

POLIO NETWORK NEWS

International Polio Network

Spring 1992 ■ Vol. 8, No. 2

SPECIAL FEATURE: SCOLIOSIS

Two polio survivors experiencing scoliosis share their insights in this issue. The next *Polio Network News* will feature information from Serena S. Hu, M.D., Department of Orthopedic Surgery, University of California—San Francisco.

“Sir Benjamin Buzz”

Doris S. Benedict, Deposit, NY

*One day the snowman, Sir Benjamin Buzz
He started to melt as a snowman does.
Down ran the crown of his icicled hat
Over his forehead and right after that
He noticed his whiskers go lolloping by
Along with his chin and his collar and tie.
Then Benjamin looked and saw that his chest
Was gliding through his coat and his vest.
And after a little he sighed, “Ho! Hum!
There goes a finger and there goes a thumb”!
And scarce had he spoken when Benjamin felt
That both of his legs were beginning to melt ...”*

—Mildred Plew Meigs

When asked about information on scoliosis the above children's poem floats into my consciousness. Why that's us! The analogy is obvious to those of us who are experiencing post-polio syndrome as well as degenerative scoliosis.

I volunteered to assist the International Polio Network in locating fellow survivors for their anecdotes and solutions. What began as a survey, developed into an impassioned mission, an urgency to share gathered information and feelings. Had I known many years ago some of the things I know now, I would not have wasted time, money, and energy going to “specialists” not equipped to understand the quirks of a polio survivor, nor capable of offering solutions. I hope my polio friends far and wide, as well as members of my own support group who shared their stories, will gain more insight into the problem of scoliosis.

▼ SCOLIOSIS AND ITS CONSEQUENCES

Scoliosis is the sideways curve of the spinal column that results in an “S” shape to the back. Scoliosis can be recognized by one shoulder being higher than the other, one shoulder appearing more

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Exploring Your Options

Linda Bieniek, CEAP, Chicago, IL

Because surgical treatment of my kypho-scoliosis succeeded not only in straightening my spine by seven inches, but more importantly, in improving my quality of life and increasing my longevity, I want others to know about this treatment option.

When I was five, I developed polio that impaired my respiratory functioning and extremities. By the time I was six, my spine began curving. At age seven, I underwent spinal surgeries and laid flat on my back in a full length body cast for a year to prevent the curvature from progressing.

Despite these childhood surgeries, my curvature measured 170 degrees by the time I was 25. My left hip touched my armpit, leaving my left lung compressed. My breathing was so restricted, I gasped in between words. My ribs protruded in front and rotated to create a huge hump on my back. My chin lay on my chest. I walked with a significant limp because my leg lengths differed by over two inches. I often struggled to function and endured incredible pain, yet I was so driven to achieve certain goals that I ignored my body's distress.

After almost dying from a bout of pneumonia in 1973, I researched my options. I traveled across the country and consulted with surgeons and specialists. I read medical articles and talked with others. I deliberated — I prayed.

I believed that if my spine was straightened, my breathing would improve. It seemed logical to me because when I braced my arms on the top of a church pew, I was able to take a deeper breath and feel relief.

I decided to undergo high-risk surgery because I wanted to live — to experience and contribute more to life. I chose a team of highly skilled professionals who used a combination of traction and surgeries to straighten my spine. For me the benefits of this treatment have been life-saving and

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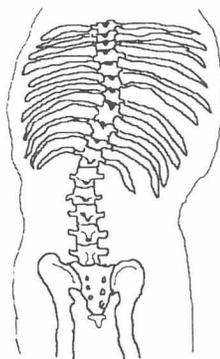
“Sir Benjamin Buzz”

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prominent than the other, and an uneven waistline. Scoliosis can be the result of a neuromuscular disease, i.e., infantile paralysis (poliomyelitis). Muscle weakness was not always recognizable after the acute stage of the viral infection. The enervation (loss of nerve cells) was sometimes insidious and slow in producing the pronounced curvature. This worsening curve can be accompanied by a twisting of the skeletal frame and the onset of serious breathing problems due to compression of the diaphragm. Scoliosis can be further aggravated by the lack of functioning abdominal muscles.

The consequences of scoliosis are instability; back, shoulder, and chest pain; gastrointestinal and urinary tract complaints; little endurance for daily tasks; exhaustion; and weakness of the arms. Survivors with scoliosis may experience restless sleep and/or sleep apnea, breathing problems, swallowing difficulty, and trouble with voice projection. Profuse sweating may also occur, usually caused by labored respiration.

After the acute polio, the damaged motor units around the spine sprouted new axons, thereby re-energizing the muscle function and aiding the stability of the spine and skeletal frame. Reports circulating recently state that sprouted axons are dying off, having been overworked through the years. The overuse and compensating strategies practiced by survivors through the years have put even more stress on remaining motor units. Not able to function anymore, they simply die off



resulting in weaker muscles. The spinal vertebrae alone cannot support the individual's body.

There is no way to stop the progression of scoliosis in an adult without surgical intervention. A few years ago surgery candidates were thought to be limited to those under 40 years of age. This is no longer true. The purpose of surgery is to lessen the curve of scoliosis by manipulating the spine to a more normal position and thereby alleviating pain. One method is to insert metal rods along the spine and bone grafts are used to fuse these rods to the spine. Sometimes this approach involves two operations: one for the front and the other for the back of the spine.

Consultation with a knowledgeable orthopedist, who “speaks polio,” is extremely important. If an orthopedic surgeon recommends a fusion, two or three opinions are suggested. The overall problem must be considered; one problem hinges upon another in polio.

▼ THOUGHTS FROM RESPONDEES

In cases of childhood polio when curvature of the spine was evident, spinal fusions and rod implantations were often done when the child became an adolescent. For the most part these surgeries seemed to have been satisfactory. However, some respondents complained of weakening arm muscles, heart conditions, spinal degeneration, severe rib cage deformity, pain, and very poor respiration. They felt that their fusions were not advantageous over the long haul, nor did they provide sustained reduction of pain. In some cases, fusions were done to aid respiration but produced the opposite effect.

One respondee, when she called the hospital for a record of the number of fusions done by a surgeon

International Polio Network

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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.

ISSUED QUARTERLY

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Special Thanks:

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Publisher:

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

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ANNUAL SUBSCRIPTION:

U.S.A.: Individual Consumer \$12; Health Professional, Affiliated Individual, Organization, Institution \$20

CANADA, MEXICO & OVERSEAS (Surface): Individual Consumer \$16; Health Professional, Affiliated Individual, Organization, Institution \$24

OVERSEAS (Air): Individual Consumer \$20; Health Professional, Affiliated Individual, Organization, Institution \$28 (U.S. dollars only)

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5100 Oakland Ave., #206
St. Louis, Missouri 63110 U.S.A.

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who recommended her for one, found that the surgeon had done ONE such operation previously. She was unable to obtain a report on the success or failure of this surgery, or if the patient had had polio. Yet another survivor reported having three unsuccessful fusions and is trying for another. Hearty soul!

Another reported an unsuccessful fusion that did not heal or diminish the extreme pain; the surgery had to be undone. The consensus of those writing to me was that suffering through a variety of back braces, casts, and fiberglass contrivances throughout the years have contributed little or nothing toward arresting the rapid progression of scoliosis, or in diminishing the pain.

One survivor foreseeing the threat of scoliosis stated that some time ago he ordered a back brace and has worn it since. He feels it staved off further damage.

Some individuals still wear the Hoke-type corset, nonetheless, the lumbar-sacro brace makes a very small contribution to stability and only somewhat aids breathing. The fancy and complicated body casts, suits of mail and various other medieval tortures, frequently with neck and chin braces, are swiftly rejected by most and put into closets. These are sometimes more painful than scoliosis itself: rubbing, bruising, digging, and adding to the wearer's instability. Recently an orthopedic surgeon commented that these cumbersome braces sometimes hinder proper ventilation. Well!

Most of the seating arrangements manufactured for our comfort and to correct improper postures were quickly challenged by most respondees. The "gel cushions" are difficult to manage and require constant kneading and adjustment. One would wish for a design similar to an automobile seat, mine seems to be posturally correct and comfortable. (I would hesitate to take the advice of a so-called "health supplier." They are not trained to prescribe.)

Respondees recommended changing positions, rest, and massage. Light exercise and not allowing one's self to get stiff is important. Attention to good nutrition and weight loss will also help improve the proper handling of scoliosis. Various pain medications prescribed by physicians do help. These

usually have to be tried for efficiency and correct dosage in handling the pain.

Respondees cautioned against carrying objects or standing for long periods of time. These acts will worsen the scoliosis.

BiPAPs, ventilators, and oxygen, among other aids, are sometimes used to assist difficulty in breathing.

The thought of a ventilator strikes fear in most polio survivors and/or their families. (IPN can connect any reader with several polio survivors who have recently started using periodic or nighttime ventilation.) Tracheostomies are NOT usually performed now, and it is no longer necessary to have a trach in order to use a ventilator. Portable ventilators with appropriate masks are now available. Adjustment to a mouthpiece and/or nose mask for nighttime ventilation is quite simple.

Some also mentioned feelings of discouragement and potential depression stating that peer and family support were paramount.

Recent studies indicate that polio patients who comply with various recommendations made by their physicians, suffer no further deterioration. Those who reject the suggestions can show further decline. One realizes the things implied here. Health professionals give us valid prescriptions for "improved" quality of life. However, in talking with my polio survivor friends I have to wonder if the end justifies the means in the road we travel? Have we rewritten the Book of Job? Polio survivors should consider all of their options.

Now seems to be the time to carefully assess where we "old polios" are going and how we should get there, without dwelling on where we have been. Much soul searching is involved! Whoever said life was easy? Santayana said, "Life is not a festival or a feast, it is a predicament." I'll buy that!

Doris S. Benedict, Deposit, NY, is the leader of the Post-Polio Support Group, Southern Tier of New York.



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Exploring Your Options

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enhancing. I believe their expertise and dedication were key factors in helping me not only survive these procedures, but also benefit from them in the following ways.

I could take deeper breaths and speak without gasping for breath in between words. My blood gases improved. My excruciating rib pain disappeared. I could walk easier and sit, stand, and walk for longer periods without being in pain. My energy increased, allowing me to continue working for another 12 years. I gained seven inches of height and could see the world from a clearer, broader perspective. I found clothes that fit and suited my needs.

In addition, I have seen people of all ages (even over 60) have their spines straightened and experience improvements in their lives.

For these reasons, I encourage you to explore your options (some may be non-surgical) with experienced orthopedic surgeons who specialize in treating scoliosis. What follows is a framework for exploring possible surgical options, though you may adapt it for any treatment decision.

My hope is that this information will support you in determining if you can improve the quality of your health and life through surgical intervention of your spinal condition.

▼ MAKING THE DECISION TO CONSULT A SCOLIOSIS SURGEON

Are any of these characteristics of your body?

Curved spine; tilted pelvis — one hip is higher than the other; swayed back; forward bending spine; hump on your back; protruding or concaved ribs; legs of different lengths.

If your answer is YES, you may have some form of scoliosis.

If you have any characteristics of scoliosis, are you also experiencing any of the following problems?

Pain in your back, ribs, legs; difficulty with mobility, standing, sitting; respiratory problems; bowel or bladder problems; numbness or loss of sensation.

If your answer to any of these questions is also YES, I recommend you consult with an orthopedic

surgeon who specializes in scoliosis to determine the possible relationship between your spinal condition and physical symptoms.

▼ WHAT DO YOU WANT TO IMPROVE?

When you consult with treatment providers, I encourage you to identify what it is you want to have happen if you undergo treatment of your scoliosis. For example, I emphasized that I desperately wanted to breathe easier — so I would have more energy to live and do what I want. If you state your desired outcomes in positive terms, (e.g. to breathe easier; to be free of your back pain) you can find out more clearly from those whom you consult if they believe you will obtain those benefits from pursuing their recommended treatment plans. I also found this approach useful in keeping me focused on my goal.

▼ ARE YOU "STUCK"? FEELING ANXIOUS AND APPREHENSIVE?

First, remember, consulting does not mean committing to anything! Consulting provides us, as consumers, with information to help us make prudent decisions about our health and well-being. For some of us, these are literally life and death issues. If you are feeling too apprehensive to even explore your options, please keep reading!

I have spoken with post-polio survivors with severely curved

spines who are unwilling to consult with a surgeon — even though they experience pain and other symptoms related to their spinal condition. I am struck by remarks like:

"I don't want any more surgery. I've had enough." "I am scared to death of surgery." "I am better off not knowing." "I have too many other stresses going on in my life." "I don't want to have to make any decisions like that." "I couldn't put my family through that."

Do you share these sentiments? If so, take some time to identify the reasons for your anxiety. Decide what you can do to resolve those fears that prevent you from obtaining information that can make your life easier or, in cases like my own, even save it. If you have had previous surgeries, and especially if they were unsuccessful, you have good reasons to fear another operation.



A few more words about fears: I encourage you to view them compassionately rather than with shame. In many cultures, fears are viewed as a lack of emotional strength. I contend that "doubt" reflects a healthy recognition that life includes disappointments and imperfections. And the reality is that there are legitimate reasons to be afraid of undergoing spinal surgery. That is why doing a thorough exploration of your options is so important. Take the time to get your questions answered and your insecurities resolved.

I suggest *The Feeling Good Handbook* by David Burns, MD, for more information and suggestions about dealing with your anxieties.

▼ GATHER INFO

Accurate, reliable data is vital in making significant health-related decisions. For this reason, I highly recommend obtaining opinions from three orthopedic surgeons whose primary practice involves treating scoliosis. Although this process is costly, remember, these decisions affect your health and life. Consider your time, energy, and expenses as an investment in determining the most suitable treatment. Think of this as a way to gain peace of mind.

▼ SEARCH FOR EXPERIENCED SCOLIOSIS SURGEONS

Collect names and inquire about surgeons from: other health care professionals, especially other orthopedic surgeons; the Scoliosis Research Society, The Scoliosis Association, and the National Scoliosis Foundation (see resources in the right column); centers that specialize in scoliosis and have been treating the condition successfully for years; persons who have undergone scoliosis treatment successfully, and persons who have been treated by the surgeons you are consulting.

In other words, network.

Select three surgeons you think are possibilities based on favorable information. Consider alternatives from different medical centers as well as from out-of-state. If you have post-polio syndrome or another major medical condition, you may want to call and find out if a particular surgeon is experienced with your condition before spending the time and expense for a consultation.

You may find the following questions useful in assessing the suitability of each surgeon and his/her treatment plans. Although these questions are directed primarily towards the surgeon, you may obtain and compare answers from others as well.

EXPERIENCE

You may gain an understanding of each surgeon's experience by focusing on the following.

How long have you been treating scoliosis?

How often do you treat patients with this condition?

About how many people have you treated with this condition?

Have you treated people with my specific conditions, e.g. similar curvature, post-polio, and/or your other medical conditions? How often?

How familiar are you with post-polio syndrome and my other medical conditions? How do you view these conditions as affecting my scoliosis and treatment of it?

Where did you obtain your training in scoliosis?

Under whom did you study?

EXPERTISE

An important indication of a surgeon's expertise is the person's record of successfully treating people with your characteristics or with more severe conditions, e.g. greater curvatures, more limited respiratory functioning.

Some factors to consider when comparing your condition with others who have undergone scoli-

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RESOURCES

The Scoliosis Association, Inc., P.O. Box 51353, Raleigh, NC, 27609 (919/846-2639) will send "Scoliosis, a Fact Sheet and Home Screening Test," to anyone who sends a business size, self-addressed, stamped enveloped. It is also available in Spanish. The Association offers membership to individuals and families for \$12.00 and to corporations, businesses, and institutions for \$30.00. Membership entitles you to receive *Backtalk*, which is published several times each year.

Scoliosis Research Society, 222 S. Prospect Ave., Park Ridge, IL 60068 (708/698-1627). If you call or write, the Society will provide the names of Board Certified orthopedic surgeons specializing in scoliosis in your area.

National Scoliosis Foundation, 72 Mount Auburn St., Watertown, MA 02172 (617/926-0397). The Foundation has prepared packets of information for parents of children with scoliosis, for adults with scoliosis, and for health professionals. In addition to the packets, pamphlets and a newsletter are also available.

Exploring Your Options

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osis treatment are: type of curvature(s); degree of curvature(s); history of previous spinal surgeries; other significant medical conditions, e.g. post-polio syndrome, diabetes, heart disease; neuromuscular condition; general health status, e.g. weight, respiratory functioning; emotional condition; commitment to improving one's health

Find out what results each surgeon's patients experienced. Although a surgeon may not have complete, up-to-date data available (many do not track their patients through the years), some generalities can be informative. From my perspective, any surgeon who makes the effort to provide you with answers that he/she may not know or have readily available shows respect for your need for information as well as your role in the treatment process.

BENEFITS OF TREATMENT

Ask about the potential benefit, including those listed below. How often have each surgeon's patients experienced these results?

Relief of pain (location and duration: all, most, some); increased mobility; increased stamina, energy; improved breathing (vital capacity, blood gases); improved functioning of bowel, bladder; increased height; enhanced self-image.

RISKS

Inquire about the possible risks, including those listed below. How often has the surgeon's own patients experienced these complications?

Infections; gastro-intestinal distress; problems with the instrumentation (rods); bones did not fuse solidly; curvature continued to progress; numbness, paralysis, or pain (temporary or permanent) that did not pre-exist; fatalities during surgery, or in the post-operative stages.

If you are interested in published data about these subjects, ask for outcome studies, especially about cases similar to your own.

PERSONALITY FIT

If you decide to have a spinal operation, you will need and want a surgeon with superb technical skills. (In situations like this, I value perfectionism!) If a surgeon's personality also matters to you, determine how effectively you can work with this person. You may find the following questions useful in analyzing how comfortable you are with each surgeon.

RESPECT

Does the surgeon:

Respect your need for information? How? Spend adequate time with you? Respond to your questions and concerns? Listen to you? Consult with you before finalizing plans? Keep you informed about his/her plans? Respond to your families' and significant others' concerns?

COMMUNICATION STYLE

Does the surgeon:

Communicate his/her plans clearly and directly? Answer your questions directly? Acknowledge your feelings and concerns? Acknowledge not having an answer or the uncertainty of some matters? Respond consistently and acknowledge a change of perspective based on additional information or considerations?

APPROACH

Do you experience:

A sense of commitment from the surgeon? Genuine concern about your well-being and that the person wants to help you? Or do you get the impression you are another "case"? A sense of hope, often a feeling of energy, that this person can help you improve your physical condition? The surgeon's confidence in his/her abilities to help you?

If a surgeon's personality does not meet your needs, you must decide whether your reactions to this person may adversely affect your undergoing treatment with him/her. Or are the disappointments tolerable? Do the person's technical attributes outweigh the shortcomings of his/her personality? Ask yourself what about his/her personality is most disappointing? Can that need be filled in other ways? For example, if you're wanting more support and encouragement, can you obtain that from other staff, family, friends? Remember — you DO deserve to be treated with respect.

TREATMENT PLANS

As you discuss your treatment options with each surgeon, I suggest you take notes and feed back your understanding of the recommendations and reasons.

Focus on your options by asking:

What are my treatment options?

What are the advantages and disadvantages of each option?

Which do you recommend for me? for what reasons?

What is your prognosis if I pursue the recommended treatment versus any other option or if I elect to do nothing?

If surgery is recommended, find out about the following:

What will you do during the surgery?

What will it entail?

Will you perform the surgery?

Who else will be present?

Will you insert anything into my spine? What?

How long will the entire process take?

How many surgeries are needed?

What else is crucial to the treatment?

Where will you perform the treatment? If you work at more than one medical center, do I have a choice?

What is the estimated recovery period?

Will I need to wear any assistive devices (e.g. braces, cast)? for how long? What is its purpose? How will it effect my mobility?

What kind of improvements do you project for me?

What complications am I especially vulnerable to?

If a spinal fusion is involved, where will you obtain the bone for the fusion?

What are the estimated costs of the entire treatment process?

How often will I need to follow-up for consultations?

If you live in another city or state, you may want to ask if she/he has a colleague near you whom you could contact if you need immediate assistance during your recovery stage.

Find out about the preparation plans. These can give you an indication of a surgeon's thoroughness, resourcefulness, and own decision-making approach. Ask questions such as:

What tests will you perform to assess my condition (e.g. lungs, heart, muscle strength)?

Will you perform these before finalizing your treatment plans? when I enter the hospital?

Will you rely on or consider previous test results?

Will I need to get opinions from other specialists with whom you work?

Will you consult directly with my own physicians or will you review their reports? If I plan to undergo surgery will you have an assessment of my emotional/psychological needs performed? Will a staff member provide me with any written information? Show me a video about the treatment process? Orient me to the facilities?

Finally, ask for the names and numbers of some of his/her patients with conditions similar to your own

who are willing to share their experiences. In talking with them, you may want to find out:

What did they find most beneficial about undergoing treatment? most difficult? most disappointing? What helped them decide to undergo treatment? What helped them through the process? How they experienced working with the surgeon and staff?

Just remember, each person's perspective of an experience may differ based on a variety of factors (including the person's attitudes toward life, others and him/herself), so talk with a number of people so you obtain a balance of perspectives.

▼ IS THIS THE PLACE FOR YOU?

Having specially trained professionals to assist your surgeon and provide many of the day-to-day services is crucial to the effectiveness of your treatment. Find out if the following staff specialize in scoliosis and are knowledgeable about your other major medical conditions: nurses, physical therapists, anesthesiologists, pulmonologists, respiratory therapists, radiologists, neurologists, orthotists.

Medical centers that have special scoliosis units usually have specially trained staff. You may want to meet with some of the key people before selecting a surgeon.

Find out if professionals are available should you need additional emotional support. And if you are a spiritual person, inquire about the availability of a chaplain.

To learn more about the facilities, you may ask:

Will I be located in a special unit that deals with scoliosis?

Are reasonable accommodations available to family and friends (especially from out of town)?

These usually are available at reduced rates and are located near or adjoining the medical center.

Ask to tour the facilities. Decide if the environment seems conducive for your recovery.

Explore what kinds of support systems are available for you — not only during the primary treatment process, but also prior to it and during the recovery period. Do they offer any structured supports for families and significant others?

▼ FINANCES

If you don't have adequate insurance coverage and financial resources, be creative, resourceful and assertive. Research every avenue you and your

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Exploring Your Options

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contacts can identify. Consult with the social service departments of the medical centers where you obtain opinions. If you have no other recourse, ask the surgeon and medical center if they will accept your insurance payments as the only reimbursement for their services.

▼ MAKING YOUR TREATMENT DECISION

After gathering info about your options from various sources, decide which, if any, you want to pursue. Decide in whatever way works for you. My most useful decision-making approach includes applying both my analytical abilities and intuition. Some suggestions are outlined below.

ANALYZE YOUR OPTIONS: TIME FOR MORE LISTS!

Once again, identify what is important to you. Review what you want to have happen if you undergo treatment. Be specific. List everything you can think of. Prioritize your objectives as best as you can.

Proceed by identifying the advantages and disadvantages, first, of each treatment option from each surgeon, and then of each surgeon based on:

Information from each and other authoritative sources, your own insights, and perspectives from others whom you respect. Given your priorities, focus on the options that offer the most advantages and the least disadvantages.

ACCESS YOUR INTUITION: WHAT FEELS LIKE IT FITS FOR YOU?

Pay attention to what you feel when you consider your options. Even business management books promote the benefits of using our intuition in making decisions. Some suggestions to help you understand your reactions are:

Think about and picture each option:

What do you feel in your body when you think about each option? Do you feel relaxed or tense?

Tension may represent fear. What part of your body usually reflects your tension?

What comes to your mind — what thoughts run through your mind — as you reflect on each option?

What is your initial reaction to each option?

What kind of feedback do others give you about your reactions when you discuss them?

If you are having dreams or nightmares, what messages do you think they are communicating?

Respect your feelings and resolve any uncertainties with a skilled professional, e.g., social worker, psychologist, if you are "feeling stuck."

After you assess your options analytically and intuitively, what, if any option, offers you the greatest potential to achieve your desired outcome. Choose the surgeon you feel will work best with you to gain the maximum results. Decide, get support, and act. Know you can revise your plans as you gain additional information and insights. My hope is that you trust and support yourself in this process.

Linda Bieniek, CEAP, (Certified Employee Assistance Professional) is a managed mental health manager for a major corporation, and has counselled employees and led workshops about personal and career issues for over ten years. She is past chairperson of Access Living of Chicago.

Linda Bieniek's article specifically addresses scoliosis surgery, however, International Polio Network feels her thoughts and comments are appropriate to consider when facing any surgery.

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Post-Polio Bibliography

"*Incidence and Nature of Dysphagia in Polio Survivors*," by Carl Coelho, PhD, and Redento Ferranti, MD. *Archives of Physical Medicine and Rehabilitation*, December, 1991, Vol. 72, pages 1071-1075.

The Correspondence section of the February 27, 1992 *The New England Journal of Medicine* (pages 640-642) published three letters questioning the conclusions in the article by Sharief et al. in the September 12, 1992 (See Polio Network News, Vol. 7, No. 4, Fall 1991. Dr. Sharief responds and the debate continues.)

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The Post-Polio Directory • 1992

The Post-Polio Directory • 1992 was mailed March 1, 1992. We will continue to sell it throughout the year (\$3 for survivors, \$6 for others). Those being mailed after March 1 will include an update insert, so the information is as current as possible. Please notify us of any additions, corrections, and deletions you know of at anytime. An remember, we have a new address and telephone number: **5100 Oakland Ave., #206, St. Louis, MO 63110 USA (314/534-0475)**. We can receive incoming FAXes at 314/645-8454. Our office hours are 9:00 to 5:00, CDT.

National Polio Research Coalition Springs into Action

We are proud to let you know that the 1991 activities to encourage favorable Congressional appropriation decisions by the Polio Society and the post-polio community at-large resulted in a **Program Announcement** issued by the National Institute of Neurological Disorders and Stroke (NINDS) in early February. Although the Program Announcement does not set aside specific research dollars for post-polio, it is a statement of the Institute's intent to seek and fund projects on post-polio which receive a good score from scientific review committees.

In late March, the newly formed National Polio Research Coalition sent a letter to researchers, post-polio clinics, health professionals, and support groups listed in the IPN directory to let them know about the Program Announcement. We are in the process of sending copies of the Program Announcement to as many interested researchers as we can find. Our goal is to make sure that any and all interested researchers are aware of the interest by NINDS to fund post-polio research projects, and to encourage them to submit applications. This is another way to convince NINDS that the interest in post-polio is ongoing and growing.

On April 30, **Lauro Halstead, M.D.** will testify before the House Appropriations Committee to request that the National Institutes on Health (NIH), specifically the National Institute of Neurological Disorders and Stroke (NINDS) and the National Center for Medical Rehabilitation Research (NCMRR) issues a REQUEST FOR APPLICATIONS (RFA) in the area of post-polio for five million dollars. The purpose of the RFA will be to investigate (a) the causes(s) of post-polio syndrome and (2) the most effective treatments.

Now is the time to write a letter to your Congressman in support of Dr. Halstead's testimony and request for an RFA from the NINDS and NCMRR for five million dollars. Include a paragraph on how post-polio symptoms have affected the way you live your life, and how more research could possibly make a difference. Send letters to your Congressman at the House of Representatives (The Honorable Xxxxxx XXXXXXXXXXXXXXX, U.S. House of Representatives, Washington, DC 20515). Please write even if you receive this after April 30th.

If your Congressman is not a member of the Appropriations Committee (**see list at side of page**), ask your representative to relay your concerns to members of the Appropriations Commit-

tee. If you have any personal connections to any Congressman, please call Jessica Scheer (301/897-8180) or Joan Headley (314/534-0475) as soon as possible.

Also, please follow your letters with a phone call to your Congressman's office in Washington. All phone calls can be made through the Capitol switchboard (202/224-3121). You will probably speak with a staff person; make your statement brief and personal.

Dr. Halstead will hear from the Senate Appropriations Committee about a date for his testimony in late May. *If you are interested in writing to your Senator at that point, please send your name and address to the National Coalition for Polio Research c/o IPN. We will send you information about the testimony date and the request.*

Your voice can make a difference! You helped in 1991. Please join us in our 1992 campaign.

Key Congressional Committees for Post-Polio Issues

U.S. House of Representatives

Appropriations Committee: Subcommittee for Departments of Labor, HHS, and Education

William Natcher (D-KY), *Chair*
Neal Smith (D-IA) staff: Tom Dawson
David Obey (D-WI) staff: Anne Georges
Edward Roybal (D-CA) staff: Jorge Lambrinos
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Steny Hoyer (D-MD) staff: Johnnie R. Hemphill, Jr.
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Carl Pursell (R-MI) Ranking Minority Member, staff: (vacant)
John Porter (R-IL) staff: Mike Myers
Bill Young (R-FL) staff: Douglas Gregory
Vin Weber (R-WI) staff: Jane Williams

Subcommittee Staff

Mike Stephens, Staff Director
2358 Rayburn House Office Building
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Phone Calls: All phone calls can be made through the Capitol Switchboard 202/224-3121. Ask for the office you are calling, i.e., the Member's office or the committee or subcommittee office. With the exception of the chair and ranking minority of each sub-committee, staff will be in the office of their member.

Letters: Room numbers are not necessary to write a Member of Congress; all mail goes through the Post Office at the Capitol.

Letters to Members of the House of Representatives should be addressed:

The Honorable (name of Member)
United States House of Representatives,
Washington, DC 20515

—RESULTS OF AUSTRALIAN QUESTIONNAIRE—

A post-polio support group was established in the state of New South Wales in 1988. As one of its first activities the group decided to survey Australian polio survivors (estimated to number 40,000) to discover whether they were experiencing similar symptoms to those reported by North American researchers. Over 300 people completed a 12 page questionnaire. The symptoms reported, the relative frequency of symptoms, the first symptoms noticed, and the time between the initial attack of polio and the onset on symptoms were remarkably similar to American findings. Severity of initial attack, but not age at that time, was found to be associated with the occurrence of symptoms.

Of the people experiencing late effects, 90% were finding it more difficult to carry out their everyday activities. Only 20% had initially had their problem diagnosed by a health professional as being related to polio although most had consulted a doctor the year they first observed symptoms. The majority of people attributed their symptoms to polio after they, or a friend, read or heard a media release. Over 70% reported considerable emotional distress when they first realized what was wrong and almost half said that they still felt depressed.

Over three quarters of people experiencing late effects had made changes in their life styles. The changes most frequently described were walking less, reducing social activities, giving up or reducing physical recreational activities, doing less housework, employing household help, and adopting mechanical aids. Employment was also affected: 16% had retired early. Of those currently employed 42% had changed or modified their employment e.g. moved to part time work, changed work routines.

The typical post-polio person had consulted practitioners from four health professions. Satisfaction with treatment provided by physiotherapists, chiropractors, occupational therapists and podiatrists was relatively high while least satisfaction was expressed toward medical practitioners who were prone to discount the reality of patients' symptoms. It is interesting that chiropractic, which has been virtually ignored in the literature as a potential treatment, was described by many as providing pain relief and improving function.

Over half of people with late effects described a treatment that had provided them with some relief and 30% described a treatment that had been useless or exacerbated their symptoms. Treatments

that received almost no negative evaluations were massage, hydrotherapy, swimming, rest, hot baths, analgesics, and special shoes. Exercise received few positive ratings.

When asked what advice they would give to someone who developed post-polio symptoms the most frequent response was to get to know other people with post-polio problems followed by advice to rest more and to find a helpful doctor.

The findings from the survey have been published in a range of Australian health journals with the aim of making professionals more aware of the needs of their post-polio clients.

The research was conducted by **Associate Professor Mary Westbrook, PhD**, Department of Behavioural Sciences, Faculty of Health Services, The University of Sydney, PO Box 170, Lidcombe, NSW, 2141, Australia. A detailed account of the findings of the research, "**A survey of post polio sequelae: manifestations, effects on people's lives and responses to treatment,**" was published in the *Australian Journal of Physiotherapy*, vol. 37, 1991, pp. 89-102.

National Polio Awareness Week

As reported in the last *Polio Network News*, Vol. 8, No. 1, Winter 1992, the Hon. John P. Doolittle (R-CA) introduced in the House of Representatives on February 5, 1992 H. J. Res. 404 designating June 1 through June 5, 1992 as National Polio Awareness Week. For this to be official, 218 co-sponsors are needed. To date, with your help, representatives from the following states have signed on.

California, 7	Ohio, 1
District of Columbia, 1	Oregon, 1
Florida, 2	Pennsylvania, 1
Illinois, 1	Tennessee, 8
Iowa, 3	Texas, 3
Louisiana, 2	Washington, 2
Maryland, 1	West Virginia, 1
Michigan, 3	Wisconsin, 1
Missouri, 2	We are short of the 218
New Jersey, 3	co-sponsors required for
New Mexico, 1	designation.
New York, 5	

International Polio Network would like to thank the leaders and individuals from the above-listed states who contacted their representatives and secured their sponsorship.

Potpourri

"Breathing Support Options: A Consumer Perspective," prepared by **Maureen Colgan**, research development co-ordinator. This 43-page booklet, complete with a glossary and resources, assists potential ventilator users in exploring the many options available. It is composed of two parts: Part I, The Process: Decisions in the Use of Breathing Support Equipment, and Part II, The Opinion: Breathing Support Equipment from a Consumer Perspective. Copies of Breathing Support Options are available at a cost of \$10.00 postpaid to organizations or individuals who can afford it. Free copies will be made available to individuals exploring their own breathing needs. Contact: Maureen Colgan, Independent Living Resource Centre, 201-294 Portage Ave., Winnipeg, Manitoba R3C 0B9, Canada (204/947-0194/TDD).



Effets a Long Terme de la Poliomyelite (the French translation of Gazette International Networking Institute's *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*) is available (for 90F) from: Bon de Commande, a Envoyer a L'Association des Paralyses de France Service Information, 17, boulevard August Blanqui, 75013 Paris, France.



"The Late Effects of Polio: A Model for the Identification and Assessment of Preventable Secondary Disabilities," the final report of the CDC sponsored study by Frederick Maynard and colleagues at the University of Michigan Medical Center is no longer available from the Centers for Disease Control but from The National Technical Information Service (NTIS), U.S. Department of Commerce. Contact NITS by telephone at 800/553-6847 (in Virginia 703/481-4650) to receive ordering information. The NTIS mailing address is: U.S. Department of Commerce, National Technical Information Service, 5285 Port Royal Road, Springfield, VA 22161. When ordering, please refer to report number PB 92-130004.



Linda Schubert is responsible for the polio display at the **International Museum of Surgical Science**, 1524 N. Lake Shore Dr., Chicago, IL 60610-1607 (312/642-6502). She is looking for photographs, posters, equipment, etc., from countries throughout the world other than the U.S. Contact her if you are interested in helping.



Polio Network News, Vol. 7, No. 1, Winter 1991 listed cases of polio reported to the Centers for Disease Control (CDC). If you are interested in updating your

chart, nine suspected cases of poliomyelitis were reported in 1991. Four of the eight suspected cases in 1990 were confirmed, and all were vaccine associated.



Polio Network News is interested in your experiences. Roberta Simon, RN, 7835 Pine Parkway, Darien, IL 60561, is still collecting information on any research medication you may be taking or have tried in the past (see *Polio Network News*, Vol. 8, No. 1, Winter 1992.) She has received several letters, most of which are negative. We are interested in positive experiences also. We are interested too in hearing about, and then sharing, any post-operative experiences. Forward them to IPN, 5100 Oakland Ave., #206, St. Louis, MO 63110.



A Word About Self-Help

Reprinted from: Self-Help Horizons, National Project for Self-Help Groups, George Mason University, Fairfax, VA 22030-4444.

When people take responsibility for themselves, that is self-help. Self-help has two distinct qualities that distinguish it from other ways of getting help:

- Self-help is free
- Self-help is peer-to-peer

Henry David Thoreau cautioned us to avoid enterprises requiring new clothes. His philosophy can be broadened to ask us to look at the cost of something before we determine if it is worth the price. Sometimes the words "self-help" are used to market ideas or organizations. The editors believe, with Thoreau, that if there is a cost attached we should proceed cautiously. If there is a price attached to "self-help" it is not self-help, it is a marketing tool; someone is using the concept to make money.

You can be a self-helper. All it takes is time and commitment.



The Effective Leader: A Handbook for Leaders of Self-Help Groups

This handbook (28 pages, 8-1/2" x 11") was created to address some basic issues faced by group leaders: finding effective ways to lead a group; promoting shared leadership; dealing with membership and organizational problems; networking and coalition building; publicizing group activities. Order from: Self-Help Network of Kansas, The Wichita State University, Dept. of Psychology, 1845 N. Fairmount, Campus Box 34, Wichita, KS 67208-1595. They are happy to provide this handbook to all individuals who request the manual. However, due to an overwhelming response, any donation you would be able to send would enable them to provide this handbook to others who request it in the future.

Our label form is being changed to include the month your subscription is due.

Leaders and Readers Write

Warner M. Linfield, PhD, of the Delaware Valley Polio Survivors' Association, P.O. Box 102, Flourtown, PA 19031, writes that he has compiled articles from its newsletter, *The Polio Post* (1985-1981), and has made them available for a donation of \$5.00 to defray the cost of printing and postage. According to the preface, it was compiled in an effort "to give our members, especially new ones, and other interested persons, an idea of the scope of our activities and information obtained during our general meetings."

Nancy Baldwin Carter, editor of *Gleanings*, a newsletter from the Nebraska Polio Survivors Association (NPSA), reports that she has gathered 50 essays (many revised from *Gleanings* editorials) in a soft-cover edition called "Of Myths and Chicken Feet — A Polio Survivor Looks at Survival." It is available from NPSA, P.O. Box 1739, Omaha, NE 68137 for \$6.95 plus \$2.00 shipping and handling.

LaVonne Schoneman, author of two *How-to-Cope* booklets, reports she has written books No. 3 and No. 4 which will soon be in print. She is currently collecting polio life stories from survivors for inclusion in another book. Contact her at: 16734 — 8th NE, Seattle, WA 98155 (206/362-0627).

Polio Network News has been requested to ask the following questions. Please send your responses to International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110.

...a neurosurgeon does not think that the burning in my chest and upper back muscles is due to my polio. He prescribed vigorous muscle exercises. Are other polio people experiencing a burning sensation in muscles?

...I have recently had cancerous growths removed from my face. Consequently, I just recalled an experience when I was about seven or eight and in a special school for children with disabilities. We were taken several times a week to a room and exposed to doses of ultraviolet light. I remember being warned not to remove the goggles. Does anyone else remember this experience?

...a reader from upstate New York would like to communicate with other polio survivors who are receiving

CALENDAR

Understanding Post-Polio Syndrome: A Symposium for Survivors and Health Professionals, Center City Hilton Towers, Philadelphia, PA, May 30, 1992.

Contact 1-800-EINSTEIN or 215/456-6051.

Well-Being for Polio Survivors,

Delta Meadowvale Hotel, Mississauga, Ontario, Canada, June 13-14, 1992. Contact: Shirley Teolis, Ontario March of Dimes, 60 Overlea Blvd., Toronto, Ontario, M4H 1B6 (416/425-0501)

Polio? What now, Holiday Inn/Bell Tower, Fort Myers, FL, July 17-18, 1992. Call 813/543-4242.

Managing Post-Polio Problems II, Delta Pacific Resort Hotel, Richmond, British Columbia, Canada, Oct 15-18, 1992. Contact: PPASS, P.O. Box 6579, Dept. #1, Victoria, British Columbia V8P 5N7 (604/477-8244)

Polio Partnership, Australasia (Australia and New Zealand) Conference on Post-Polio, the Paris Hotel, North Terrace, Adelaide, November 14-16, 1992. Contact: Heather Trenorden, Neurological Resource Centre of S.A., Inc., 37 Woodville Road, Woodville, South Australia, 5011 (08/268-6222).

assistance through the Shaw Act.

...are there groups which have noticed an incidence of aneurysm?

...I would like to hear from persons who use a scooter to assist their mobility. I can drive myself, but need a lightweight dependable machine which I can handle myself for shopping, garden tours, and getting around a college campus. I have collected enough technical information; I am interested in any personal suggestions or advice. (Please send the scooter information directly to Lois D. Jeavans, Box 100, Millboro, VA 24460.)

... have you had individuals complain of gall-bladder-like symptoms before or after surgery? Do you know anyone who is studying the upper GI tract of polio survivors?