



Colorado Post-Polio Connections

VOLUME 23 NUMBER 3

FALL 2008

IN THIS ISSUE

Learn from My Mistakes
... p.1

In My Opinion ... p. 2

Post-Polio Breathing and
Sleep Problems Revisited
... p. 3

Sunny Weingarten,
Inventor ... p. 6

And by the Way ... p. 8

Book Review: Polio
Voices by Julia K. Silver &
Daniel Wilson ... p. 9

**A special thanks to Oran
V. Siler Co. and to Easter
Seals Colorado for
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Learn from My Mistakes!

By Nonda Paarlberg

I am not the person to consult about handling whatever breathing problems come your way, and I suspect that I was referred to the editor for that very reason. It is a tale of what not to do and perhaps some red flags to watch for in your own behavior or thought process. Now I've been on oxygen daily and a BiPAP at night for the last 18 months. It wasn't my idea, and there are things I don't like about it. However, I waited until the eleventh hour and it was a very near miss.

I didn't go in to the doctor about shortness of breath because there was nothing he could do, or so I thought. My scoliosis is a structural problem beyond repair, and if I had to sit up all night in order to sleep, I would. Anyway, it was only for a few minutes ... part of the night ... some nights ... most nights.

Several months after these mild beginnings, I began to fear sleep. Would I wake up? I made it into a joke with myself. One day in January 2007 it was so bad that I asked a friend to drive me to the ER after work. X-rays showed pneumonia, so I was admitted—for a night or two, I figured. They gave me oxygen, which was *so welcome*, and sent me upstairs. I called a couple of people on my cell phone so they'd know where I was, and to feed the cats. I don't know what happened after making those calls; I probably nodded off in the middle of an interview on *Charlie Rose*.

The next thing I remember is some nonsensical waking up and falling back away into a drugged fog. A strange room surrounded my bed, an ungodly uncomfortable bed in which I couldn't move my arms to turn myself. *(Continued on page 5)*

In My Opinion . . .

Recently a member of our Colorado post-polio community died as the result of respiratory complications. His loss, as with the loss of other polio survivors we know, regardless of the cause, hits us in a special way because we all know the struggles that we have had to deal with in life. We are again reminded of our own vulnerability.

For polio survivors, potential respiratory problems are especially toxic because those of us who had respiratory problems at the onset of polio have deep-seated memories of difficulty breathing and, for many, the iron lung. And, no one wants to return to that frightening part of our lives. Yet, as we age, those muscles that control our breathing can weaken or we can become vulnerable to the effects of sleep apnea, a condition that erodes our health and makes us vulnerable to other health problems.

Many, maybe most, of us do not and will not have to be confronted with respiratory issues, but awareness of the possibility, consultation with a doctor if there are questions that come up, and following up with proper treatment can keep us alive. And for some of us, that means being aggressive with doctors, not accepting their “It’s a part of aging,” or “Our tests are inconclusive,” when we are feeling that we are not getting enough air or that we might have sleep apnea because we wake up tired every day. After all, we live in our bodies and we know them best.

Nonda Paarlberg’s story about the consequences of her inaction and Sunny Weingarten’s life story are just two examples of dealing with breathing issues. One is the story of a lifetime of dependency on the iron lung and respirators and how he dealt with it and the other is the story of recovery and return to needing help later in life. Both stories contribute to a compelling reason for all of us to be alert to what is happening to our bodies.

The Post-Polio Health International article helps us to understand the intricacies of current technologies and can do a lot in calming fears and providing rational information about what can be a frightening subject for some. It can also give some guidance when talking with your doctor about your own issues.

Jim Oxley has again provided us with a thoughtful book review. His very thorough review will give you a good history of polio in America. Thank you, Jim.

Margaret C. Hinman, editor

For Colorado residents only—Colorado Easter Seals sometimes receives donations of durable medical equipment, including everything from crutches to motorized wheel chairs. If you would like to be considered as a recipient of one of these donations, contact Nancy Hanson at Easter Seals, 303-233-1666, ext 237, for further information.

Post-Polio Breathing and Sleep Problems Revisited

Judith R. Fischer, MSLS, Editor, *Ventilator-Assisted Living*, and Joan L. Headley, MS, Editor, *Post-Polio Health*

“*Post-Polio Breathing and Sleep Problems*” was published in the fall of 1995 (*Polio Network News*, Vol. 11, No. 4). As a result of the continual flow of phone calls and emails from polio survivors and family members about this life and death topic, Judith Fischer, editor of *Ventilator-Assisted Living* (our other quarterly newsletter), and I decided to revisit and revise the original article. Our goal is to educate and to clarify misinformation about breathing problems of polio survivors. —Joan L. Headley, Editor, *Post-Polio Health* (ventinfo@post-polio.org)

New breathing and sleep problems in aging polio survivors can be insidious and often go unrecognized by either polio survivors, their family members or their health care providers. Polio survivors may have weakened breathing muscles as a result of the initial damage by the poliovirus; the lungs themselves were not affected. Those who were in an iron lung during the acute phase should be aware of the potential for developing problems later in life and educate themselves in order to recognize important signs and symptoms which may indicate underventilation which may lead to respiratory failure. Even those who did not need ventilatory assistance during the acute phase may also be at risk for underventilation and should be aware of problems with breathing and sleep.

Underventilation (hypoventilation is the medical term) means that not enough air

reaches the lungs to fully inflate them. The result may be too little oxygen and too much carbon dioxide (CO₂) in the blood.

Underventilation can be caused by one or more of the following: weakness of the inspiratory muscles (mainly the diaphragm and rib muscles) for breathing in, weakness of the expiratory muscles (the abdomen) for breathing out and producing an effective cough to clear secretions, scoliosis (curvature of the spine), and sleep apnea.

Other factors contributing to a polio survivor’s breathing problems are a history of smoking, obesity, undernutrition, and other lung diseases such as asthma, bronchitis and emphysema.

Vital capacity (VC) is the volume of air that can be expelled after taking a big breath and is a measure of how well the lungs inflate. VC normally decreases with age, but this decrease in VC is more serious in an aging polio survivor with weakened breathing muscles. Many polio survivors had impairment of their inspiratory muscles, and the normal changes due to aging may cause them to lose VC at a greater rate. Polio survivors may not experience symptoms of underventilation until their VC falls to 50% or less of predicted (normal).

Signs and symptoms of underventilation during sleep include:

- ⊗ Inability to breathe when lying flat—the need to sleep sitting up (orthopnea)
- ⊗ Inability to fall asleep and/or to stay asleep (insomnia)
- ⊗ Anxiety about going to sleep
- ⊗ Restless fragmented sleep with frequent awakenings
- ⊗ Shallow breathing or pauses in breathing

(Continued on page 4)

- ⊗ Awakening from sleep with choking sensation
- ⊗ Nightmares, night sweats, bedwetting or need to urinate frequently
- ⊗ Excessive daytime sleepiness
- ⊗ Morning headaches
- ⊗ Worsening mental status and impaired memory, concentration and cognition

Other symptoms may include:

- ⊗ Shortness of breath on exertion
- ⊗ Fatigue or exhaustion from normal activities
- ⊗ Claustrophobia and/or feeling that the air in the room is somehow bad
- ⊗ General anxiety
- ⊗ Difficulty in speaking for more than a short time
- ⊗ Low voice/volume speech with fewer words per breath
- ⊗ Use of accessory muscles, such as neck muscles, to breathe
- ⊗ Weak cough with increased respiratory infections and pneumonias.

Polio survivors experiencing one or more of the above signs and symptoms should seek a respiratory evaluation (simple and noninvasive pulmonary function tests) by a pulmonologist, preferably one experienced in neuromuscular disorders. Physicians are listed in the *Resource Directory for Ventilator-Assisted Living* (www.post-poli.org/ivun/d.html).

Pulmonary function tests should include the following measurements. The values that indicate a warning sign for respiratory problems are in parentheses.

- ⊗ VC—upright (<50%)
- ⊗ VC—supine (a drop of >25% from upright to lying down)

- ⊗ MIP—maximum inspiratory pressure (<60 cm H²O)
- ⊗ MEP—maximum expiratory pressure (<60 cm H²O)
- ⊗ Peak expiratory cough flow (<300 L/min)
- ⊗ End-tidal CO² (>45 mm Hg)
- ⊗ Overnight oximetry may be prescribed to detect episodes of oxygen desaturation (<88% during sleep).

Management of breathing and sleep problems can be achieved largely through the use of nocturnal noninvasive ventilation, commonly in the form of small, lightweight bilevel positive pressure units. The units have a long tube/circuit that attaches to a mask (nasal, facial or oral), nasal pillows or mouthpiece worn during sleep. Polio survivors may find themselves gradually extending periods of ventilator use, perhaps during a daytime nap. Some polio survivors may need to use a volume ventilator to guarantee delivery of a larger volume of air than a bilevel unit can provide. Noninvasive ventilators may eventually fail, and invasive tracheostomy positive pressure may be necessary.

Treating underventilation with oxygen therapy instead of ventilation can lead to respiratory failure and death because supplemental oxygen can blunt the function of the brain's respiratory control center. However, polio survivors who use assisted ventilation and have additional medical problems such as COPD, pneumonia or heart problems, or who are undertaking long airplane flights (Ed. note—or who live at higher altitudes), may benefit from oxygen therapy under careful supervision. Polio survivors may also have sleep apnea contributing to underventilation. (*Cont. on p. 5*)

Post Polio Breathing *(From page 4)*

Sleep apnea, an interruption of breathing during sleep, can be obstructive, central or mixed. Obstructive sleep apnea (OSA) is the most common form and is prevalent in the general population. The standard test for OSA is a sleep study; the standard treatment is the use of a continuous positive airway pressure (CPAP) unit with a nasal mask or nasal pillows during sleep. However, polio survivors with both weakened breathing muscles *and* sleep apnea should use bilevel positive pressure or volume ventilation, not CPAP.

Thanks to Lisa Krivickas, MD, Spaulding Rehabilitation Hospital, Boston, Massachusetts; E.A. Openheimer, MD (retired), Lost Angeles, California; and Mark H. Sanders, MD, University of Pittsburgh Medical Center, Montefiore University Hospital, Pittsburgh, Pennsylvania, for their review of this article.

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Learn *(Continued from p. 1)*

Cruel, ignorant people came and went, ever triumphant when an alarm went off and they raced in to tie my arms down after a short reprieve. “See! I told you she'd try to pull it out again!” I couldn't talk back to them because of a trach in my throat. *A trach!* There was no escape and no way to protest. Eventually I learned that it had been three weeks since I'd gone to the ER. Friends and family say I'd been conscious off and on, but I don't remember their visits.

So, how did I get there? When it comes to getting past denial and fear, I just don't. Throughout my life, I have adjusted to difficult circumstances in my own way and think about them as little as possible. Fear is a hotly contested secret that I keep

from myself. When that fails, I find an interesting diversion. But then, who *is* good at this stuff? Aren't we wired to either fight against our threats, or run like hell from them? I'm a pro at the second option, if you equate running with avoidance. Fighting back, however, is a mystery because I really don't know what I'd be fighting *for*. I do know I never want to go back to seven weeks in acute care and rehab.

It scared me when an old doctor-friend told me recently that I probably needed a ventilator, but would have to move into a care facility for that. He's a *pulmonary* doctor, so he knows what he's talking about, right?! Never mind that I have an article on ventilator use gathering dust around here somewhere, from Dr. Eulberg, which I never found the time to read. Or that Mary Ann Hamilton (former editor of the Connections and leader in post-polio activities in Colorado) was a friend I discussed related issues with, and then promptly forgot, because it wasn't going to happen to me. It's actually a *noninvasive ventilator* that I would be using, *at home*, and not half scary.

I've almost always had less air in my system—less than most people anyway. Once I recovered from the acute phase of polio in the 50s, breathing was again taken for granted. The monster whooshing thing that had swallowed me repeatedly, except for my head, was just a nightmare. And there was that one where nobody could hear me calling because no sound came out? The adults in my life said that for a little girl, I had quite an imagination.

So, life went on. I suppose it began to affect me again in the '80s and '90s, *(Continued on p. 6)*

Learn

(Continued from p. 5)

along with the muscle weakness and fatigue. All my attention was focused on maintaining some strength and energy, which meant using a wheelchair part of the time, taking an afternoon nap when I was worn out, and cutting down the strenuous work . . . the post-polio drill. It felt like I was bowing down to the almighty Inevitable Polio God. I didn't even see my breathing as an issue.

The first conscious sign of a problem probably was way back when I suddenly couldn't tolerate marijuana. One moment I was calmly anticipating my turn at the pipe, and the next moment I was weak beyond recognition. No one else at the house had a reaction, but it was my last time. Cigarettes, however, had cunning ways of staying with me no matter how many times and ways I quit. After roughly 25 years and two second-hand-smoke cats, I had my last smoke. Oddly, it made little noticeable difference.

Why was my head still splitting and my neck a mass of taut ropes in the early mornings? Wasn't I getting enough coffee? How could that be, when by early afternoon I was wasted and hadn't done anything physical? I used to say to myself, "But I didn't *do* anything!" What was the use of really quitting nicotine if I wasn't feeling great as a result? And the weight gain! It had been bad enough as I was using the chair more and more, but now my old clothes were just a joke. I had such swelling in my legs and feet in the winter months that I had to switch from shoes to moccasins. *Everything* was going to hell. I had long since given up the bike, and even gradually the walking.

I wasn't about to consider some nonsense about sleep apnea and the rest of it. Seven months later, I went in to the ER.

Sunny Weingarten, Inventor

By Jeanine Ellison-Fisher & Margaret Hinman

Sunny was born in August, 1942, and raised on a 110-acre farm in Thornton, Colorado. Even before being old enough to start school, Sunny rode down the lane every day, bareback on his own horse, Rex, and with his dogs, to fish until the sun overhead told him it was time to head home to do his chores. Everyday, that is, until school started, and even then, he apparently left school a little too early in the day and a little too often, in order to keep fishing. Everyday that is, until his teacher had a little talk with his father.

Everyday, that is, until July 1949, when Sunny was struck with Polio. Sunny went to Children's Hospital in Denver, and Rex died a week later. "Dad said he got polio from me or I got it from him." He was hospitalized on a Sunday. His parents left him on a gurney. Mom cried, Dad didn't say a word. "They were advised not to say anything to me." Sunny was really scared, terrified, and how much the spinal tap really hurt bad, and later, the pain from the penicillin shots. He was 7½ years old.

In the hospital, every once in a while someone would come to check on him; people came in masks. He was in an oxygen tent at first, but by Thursday he became unconscious so they put him in an iron lung. When he woke up in the iron lung he describes the odd feeling he had that was like being run over by a car, and the inside of the iron lung looked like the underside of a car.

(Continued on p. 7)

Sunny Weingarten *(Cont. from p. 6)*

On the boys ward, Sunny made a lot of friends with whom he pulled a lot of tricks. They managed to cause occasional chaos in the hospital, too. One Friday they plugged up the pool and by Monday when the staff returned to work, the therapy room was flooded! His line? “They couldn’t pin it on us but they always suspected.”

They also tried to “bomb” with water balloons unsuspecting passers-by, particularly ladies, who walked below their hospital floor. Sunny was the person chosen to transport the balloons, on his chest and stomach, in the wheel chair. Their aim and timing was not very good, luckily for their victims, as they never hit anyone.

This story is about a guy who is ventilator dependent; and “out of necessity, the inventor of the first Porta-Lung. No one predated his invention. When he went home from the hospital, he went in an iron lung which weighed 800 lbs. and he was in it for over 35 years. But in 1975, realizing he was stuck at home every night, so “out of necessity” he put his mind to it and designed the first prototype Porta-Lung which weighed 100 lbs. and fit into a van.

Sunny wanted to travel. Over his lifetime he has travelled over 50,000 miles with his Porta-Lung in his van. With this new-found freedom, he traveled from 1976 to 1985, all over North America to 48 states, Canada and Mexico.

His Porta-Lung is even more effective than the iron lung because it provides higher pressure levels, and variable inspiration/expiration ratios provided by a portable, separate pressure unit. It’s a portable, aesthetic space capsule,

maintenance free and 100% effective because of total body coverage of the pressures.

After incorporation in November, 1985, he and his partner developed a better Porta-Lung, a negative pressure ventilator which they named Responics. They unveiled it in Atlanta, Georgia. It was approved by the FDA. The airlines accepted it for no charge. They produced three different sizes of the Porta-Lung, including a small one for children, and they distributed hundreds of them around the world. For 21 years they produced it. They made it available to 46 different states, and 11 foreign countries, including China, and Thailand. His invention was published in prestigious medical journals.

Sunny now uses a Positive Pressure Ventilator with a custom mouth piece. Over the years, he has tried 6 different mouth pieces and finally found this one in Texas that does not destroy the tissues around the mouth.

There are stories to tell about Sunny, his baseball coaching, and the famous people he has met. Sunny lives in a remodeled home surrounded by many trophies and framed pictures on the wall for all 15 of his teams, the boys’ baseball teams he coached for many years. For some of those boys he was not only a coach but a counselor and a mentor. His teams “always won.”

The City of Thornton was looking for the name of an individual who had contributed the most to recreational athletics over the last decade or two, and they selected Sunny. In honor of his achievements they named a baseball park after him. *(Continued on p. 8)*

Sunny Weingarten *(Continued from p. 7)*

Sunny has been a Bronco fan from the first, attending nearly all of the home games and two Super Bowls, including the one in St Louis. At the time, he bought a Cessna 182, a 4-seater Skylane, put his buddy in the pilot's seat, and proceeded to have a good, eventful, challenging, exhausting and sleepless time at the game. His adventure included a dramatic flight home when they were running on fumes, nearly out of gas, and had to dive straight through a little pocket in the clouds to land on a nice smooth grass field near Athens, Texas. Arriving home at the Jefferson County Airport, Sunny was limp and tired and hungry and relieved to get in the wheel chair!

His constant and avid support of the Broncos, even with a respirator and in a wheel chair, led him to be selected as the representative fan who was present at the groundbreaking ceremony for the building of Invesco Field at Mile High Stadium, the new Bronco playing field.

Sunny, larger than life himself, is a guy who seems to have a knack for meeting famous people, like Billy Graham, Mohammad Ali, and Lyle Alzado, a former Denver Bronco. On his wall is a framed letter from President Eisenhower and a letter "hand-typed" by Eleanor Roosevelt!

Sunny has always been convinced that someone in a respirator could lead a fruitful and meaningful life, and he proceeded to prove it with his own life. At this time, Sunny is the longest living person who is on a ventilator in Colorado. Now more "tired than retired," he plans to write his life story. What a story that will be!

And By the Way . . .

Here are some ways that other polio survivors have learned to deal with changes that happen as the result of aging, new health problems or returning symptoms of a disability:

- As problems sneak in and things happen, I have learned to gradually adapt, not necessarily consciously.
- I have to think when I walk. This is an adaptation that keeps me from falling.
- It takes time to make changes.
- I make changes in very small steps, gradually.
- I find myself using others to help me and then things seem to fall into place.
- I cheat by using behaviors that may not be the "acceptable" ones that others use.
- I find myself compensating with other muscles and don't use muscles that are there.
- I am not a worrier, so I face things as they come.
- I have used some coping mechanisms throughout my history of polio and I apply them to new problems.
- I read the literature on the problem, get the facts, look at the options, and make the best choices based on the information.
- As I have aged, I have more breathing problems and shortness of breath. I have a weakened diaphragm and I am afraid and nervousness. I am dealing with a lack of information and denial by doctors. I need to get a medical opinion from someone who knows about polio and who cares about me.

**Book Review – POLIO VOICES:
An Oral History from the American
Polio Epidemics and Worldwide
Eradication Efforts** by Julie K. Silver,
M.D. and Daniel Wilson, Ph.D.

Reviewed by Jim Oxley

The senior author is well known through her writings on polio, post-polio and the syndrome. This book is based on an Oral History Project, conducted by the Spaulding International Rehabilitation Center for Polio at Framingham, MA. Dr. Silver and her co-author, Dr. Wilson, a polio survivor himself, have produced a book that is unique in content and well organized by chapters on the epidemic years, convalescent periods, impact on the families and the current syndrome years.

They also wrote about the legacy of volunteerism, the impact of disability rights in America and the effect the disease has had on advances in medicine. They orally interviewed a number of polio survivors across the U.S. and arranged the stories by decades according to the time that the person contracted the disease.

The first sizeable and well-documented polio epidemic occurred in Vermont in 1894. Two more epidemics were reported in New York in 1907 and 1911. Another outbreak happened in the northeastern states in 1916, where 27,000 cases and 6,000 deaths occurred in twenty-six states. We all can relate to the FDR years and the efforts to raise money through the March of Dimes for research and rehabilitation.

The National Foundation for Infantile Paralysis (NFIP) was founded to receive and administer the donations and by 1959 it had

raised \$622 million and spent \$315 million on polio care, \$55 million on research and \$33 million on educating health professionals. The authors stated that the Foundation “clearly hastened the end of the polio epidemics and softened the blow on those who had polio.” The Salk and later the Sabin vaccines eliminated polio as a public health menace. There were 57,879 cases in 1952 and by 1965 there were only 73, this after the introduction of the Sabin vaccine in 1962. Considered a miracle in modern medicine, the vaccines stopped the incidence of new polio cases, but left the victims, their parents, rehab centers, medical professionals and others to deal a myriad of post polio problems.

The stories the authors captured in the interviews bring back memories, good and bad, to all of us who had polio and to those who lost loved ones among families and friends and in communities across the land.

I was amazed when I read of the ages of those at the time they came down with polio. Several got the disease during the first 24 months of life. The youngest was at birth, probably because the mother had polio at or soon after delivery. The mother died shortly afterwards. Another case was reported at the age of 40 days and many were between 9 and 22 months. A person of any age was not immune to the disease. The oldest person reported in the stories was 38 years old and his case was probably a result of some bad vaccine that escaped the critical inspections of the day.

So many of the stories related to the isolation and quarantines that kept children from their families while they were in an iron lung or at a rehab center. During the spread of polio’s *(Continued on p. 10)*

Polio Voices *(Continued from p. 9)*

worst epidemics and before the cause and was learned, families who had a polio survivor were often ostracized by having signs put in their yards and avoiding all contact with children next door or down the street. Even many schools were reluctant to accept a “polio student.” And, some communities had special schools for the disabled. It was difficult for some children to be accepted in a regular school and teachers were baffled as to how to teach these “special kinds of students.”

Polio was contracted in many different situations. Some got it while traveling on vacation or to a foreign country. Others were away from home and had to deal with so many unknowns. A high degree of discrimination, even racial, was evident in the country during and after the epidemics. Many polio survivors became activists in the political arena and helped establish groups of people who lobbied Congress, this leading to the enactment of the American Disabilities Act of 1990.

A story about the iron lung was told in the 1930s by the wife of the inventor, Madelene Emerson. Her husband invented the machine that was used widely during the epidemics, even though Philip Drinker of Boston’s Children designed the first lung. Emerson traveled the country and gave demonstrations to the medical community. He was really the marketer and the two men had to settle in court who should get credit for the invention. Emerson won the suit and his lawyer waived his fees in the end, mainly because he saw how many people were being helped by the machine. Ironically, Emerson came down with polio and had to use the lung for a short period.

Dr. James Yamazaki tells the story of one of his colleagues who came down with bulbar polio during his training at the Children’s Hospital in Cincinnati in the late 40s. No other resident got polio but his friend was put in an iron lung for some time, eventually recovered and became professor of pediatrics at the University of Cincinnati. Dr. Albert Sabin was the attending physician at the time.

The convalescent period for those who had survived the acute attack of the virus was, for many, long and arduous. Some moved from the iron lung to rocking beds or chairs, becoming less dependent on forced breathing. Others had to be fitted with braces and other devices while many had to under go surgery to correct muscle and bone damage. These procedures usually occurred years after recovery when stabilization had occurred, usually well beyond their growth years. Much of the surgery was experimental because each patient required different procedures. Adjusting back into the work force or school settings were challenges for everyone, including families, employers, universities and collages.

Financial burdens of polio were overwhelming for many families. Think of the dilemma when the “bread winner” was unable to work, and his or her spouse cared for the other children and still had to go to work. Fortunately, for some the March of Dimes assisted or covered the costs of hospitalization, therapy and various devices, but they did not cover lost wages or lack of employment. Health insurance was hardly known in the epidemic years.

One of the heartwarming stories about living with polio *(Continued on p. 11)*

Polio Voices *(Continued from p. 10)*

described a boy/man who had been in an iron lung, then came home to be rejected by his friends. He did have a younger brother to play with. His greatest times of excitement were when he was allowed to ride the garbage truck. Friendships developed when he got into high school sports and excelled in football and baseball. "I always felt if I didn't have polio, would I have more dates? Or would I have been more popular with girls?" He concluded "that the problem that I had, is that disabilities exist with your own mind. If I had to do it over again, I would ask more out, because the ones that I went out with me never saw me having a handicap."

The authors devoted an entire chapter to "The Legacy of Volunteerism" and noted how many people volunteered their time and services in hospitals, rehab centers, raising money through the March of Dimes and lobbying in the states and in Congress. Of late, the world eradication efforts of Rotary International have required unprecedented effort of volunteers backed by money from their own pockets. The latter project started in the mid-1980s with the goal to eradicate polio in the world by now. Their success has been phenomenal. Only a few pockets of infection are still known in south central Africa and in Egypt.

Many foreign countries had what they called crawlers, polio stricken children who were unable to stand up or walk. They shuffled along the ground on their hands and knees to move anywhere. Most were ignored and considered outcasts. No orthopedic doctors were available in most of these country and again, Rotary International stepped in with teams of

medical professionals and completed successful surgery on as many as they could reach. For example, in Malawi there were as estimated 25,000 crawlers. One team of doctors did 2,400 operations in one visit. The results were so heartwarming that a doctor went back three times to volunteer his services.

In the late 1970s and 1980s many survivors, as well as doctors, were puzzled and dismayed to see symptoms of pain, fatigue and muscle weakness in post polios. After 20, 30 or 40 years since the onset of the disease what could be happening now? Are we getting polio again? Is there another epidemic around the corner? Most doctors had little or no knowledge of the disease itself. But those afflicted soon raised enough concern that some in the medical professional dedicated themselves to research and studies of those with symptoms that we now call the post polio syndrome. It was learned that the old adage "use it or lose it" did not apply anymore. In fact some found that the more they used their muscle the worse they felt. Ultimately, out of all the case studies done up until the present have shown that over use of affected muscle and some of the muscles that compensated for the weak ones during the last decades have weakened them, and made us painfully aware of a decline in our physical and in some cases our psychological well being. "Conserve to preserve" has become the motto today as post polios have experienced the syndrome and aging has made it necessary for us to re look at how we live.

In closing, this book is fun to read and one that can serve as a coffee table book, picking it up at one's leisure to enjoy the stories. It's also of interest to those who like a bit of history.

This Is Your Newsletter-----

Colorado Post-Polio Connections is a newsletter by and for polio survivors, their friends and others who are interested in being part of our network. The editors and staff invite your contributions to the newsletter. If you have comments, articles, or suggestions for topics for future issues, please email us at post-poliocolo@comcast.net or write to us:

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Our next issue will focus on durable medical equipment. We need suggestions from you as to what questions you have about those canes, crutches, walkers and wheel chairs for the “And by the Way. . .” column.

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