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## PHI Remembers Gini Laurie on the 30th Anniversary of Her Death



Gini Laurie

This June marks the 30th anniversary of the death of PHI's founder, Virginia "Gini" Grace Wilson Laurie. Sometimes referred to as the "grandmother of the independent living movement," Gini worked tirelessly for more than three decades as she campaigned against the institutionalization of people with disabilities, and for the rehabilitation and personal

assistance services that would make an empowered life possible for them in their communities. Gini worked to develop international networks of polio survivors and other people with physical disabilities, healthcare professionals in the field of rehabilitation, policymakers and disability rights activists. To mark this occasion, PHI asked those associated with the organization during her time and others that knew her to recount a memory or write some remarks on her considerable legacy.

### **Mickie McGraw**

I was 11 years old and a patient on the Toomey Pavilion polio ward at Cleveland's City Hospital when I met Gini Laurie in 1953. I will always remember that first meeting because, as I would later come to know, Gini was a unique, charismatic individual who made a lasting impression on those she met: I was lying in my bed waiting for afternoon therapy, when I heard a strange noise in the hallway outside of my door—I couldn't believe it, but I was sure I heard the crowing of a rooster and it was getting louder as it came closer to my room. Suddenly a tall, stately woman in a bright yellow volunteer uniform appeared in my doorway, where she finished off a rooster crow that would have wakened anyone within hearing!

The "rooster" turned out to be Gini Laurie. She introduced herself and told me about all the fun things we could do together, interspersing her introduction with a series of other animal calls, including a wonderful, barking, clapping seal. I didn't know it then, but my life changed from that day forward. Gini opened up a world of possibilities for me at a time when polio seemed to have temporarily set limits on my future. She helped me "see" a new self and to experience alternative ways of "being" that new self. Step by step, day by day, year by year, she mentored me and nurtured my gifts at the same time that she showed me ways to move through any challenges.

Gini was dedicated to her "Toomey" friends—she came in costumes, brought us colorful toys and games, cooked us pancake breakfasts, and seemed to know how to lift each of us up on those days we were down. And she was in it for the long haul—when we were discharged, she began the *Toomey Gazette* newsletter so we could keep in touch and support each other. Over the years in a variety of forms, the *Gazette* expanded to include all disabilities and thousands of related topics and is now the highly-respected Post-Polio Health International organization.

Though she had no guidebook or special training in rehabilitation or disability issues, Gini listened, learned and led. She opened her home and her heart and touched the lives of one person at a time. And through her publications, conferences and international outreach, she also significantly improved the lives of tens of thousands more through her positive impact on the disability rights movement. I am just one of her many "kids" as she called us—because of her, we are living productive lives around the world. I can still hear that crowing rooster and know she is urging us to carry on her good work!

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*Mickie McGraw is an Artist/Therapist, Co-Founder of Art Therapy Studio in Cleveland, Ohio and a founding member of early Rehabilitation Gazette Board.*

### **Joyce Tepley**

It was July of 1952. Cleveland, Ohio. The last polio epidemic was raging its way across the United States. I was nine years old and my brother was eight months old. We both got it, paralyzing his right arm and my back and legs. In the initial stage, we were treated at City Hospital. Polio wards were set up and hundreds of us were slowly recovering some of our muscles. After a month, my brother was sent home with care instructions. I could breathe on my own and regained enough strength to be transferred to a children's rehabilitation hospital for nine months of intense treatment learning to walk again.

I did not know it at the time, but while at City Hospital, I was put on a list by Gini Laurie to receive

a newsletter containing stories of children who got polio just like me. When I finally got back home, that newsletter, compiled and written by a woman who lived near me, became a major source of support. Like so many of us who got polio, we tried hard to live a normal life but felt isolated and not quite good enough. That newsletter helped me feel less alone because of our common experience.

I never met Mrs. Laurie until the late 1980s when she organized a polio conference addressing the new health problems people with polio were having. It was an honor to meet her and tell her how much a little girl appreciated her generous kindness that made a huge difference in my life.

*Joyce Tepley, LMSW, is retired from a forty-year career in social work and is the author of Thriving Through It – How They Do It.*

### **Allen Goldberg, MD**

As a young physician, I was given the assignment by Dr. C. Everett Koop, MD to find solutions for children who were “living” in an acute ICU on long-term mechanical ventilation with no place to go. I was led to a number of mentors who lovingly encouraged me (and my wife Evi) and guided our path. They included persons with disability from the polio era who were also dependent on long-term respiratory support (such as Margaret Pfrommer in Chicago). They were all inspired by Gini (and Joe) Laurie who shared their insights and knowledge and expanded our network of experienced leaders and mentors.

Gini was a loving person of the highest integrity with enormous ability to inspire all who knew her and were given the privilege of working with her. Our first partnering was the historic 1981 International Year for Disabled Persons Conference, “What Ever

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***PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.***

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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.

Happened to the Polio Patient?”, held with the sponsorship of The Rehabilitation Gazette, National Foundation-March of Dimes, The Rehabilitation Institute of Chicago, and Care for Life. This was followed by many other events and initiatives to provide consumer-directed information that has fostered the partnership between very special doctors (she called them “real doctors”) and disabled persons and their families.

My last meeting with her was with Dr. Augusta Alba. We talked about the future of our efforts. I remember most her energy and commitment and her encouragement to continue and expand our efforts. This was the beginning of many initiatives still going on today by many dedicated people around the world. I have been committed to keep the promise and am grateful for the partnership of Post-Polio Health International, including International Ventilator Users Network and the CHEST Foundation, which is focused on education of health professionals to promote the understanding of the principles we all learned from Gini.

*Allen Goldberg, MD, Master FCCP, Pediatric Home Health, Loyola University Medical Center (retired), is an honorary board member of PHI.*

### **Audrey King, MA**

It was 1980 and many Ontario, Canada post-polios were experiencing increasing health problems. We didn’t know where to turn. Since the advent of the polio vaccine it seemed like all medical interest and professional expertise in helping people with polio paralysis had disappeared. My search for answers led me to the Rehabilitation Gazette which featured a news item about an upcoming conference—“Whatever Happened to the Polio Patient?”

I telephoned the number and found myself talking to Gini Laurie. I wanted to find out what this conference was all about and whether or not it would be helpful. I discovered that post-polio people all over the world were having the same difficulties and this is why such a conference was being convened. About a month later I received the conference program brochure. Imagine my shock and horror in discovering that my name was on the program, as I was supposedly going to be talking about the situation in Ontario, Canada.

My first reaction was one of shock. Then I was angry. I had not been asked to do this and even if I had I would not have necessarily agreed. My third reaction was, “I will darn well show them.”

I began researching the topic. I phoned the Ministry of Health. I talked to the March of Dimes, who had

been very involved in the early epidemic days but, since the vaccine, was no longer involved in this area. I searched out and interviewed retired nurses. And, I tried to survey as many post-polio individuals as I could find in the Toronto area to get a better picture of the difficulties people were having.

I did attend that conference, and I did speak. I came back filled with important knowledge and information. I approached the Ontario March of Dimes and challenged them to pick up the ball and start supporting polio people—because they were the only disability group that had no organization to assist them. And they did, making me the first chair and establishing post-polio support groups across the province. We held several conferences, and Gini Laurie came up, stayed at my place, and addressed the audience as a keynote speaker.

It was only later that I began to realize how Gini worked and why she was so effective. She challenged people. She threw out the gauntlet which many of us picked up, going back to our various corners of the world and establishing much-needed support groups.

She was the glue that held us polio people around the world together.

*Audrey King, MA, is a polio survivor and retired psychologist from Toronto’s Holland Bloorview Children’s Rehabilitation Hospital. She has authored several books in addition to writing and lecturing internationally on a broad range of disability issues.*

### **Martin B. Wice, MD**

I met Gini Laurie in 1987 shortly after I moved back to St. Louis. Gini was a force with which to be reckoned. Her prior correspondence with polio survivors led to the realization that there were late effects from prior poliomyelitis. She was instrumental in helping me develop my post-polio clinic. From her kitchen table, her telephone, her manual typewriter, and with the mail service, she produced newsletters, organized international post-polio conferences, and most importantly, advocated for those who had polio and other physical disabilities along with home ventilator users. Her concern for the physically disabled was infectious. She inspired countless polio, home ventilator survivors and their families to have as fulfilling a life as possible. She helped educate health care professionals and community leaders to better meet the needs of the physically disabled. When she required more resources for her “GINI” organization, she would put out calls to her loyal supporters and

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“brown bags” with financial aid would appear. Her legacy continues not only with Post-Polio Health International but also with the Independent Living Movement. Her spirit lives on supporting the new generation of all physically disabled individuals, even those who never had the privilege to have known her.

*Dr. Wice, past President of PHI, currently serves on its board of directors.*

### Gayla and Arthur Hoffman

Gini Laurie changed my life. My husband Arthur and I bought the house next door to Gini and Joe Laurie in the Central West End of St. Louis in 1976. Thirty years or so younger than they, we were told they were a nice older couple. Then we met them. We discovered the irresistible force that was Gini and her charming partner Joe, who was devoted to her.

Could we kids help, Gini asked. Of course. There was no other answer.

We soon heard about her family’s personal history with polio, her volunteer activities in Ohio with polio survivors in iron lungs and her founding of the *Toomey J Gazette*. By 1976, this had expanded into the *Rehabilitation Gazette*, a publication that encompassed people with all disabilities. But her first love was polio survivors and their stories of accomplishment. Her philosophy was that if you had a brain, that was all you needed.



In the process of helping, we learned so much. And we met wonderful people. Yes, most had disabilities, but as Gini said, they had their minds and more, and that is what mattered.

It wasn’t long before we were invited to dinner, the first of many gatherings, that over the years included people with all manner of disability: polio survivors, of course, but also people with spinal cord injuries, blind people, deaf people, a McArthur Genius award Fellow, people who started the first Independent Living Centers in America; medical professionals including the Surgeon General of the United States (the one who got health warning labels on cigarette packs) and many more.

Long before HGTV popularized the “open concept” style of living, the Lauries were practicing it. They had combined their large living and dining rooms and added a galley kitchen at the end. Their table expanded to accommodate however many folks were there. Dinner was usually a soup (often vegetable/lentil), followed by a salad and some kind of sweet for dessert, and always free-flowing wine. It was not unusual to have a half a dozen, or more, people using wheelchairs in attendance.

We were enriched by all of these experiences. For example:

- The scholar from Germany who was blind. We put him up in our house (second floor) and were concerned about it. After his first visit with his dog, he knew our house as well as we did.
- The Japanese gentleman who came to America to meet Gini. He also stayed with us. As he left, he walked about 10 paces, turned and bowed. We returned the gesture. He walked a bit further, turned and bowed. Again, we returned the gesture. By the time he got out of sight, we were exhausted.
- The deaf group for whom Gini gave a cocktail party. We arrived to find the guests engaged in animated, but silent, conversations—using sign language. Gini beamed as she surveyed the room.

We have never forgotten the things we learned from her, or the fascinating, amazing, interesting people to whom she introduced us. Gini has had a profound influence on our lives and remains, every day, an inspiration.

*Gayla Hoffman is a former editor of Post-Polio Health and Ventilator-Assisted Living.*

## Joan Headley

I started working with Gini Laurie on August 17, 1987. She was diagnosed with esophageal cancer at Thanksgiving 1988 and died in June of 1989. She was seriously ill seven of the 22 months that I knew her.

Her notable reputation in the post-polio and independent living communities was well established when we met.

We were invited to dinner one evening where she happily engaged everyone in conversation. She was quiet on the way home, and I let her be so. When I dropped her off, I said, "You asked about all of them, but no one asked about you." "Sweetie, how nice of you to notice," she replied. Our relationship was closer after that exchange.

When she was diagnosed with cancer, we discussed how we would handle it. She decided that if people asked how she was, she would tell them. Many, who called wanting something of her, never asked.

I had driven her to the dinner because her van had been ransacked one night. She took one look, cried and sold it. Her tears were a result of seeing the desecration of the vehicle that held so many pleasant memories of traveling with her husband, Joe.

The second time she teared up was during a meal she had invited me to eat with her. At dinner she told me it was the anniversary of Joe's death in 1985 and she did not want to be alone.

The third and final time I witnessed her tears was at the kitchen table while we were discussing an article about hypoventilation in polio survivors. She wanted it to be on the cover and issued as a "warning."

She shared the memory of her beloved brother Bobby, a survivor of polio, who she watched die in his early 20s struggling to breathe.

During her final months of her life, we planned and executed the fourth GINI conference. Opinion was divided as to whether she should attend because her weakness required the use of a gurney.

She called me to her bedside and asked permission to go to the hotel. I thought, "You are asking me!" Without hesitation I said, "These are your friends; this is your organization. If you want to go, by all means go." She did.

Many people with disabilities remember her for encouraging them to live.

I remember her for teaching me how to die. Her choices of how to face serious illness and death

confirmed that our final days can be lived peacefully and with dignity.

*Joan Headley, MA, served as Executive Director of PHI until her retirement in 2017.*



## Fred Maynard, MD

Everyone who knew Gini Laurie experienced her passionate energy and enthusiasm for improving the lives of people with physical limitations after paralytic polio. Sometimes called the "Grandmother of the Independent Living Movement," she strove to create a world in which people with physical disability were not impeded from reaching any goal they chose through personal and societal adaptation and/or accommodation. She admired achievements, little and big, and also knew that life needed to be fun. I can never forget the playful abandon of ballroom dancing with people in motorized wheelchairs or using crutches and braces as everyone spun together after banquet dinners on the last day of those early GINI Conferences. She also had a deeply spiritual Christian faith that led to conferences including panel discussions on the ethical issues around death and dying for people with severe disabilities, as well as Sunday morning church services.

Who can forget seeing her attend the 5th International Conference on Polio and Independent Living while in a reclining chair on oxygen as she was dying of terminal cancer? I will always remember the pride I felt when she informally granted me her "Honorary RD" (Real Doctor) degree. She surrounded herself with authentic people and always related to the most severely impaired polio survivors as 'real people' who deserved equal opportunity for having the full range of human emotions and experiences. May her spirit live on to inspire others with special challenges!

*Dr. Maynard, past President of PHI, currently serves on its board of directors. ■*