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LESSONS LEARNED — FUTURE CHALLENGES

JOAN L. HEADLEY, EXECUTIVE DIRECTOR, GAZETTE INTERNATIONAL NETWORKING INSTITUTE,
SAINT LOUIS, MISSOURI

In 1987, when I was about to turn forty, when I had accepted the fact that I would not have children, and when I found I could diagram and discuss the functions of all the body systems of a frog while planning dinner, I sent resumes to several schools including doctoral programs, hoping for a change and a challenge. The day I dropped them in the mail, I received my *Polio Network News*, so I wrote one more cover letter inserting a paragraph about having had polio, knowingly playing the "polio card" for the first time in my life, and sent the letter to a Gini Laurie and Judith Raymond at Gazette International Networking Institute, publisher of *Polio Network News*.

By August, I had quit my teaching job of 18 years, put my house on the market, and moved to Saint Louis to work with Gini Laurie and for G.I.N.I. She had explained to me that the organization supported the independent living philosophy — the philosophy that people with disabilities should be integrated into society, not isolated: that they should have an opportunity to receive an education, be employed, have a family, have access to appropriate health care and personal assistance; in short, have an opportunity to do all the things that others can do, including failing classes while getting the education, being fired, and getting divorced. She also explained that through her 30-some years of work for polio survivors and people with disabilities, she was most frustrated by two things — "UBI" (universal bureaucratic idiocy) and the "edifice complex" exhibited by people who felt they could not act or help until they had all the hierarchy in place and a large building built.

People with disabilities, she felt, no matter what issue they are facing, immediately need two things: accurate information and the connection to others, specifically people who have knowledge based upon a similar experience and the willingness to share it. "We network by sharing vital information," she said, "through our publications, our conferences, and

through all the mail and phone calls we receive, changing one life at a time, hoping and knowing that those who are affected go on to change the lives of others."

It all made sense to me. I had polio at the age of 15 months and was not hospitalized. Having had polio was part of who I was — a girl from a small town in Ohio with parents who made me feel loved for the person I was and encouraged me "to do my best." I had a sister who was four years older and a brother

13 months younger — born immediately after me because my father, back from the War, wanted a son. My version of the story that I heard and re-told many times was that Father wanted a son "too," not "instead."

Having attended college during the '60s, the whole concept of the "wrongness" of excluding people who were different resonated in me. Because of the level of my disability, I personally had never been excluded for architectural reasons and had never felt excluded based on attitude. However, because of my permanent limp, I instinctively did know what it was like to be and feel different. Being a veteran biology teacher, I was committed to education and knew the power of knowledge. G.I.N.I. was in need of an employee, and I accepted the challenge.

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What lessons have I learned?

I have learned that many polio survivors remember their acute polio experience — some with very traumatic stories to tell, and some with hilarious stories to tell about hospitalization; some who played football before polio but could never play again due to the extent of the paralysis, and some who due to rehabilitation and desire did play again.

Some spent their childhood in special schools, isolated from other children. Some were educated with children without disabilities, at times being ridiculed.

There are polio survivors who sleep in iron lungs or on rocking beds or who use portable volume ventilators at night, and run their own businesses, teach in universities, preside from the bench by day. But there are also polio survivors who have a limited education. There are polio survivors who are blue-collar workers doing hard physical labor so they, too, can put their children through college and pay the mortgage.

Some polio survivors with significant disabilities use personal assistance services and are living on their own — not institutionalized; there are polio survivors in their 50s and 60s with rather significant disabilities — not institutionalized, but living with their parents who are in their 70s and 80s.

There are parents of polio survivors who did the very best they knew how in the medical, social, and psychological context of the '40s and '50s, when most of us had polio, who are now confused and a little "hurt" when we discuss the late effects of polio. They interpret our discussions to mean that we are blaming them for their actions years ago. There are polio survivors who are protective of their parents and are reluctant to openly discuss some of these sensitive past experiences.

I learned that polio survivors refer to themselves in different ways: some call themselves "polios," a term dating back to acute polio rehabilitation. Some are offended by the term "polios," saying that people who have had cancer do not call themselves "cancers."

JOAN L. HEADLEY, born and raised in northwest Ohio, received her BS in biology from Huntington College (Indiana) in 1965 and her MS in education from Indiana University in 1973. All 18 years of teaching was with the Lakeland School Corporation in LaGrange, Indiana. This August marks her tenth year of work with G.I.N.I.

Some refer to polio survivors as dinosaurs, minimizing us as people and our current needs, not acknowledging that some of us have, based on average life expectancy, another 25 years to live, or that the World Health Organization estimates that 12 million polio survivors live in the world today.

We must think about what we call ourselves because it reflects how we think about ourselves. As Al Siebert, PhD, one of our 1994 speakers, and author of *The Survivor Personality* says, "People who adopt the victim style are thinking, 'If only other people would change, my life would be better.' " And as he further explains, "Of course, it is true, our lives would be better if everyone else changed to our liking, but the reality is that that is unlikely." According to Siebert's study of life's most successful survivors, they recognize that the world constantly changes and that constant learning is required; that being flexible is an absolute necessity. Successful survivors are good troubleshooters, having empathy and the edge when it comes to intuition, creativity, and imagination.

I have met loving spouses and families who are supportive of their family member with the disability. I know some spouses who are tired, ill, aging, and in need of support themselves.

I have spoken with physicians who do not understand post-polio problems; however, I am privileged to know many who give of their time, expertise, and talents to help us, to tell us the truth, not just what we may want to hear, and to educate their fellow health professionals.

From listening at conferences and to other polio survivors, I know that some of the best polio doctors are not the greatest conference speakers. I have learned that good polio doctors are good listeners. I also have learned that polio survivors need to listen as well.

Some polio survivors are well-educated about their own polio, but many others have not had the occasion to give much thought to polio until now.

I hear from polio survivors who feel the message about post-polio needs to more prominently broadcast. Simultaneously, I hear from polio survivors in the work force who fear every media message about the potential fatigue and weakness of polio survivors because it might jeopardize their job status.

There are polio survivors who attend support groups; some who have dedicated hours to coordinating support groups, finding energy in this association. There are polio survivors who receive support from their families, synagogues, or churches and do not choose to associate with other people with disabilities.

I learned that the late effects of polio and post-polio syndrome have many faces and varying definitions;

that the major symptoms of pain, fatigue, and weakness can be caused by many other things. I learned that treatments have many faces as well, that we must be careful when touting specific ones. The treatment for fatigue, the major cause of which is respiratory muscle weakness, may be night-time ventilation. Fatigue due to failure at the neuromuscular junction has potentially another treatment, or fatigue related to depression, which may or may not be related to polio, has yet another potential treatment.

I learned that having had polio can explain some of our problems. I also realize that polio may be getting some unwarranted blame. It has been suggested to me that polio is the reason I did not marry and have children. After some introspection, I have concluded that I have enough faults to account for the fact.

There are survivors who have received information about the late effects of polio, taken action, "found the balance," and have moved on with their lives. I also know that some of these same people who made an adjustment five or six years ago are now calling again, sensing a need for another readjustment.

I learned that there are polio survivors all over the world who are experiencing the consequences of having had polio; that polio is not completely eradicated in some countries; and that therapy for the acute polio is not always available. In some countries, polio survivors and other children with disabilities do not have access to an education or hope for future employment. Some people with disabilities live in countries where they are shunned. There are also countries in which survivors have developed their own outstanding networks regarding post-polio and disability issues to meet the need within their own culture, their own medical establishment, and their countries' social policies.

This list is just a small part of what I have learned. Within the list are many challenges. The question is: how will we meet those challenges?

We who are involved in the Network need to recognize that polio survivors and health professionals are not all alike. For many of the questions, there are no cookie-cutter answers. We need to listen to each other — health professional to health professional, polio survivor to health professional, health professional to polio survivor, polio survivor to polio survivor. We must stay up-to-date on post-polio and disability issues, continually re-evaluating what we have to offer. We need to be open-minded but also to think for ourselves. To find solutions for ourselves as polio survivors or as health professionals, each of us will need to invest something — our time, our talents, perhaps our resources. Then we must pass our solutions along. In doing so, we must think carefully

about what we say and how we say it, knowing that there are consequences of misinformation, too little information, or information out of context.

I am not saying here that all information must be AMA approved. I am well aware of the fact that when Gini Laurie approached the medical community in 1981 with post-polio issues, many did not receive her. I am also not saying that there is no room for differing opinions because there are unresolved issues. The G.I.N.I. tradition is relating experiential stories which expose problems and offer what works, opinions if you will. But those stories and opinions can and should include facts and resources. As someone once said, "Everyone has a right to be wrong about their opinions, but no one has the right to be wrong about their facts."

The reason the *Polio Network News* was in my mailbox that April day in 1987 was the result of my first exposure to the late effects of polio being misinformation. While shoe shopping with a friend, she said, "Joan, I do not want to scare you, but have you read that polio survivors are getting polio again?" I reacted as a biology teacher, immediately thinking about the poliovirus and acute polio, and I had an immediate and physical reaction to the statement: a reaction in that part of me somewhere between my heart and stomach. My next reaction was to try to find accurate information, a search that led me to G.I.N.I., an organization which believes in the power of information, the independent living philosophy, and the resourcefulness and generosity of man- and womankind.

We are pleased to welcome you to our Seventh International Post-Polio and Independent Living Conference — offering you an opportunity to learn from each other, to be energized by each other, to find solutions, and then in turn, to become part of the solution. ☞

This issue of *Polio Network News* initiates our publication of the presentations from G.I.N.I.'s Seventh International Post-Polio and Independent Living Conference, May 1997.

Most speeches were captured in realtime by Kimberly A. Pfeinger, CRS, CRT, Saint Louis, Missouri, and displayed immediately on a screen in the conference room. These edited transcripts are submitted to each speaker to check for accuracy, to add thoughts and resources, and to modify a speech with or without slides into the readable, written word. Presentations from the Home Mechanical Ventilation Forum will be published in *I.V.U.N. News*.