

# INTERNATIONAL POLIO NETWORK POLIO NETWORK NEWS

WINTER 1994 ♦ VOL. 10, NO. 1

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## WE CALL OURSELVES SURVIVORS

G.I.N.I. has been publishing since the 1950s. Copies of *Toomeyville Gazette*, *Toomey j Gazette*, and the *Rehabilitation Gazette* reveal that through the years individuals who had polio have been called polio patients, wheelchair patients, polios, iron lung polios, multiplegics, respos, horizontals (severely disabled) vs verticals (non-disabled), upside down polios, polio quads, handicapped, physically handicapped, disabled, post-polio people, and polio survivors.

The 1980 *Rehabilitation Gazette* (Vol. XXIII) contained the article "Watch Our Words" noting that 1981 would be the International Year of Disabled Persons, not "handicapped" persons, or "crippled" persons. The politically correct article argues against generalizing which impersonalizes, negative images which reflect small expectations, words which imply people with disabilities are asexual, and labels which assign superhuman qualities.

Since that time, G.I.N.I. publications have consistently used terms such as people with disabilities, ventilator users, and polio survivors, never accepting the euphemistic "physically challenged." Over the years a few readers have expressed their dislike for the term survivor. With a better understanding of what it means to be a survivor, they may change their mind.

In 1993, Al Siebert, PhD, published *The Survivor Personality* (ISBN 0-944227-06-6), in which he describes survivors and their qualities.

Dr. Siebert first became interested in survivors when he served in the Army in the early '50s. Part of his paratrooper training was conducted by individuals in a unit that had survived capture by communists in Inchon. He realized that these survivors had characteristics "which tipped the scales in their favor." He "decided to work backward. I look for people who had survived a major, stressful personal crisis which was surmounted in some way by their own personal effort, and which resulted in them being stronger and more capable than they were before."

Dr. Siebert interviewed "hundreds of people, survivors of the World War II Bataan Death March; Jewish survivors of the Nazi Holocaust; ex-POWs and Vietnam

veterans; survivors of cancer, polio (he spoke with Ed Roberts and Dorothy Woods Smith), head injury, and other physically challenging conditions; survivors of co-dependency, abuse, alcoholism, and addiction; parents of murdered children...."

The following extended excerpt from his book describes what he learned:

"I learned that most survivors are ordinary people with flaws, worries, and imperfections. When people call them heroes they disagree. 'We just did what any reasonably sensible people would have done,' say two women who were lost for a week in the mountains during freezing winter weather. 'We aren't heroes,' they keep saying to people awed by their survival.

"I learned that a few good people are born survivors. They are the natural athletes in the game of life. Just as some people are born musicians, writers, artists, or singers, some people are gifted in living. The rest of us need to consciously work to develop our abilities. Just as we would have to take lessons and practice diligently to become artists or musicians, we have to work at learning how to handle job pressures, difficult people, conflict, negative situations, unwelcome change, and crises.

"I learned that some of life's best survivors grew up in horrible family situations, and that many of the people least skillful at coping with life's difficulties have come from ideal homes. Many of the best people in our world have been through experiences that no public school could get away with arranging. They have been strengthened in the school of life. They have been abused, lied to, deceived, robbed, mistreated, and hit by the worst that life can throw at them. Their reaction is to pick themselves up, learn important lessons, set positive goals, and rebuild their lives.

"I learned that people seldom tap into their deepest strengths and abilities until forced to do so by a major adversity. As Julius Segal, the distinguished survivor researcher has said, 'In a remarkable number of cases, those who have suffered and prevail find that after their ordeal they begin to operate at a higher level than ever before ... The terrible experiences of our lives, despite the pain they bring, may become our redemption.'

"Lt. Commander Charlie Plumb, for example, was a navy pilot shot down early in the Vietnam war. He

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**Dr. Siebert will be the Dinner speaker, Thursday evening, June 16, during the Sixth International Post-Polio and Independent Living Conference in St. Louis, MO.**

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was held in a prison in Hanoi for six years in a stone cell 8 feet by 8 feet in size. He had no window to look out and nothing to read. He was frequently hog-tied, repeatedly beaten, and subjected to grueling interrogations. Yet, in retrospect, when he talks about his experience as a POW he says 'It's probably the most valuable six years of my life. Amazing what a little adversity can teach a person....I really felt there was some meaning to that, to my experience itself.'

### Thriving vs. Self-Victiming

"I became curious about a fascinating difference in people. Some, like Charlie Plumb, can go through a torturous experience and say 'It was horrible, but it was the most valuable experience of my life.' At the other extreme, some people who are healthy, employed, and living in safe communities with their families, complain about their lives as though they were being tortured.

"The victim style is revealed in statements that repeat this complaint: 'If only other people would change, my life would be better.' There's nothing wrong with that belief, of course, because it's true. Each of us can name several people who would make things better for us if only they would change how they act. It is extremely unlikely, however, that others will voluntarily change themselves to make your life easier. You are the only person on the planet that you can really do something about. Fortunately, you were born with an ability to learn how to handle unfair situations and distressing experiences. You can learn how to respond effectively to life's challenges. You can acquire a learning/coping response as an alternative to feeling like a victim who blames others.

### "A Teaching Challenge For Me: A Learning Challenge for You

Years of observing and learning about life's best survivors has convinced me that:

- ☐ A survivor style develops out of every day habits that increase chances of survival should it become necessary.
- ☐ A survivor style can be learned, but it can't be taught as one would teach a sport or skill.
- ☐ People trained to act, think, and feel as instructed cannot cope with life's unexpected challenges as well as a person with a self-discovered personality.

"A frustrating situation for a teacher! How can I teach what can't be taught? How can I offer expert advice about survivorship when people who try to do what an 'expert' says actually lower their chances of coping well with unexpected difficulties?

"My way of handling this teaching and learning challenge is to explain the situation and offer coaching

tips on how to manage your own learning. If you've read many 'self-help' or 'self-improvement' books, you may have noticed that the authors often start by saying that none of the existing self-help books worked very well for them. It was only after they compiled their own list of habits or principles that they finally found the way to greatness, effectiveness, excellence, prosperity, wealth, love, power, and good digestion. Their book, they say, will save you from the time and struggle of reading any other books.

"The effectiveness of workability of any plan, however, comes from the learning struggle. Through trial and error you learn what works and what doesn't work for you. The best self-improvement comes out of real life, everyday experiences, not from books or workshops that tell you what to learn.

"Thus, my approach is to provide guidelines on how to learn good surviving, coping, and thriving skills. This is a book of useful questions and practical guidelines, it is not a book of instructions. It is a manual for discovering inborn abilities that no other human being can reveal to you. Only you can discover them. In the school of life the responsibility is on the learner, not the teacher." ■

*The Survivor Personality* can be purchased for \$14.95 (p&h included) from Practical Psychology Press, P.O. Box 535, Portland, OR 97207. For credit card orders, call 800/858-9055.

### International Polio Network

5100 Oakland Avenue, #206  
St. Louis, MO 63110-1406 U.S.A.  
314/534-0475  
314/534-5070 Fax

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ISSN 1066-5331

*Polio Network News* is an international newsletter for polio survivors, support groups, physicians, health professionals, and resource centers, to exchange information, encourage research, and promote networking among the post-polio community.

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**EDITOR/EXECUTIVE DIRECTOR** ♦ Joan L. Headley

**SPECIAL THANKS** ♦ Margaret E. Backman, PhD,  
Vicki Johnson, RN, Joseph B. Leone, and Al Siebert, PhD

**PUBLISHER** ♦ Gazette International Networking Institute  
(G.I.N.I.), 5100 Oakland Ave., #206, St. Louis, MO 63110-1406  
U.S.A., 314/534-0475

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