you tried to be as normal as you could. If they told us we couldn't do something, we'd find a way to do it."

Contributions and Donations



Ruth Creagh
Darryl Jakes
Jacquie Schmidle
*Frann Miescher



Condolences to the families

from Polio Epic,

to all the families and friends who have lost a loved one

Major Ed Boyles (Ret.)

Joseph Duchene

HELLO and WELCOME to our NEW MEMBERS
Be Sure to meet and get to know our new members!
Peter and Wallis Ann Anelli



FROM THE TREASURER...

The end of our 2010-2011 fiscal year is coming to an end August 31, 2011. That means as of September 1, 2011 your dues will be applied for the 2011-2012 fiscal year.

CHECK the date on the address label; if it says 2011, you are paid through August 2011. If it says 2012 then you are paid up!

Keep POLIO EPIC Up-To-Date:

Are you moving? Are you going to a cooler climate for the summer?
Please let us know...

- If you know you are moving, please contact us with your new address.
- If you are seasonal (snow birds), please remind us of your summer address and let us know approximately when you are leaving and when you are due to return. **THIS WILL HELP POLIO EPIC KEEP OUR RECORDS UP-TO-DATE**

Contact Nannoe if you have any questions at **520-797-6898** or email her at Nannoe1@aol.com. If you wish to receive our newsletter via email, be sure to add your email to the dues form and add Micki's email to your address book Mickiminer@msn.com

Vaccines and foreign aid: a shot in the arm that will be felt all over the world

Excerpted from The Telegraph.

Polio eradication is much closer. There are three types of virus and Type 2 was eradicated in 1999. As of June 8, 195 cases caused by the other two had been identified worldwide. Polio is very different from smallpox. Most infections are silent, and migration from one country to another by those who are well but shedding the virus has moved the disease effectively. There have been political objections to vaccination in some countries, so the final stages of eradication are hard. But there is enough optimism that success will come soon for detailed planning to have been done for the post-

eradication era. The main problem is that although, due to its ease of administration, oral vaccine has obvious advantages, it contains live virus that spreads from immunized individuals to the unimmunized. So to ensure extinction, surveillance and, where necessary, vaccination with dead vaccine will go on. The taxpayers' additional £814 million is going to a first-class humanitarian cause. That 1.7 million children die from vaccine-preventable diseases every year makes the case. But it is not just overseas aid; that money will also lead to the development of better vaccines which we can use, too.

Hugh Pennington is emeritus professor of bacteriology at the University of Aberdeen

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Name _____ Spouse/Partner _____ Date _____

Address _____ Phone (_____) _____

City _____ State _____ Zip _____

If you wish to receive our newsletter via email: _____

PLEASE PRINT CLEARLY

_____ I am sending in my/our annual dues of \$10.00 per person for 2010-2011 fiscal year.

_____ I am sending my back dues of \$ _____

_____ I am sending in a *tax-deductible* donation in the amount of \$ _____.

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_____ I am UNABLE TO PAY dues at this time, but wish to continue my membership and receive the newsletter.

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_____ Check here if you do not want your name, address, phone number and email listed in the
POLIO EPIC DIRECTORY

_____ I would like to be more involved in Polio Epic. Please contact me at the number above.

We welcome your comments and suggestions. Thank you!

Make checks payable to POLIO EPIC and return this form to: Polio Epic, P.O. Box 17556, Tucson, AZ 85731-7556

POLIO EPIC, INC



1985 - 2010

Wadleigh Grant

Could you use up to \$400.00 to help get the disabled help items you need?

Polio Epic, Inc., is accepting applications within it's membership for a one-time grant of financial assistance. This program is made possible by a bequest Polio Epic received from Frank Wadleigh, a long time member and supporter of our efforts. The purpose of the program is to improve the quality of life for members, while supporting the overall mission of Polio Epic. Reasons for requests can be as varied as the members making them, all are seriously considered

Contact: Dave Marsh at 327-3252 or davidmarsh74@yahoo.com