

Looking Back, Moving Forward

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Joan in the PHI office.

On August 17, 1987, I walked to the end of my dock, spit in the lake for luck, and headed to St. Louis, Missouri, to work for Gazette International Networking Institute (GINI).

I had celebrated my 40th birthday in May, and for me, 18 years of teaching high school biology by diagramming the inside of an earthworm and other representative animals, was enough. My expectation was to continue to be an educator, but behind the scenes, working with Gini Laurie, the organization's founder, and known by many as "the grandmother of the independent living movement."

I was hired by Gini and Judith Raymond. I was replacing Judith, who became Judith Fischer on September 14, 1987 when she married D. Armin Fischer, MD, a pulmonologist living in Southern California. Judith has remained a valuable friend and resource, and for 25 years has been a faithful volunteer for our affiliate, the International Ventilator Users Network.

I was hired to be a worker bee in support of Gini Laurie (www.polioplace.org/people/gini-laurie) as she accepted more and more speaking engagements and to assist in planning for the future of the organization, because on June 10, 1988, she would celebrate her 75th birthday. Within 22 months, she had major surgery for esophageal cancer and died. Future funding sources were not assured.

So now what? I had sold my house on the lake and left my teaching job in northeastern Indiana. Half joking, my parents had promised me that if this adventure failed, I could move back home. Now, I was facing that possibility.

The early '90s are a blur to me, and someday, I will re-read the board meeting minutes and my reports to better appreciate the many people and groups who were supportive, offered sage advice and provided me cover from the naysayers.

I, unlike some persons who had polio, never thought my polio was in the past or that I would never have problems. In the seventh grade, we received the results of a vocation test. My friend, Steve, commented, "This test must be wrong. You, the tomboy – a librarian?" I distinctly remember I had answered all the questions about the future with the most sedentary of responses, thinking, if I can't run as fast as my friends can now, what will I be like when I am old like my parents, then in their 40s.

My first exposure to anything "post-polio" was that the virus was re-activating. I wasn't prepared for *that*. In fact, looking for answers is how I found the GINI organization in 1984.

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Joan teaching biology in 1975

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"I have learned a lot ..."

My propensity to labor over decisions served me well, because it is coupled with the philosophy of not looking back – always looking forward. Gini asked me in my interview if I loved learning, "because that is why I love what I do." I said I did. She was right. I have learned a lot during the last 25 years and still learn each day.

I learned about polio, which had been a minor part of my life. I was 15 months old in August of 1948, the time I had polio. I was never hospitalized, but was left with permanent



Joan with a broken arm from falling off a bicycle in 1958.

visible muscle loss in my left hip and from the knee down, including my foot. I have a vague recollection of my mother showing me the front page story in our newspaper about the Salk vaccine. In elementary school, I recall looking in the *World Book* under poliomyelitis and was not impressed because the entry was so short. During the first month in St. Louis, I read John R. Paul's *A*

History of Poliomyelitis (Yale University Press, 1971). I was impressed.

Asked to introduce myself at my first support group meeting, I spoke of my education, and as I started to mention my last job, a lady interrupted, "No, no, we want to hear about your polio." I had the distinct feeling I disappointed them. Maybe this was the genesis of my insistence over the years that each polio person has an opportunity to speak for themselves and, perhaps more importantly, speak only for themselves.



The late Jack Genskow and Gini Laurie with Joan.

Once on the job, I had to learn the language of printers and editors and tried to improve my handwriting legibility. A former student once accounted for his grade improvement by stating, "I learned to read your handwriting." (I am sure Sheryl Rudy Prater, our unflappable graphic designer would heartily agree.) And, I definitely learned to appreciate my high school English teacher and diagrammed many a sentence in my head while editing and writing.

"Computers made everything easier ..."

I learned about computers and databases and longed for the day when all I needed to know about the computer was what button to push, like a telephone. That day arrived in the form of new technology and talented younger staff who know all the right buttons to push (and who learned to read my handwriting).

Computers made everything easier and faster – creating newsletters and directories, answering letters, seeking answers from experts, making mailing labels.

The Internet made everything and everyone's opinion available and freely accessible. The latter impacted us, because up to then, our organization was one of a very few that maintained a connection over the decades with polio survivors. We were a major creator, collector, screener and distributor of information about independent living, the late effects of polio



Gini Laurie and Joan at a Support Group Leaders Meeting in 1988.

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Joan (back row, left) with the PHI Board at a meeting in 1997.



and living at home with a ventilator – a trusted, accurate source. What was once available from us alone now appeared to be available from many sources.

Over the years, people have become very sophisticated, discriminating users of the Internet. We met this technology challenge, and today, we have a major online presence with three comprehensive websites and two Facebook pages, after successfully transitioning the GINI organization to Post-Polio Health International (PHI), a membership organization.

“... the early fight for disability rights”

As I learned more about polio, I read about independent living and the early fight for disability rights. I learned about the passage, in 1973, of the first federal civil rights protection for people with disabilities, Section 504 of the Rehabilitation Act, and the subsequent 28-day sit-in at the San Francisco federal building that forced the signing of regulations in 1977.

I learned that Gini Laurie was a member of the American Coalition of Citizens with Disabilities (ACCD), hosting the board in her home in St. Louis in the early '80s. By the late '80s, she was called one of the grandmothers of the independent living movement. If she was “one” who was the other?

I learned that another was Mary E. Switzer, who held several governmental positions at vocational rehabilitation, a program that assisted people with disabilities in getting an education, so they could get jobs and ultimately contribute to society.

I had a flashback: As I stepped up to pay my first semester bill for college, I was told that my fees had been lowered, “because you are handicapped.” I had never been called that, and I didn't like it, but I certainly accepted the money for the next four years. Since then, I believe that I have contributed to society, and I have paid taxes for more than 45 years.

“... independent living is a philosophy”

Today, independent living is often used to describe one of the levels in the living choices for people who are aging. To disability activists, independent living is a philosophy and it is the philosophy that guides our work. In a nutshell, PHI promotes the inclusion of people with disabilities into all of life's activities, such as getting an education, being employed, being part of family and having fun. Everything we do aims to help polio survivors be a part of life with its rights and responsibilities, its highs and lows, by providing information and a connection to people who share the common concern and experience.



Justin Dart (right), activist and advocate for people with disabilities, presents the Distinguished Service award to Gini and Joe Laurie on behalf of President Ronald Reagan in 1983.

Judith Fischer and Joan at the American Academy of Physical Medicine and Rehabilitation conference in 1997.



PHI's *modus operandi* for years has been one of not building an empire but of encouraging the creation of community-based independent groups. As I travel, I meet active post-polio groups whose current leadership has no idea that their origin can be traced back to us.

Inevitably, I am asked how many chapters PHI has. We have none. In the months after our founder's death, I sought out the advice of non-profit consultants. I was explaining to one about our network, and she quickly interrupted me saying with confidence and with an edge of pity, "Networks don't work." At that time, it seemed to me I had but one choice: make it work.

"... the glue that held polio survivors together"

A network is composed of independent parts working together as an interdependent whole. In our case, we wanted to continue to be "the glue that held polio survivors together." That goal was coupled with the idea that we wanted to help polio survivors to do for themselves – to help show them the way. I struggled with this idea because I wanted to "fix" things.

It finally became clear one day when Allen Goldberg, MD, an old friend of the organization, told me, "We are process people." Process is defined as a series of actions that produce a change or development; a method of doing or producing something; a forward movement. Our organizational goal has been to keep moving things forward – forward towards better health care, better access, better acceptance and inclusion.

I am convinced that our work has been about facilitating personal growth by being a post-polio resource that people can tap as they go about life. Let me interject here that I am prone to liking facts and action and less inclined to liking the purely inspirational examples of disability. I do admire, however, many people who had polio. As many have said over the years, "My choice was to be part of life or not to be part of it. I choose to be part of life." For some, that meant typing with their toes. For others, walking meant learning to walk a second time. For others, never walking became their normal; and for some, it was sleeping each night using a ventilator.

Our educational materials and opportunities help people, using polio survivor Hugh Gallagher's expression, "come to terms" with having had polio. Just last week, we were asked to mail information without a return address, so no one would know it was from a polio group. It was not unusual 15 years ago, for people – typically men – to call, ask many questions, and finally admit, they had never spoken with another person who had had polio. In fact, it was not that unusual for people to be the only person in their community who had polio or survived polio.

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Isabella Schwartz, MD, and Zeev Meiner, MD, with Joan at a conference on Post-Polio Syndrome in Copenhagen in 2011. Drs. Schwartz and Meiner and a team from the Hadassah Medical Center in Jerusalem received a \$25,000 grant from PHI's Research Fund.

Joan giving the keynote address in Osaka during Japanese Ventilator Users Network's Home Mechanical Ventilation Symposia (Sapporo, Tokyo, Osaka), 2004.



PHI Board President Marty Wice, MD, Joan and Jacquelin Perry, MD, at the 8th International Post-Polio and Independent Living Conference in 2000. Dr. Perry and Dr. Augusta Alba were recognized for years of dedicated service and support of polio survivors, combining medical expertise with practical advice.

“Success and a happy and useful life ...”

After acute polio, they went back to school with their old friends and, along with their parents, achieved what the literature of the March of Dimes stated, “Success and a happy and useful life are as possible for the infantile paralysis victim as for anyone else.” (*Doctor ... What can I do ...?*, The National Foundation for Infantile Paralysis, Inc., Publication No. 34, 7th Printing-Revised 1946.)

A few polio survivors took very active roles in the disability rights movement, changing lives by changing policy. Others became active when the late effects of polio were identified by founding support groups, providing very personal face-to-face opportunities fulfilling the self-help idea of “needing help, finding help, staying around to help others,” being involved in the process and helping others do the same.



PHI Board President Larry Becker (left), Joan and PHI Board member Marny Eulberg, MD, (right), served with representatives of the Warm Springs Institute for Rehabilitation as the organizing committee for PHI's 10th International Conference at Warm Springs in 2009.

Exasperated, one day she replied, “Well, I guess when they are all dead, she will be, too!” You know the question. Twenty-five years ago people were already saying, “No one gets polio anymore. Is there a job to do?”

The short and obvious answer is yes. What about the next 25 years?

“What about the next 25 years?”

I am pragmatic. Our numbers are decreasing. A way to slow or stop the deterioration of polio-affected nerves and muscles remains elusive and funding for research is limited. The early post-polio champions within the medical community have retired. Many early polio survivor advocates are deceased. The world's economy is unstable, affecting health care systems, retirement plans and social programs; political discourse is divisive, pitting one group against another.

I also am optimistic. The early medical champions left us their knowledge and PHI has captured it; the post-polio advocates showed us the benefits of speaking out and for ourselves. The Americans with Disabilities Act passed and progress is being made on the United Nations Convention on the Rights of Persons with Disabilities.

I live in a city that reports a murder or two every few weeks; a state that is famous for not acting until you “show me;” a state that ranks 36th in per capita expenditure for K-12 education; a state and city with a jobless rate of 7.3-7.5%; and a state that is caretaker to large stretches of the

Joan (back row, right) and the PHI board at the annual meeting in 2007.



Missouri and Mississippi Rivers – all issues I care about. It is becoming more and more difficult to know who to believe and what is fact about laws and policies that affect me personally. However, each time I vote, now, I ultimately vote for what I feel is in the best interest of us as persons aging with disabilities.

The cutbacks in health care and social programs increase the value of our work, making it more important, as it provides access to critical post-polio information and advice. PHI is a consumer-based organization that



Joan speaking at a rally in St. Louis in celebration of the 10th anniversary in 2000 of the passage of the Americans with Disabilities Act.

bridges the gap between survivors and health professionals. Polio survivors set the agenda of our activities; health professionals voluntarily contribute their expertise and advise us. The voluntary commitment of time and dedication by friends of PHI – both survivors and interested professionals – is humbling.

Over the years, I have communicated with hundreds of polio survivors and sent out tons of information. Early on, I thought, “now they have the answers,” but I quickly learned that

we each deal with our past polio and our new problems in our own way and in our own timeframe. I believe it is the best way. Having had polio is a unique and highly personal experience. Since I had polio at 15 months, a person who had polio is who I am and have always been.

“... there continues to be something new”

While many say there is nothing new, there continues to be something new for each of us. For me, it is new weakness in my left arm noticed about four years ago. (You only drop orange juice once, if you are the one who cleans it up.) For me, right now, targeted exercise eliminates my pain and reduces my fatigue. I assume this will change. In the meantime, I will go to the symphony, tend to my flowers, read the old classics and who-dunits and watch the St. Louis Cardinals play baseball.

I am comforted by knowing that PHI exists. I trust you are, too. ▲



Joan and Brian Tiburzi, Assistant to the Executive Director, in the St. Louis PHI office, 2012.