

Now called
Post-Polio Health

polio network news

Crutches Anyone?

Thomas Fetterman, Southampton, Pennsylvania

Walking sticks have aided bi-pedal man since the dawn of our evolution as an assist to climbing, an aid to steadying ourselves, a probe, a reaching tool, a weapon, an artistic expression, and, for some, a weight-bearing device to facilitate ambulating.

As we became more sophisticated, our walking sticks developed specialized functions for specific needs such as a hook-shaped top to herd sheep or a T-shaped top to nestle in the pit of the underarm for a rudimentary crutch. Form was driven by its need to function and was shaped for the individual's needs often by the individuals themselves.

The mid-19th century brought this country two things that changed the humble walking stick forever: the Industrial Revolution and the battlefields of the Civil War and World Wars. The wholesale demand for crutches spurred by a sea of casualties disallowed the luxury of hand-whittled, custom-designed, walking devices. Crutch mills were born in the abundant hardwood forests of New England to meet the demand.

A major design change from the T-shaped underarm crutch took place as the bow underarm crutch was developed. Called splits, they are made from a single long piece of hardwood cut down 3/4 of its length with the top spread apart in a "V" shape, into which a wooden, cradle-shaped underarm piece is fixed to the top, and a handle is added lower down.

This underarm bow crutch was useful to the many soldiers who

had leg amputations because they could tuck their upper arm tightly between the bows and walk without a hand on the handle, freeing an arm. Though underarm crutches are less energy efficient and more cumbersome than forearm crutches, they are still preferred today by many long-term users for this carrying ability.

For those who could afford the cost, a deluxe sling top, leather-wrapped crutch was designed. The bows above the handle are steam-bent to form subtle opposing "S" curves that function like leaf springs as they are drawn together when body-weight is applied. The soft sling top is still the most comfortable and least deleterious underarm crutch available today.

Although the vulcanization process patented by Charles Goodyear in 1844 allowed for the creation of a metal device that held a rubber pad to be affixed permanently to the wooden crutch end, rubber tips did not become common until the turn of the century, when hard, smooth, man-made surfaces became dominant.

World War I brought the need for more advances in crutch-tip technology. In 1919, George Hippwood patented a sophisticated crutch tip with an air bladder inside. His patent also shows one of the first height-adjustable underarm supports that later evolved into the adjustable underarm crutch issued by hospitals today to the short-term user.

The early polio epidemics brought a variety of problems. When a person's legs and arms were

weakened, both the biceps and the triceps had to be supported. With Franklin D. Roosevelt's help, the Warm Springs Crutch was designed with a metal cuff above and below the elbow.

Others, like me who had paralyzed legs but unaffected arm strength, were issued the Kenny arm-band crutch. Named after Sister Kenny, it is a wooden bow crutch similar to the sling-top, wooden-bow crutch; but instead of the sling top, it has a wide circular leather band attached to the top of the crutch that fits loosely around the forearm.

Issued to many polio survivors, this crutch was particularly good for children. The soft leather cuffs were very forgiving during falls because they did not entrap the arms. Kenny crutches are usually associated with polio poster children.

World War II and the Korean War, along with another polio epidemic, provided customers for the next major change in crutch design. The forearm crutch, often referred to as the Loftstrand crutch, the brand name of one of the early manufacturers, was a boon to its users. Made out of aluminum tubing, it now dominates the world's long-term crutch user

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market. Because they have adjustment holes above and below the handgrip, one size fits all.

As an active teenager, I destroyed these aluminum forearm crutches at the rate of three or four pairs a year. Before they failed completely, they clicked and clacked with every step: I sounded like the "Tin Man" echoing down the halls of my school. Everyone would see me coming, but I was always more annoyed that they could hear me coming as well.

My parents bought the available rubber crutch tips by the case. But the hollow end of the crutch tube would cut through the bottom. I fell regularly.

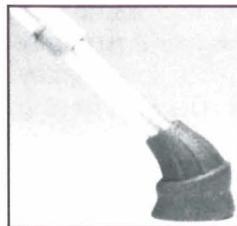
During the hours that I spent repairing my crutches, I developed a large stock of broken crutch parts and some passable mechanical skills. Many years later, when I had shaken off the paternalistic pressure to accept these fragile, noisy, callous-causing, institutional gray crutches as my lot in life, I set out to change things.

In the late 1980s, after 30 years of crutch walking, my shoulders ached more and more when I was active. My doctor told me to slow down and take aspirin. Instead, I decided to design a shock-absorbing system for crutches.

An engineer told me that my shoulders support approximately three times my body weight with each step. And because, like many active people, I walk between 6,000-8,000 steps a day, literally tons of negative ground impact strike my hands, arms, and shoulders. No wonder they ache!

After considerable experimenting, I developed and patented a crutch tip design that has a built-in shock-absorbing gel polymer pad called *Absorbalite™*. An oversized steel disk is chemically bonded

above the gel pad. The crutch shaft becomes a piston rod as it pushes against the disk and gel pad. The pad and side walls of the tip balloon out as the gel distorts and transforms the impact forces into heat instead of passing the energy up the crutch shaft to be absorbed by the body.



This design has resulted in relief from the "crutch pain" for me and many others (more than 30,000

pairs sold). Because they are hand assembled and use expensive materials, *Performance™* tips and the smaller *Tornado™* tips seem pricey at first. However, they wear three to five times longer than ordinary tips, so they are a good value.

The more I spoke with my crutch-tip customers, the more I realized that we shared the same complaints about manufactured forearm crutches. In 1991, I joined with Enabling Technologies who design and build excellent quality *Superlite™* custom-made crutches. In these crutches without

adjustment holes, the strength and durability are substantially increased, and they are forever silent because they have no moving parts. Much lighter than manufactured crutches, they will even float on water.

We now offer a wide selection of bright dipped anodized colors. And, to protect the bottom six inches of the crutch used to hold a door open, we install black PVC door guard sleeves.

Our high-tech, high-style crutches have not gone unnoticed. Last year when President Clinton injured his knee and was questioned about his snazzy black *Superlites*, he replied, "I call them my Stealth crutches ... I think they were developed as an offshoot of B-2 technology. I like them quite a lot."

We now hand make many different styles of crutches to order as in the old days, often making them from tracings of existing crutches. We also create new designs to meet specific needs.

As we move into the next century, our goal is to preserve the best of the past while using the materials and technology of the future.



For more information, contact Thomas Fetterman, Inc., P.O. Box 174, Southampton, PA (Pennsylvania) 18966 (215/355-6941 or 888/355-6941). ■

The next issue of *Polio Network News* (Vol. 14, No. 4), will feature recent advances in crutches. Readers are invited to send information (description, advantages, and source) about their favorite crutches.

Marriage: A Two-Way Street

Joyce Ann Tepley, LMSW/ACP, LPC, Dallas, Texas

I'm going to tell you a story of a marriage — my marriage. In telling this story to myself as I was preparing for this speech, I created some axioms (page 4) about how polio affects my marriage. I don't know how universal these truths are, but as you read my story, compare your life with mine. I've learned a lot from having polio. It has been, and still is, my best teacher.

When Phil, my husband, and I met back in the mid-1970s, we were in our early 30s. I had polio when I was nine and was stabilized in my health. I had been working as a social worker at a mental health clinic for eight years. The year we met I decided to leave the clinic, my first job, and open my own private practice.

My health was stable; my career was established. It was a good time to take a risk in my professional and personal life. I was tired of having short-term relationships and decided that it was better to be alone. Having an independent spirit, I was not afraid to spend a lot of time by myself. In fact, the opposite was true. I wasn't sure I could live with another person or handle the closeness that marriage demanded.

Phil and I developed our relationship slowly. Divorced after only one tumultuous year of marriage, he was not ready to make a commitment. His job was sending him to Michigan for six months in the dead of winter, and he wanted to write to a friend. I liked him and the idea of getting to know him from a distance. Besides that, I was busy building my practice and did not need to be distracted from my professional goals.

After five months of letters and phone calls, he invited me to Michigan for my birthday, which started the romance part of our relationship. When Phil moved back to Dallas and continued to travel with his work, we developed the habit of spending the weekends together.

As with all relationships, we had a lot to work out the first few years when the infatuation wore off. We were very different in many ways, but had similar values. I'm a tidy housekeeper. He likes books and papers in precarious piles. I have a greater need for control and like to be physically active. He is more even-tempered and likes to be physically comfortable. (Sitting in his easy chair for hours with a good book is his idea of a perfect afternoon.) I'm more emotional. He's more intellectual.

We both believe in not escalating arguments beyond a certain point. We never walk out on each other or call each other names. We solve our differences before the end of the day. Over an eleven-year period, we worked out a comfortable arrangement of just the right amount of closeness balanced by a good amount of independence. We were afraid that getting married would ruin our relationship. I felt that I would rather yearn for Phil than be sick of the sight of him.

A combination of things tipped the scale towards getting married. Around 1985 when I was in my early 40s, I noticed increasing episodes of extreme fatigue. I saw an article in the newspaper about a polio support group for people who were having similar problems. I went to one of the meetings and felt awkward about hav-

ing to think about polio again. All these years it had been in the background of my life. It had not kept me from living a full life, and it made very little difference to Phil, which was one of the reasons I liked him. He recognized how polio had shaped my character and was a major part of who I was as a person. He didn't treat me like an invalid.



Phil Hughes and Joyce Ann Tepley

I started to research post-polio and was evaluated by a physical therapist. I got lightweight leg braces and bought a three-wheeled scooter. The next year I had my breathing evaluated and started using a ventilator to rest my breathing muscles at night. Even with all these changes, I was still having trouble maintaining my health and my private practice. Phil was worried about me and was helping me financially.

CONTINUED ON PAGE 4

JOYCE ANN TEPLEY'S Marriage Axioms Involving a Partner with Post-Polio

1. No matter how hidden, polio is the third entity in the marriage.
2. The non-disabled partner must be able to identify with disability.
3. The effects of polio cannot be integrated into a marriage if the experience of polio is not integrated in the polio survivor.
4. It's not just the physical effects of polio that adds extra stress on a marriage. It's how the partners deal with the emotional and mental effects.
5. Disability tends to exaggerate all the ordinary issues of marriage.
6. When post-polio syndrome enters a marriage, "for better or for worse, in sickness and in health" must be dealt with sooner rather than later.
7. The partner with polio will most likely be an over-achiever.
8. When post-polio syndrome enters a marriage, the partner with polio must begin to do less and, consequently, the non-disabled partner must begin to do more.
9. For a healthy marriage, the non-disabled partner must have a degree of unselfishness and the disabled partner must have a degree of ego strength.
10. A good marriage is based on monotony (routine) and familiarity with occasional change. Too much change, too quickly makes the relationship unstable.

At that time, my grandparents and mother were in failing health, and I was going back to Ohio as much as I could to be with them.

Phil was also facing several changes. The company he worked for went bankrupt, and he had to look for another job. We had talked about marriage over the years, but always concluded it wasn't for us. But with the older generation of my family dying off, and his parents getting older, family was becoming very important to me.

With that thought primarily on my mind, I got down on my knees, literally, on Phil's birthday in 1987 and asked him to marry me. After many delays, we wrote our vows and set the date. I'll never forget my surprise during the ceremony when I heard Phil promise to be my "helper." Over the last ten years of our marriage, he has kept that promise.

We have essentially been together now for 22 years and over that period of time, as a counselor of relationships and a student of my own, I have observed certain truths.

Over half of all marriages end before seven years. We expect a lot from a marriage; marriage is not easy to maintain. It's complicated enough without adding disability.

I wondered why people stay together against the odds, and I came up with Axiom #10. I think you have to have a high tolerance for routine and find starting all over with someone new abhorrent. It took me several years to teach Phil how to hold his arm just right so I could hold onto him comfortably when we walk together. Now he automatically waits and sticks out his elbow.

(A friend of mine who has polio is staying in a less than satisfying

marriage partly for that reason. Her husband knows just how to help her transfer in and out of the wheelchair and car.)

Phil already knew and accepted me as a polio survivor. As in Axiom #3, I had worked long and hard to emotionally accept myself as "different" growing up. When he met me, he was impressed with my confidence. Polio was not just a life-altering experience I had in my past, but a part of me. I saw myself as a healthy person emotionally and physically. But when I became weaker physically, it shook my confidence, and I was challenged again — how to again integrate polio into my life in another way.

We had to adjust our lives around my health problems. Phil had to assume most of the financial burden since I could not work full-time anymore. We started proving Axiom #8. There were days I stayed in bed grieving the death of my mother. He would come home from work and handle all the household chores. The physical things were hard enough, but the greater dilemma for him was handling my emotions.

As in Axiom #4, I believe that physical problems are more easily solved than emotional ones. Emotions are tied to perceptions, attitudes, one's character makeup, or how one's family of origin handled feelings. I've been fortunate. I picked a partner who could identify with disability. (Axiom #2.) He was a fat child growing up, and he knew what it was like to feel different. His family taught him to accept people as they are. He never felt threatened by people who were different unless they were malevolent.

I'll conclude with Axiom #9. In our marriage, the line between who is disabled is getting thinner. We're both getting older, and

Phil is developing his father's disease of arthritis. Neither one of us is "doing more" any more. We're starting to plan for the day when we'll both need more physical help than we can provide each other.

Phil has been my faithful caregiver, and I have learned to accept help without feeling diminished. I have been his faithful companion, giving him support through all the changes in his life. He has learned that he could live comfortably with another person without compromising his integrity. What more could one ask of a marriage? ■

Post-Polio Bibliography

◆ Kemp, B., Adams, B., Campbell, M. (1997). Depression and life satisfaction in aging polio survivors versus age-matched controls: relation to postpolio syndrome, family functioning, and attitude toward disability. *Archives of Physical Medicine & Rehabilitation*, 78, 187-192.

This investigation compared depressive symptoms and life satisfaction scores between people aging with polio and an age-matched sample of non-disabled individuals, as well as among polio survivors by change in symptoms; and assessed the role of family functioning and attitudes towards disability in mediating the relationship between post-polio syndrome and outcome measures of depression and life satisfaction.

The average depression scores for both samples were within the normal range, and were not significantly different with mean values of 5.5 and 4.2 for polio survivors and controls, respectively. The percentage of persons scoring in the highest category of "probable major depression" also did not differ between groups. It was only for the middle category of "significant symptomology" that polio survivors outnumbered controls with 22.2% of the sample falling into this range com-

pared to only 12.5% for the non-disabled group.

The biggest differences in depression scores were observed within the polio sample rather than between groups. Polio survivors meeting the criteria for post-polio syndrome had an average depression score of 6.5 (n = 66), which was significantly higher (p < .05) than the average score of 4.2 observed for those in the combined non-symptomatic and physical-symptoms-only subgroups.

This study found no overall differences between people with polio and age-matched nondisabled persons on either the mean level or the percentage of persons with high scores on a standardized depression questionnaire.

Nevertheless, over one-quarter of post-polio persons had scores high enough to warrant consideration of some treatment or intervention. A separate assessment by clinical psychologists using standard diagnostic criteria further supported these findings. Also, certain subgroups of persons with polio were at higher risk of depressive disorder. *Those with more post-polio change, lower attitude scores and lower family functioning had higher depression scores. Even more important than post-polio change was the person's attitude toward disability and family functioning, especially when both were low.* Under these circumstances, the average depression score jumped to a high of 10.8.

Of special concern is the fact that treatment of any kind for people with probable depressive disorder seemed non-existent. Among those with high scores, not a single person was in counseling or taking an antidepressant medicine even though several seemed like obvious candidates on clinical examination.

MARGARET L. CAMPBELL, PHD,
DOWNEY, CALIFORNIA

Dr. Campbell will be leaving the Rehabilitation Research & Training Center on Aging with Disability at Rancho Los Amigos Medical Center to pursue other challenges.

◆ Agre, J., Rodriguez, A., Franke, T. (1998). Subjective recovery time after exhausting muscular activity in postpolio and control subjects. *American Journal of Physical Medicine & Rehabilitation*, 77(2), 140-144.

This study demonstrated that the subjectively determined time to complete recovery after the performance of exhausting muscular exercise was greater in unstable postpolio than in stable postpolio or control subjects. The stable postpolio and control subjects did not differ in subjectively determined recovery time. The cause for these findings is unknown and requires further investigation. ■

international polio network

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Living with Polio in the Slovak Republic

Zora Kmetova

The history of Slovak polio survivors is closely connected with the history of medical treatment in the common state of Czech and Slovak – Czechoslovakia.

Most people who had polio in the 1950s were treated in the Czech spa, Janské Lázně. Janské Lázně was one of the first places in the world where the special method of the Australian Sister Kenny was introduced. Before she could visit Czechoslovakia, her colleague, Sister Curtis, introduced this medical treatment in 1949.

In addition to Janské Lázně, patients from Slovak were treated in Velké Losiny. We spent long months and years with



specialised personnel trained in progressive methods. It was a very strange life. We sang many polio songs and had our own polio anthem. We lived as one family, first as ill but inquisitive children, later as young, no doubt disabled, but unbelievably tenacious people, desiring to convince others of our physical and mental abilities.

We attended Czech schools and found many life-time friends and partners from Italy, Germany, the Arabian states, and other countries.

Because of the eradication of acute poliomyelitis in Czechoslovakia in the 1960s, interest in polio by the medical community decreased. The health problems of polio survivors were not addressed as completely as before.

In 1993, when Czechoslovakia was divided into two separate states – Czech and Slovak Republics – the situation for Slovakian polio survivors became more complicated. Polio problems had not been treated as extensively in Slovakia as in the Czechlands. We had no specialised polio centres, so patients were treated in ones for motor diseases. Thanks to some specialists at the spa, Trenčianske Teplice, we have found adequate but not specialised care.

Treatment in a spa lasts four weeks and a survivor can visit every two years if an insurance company approves it. Slovak polio individuals can, as other people with disabilities, get partially reimbursed for some orthotic devices while corsets, orthopaedic devices, and mechanical and electrical wheelchairs are free.

People with disabilities in Slovakia also can ask for financial aid to adapt housing, buy cars, set up telephone lines, and to provide public transportation, outdoor recreation, and treatment for non-working individuals. The financial aid available for buying a car does not cover the high purchasing cost, so a car remains an unfulfilled dream for many.

Over the years, as the polio population grew older and its stable health began to change, and as the political and economical conditions in Slovakia changed, it became a necessity to connect with people having similar problems and to exchange views with other polio survivors. The Polio Association of the Slovak Republic, headquartered in Trenčín, West Slovakia, was established in 1992.

Our association, through information and consulting activities, develops programs to help solve problems specific to polio survivors. It is encouraging its 300 members to inform health professionals about their personal, specific problems.

All members receive an irregularly published journal, *Informator Asociacie Polio v SR*, which provides practical advice and information about laws related to social or health service. The association is trying to register all polio survivors in Slovakia, possibly 3,000.

Most members are still employed, but some have been forced to retire early due to their health. The future quality of life for polio individuals is of great concern for all of us. Some members of the Association Council are also working in the various social departments of state administration as well as the Slovak Association of Disabled People. They submit official proposals to change laws which assist people with disabilities.

The Polio Association organises social/rehabilitation courses throughout Slovakia. Every year at least two meetings are held in an attractive location where specialists are invited to speak about specific health problems.

All the work of the association is done on a voluntary basis. We are of the opinion that international solidarity and cooperation can create an understanding of the needs of polio survivors. ■

Zora Kmetova, Slovak Polio Association, u/M. Razusa 3, 911 01 Trenčín, Slovak Republic

... and in the Czech Republic

Ála Wokoun

Greetings from the polio survivors of the Czech Republic, the western part of former Czechoslovakia. Our country has a long tradition of caring for people with the late effects of polio and has applied the best experiences from abroad.

The first European institute providing special care for polio survivors was founded at Janské Lázně Spa in 1935. Because the chemical composition of the spa springs was similar to the water at Warm Springs, Georgia, USA, the Warm Springs treatment was adopted.

In spite of political changes and the Cold War, the Kenny method was also accepted in our country and every new case of polio was treated, free of charge, for two years with hot packs, stimulation, and reeducation of affected muscles. The Salk vaccine was introduced in 1957 and all children of Czechoslovakia have been vaccinated with Sabin's "syrup" since 1960.

Year	Czechlands	Slovakia	Czechoslovakia
1945	594	120	714
1946	295	119	414
1947	577	142	719
1948	2063	322	2385
1949	414	118	532
1950	444	92	536
1951	583	159	742
1952	742	276	1018
1953	1895	452	2347
1954	794	286	1080
1955	133	85	218
1956	388	249	637
1957	636	435	1074
1958	231	81	312
1959	131	167	298
1960	33	28	61

SOURCE: F. Pokorný, *History of poliomyelitis in Janské Lázně* (In Proceedings from first conference with international participation about post-polio syndrome, 1991.)

When acute poliomyelitis was eradicated in the '60s, our polio survivors were not forgotten. They continued to receive free rehabilitation treatments at Janské Lázně Spa and Velké Losiny Spa.

In 1968, we began correspondence with Gini Laurie, the founder of Gazette International Networking Institute, and, since then, Czech polio survivors have continued to receive information from GINI.

Many of the 10,000 Czech polio survivors are experiencing the late effects of polio. For the protection of their interests, the Association of Polio Survivors in the Czech Republic was established in 1990. It immediately organized a medical conference on the late effects of polio and coordinated the second Czech medical conference on the late effects of polio in 1993.

Our association publishes informative quarterly bulletins. At our yearly fortnight meetings, we acquaint members with the information from abroad about the late effects of polio. Then, all international literature is housed at our special library in Sumperk.

The current rehabilitation treatment of Czech polio survivors continues in four spa institutes (Janské Lázně, Velké Losiny, Tereziny Lázně, and Vráz.) The Czech General Health Insurance Company covers transportation, accommodations, meals, and 3-7 week treatments every second year. If there is a danger of a deterioration of our health condition due to the late effects of polio, the free spa rehabilitation treatment is repeated every year. Polio survivors with manual wheelchairs whose overused upper limbs are

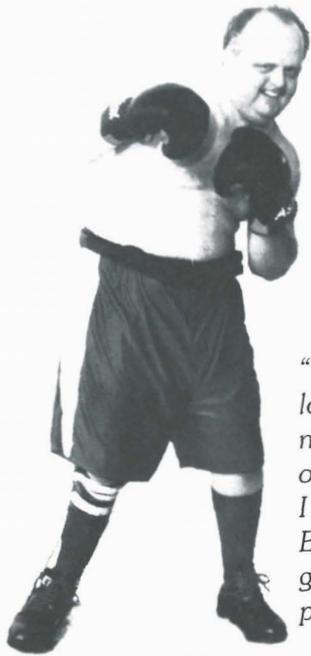


getting weaker receive free electric wheelchairs from the Health Insurance Company or a fifty percent municipal contribution. Additionally, a system of personal assistants for independent living is developing. ■

Ála Wokoun, Chabarovická 1333, 182 00 Prague 8, Czech Republic

Ála Wokoun had polio 53 years ago and underwent rehabilitation at Janské Lázně Spa. In the Czech Republic, he fights against architectural and transportation barriers.

Ála uses the following argument when advocating for accessibility to his country's older buildings. "Some protectors of historical buildings do not allow any architectural adaptation on behalf of wheelchair users: a side entrance, a side ramp, or a hidden lift. They do not comprehend that a non-paralyzed visitor suffers less from architectural adaptations than a wheelchair user, who cannot enter and experience the historical or art heritage, suffers without them. Protectors of historical purity forget that electricity and telephones have been installed, and the historical purity has already been destroyed."



THE POLIO BOXER STORY

Jeff Whipple, Sarasota, Florida

"You're lookin' at the new champion of the world. I am the Polio Boxer. I am going to kick polio's butt."

Those are the first lines Roger Freeman says in "The Polio Boxer," a one-man play based upon his experiences with polio. Roger battled polio when he was a baby in 1953, before the first vaccinations. Now there's a rematch as he experiences post-polio syndrome. But this time, he's determined to win the fight.

The play takes place in a boxing ring and Roger is quite a sight in boxing shorts and gloves. He is, to put it gently, not an athlete and there's a large brace on his right leg. But that is okay because this boxing match is a symbolic fight with polio; Roger never actually throws a punch. The play is really about Roger's dynamic zeal for life and his determination to live without limitations.

Roger is an experienced actor for stage and screen, and I first met him in 1992 when he was cast in a production of one of my plays. It was then that I first started notes for the "The Polio Boxer." Five years later, after many interviews and rough drafts, I finally had the script finished. I was nervous about showing it to Roger, not knowing if he would like it. He cried when he read it, feeling

both the happy and sad emotions of his life story. A month later he was performing it before a live audience and they too felt those emotions.

Since then, other theaters have produced the show, and the audience response has been positive. The play provides a lot of information about the "forgotten" disease, but it is about more than polio.

Roger's story is universal. It is really about overcoming problems and creating a terrific life. After the performances, I have talked to audience members and it's amazing how many of them are so eager to tell their own experiences with polio or how they knew someone who had it.

In the show, Roger talks directly to the audience, laughs, sings, dances, and sometimes shows his anger against polio. He likes seeing the faces in the audience and making eye contact. Though the play has him going to emotional and physical extremes for ninety minutes, the shows get him so charged up he cannot sit still for hours afterward. But it wears on him physically as he is, at age 44, coming to terms with post-polio syndrome.

Earlier this year, we met with a post-polio support group in Florida. Roger walked in wearing his boxing outfit and performed some scenes from the play. The group was captivated and deeply moved. Later several of the polio survivors said, "I've always wanted to say that! It's just how I feel."

Roger just loves doing the show and we are both eager to bring it to more audiences. The play is designed to entertain both people who know nothing about polio and those who have lived with it their whole lives.

We will perform "The Polio Boxer" in traditional theater settings or in community centers. For more information, contact Jeff Whipple, 4050 Tallevast Road, Sarasota, FL (Florida) 34243 (941/351-9205). ■

Roger Freeman has appeared in dozens of plays, several feature films, and television. In 1992, Freeman originated the role of Carl in Jeff Whipple's play, "Tunnels in the Crust," at the Arcade Theater in Fort Myers, Florida. He recently played a cook in Disney's soon-to-be-released "Gone Fishin'." He studied at the Acting Studio in Nashville, Tennessee, and the American Film Institute in Los Angeles, California. Freeman lives in Fort Myers, Florida with his wife and teenage son.

Jeff Whipple has developed award-winning careers in both visual art and playwriting. His plays have been featured in dozens of staged readings and fifteen productions in Chicago and Florida. His screwball comedy, "The Tourist Trap," was produced at The Players Theatre in Sarasota, Florida in January of this year and his newest play, "The Polio Boxer," was performed at the Caldwell Theatre in Boca Raton in March. In 1980, Whipple received a Masters of Fine Arts in Painting from the University of South Florida. He is a frequent lecturer at colleges and art centers and has taught at several colleges, including Arizona State University and Northern Illinois University. He has been awarded four Individual Artist Fellowships from the state arts programs of Illinois and Florida.

Sleep and Bladder Health Among Polio Survivors

All readers are invited to complete the survey. It may be reproduced for distribution to polio survivors.

Dear Friend:

You have been selected to participate in a research study to determine if survivors of polio experience sleep-related breathing problems and, if so, if having to urinate frequently during the night is a problem. Please do not put your name on the survey; your participation in this survey is entirely voluntary. Your consent to participate is granted by completing the following questionnaire and returning it to the investigator.

In general, most health professionals and the lay public know very little about sleep disorders. The purpose of this study is to determine how widespread sleep problems and sleep-related breathing problems are among people who have had polio. Information obtained from this study will be used to direct future research as well as provide additional knowledge regarding the health needs of individuals who have survived polio.

The following items and the Sleep Survey (33 items) will take about 20 minutes to complete. When finished, send the survey to the address listed below.

Any additional comments you may have about your sleep problems are also welcome and may be included with this survey. For any questions about this study, you may call Mary Umlauf, PhD, RN at 205/934-7532.

Return survey to:

Sleep & Bladder Health Survey
Center for Nursing Research
University of Alabama
School of Nursing
Birmingham, AL 35294-1210 USA

TELL US ABOUT YOURSELF

- A. Country of Residence _____
Zip Code (if in USA) _____
- B. Gender: Male Female
- C. Age _____ Height _____ Weight _____
- D. Age when first contracted polio _____
- E. When were you diagnosed with polio? Year _____
- F. Did you have any breathing problems during the time you had polio? Yes No
If yes, describe: _____

- G. Since recovering from polio, have you now been diagnosed with post-polio syndrome? Yes No
If yes, describe symptoms: _____

SLEEP SURVEY

This short survey will tell us about your problems with sleep and if you have problems caused by having to urinate frequently through the night. It is very important to answer every question because there are many different types of sleep problems, not just nocturia.

In answering the questions, consider each question as applying to the *past six months*.

Some people work nights or rotating shifts. Others have changeable bed-times. So, when we ask questions about your sleep, we will mean the time when you have your longest sleep of the entire day.

Most of the questions are simple statements. You answer by circling a number from 1 to 5. If you strongly disagree with the statement, or if it never happens to you, answer "1." If the statement is always true in your case, or you agree strongly with it, answer "5." You may also answer "2" (rarely), "3" (sometimes), "4" (usually), as well as "NA" for items that do not apply. Notice that the "answer key" appears at the top of the page to remind you what is meant by the numbers. Please answer all the questions to the best of your ability.

KEY:

- 1 Never (strongly disagree) 4 Usually (agree)
2 Rarely (disagree) 5 Always (agree strongly)
3 Sometimes (not sure) NA Not applicable/Don't know

Please circle the number that applies using the key provided at right:

1. I get too little sleep at night.
1 2 3 4 5 NA
2. I often have a poor night's sleep.
1 2 3 4 5 NA
3. I have trouble getting to sleep at night.
1 2 3 4 5 NA
4. I wake up often during the night.
1 2 3 4 5 NA
5. My night sleep is restless and disturbed.
1 2 3 4 5 NA
6. At night, my sleep disturbs my bed partner's sleep.
1 2 3 4 5 NA
7. I snore in my sleep.
1 2 3 4 5 NA
8. I am told that I snore loudly and bother others.
1 2 3 4 5 NA
9. I am told I stop breathing ("hold my breath") in sleep.
1 2 3 4 5 NA
10. I awake suddenly gasping for breath, unable to breathe.
1 2 3 4 5 NA
11. I sweat a great deal at night.
1 2 3 4 5 NA
12. Now, I am very sleepy during the day and I struggle to stay awake.
1 2 3 4 5 NA
13. I often have to let someone else drive the car because I am too sleepy to do it.
1 2 3 4 5 NA
14. I am excessively sleepy during the daytime.
1 2 3 4 5 NA
15. I wake up in the morning with a headache.
1 2 3 4 5 NA
16. I have, at some time, had trouble with bedwetting.
1 2 3 4 5 NA
17. I currently take a *non-prescription* drug from the pharmacy to help me sleep.
1 2 3 4 5 NA

18. I currently take a *non-prescription* drug to stop me being so sleepy and fatigued in the daytime.
1 2 3 4 5 NA
19. I take a prescription drug, which the doctor gave me, mainly to help me sleep (sleeping pills, anti-depressants, tranquilizers).
1 2 3 4 5 NA
20. I have chronic chest disease (bronchitis, asthma, emphysema).
1 2 3 4 5 NA
21. My snoring or my breathing problem is much worse if I sleep on my back.
1 2 3 4 5 NA
22. My snoring or my breathing problem is much worse if I fall asleep right after drinking alcohol.
1 2 3 4 5 NA
23. My snoring or my breathing problem is much worse when I have an allergy or infection in the nose, throat, or chest.
1 2 3 4 5 NA

QUESTIONS

24. How many times do you get up at night to urinate? _____
25. How many daytime naps (asleep for 5 minutes or more) do you take? _____
26. Overall, how do you rate your health?
(circle one choice below)
Excellent Good Fair Poor
27. Do you have any pain or burning when you urinate? Yes No
28. Do you have any trouble starting the stream when you want to urinate? Yes No
29. Once your urine stream starts, does it stop and start? Yes No
30. When you are done, do you feel like your bladder is empty? Yes No
31. Is getting up during the night to urinate bothersome to you? Yes No
32. Do you have accidental urine leakage? Yes No
33. Do you use a urinary catheter? Yes No
34. Do you take a water pill (diuretic)? Yes No
Name of drug _____

*An abbreviated version of the Sleep Disorders Questionnaire by Douglass, et al, 1990 & 1994.

Readers Write

"I received word from the Office of Hearings and Appeals (Social Security Administration) that the Administrative Law judge ruled in my favor and that Medicare will pay for a pov (power-operated vehicle), a three-wheeled scooter. It took more than two years and appeal after appeal.

"But I made the case that the pov would 'improve the ability of chronically disabled persons to cope with normal domestic, vocational, and social activities;' that the pov was medically necessary (even though I can be ambulatory for short distances) 'to support muscle tissue and not to create muscle fatigue;' that I could not use a manual wheelchair; (is) 'reasonable and necessary for the diagnosis or treatment of an illness or injury as to improve the functioning of a malformed body member.'

"Another requirement I met was to have a specialist in physical medicine provide my evaluation and prescribe the pov (could have been an orthopedic surgeon, neurologist, or a rheumatologist).

"My advice to others it to know the Medicare rules and definitions; get the prescription for the scooter along with a comprehensive letter of medical necessity by a physician from a medical specialty listed in the rules; describe what the scooter is expected to do and support with medical facts; appeal as necessary; jump through the hoops with a professional attitude, coolness, politeness, and never with anger; appeal.

"If I can help others, please have them contact me."

ROBERT THAYER, 304 Patio Place,
Clinton, MS (Mississippi) 39056-5380

Have you heard about ...

... **swimming attire which provides extra warmth and support from Water Wear**, P.O. Box 687, Wilton, NH (New Hampshire) 03086, 8 a.m. to 5 p.m. EST, M-F (800/321-7848 US, 888/265-6711 Canada, 603/654-9885 outside US & Canada, 603/654-6426 fax).

World Wide Aquatics, 10500 University Center Drive, Suite 295, Tampa, FL (Florida) 33612-6462 (800/726-1530, 800/543-4459, 813/972-0818 overseas, 813/972-0905 fax).

... **Access-Able Travel Source**, which has information about accessible travel destinations and the best ways to get there. Contact them at P.O. Box 1796, Wheat Ridge, CO (Colorado) 80034 (www.access-able.com).

... **Scoot-Around North America**, headquartered in Winnipeg, which has linked up over 100 independent scooter rental companies in over 75 locations across North America to put travelers in touch with a rental company which guarantees that a scooter will be waiting at their destination. Scoot-Around takes care of the arrangements, charging a nominal fee for the link. Contact them at 83 Waterbury Drive, Winnipeg, Manitoba, Canada RP3 1R6 (888/441-7575, 204/772-6944 fax, or www.dpmg.com/scoot-around).

... National Easter Seals' Web site of **city-by-city information on accessible transportation** - www.projectaction.org.

... polio survivor Leonard Kriegel's new book, **Flying Solo: Re-imagining Manhood, Courage, and Loss**, published by Ballentine (ISBN # 08-070723-03).

... a creative nonfiction account of the "Miracle of Hickory," a 1944 emergency polio hospital built,

equipped, staffed, and in operation in Hickory, North Carolina, within 54 hours. **The Grit Behind The Miracle** was published by University Press of America. For copies (\$39.50), contact High Point University Bookstore, University Station, Montlieu Avenue, High Point, NC (North Carolina) 27262-3598 (336/841-9221 or bookstor@highpoint.edu).

... **Bitter or Better: It's Up to You** (ISBN # 0-9653845-7-8) by author, speaker, humorist, and polio survivor Marion S. Wikholm, MSW, BCSW. Part I is autobiographical; Part II offers suggestions - how to become better, with humor and the expertise of a psychotherapist, and not bitter. Contact Marion at 4333 Loveland Street, Metairie, LA (Louisiana) 70006-4197 (504/883-6329, 800/673-1652, 504/887-1806 fax, or mwikholm@aol.com).

... The President's Committee on Employment of People with Disabilities **Job Links** area on its Web site (www.pcepd.gov/joblinks.htm).

... the National Organization on Disability's (NOD) campaign to enhance greater religious opportunity for Americans with disabilities. Known as the **Accessible Congregations Campaign**, NOD's Religion and Disability Program seeks the commitment of 2,000 congregations of all faiths to welcome people with disabilities as full and active participants by the Millennium. To receive a free information packet, contact Lorraine Thal, Coordinator, Accessible Congregations Campaign, National Organization on Disability (NOD), 910 16th Street NW, Washington, DC (District of Columbia) 20006 (202/293-5960, 202/293-7999 fax, or www.nod.org).

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... www.quackwatch.com

... www.post-polio.org

... www.abledata.com for product information.

... **Parents' Benefits** – If you're 62 or older and a deceased son or daughter supported you, you may be eligible for parents' benefits from Social Security. Here are some of the requirements you need to meet for parents' benefits: you must be 62 or older; you must have been receiving at least half of your support from your child; your son or daughter must have been fully insured with Social Security; and you have not remarried after your child's death.

To qualify as parent of your deceased child, you must be either: the natural parent of the worker; the stepparent of the worker by a marriage before the worker reached 16; or a parent who legally adopted the worker before his or her 16th birthday.

Call Social Security at 800/772-1213 and ask for the booklets, *Social Security: Survivors Benefits* and *Social Security: Understanding The Benefits*.

... **Polio – The Haunting Ghost**, a 59-minute video about the late effects of polio with interviews of polio survivors and health professionals in western Massachusetts. The project was master-minded and accomplished by polio survivor Carroll H. Dwyer III, East Longmeadow, Massachusetts.

To order, send \$38 (includes shipping and handling) to Springfield Cable Endowment, c/o Thomas Kruc, 1 Monarch Place, Suite 1300, Springfield, MA (Massachusetts) 01144-1001 (413/733-0121).

... **Living with the Late Effects of Polio**, in which the English producer, Jackie Spreckley, herself a polio survivor, conducts a personal investigation into the symptoms and day-to-day realities of living with the late effects of polio. Several British Polio Fellowship (BPF) members talk frankly about the loss of mobility, fatigue, and the lifestyle adjustments that have become necessary for them. The video also includes interviews with health professionals, including hospital consultants, and a former pain management specialist.

The video was produced during 1997 as part of the BPF initiative, "Outreach 2000," a campaign to find every polio survivor in the British Isles. For U.K. orders, send £7.50 (includes shipping and handling) to The British Polio Fellowship, Ground Floor, Unit A, Eagle Office Centre, The Runway, South Ruislip, Middlesex HA4 6SE (0181 842 1898, 0181 842 0555 fax, or british.polio@dial.pipex.com). Contact BPF for details on overseas orders.

For a version compatible with American equipment, send \$20 to International Polio Network, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915. ■

Calendar

International Polio Network (IPN) invites all post-polio related groups to submit details of upcoming meetings. Send the name of the event, dates, location, and contact information to Sheryl R. Prater at GINI, 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63108-2915, 314/534-5070 fax, or gini_intl@msn.com.

1998

Future Approaches for Polio Survivors, AUGUST 28-29, Holiday Inn/Northglenn (a suburb of Denver). Contact: Mary Ann Hamilton, 1185 S. Williams Street, Denver, CO (Colorado) 80210 (303/722-6945, 303/722-7386 fax, or hamil1185@aol.com).

Post-Polio Conference, OCTOBER 2-3, Ramada Inn, Anderson, IN (Indiana). Sponsored by the Central Indiana Post-Polio Support Group. Contact: Ellen Crim, 338 West 38th Street, Anderson, Indiana (IN) 46013 (765/649-3648, mcrim1361@aol.com).

Seminar, OCTOBER 10, 1:00-4:00 pm, Grant Sawyer State Building, Las Vegas, Nevada. Contact: Caroleanne Green, National Polio Care Advocates, 741 Gullwing Lane, North Las Vegas, NV (Nevada) 89031 (702/649-9361, 702/649-6824 fax, or send LSASE for packet (no registration fee)).

International Polio Congress and Industrial Exhibition, OCTOBER 30-31, Jena/Thuringia, Germany. Contact: Bundesverband Poliomyelitis e.V. c/o Hendrich, Thastr. 27, D-35392 Giessen, Germany (+49/30/805-3593; +49/30/8060-2251 fax, www.members.aol.com/poliomed/ or WEFMurach@aol.com).

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