

# POLIO NETWORK NEWS

International Polio Network

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## A Review of Swallowing Difficulties in Post-Polio Individuals

Roberta Simon, R.N.

In response to a request in the Spring *Polio Network News* (Vol. 6, No. 2), I received several letters from individuals experiencing swallowing difficulties (dysphagia) that I would like to share. First, I would like to say that most letters were from people who knew they had had bulbar polio. A few individuals were uncertain because they were young at the time of their original illness, and they had not been told of any such problem by their family members or had not obtained their hospital records. One individual had hospital records but felt they were vague as to the involvement.

In looking at some of the personal experiences shared with me, I found that swallowing difficulties are no different than other difficulties we are experiencing. They vary greatly with each individual. It is pretty obvious that we are just as unique with these experiences as we are with all other aspects of the late effects of polio. In other words, an individual evaluation and a treatment plan must be developed for each one of us.

Swallowing is a complex mechanism involving many functions. If any of these areas are affected, different symptoms develop. (We will discuss this aspect in detail later.) First, I want to share with you a summary of the letters I received.

One person had a hiatal hernia and symptoms were controlled with medication. (The author would like to  
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## "Prescription for Pain" from Fifth International Polio & Independent Living Conference in Saint Louis

Polio survivor, **Sunny Roller**, Ann Arbor, MI, introduced the topic of pain by sharing her experience and personal point of view. A panel of physicians then offered thoughts and solutions to the problem of pain. The panelists included **Ernest Johnson, M.D.**, The Ohio State University College of Medicine, Columbus, OH; **Thomas P. Anderson, M.D.**, Spaulding Rehabilitation Hospital, Boston, MA; **Frederick Maynard, M.D.**, University of Michigan Medical School, Ann Arbor, MI.

**SUNNY ROLLER:** New pain, muscle weakness, and general fatigue are common complaints of post-polio individuals who fought polio once and won, but are now reluctantly having to return to rehabilitation after a 30-40 year reprieve.

Along with muscle weakness and fatigue, new pain is the most common complaint of people with the late effects of polio. It is what drives them to the doctor's door, causes sleepless nights, and eats away at their ability to get through a productive day. My pain came in dual form. It was both physical and emotional, each form feeding the other and gradually increasing over the course of four years, to finally overwhelm me.

It became something I couldn't just get through by minimizing, like I always had in the past. It's hard to clearly remember but I must have continually lived in some kind of pain since contracting polio when I was four years old. During the acute stages I was completely paralyzed: only able to move one finger. The physicians gave me ten days to live.

For the next ten years, I worked with the determination of an olympics-bound athlete coming back from that near-death experience. No pain, no gain, the voices would say. My parents became my primary coaches, providing the encouragement, resources, and training that I needed. How, I wonder, did I assimilate the emotional pain they inadvertently must have communicated at the loss of a healthy child? They were my private rehabilitation team. Nine months in

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## "Prescription for Pain"

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a rehabilitation hospital-school. Ten years of exercise routines and five major orthopedic operations.

As I grew, I know they gave me morphine in the hospital, but I don't clearly recall the pain it alleviated. I was scrutinized by tall, well-tailored doctors in gray suits and shiny black shoes once every month. At the age of fourteen I was happy to say good-bye to their alert somber faces and objective eyes. I remember hating to get new shoes because I had to stuff crooked feet into straight shoes. It was the same with new braces that pulled and pinched and poked in new places. But I did manage it all with success, often ignoring the irritations and riding along on my personality.

I went to suburban public schools. I was mainstreamed. I graduated from a state university in 1969. I taught high school college-prep English for ten years, then supervised a university co-ed dormitory for three years while working on my Master's degree. Suddenly, I started to cave in. It was thirty years after I had contracted polio: I was 35. I didn't understand what was happening to me. I started to feel a tremendous amount of new pain in my back and left hip area when I would sit up in bed every morning. All of my physical activity, including standing, sitting, walking, or reclining became more and more uncomfortable, and I was losing much stamina. I resigned from my job at the University because of the pain, weakness, overall exhaustion, and a pervasive new sense of inadequacy.

After seeing five medical specialists who each told me something a little different, and nothing that seemed

conclusive, I was referred to the Post-Polio Clinic at the University of Michigan Medical Center. The following evaluation and prognosis became the ones that I intuitively accepted: post-polio syndrome, inflamed tendons in left hip area, bad scoliosis, rotated pelvis, some arthritis, some deformities, lose ten pounds, take aspirin for musculoskeletal pain, go to physical therapy, use an electric cart, get a right shoe lift, conserve energy.

When the physician told me all the things that were "wrong" with me, my tears revealed relief in that formal knowledge, and initiated my submersion into a whole new set of feelings that I had never experienced with such intensity. As unique as our distinguishable disabilities are, so the intensity of our feeling will vary. Nevertheless, the late effects of polio generate similar emotional responses that do not go away quickly.

One of the first and strongest emotions that I felt when the doctor told me to slow down ... things weren't going to get better ... expect a one percent per year muscle loss ... make adjustments, was an overwhelming amount of emotional pain. Why me? Again? Emotional pain layered on top of physical pain. What did I do to deserve this?

There is an amount of grief accompanying a new sense of loss. So much of me ... gone. Not only had I lost some of my energy level, strength, stamina and functioning; I was starting to lose my earning power. I could never be the yuppie that I always wanted to be. Would I ever own a house? Would I ever be able to earn enough money? How can this be? I was one of the golden, talented, socially-aware baby-boomers! I felt tricked, and hence, very, very sad. I also felt that I had lost my sense of identity. I had been a teacher and I was proud of it. Would I be able to endure a six-hour

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day, trying to stimulate and motivate the typical American teenager? I was lost and my sense of self-worth plummeted to almost zero. Who am I now? Suddenly I was just a sick person: a needy woman with a lost capacity for giving. Would I look so funny that they wouldn't want to be seen with me? Would I have any sex appeal?

Fear becomes an insidious intruder. What's going to happen to me physically in five years? Ten years? What will it really mean to lose one percent a year? Will I lose the use of my right hand? How will I write? I love to write. Will my respiration go next? I don't know. Financially, what is going to happen? Will I be able to get disability pay? Is insurance going to cover me?

Another strong feeling that I have is guilt. Now that I'm more disabled, how much more of an imposition will I be to those around me? I am already more of a burden than I would choose to be: people have to help me constantly, in spite of an achieved amount of independence on my part. Surpassing all of those feelings is anger, sometimes qualifying as rage. Why did nature do this to me? It is not fair.

Due to these unwanted complications that I'm trying to deal with, I feel very high levels of stress. There are so many new changes and adjustments to make. There are so many complexities to deal with physically, emotionally, intellectually, and spiritually. I feel ashamed, vulnerable, and defensive because I've been weakened. Yet I still need to maintain some pride. I am also resistant to any new plans for rehabilitation. I don't want to walk back into a hospital. I was in hospitals for 14 years and they were sad places filled with trapped people in pain.

Pain was all over. Inside and outside. The worse I felt, the harder I fought. The more I fought, the harder I was on myself. "What's wrong with you?" "Get going!" "Quit thinking about yourself so much!"

But today, six years later, the overwhelming pain has subsided. Within nine months of my physical therapy and getting a shoe lift, I was back to minimal, manageable physical irritations. With the help of several kind, patient, respectful professionals and dear friends, I have gradually renewed and found relief from many of the self-doubts and much of the self-abuse. My objectivity is restoring itself. The emotional pain layered on top of physical pain may never go away completely for me, but it can be managed. And that's great to know. There is hope and there is help. One must actively choose to be hopeful and assertively seek that help for it's out there — waiting to be discovered.

**DR. JOHNSON:** Pain is an impulse along the nervous system until it reaches the sensory cortex of

the brain when it becomes modified and is expressed as pain in your consciousness. One of the things that affects your perception of pain is a memory of a previous experience. If you have never experienced pain, you won't appreciate it as much. On the other hand, if you have experienced it in the past, it can be very severe. The most important consequence of the pain is how you respond to it.

The number one reason post-polio people seek help in our program at Ohio State is pain. Only after we gather history do they say, "I'm losing a little strength, or I can't do what I did before."

The number one treatment method is to find the cause and remove it. This requires some investigation. Once we have determined what causes the pain, we suppress it by overloading the input.

Putting a tight bandage on a cut will alleviate pain. The TENS unit (transcutaneous electrical nerve stimulation) works on the same principal. We use medications to suppress the kinins, which are chemicals that the body releases to stimulate the pain fibers. We can block the transmission of pain by injecting novocain. We can occupy the pain receptors in the brain, so that the impulse will not cause the appreciation of pain. We attempt to increase our intrinsic narcotics so they'll occupy the pain receptors, and then we won't need extrinsic narcotics like morphine.

Fibrositis or fibromyalgia causes some muscle and in our judgment is the most common cause of muscle pain in any population. We diagnose it clinically with these findings: 1) the jump sign 2) a "ropey" consistency under palpation 3) extreme dermatography (which means you can write on the skin and if you wait just a few seconds more, that reddened area will actually raise a little bit) 4) complete relief of pain in about ten minutes when sprayed with ethyl chloride or fluorimethane.

Fibrositis causes pain in the posterior shoulder, the neck, the low back, the lateral buttocks, and the thigh. We have to exclude other reasons for pain, but if it turns out to be widely scattered muscular pain the diagnosis is usually fibrositis.

The onset of fibrositis or fibromyalgia is insidious. Some doctors may say there's nothing wrong with you. We see it often after an acute injury. We call it muscle strain and treat the acute muscle pain with an injection of novocain and a cold pack, or fluorimethane coolant spray, ice massage, and superficial heat.

We also have another technique to raise the threshold of muscle pain. Individuals are put on a low sodium diet and a medication, such as Lasix, for three successive days each week. Of course, we make sure that

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## "Prescription for Pain"

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they have plenty of potassium. Dried apricots, bananas, and orange juice are foods that are high in potassium.

Several of our post-polio people go through the sleep lab in order to identify any sleep disturbance which is generally referred to as a non-restorative sleep pattern. Individuals sleep for eight hours or the pain may wake them up a couple times. When they wake in the morning, they feel as if they haven't had any sleep at all. We use Amitriptyline at that time.

**DR. ANDERSON:** There are many different classifications of pain for people with residuals of polio. It might be an oversimplification to say that there are two principle types; one is joint pain and the other is muscle pain. The joint pain is usually straight-forward and due to mechanical stresses on the joints from weaknesses or deformities or tightness.

But the muscle pain due to fatigue or overuse of a weak muscle is complicated, and I'll leave that for someone else to cover.

What I want to talk about is pain associated with contracture or tightness. I am old enough to have had a lot of experience with acute polio and have been following polio survivors for over forty years. During the acute phase of polio, tightness is often the most prominent symptom. If you ask people, they don't remember the weakness as much as the tightness and that tightness was often quite painful.

After Sister Elizabeth Kenny came to this country from Australia, polio was treated with hot packs and stretching exercises. If one did a survey it would be interesting to see how many of the deformities were due to weakness and how many were due to tightness? There are many people who feel that tightness plays a greater role in producing deformities after polio than weakness.

The tightness that was present in acute polio tends to recur. Many people, including a lot of physicians, tend to overlook this. There's something that can be done about the tightness and it's important not to forget that.

You question people about their care with acute polio, and they recall years of exercises. Generally, people were told that they should go through some exercises, not to get themselves stronger, but to prevent reoccurrence of tightness. Many were told that they should be doing these every day for the rest of their lives. My guess is that very few people took this seriously and after awhile they forgot why they were

doing the exercises. In addition, they were not getting any stronger and wondered why exercise. They discontinued them, and then the tightness tended to subtly sneak back. (I recently reviewed the literature on post-polio and I was disappointed to see how few authors mention the reoccurrence of tightness.)

Recently with one of my residents, I saw a 67-year-old woman who had pain in her calves. I asked if she had heel cord tightness. Obviously, the answer was no because both ankles would come a few degrees above a right angle. Knowing it was supposed to be more than a few degrees, we taught the woman how to stretch her heel cords. She said, "I remember doing that when I was a child." She did the stretches in the office and walked some more. She said, "The pain's gone!" That was rather dramatic, but I don't think the resident will ever forget the point. It's subtle but some people can lose an enormous range of motion in their shoulders due to tightness and experience no pain. Somebody else loses only a few degrees and it becomes painful.

What causes this pain? Is it due to the tightness itself? Is it due to fatigue in the tight muscle? Or is it due to fatigue in the antagonistic muscle?

There is a phenomenon that occurs in polio where the weakness tends to be new. It occurs 30 years or more after the onset of polio and people know they were never that weak in that muscle before. An explanation is that the muscle may be antagonist of one that has tightness. A common example is the dorsiflexor muscles that pulls the foot up to clear the toe while walking. If tightness develops in the calf muscles, the dorsiflexors have to work harder against that tightness to pull the foot up. The dorsiflexors can become weaker over a long period of time.

We see this, not only in polio, but in people who have contractures associated with spasticity or other kinds of problems. The interesting thing is that when a muscle has to work against tightness in its antagonist, it has to work extra hard and it can develop pain and/or weakness.

During the acute phase of polio, even though the stretching exercises were not pleasant and not comfortable, individuals remember that after the stretching exercises were done, they often felt very relaxed and relieved and would take a good nap. So, even though stretching exercise is uncomfortable, it does help relieve pain.

I believe that one of the important parts of the examination is to check the polio patient for tightness because it's an ever present problem with anyone who has ever had polio. This is a phenomenon that is present in the acute stage and it tends to stay with



people who have had polio. My suggestion is that in the management of residuals of polio, particularly pain, we should remember to check for tightness, and if it's present, institute correction. Stretching exercises are quite painful and some heating beforehand helps tolerating the stretching.

**DR. MAYNARD:** If we are clever enough to find the causes of a pain problem, most of them can be diagnosed and treated. There are actually few mysteries about the pain problems that are occurring among people with a history of polio. I would like to discuss the most frequent kinds of pain problems seen in our Post-Polio Clinic according to the location of pain in the body.

First of all, we see a lot of pain problems in the upper limbs. Many of the people with polio had worse involvement in their legs, and therefore they have been using their upper limbs for most of their life activities. This results in frequent stress and strain syndromes to upper limb muscles and joints. When degenerative arthritis occurs in the shoulder joint, it can be treated with physical therapy, anti-inflammatory medication, and icing. If a shoulder joint is very severely involved, steroid injections can be helpful when used judiciously. Shoulder pain more often results from tendonitis or bursitis and it responds to traditional therapeutic approaches.

Elbow and forearm pain usually results from repetitive strain. In the so-called "tennis elbow syndrome," or lateral epicondylitis, there is a very small ripping of the fibers that attach the forearm muscle to bone, and they get inflamed when their stretched harder than the forces they can withstand. Ripping can also happen in a muscle tissue, particularly when it is "eccentrically loaded." An eccentrically loaded injury occurs when a muscle is contracting at maximum force while it is being elongated. As an example, consider the biceps muscle that flexes the elbow. When it is controlling the fall of a heavy object in the hand, it is much more subject to injury than when lifting the same weight because its maximum contraction force results from shortening of microscopic muscle fibers while at the same time the entire muscle body is being elongated. These eccentric contraction injuries are often subtle, and, if they occur repetitively, can be chronic and very painful.

Pain can respond to heat or ice, but ice is more effective when injuries are acute. A gentle amount of repetitive stretching followed by resting allows the muscle injury to heal. However, although pain subsides when an injured muscle is rested, it then becomes weaker and can be more easily irritated and strained again when it is next used. Thus, rest alone can lead to a vicious cycle of pain and strain.

The goal of curative treatment is not to immediately eliminate the pain but to begin stretching the muscle and its fiber attachments to bone so they can handle higher forces without strain. When this is accomplished, pain will begin to resolve. For the patient, participation in the strengthening exercises takes a lot of patience, persistence, and belief that the pain will get better! A physician also must believe in the effectiveness of the treatment because if he/she does not persevere with this approach and radiate optimism and conviction, then he/she will not be able to support a patient in following through with the treatment program.

Pain in the hand and wrist often results from "wear and tear" arthritis. When using wheelchairs, crutches, and canes, most body weight is transmitted to the thumb side of the wrist and to the lower joints of the thumb. People who depend on their upper limbs for their functional independence can find these pain problems very disabling. Joint injection, short-term splinting to immobilize the joint, anti-inflammatory medications, and judicious use of ice and heat are the best treatment approaches when prescribed on an individualized basis.

Research studies done at the University of Michigan have shown that carpal tunnel syndrome (CTS)\* is very common among post-polio survivors and is related to cane and crutch use, wheelchair pushing, and using hands for transfers. During all of these actions, the wrist is generally kept in a fully extended position and body weight is transmitted through the wrist. Large compressive forces are generated at the wrist in the space where the median nerve runs through the carpal tunnel. This can compress the nerve and produce tingling and numbness of the hand and forearm. It can also result in atrophy of the small thumb muscles of the hand or sensory loss around the thumb.

Because thumb damage is such a common sequela of acute polio, it is hard to tell whether its presence is new and whether it is from carpal tunnel syndrome or post-polio muscular atrophy. Traditional treatment for CTS with splints, injections, or surgery is often ineffective in post-polio patients so preventative measures are very important. One preventative intervention is changing how the hands are used. Crutch and cane handles that are much wider, or have rounded and cone shapes, can better distribute weight through the wrist and hand and lead to reduced irritation and pain. Changing use patterns is one of the most important treatment strategies for all of these upper limb problems. If the pain is from repetitive strain, you must change how the injured part is being used.

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In my experience, most hip girdle pain is due to muscle strain. Muscle tightness and myofascial pain must be looked for and does occur, but pain more often results from straining hip muscles repetitively during walking. Again, effective treatment often necessitates changing walking patterns. One of the simplest ways to relieve hip muscle strain is by using a cane. One lady bitterly complained to me about hip girdle pain, and I recommended that she correct her gait abnormality by using a cane. However, she had what I call "canophobia." After lengthy debate, I suggested that if she broke her leg, she would use a crutch until the fracture healed and that her hip pain was a similar problem. I urged her to use the cane long enough to find out whether or not it would eliminate her pain. Afterwards, she could decide whether she preferred the pain or the cane. I think this analogy was helpful because it allowed her to stay in control of her own life and make her own choice.

A common source of pain around the knee is genu recurvatum or "back knee." The cause of this problem is stretching of the capsule on the back of the knee joint which can result from new weakness of the quadriceps muscle, from stretching of the ligaments, and from cartilage degeneration. Knee problems occur when supporting structures are not protected by strong muscles and when people walk with abnormal limbs and gaits. Short-term treatment can involve anti-inflammatory medications, icing and stretching, and range-of-motion exercise. Once again, only changing the use pattern of the knee joint will solve the problem. When the knee pain is chronic and severe, bracing is usually the only effective treatment.

Back pain is common in the general population and also among polio survivors. I use the services of our entire physical medicine rehabilitation department to treat low-back pain. Changing walking patterns can again be very helpful for reducing chronic strain. At other times vigorous joint mobilization techniques and manual therapy is needed to correct vertebral malrotations or other problems of the spinal column. These conditions frequently occur in post-polio survivors with long-standing structural abnormalities associated with scoliosis or a short leg. Another example is a chronically rotated pelvis that may rotate even further and become the source of new pain. Exercise programs can sometimes help resolve chronic back pain if abdominal or hip muscles are sufficiently functional to be further strengthened. Frequently, they are not. Sometimes a simple abdominal support garment or girdle can substitute for severely weakened abdominal muscles and can make just enough of a

difference to relieving back strain that pain becomes manageable, and a person can remain active.

Sitting posture in chairs is also very important. A great deal is now known about the biomechanics of sitting and sitting postures. Engineers, physical therapists, occupational therapists, and seating experts assess structural abnormalities of the back in our spinal cord injury and post-polio populations. They may recommend lumbar rolls, ergonomic chairs, and/or special seat inserts to prevent chronic strain associated with sitting.

When all of these approaches for controlling pain fail, techniques like transcutaneous electrical nerve stimulation (TENS), biofeedback, imagery, and cognitive restructuring are tried. Pain should not always be thought of as bad since it can serve as a warning signal. Psychologists and support groups can help people understand this. Additionally, stress and emotional pain may keep muscles tight and interfere with patients taking appropriate actions for resolution or control of chronic pain problems.

Finally, when polio survivors are facing a difficult and confusing problem that does not fit into one of these categories, they will need to engage themselves with a doctor and therapist who can listen and communicate with them. As a team, they can usually solve the riddle of pain and find an effective management program. On the whole, I have found post-polio individuals willing to engage themselves in such a process and do their half of the work toward discovery of an acceptable solution to pain problems. An acceptable management strategy, rather than a complete cure for pain, is often the only realistic short-term goal. Subsequently, the pain may either slowly disappear completely or fade into the background.

### \*RECENT, RELATED PUBLICATION

"Coping with Carpal Tunnel Syndrome" by Gunter R. Haase, M.D., Alexander C. Johnson, M.D., and Oscar M. Reinmuth, M.D. Patient Care, July 15, 1990.

## NEW POST-POLIO CLINIC

John Penek, M.D., FCCP  
John Bach, M.D.  
The Breathing Centers  
Morristown and Edison  
New Jersey  
1-800/634-5864

## TIPS TO COMBAT THE STIGMA OF CHRONIC PAIN: AN EVEN DOZEN\*

1. Look for health care professionals with training and experience in the field of pain management. Remember that not all health care professionals are skilled in pain management.
2. Join support groups so you can benefit from the advantages of being with others who have chronic pain. Anson refers to the several hundred years of combined experience found in members of a typical support group. "Share with others and the burden lightens," he observes.
3. Communicate honestly about your pain with your family and friends. Heinrich advises other pain sufferers to strike a balance between talking too much about pain and being dishonest about it.
4. Educate others about the experience of chronic pain. "Be honest about what living with chronic pain is like," Gentleman says. "But try to get control over your emotions first because people have trouble absorbing information when it's loaded with emotion."
5. Accept whatever other pain sufferers are experiencing. "Practice acceptance of both yourself and others," Heinrich advises.
6. Don't reinforce negative stereotypes others might have. Also, don't make assumptions about what others are thinking and feeling about you. "Instead, check them out to be sure your perceptions are correct," Baither suggests.
7. Treat yourself with respect. "You have to love and re-spect yourself first, before other people can," Lockaby says.
8. Demand respect from others. Challenge negative stereotypes.
9. Accept responsibility for coping with your pain. "You'll be a prisoner of your pain if you don't take charge of your own life," asserts Filner. You are not responsible for your pain — but you are responsible for what you do about it and how you live your life.
10. "Give your doctors permission to not cure you," Heinrich advises. "I ask them to just help me be as comfortable and functional as I can be."
11. Resist the temptation to blame yourself for your pain. The question, "Why me?" often doesn't have a good answer.
12. "Develop a sense of humor," Heinrich advises. When all else fails, a humorous outlook can be your saving grace.

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year. Also available is a price list of back issues and select articles on pain, pain management, and alternative therapies.

### OTHER RESOURCES

*Chronic Pain Letter* is a six-page newsletter devoted to news about chronic pain management. It is geared to both professionals and consumers. A one-year subscription (6 issues) is \$20 for individuals and \$35 for professionals and institutions. For more information, contact *Chronic Pain Letter*, Box 1303, Old Chelsea Station, New York, NY 10011.

*Topics in Pain Management* is a four-page monthly newsletter for health care professionals. Annual subscriptions are available for \$55 from Williams & Wilkins, 428 East Preston St., Baltimore, MD 21202.

The National Headache Foundation (NHF), 5252 N. Western Avenue, Chicago, IL 60625 (1-800-843-2256 outside Illinois or 1-800-523-8858 in Illinois).

U.S.A. Fibrositis Association, Riverside Hospital North Medical Building, 3545 Olentangy River Rd., Suite 8, Columbus OH 43214 (614/262-8020).

*Fibromyalgia Network* is a 10-page quarterly newsletter devoted to news about fibromyalgia/fibrositis. Articles include news of current research as well as information on support groups and coping with fibromyalgia. A one-year subscription is \$12. A complimentary copy is available on request. For more information, contact *Fibromyalgia Network*, 7001 School House Lane, Bakersfield, CA 93309.

*Arthritis Today* is the national consumer magazine of the Arthritis Foundation. It is available only to members of the Arthritis Foundation. Anyone donating at least \$15 can join. Contact the Arthritis Foundation Membership Center, P.O. Box 96012, Washington, DC 20090-6012 or your local Arthritis Foundation chapter.

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## Swallowing Difficulties

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note that hiatal hernia is extremely common in the general population and is not related to post-polio or polio problems.) Choking on liquids was another complaint heard from several people, with some having less difficulty swallowing cold liquids or thicker liquids such as nectar or tomato juice. One individual, however, stated that only hot drinks were tolerated. Another person found that food could be better swallowed when lying down. This is *not recommended* as the risk of aspiration (food entering the airway) is greatly increased by being in a recumbent position. A third person reported more difficulty swallowing when fatigued. Still another reported difficulty chewing and jaws becoming fatigued when eating.

Esophageal motility problems were reported by several people with "heartburn or indigestion" reported by one person. Another experienced periods of nausea and vomiting following meals or a feeling of fullness after eating only a small amount of food.

One person reported receiving tube feedings for nine years following polio and then treatment with hypnosis for re-education to the swallowing process. This worked well for 38 years but difficulty is being experienced again, and a feeding tube is in place at present.

I'm sure you can already see that what I stated previously is true. There are definitely a variety of problems among us. Now, let's have a lesson in swallowing mechanics to better understand all of this.

### HOW DO WE CHEW AND SWALLOW?

The first phase of the swallowing process is the oral preparatory phase. During this phase, we take the solid or liquid we are about to eat into our mouth. Our lips should come together so that food or liquid will not leak from the sides of our mouth (this is what occurs if weakness develops in this area). Next, our jaw and teeth rotate and contract to initiate the act of chewing and to form the food into a bolus prior to the swallow. A bolus is a masticated (chewed) bit of food.

The second phase is the oral phase. During this phase, the bolus is moved posteriorly by the tongue to the

region of the anterior faucial arch (near the tonsils) where the swallowing reflex is triggered.

The third phase of swallowing, called the pharyngeal phase, now begins. The pharynx is the part of the alimentary (relating to nourishment or nutrition) canal located between the mouth and the esophagus. After the reflex is triggered, the food bolus is pushed into the pharynx. The soft palate (soft section of the roof of the mouth which extends between the pharynx and the nose) then moves back and up preventing food from entering the nasal cavity. The airway is protected by closure of the vocal folds and larynx, directing the food bolus into the esophagus. The esophagus is a muscular tube that leads from the pharynx to the stomach.

The fourth phase, or esophageal phase, is when the food or liquid passes through the cricopharyngeal port into the esophagus. The swallowing reflex is triggered, and the food is carried by peristalsis (a squeezing and relaxing motion) to the stomach. At this point, the sphincter or valve at the top of the stomach relaxes allowing the food to enter. The top one-third of the esophagus is innervated by motor neurons and may be or might have been affected by polio. The lower two-thirds is a different type of muscle (smooth or involuntary) and is not innervated by motor neurons, and therefore could not have been affected.

The triggering of the swallowing reflex causes a number of activities to occur simultaneously. All are necessary for a successful swallow. These include the elevation and retraction of the velum (or covering) which prevents food or liquids entering the nose from the oral cavity. The muscular activity which carries the bolus through the pharynx must be initiated. The larynx must elevate and close at three points for the airway to be protected. (These are the epiglottis, false vocal folds, and true vocal cords.) Relaxation of the cricopharyngeus muscle must occur so that the food may pass from the pharynx to the esophagus. And the epiglottis, a plate of cartilage behind the tongue, must cover the airway when you swallow.

### WHAT CAN GO WRONG?

First, if the muscles involving the lips are weak, you can leak the contents of the mouth and drool, losing liquids or food. Next, if the jaw is weak it is difficult to chew food and fatigue may become a problem. Weakness of these muscles may also create instability of the jaw causing pain which may be misdiagnosed as TMJ (temporal mandibular jaw malformation). Chewing food adequately may also be a problem with weakness in this area. Tongue weakness may make it difficult to move food to the back of the mouth and difficult to swallow certain consistencies. Diet modification may be indicated with any of these difficulties.

We welcome items or articles for the  
*Polio Network News.*

Please send them to Joan Headley,  
4502 Maryland Avenue, Saint Louis, MO 63108 USA.

Pharyngeal weakness may cause choking, coughing, or food being aspirated into the lungs resulting in pneumonia, if the airway is not protected. Some food may also become lodged in the valleculae (a groove between the base of the tongue and the epiglottis). This may become a problem because the residual food may trickle down into the unprotected airway causing aspiration but may be controlled by alternating liquid and solid swallow, thus eliminating the build-up of food. Liquids tend to move through the pharynx by gravity, where solids require coordinated muscle activity to carry the food through the pharynx. An absence of the swallowing reflex may also cause difficulty with this phase and choking may occur.

Esophageal weakness is manifested by nausea or indigestion following the intake of small amounts of food or by a feeling of fullness. At times, vomiting may also become a problem when food remains in the esophagus and does not pass into the stomach.

There are numerous problems which may occur, and this explains why we all have different symptoms or difficulties. Like all other aspects of the late effects of polio, we all lost different motor neurons, and therefore have different problems.

Diagnosis for post-polio problems are the same as for any other swallowing difficulty. The first step is a referral to a gastroenterologist or otolaryngologist (depending on your symptoms) to have a videofluoroscopy examination of the swallowing process by a trained speech pathologist. Be sure that the facilities for a proper swallowing study are available as a barium swallow without the video capability is not always able to diagnose the problem. The video recording is an important part of the test so that the swallowing process may be reviewed in slow motion. The tape is reviewed again when the next follow-up study is ordered and any progression may be noted. This procedure is known as a modified barium swallow. Very small amounts of barium (2-4cc) are presented such as a thin liquid, puree, and solid. One of these is usually barium paste on a cookie or cracker, hence the name "cookie swallow."

If nausea and abdominal fullness is a problem, they may also wish to study the esophageal function which may involve having a barium swallow using fluoroscopy, an upper gastrointestinal study, an esophagoscopy, or manometry studies of the esophagus. All of these studies look at how the food is moved through the esophagus. Several medications and treatments are used to assist with this difficulty.

Oral and pharyngeal phase difficulty may be treated by modifying the diet or the way food or liquids are consumed. The real secret to success, of course, is to have a thorough evaluation and a follow-up visit with

a speech pathologist who can advise you as to *what may help with your problem.*

## WHAT ARE OTHERS DOING OR TRYING?

The first statement to be made here is that you should have swallowing studies, either a modified barium swallow, an upper gastrointestinal study, or both, and a medical evaluation if you are having difficulty eating. Trying to diagnose and self-treat your problem may prove to be dangerous and probably inadequate as well! There are health care professionals with training ready and able to assist you. An important member of this team is a dietitian who may be able to assist you in identifying the most suitable consistency of foods in addition to planning a well-balanced diet which can be tolerated.

### Here are a few common sense suggestions:

- Chew slowly. If you are having trouble chewing, you certainly do not want to take large bites and gulp your food. This applies to liquids also. Big gulps are out—as are large bites. Do not talk while eating because this increases the risk of aspiration. Liquids are, at times, managed better if the chin is tucked down to delay the swallow. Tucking the chin increases the vallecular space, thus catching material leaked from the oral cavity prior to the triggering of the swallowing reflex.
- If you are choking on your saliva, avoid foods which will thicken your secretions. This includes milk and milk products. Remember to discuss calcium supplements with your physician if you do have to limit milk products in your diet. Choking may also be controlled by eating in an upright position at all times. If you notice that a certain food or type of food causes choking, avoid it.
- Do not eat when fatigued and consider eating several small meals if eating is difficult. Combining different textured food also makes eating and swallowing easier for some, such as placing a sauce or gravy on a dry, difficult-to-swallow food. Meats often fall into this category.
- If liquids are a problem, you may thicken them with various commercial starches or preparations to facilitate swallowing. Liquid soup broths are not recommended with tongue weakness as it is difficult to prepare them to swallow without choking. Cream soups are better tolerated as are juices with a thicker consistency such as nectars and tomato juices.
- If medication is a problem, applesauce or jelly may help with the swallowing process and so can drinking

(continued on page 10)

## Swallowing Difficulties

(continued from page 9)

water through a straw to get the water to the back of the throat. However, it is a dangerous practice to elevate your chin to get the medication to the back of your throat for it may cause aspiration. Raising your chin causes the vallecular space to disappear and swallowed material may drop directly into the airway. *Avoid this practice!*

- ❑ If choking or chewing is a problem, you definitely want to cook all foods until they are soft. Crisp-tender or raw vegetables, crisp apples, difficult to chew fruit, and tough meats are off limits. Juicy fruit, such as watermelon, may also be a problem.
- ❑ Esophageal problems can be managed by eating in an upright position and drinking a glass of water after eating, thus clearing the contents of the esophagus into the stomach. These may or may not work for you. Medications are also assisting with this difficulty. If a stricture is found with esophageal evaluation, dilation may be needed on occasion.

### *Renewal Notices for Polio Network News and other G.I.N.I. Publications.*

Thank you for renewing so promptly and for the added donations. Your support is so important. Please question us if you believe we have mailed you a G.I.N.I. Subscription and Publication Order Form (which doubles as our renewal notice) in error. We continue to combine all our lists and some of you may still be in the computer twice (once under *Polio Network News* and once under *Rehabilitation Gazette*). Some of you may be in the computer under your name (Henry C.) and also under your initials (H.C.) and may receive two notices. Please let us know if this is the case. Some of you are also listed under your home address and your professional address, and consequently may receive two notices. We will delete one if you choose, but some of you prefer both.

We mail the notices and the newsletter within the same four week period. The notices mailed recently were for individuals needing to renew in December, January, and February.



- ❑ If weakness is present on only one side of the body, turning the head to the opposite side while swallowing is at times helpful. One person was advised to apply pressure on the neck while swallowing.
- ❑ Weight loss may be a problem for some and in those cases a high protein or high calorie liquid substitute is advised. This should only be done with your physician's assistance, so your nutritional intake and balance may be monitored.
- ❑ Surgical intervention is the extreme end of treatment for these difficulties. Care must be taken in any corrective surgical procedure because of the weak underlying muscle structures. This is true of any surgical corrective surgery on post-polio people and is why corrective orthopedic surgery or gastrointestinal surgery involving the esophagus is not often recommended.
- ❑ Vocal cord weakness is a problem for some. Speech therapy is helpful in providing compensatory techniques. At times a small microphone to amplify the voice is being prescribed. Fatigue seems to play a role in voice weakness as well as ventilation difficulties. This must be evaluated on an individual basis.

### **RESEARCH — WHAT'S HAPPENING!**

I wrote four letters to people who I had heard were involved in swallowing studies. Three were physicians and one was a speech pathologist. Two did not reply. Dr. David Buchholz from Johns Hopkins wrote that his only published material was in 1987 following the Warm Springs, Georgia, conference. At that time they had evaluated 13 patients with dysphagia (swallowing problems). He stated they had other publications in progress.

Dr. Carl Coelho from Gaylord Hospital in Wallingford, Connecticut, was gracious enough to share his unpublished information with us. We thank him for that because as a former research associate at a national laboratory, I know that researchers closely guard their unpublished information so no one else takes the credit for their work. We are appreciative of his sincere interest in us! **THANK YOU!**

Dr. Coelho's study is on 22 patients with swallowing problems. They ranged in age from 40-69 with an average age of 53.1 years. The average person evaluated was 41.8 years following polio. Pharyngeal problems were most common, followed by bolus formation, and a delayed swallowing reflex. He reports an incidence of dysphagia in approximately 18% of the group studied. The problems range from very mild to severe. Some patients had more than one area of swallowing involved, while others had only one area

(continued, next page)



of weakness. He stressed that no two subjects were the same. Individuals with a reduced capacity to generate a productive cough as well as dysphagia were most likely to have serious involvement. He suggests that anyone with a swallowing problem be referred for a modified barium swallow and stresses that this is not the same as an esophagram. This test is stated to be critical in defining the swallowing dysfunction. He suggested that a more normal size bolus of approximately 20cc of contrast media be used for this evaluation. This test is also stated to be the key in identifying the most suitable non-invasive compensatory techniques to facilitate swallowing. Minor modifications of positioning during the swallowing are stated to yield significant improvement in function.

Some of his suggestions are turning the head, tilting the chin downward, alternating liquids and solids, and avoiding certain food consistencies. He also believes that a medical team which includes a radiologist, pulmonologist, speech pathologist, and dietitian be involved with the evaluation and management process. Fatigue was found to be a factor in swallowing difficulties, and therefore eating should be avoided when fatigued. Swallowing assessment should be evaluated at regular intervals to monitor progression as well as whether or not compensatory techniques continue to be effective. A relationship between swallowing and respiratory impairment was studied with the results suggesting that although impaired breathing may complicate swallowing dysfunction, it does not appear that one can be predicted from the other.

This study will be continued to monitor the progression of swallowing problems, and they welcome other polio individuals with these difficulties into their study. This is also true for the Johns Hopkins Group.

I want to thank all of you for sharing your experiences with swallowing difficulties. Without your assistance this article would not have been possible. All of your letters and telephone calls were of value to me. A big THANK YOU for a job well done! I hope this article will assist you in finding the help you need. If you have a problem not addressed here, write or telephone and we'll talk about it. **Roberta Simon**, 7835 Pine Parkway, Darien, IL 60559 (708-969-0287).

**Acknowledgements:** I want to thank **Carl Coelho Ph.D.** for editing this article. He may be contacted at Gaylord Hospital, P.O. Box 400, Wallingford, CT 06492 (203/284-2880).

## Post-Polio Directory 1990

*Please add the following:*

Susan Case  
Burlington County Support  
Group

1468 B Juliustown Road  
Fort Dix, NJ 08640  
609/723-8314

Susan Bridges  
1610 Shetter Avenue,  
Apt. #131

Jacksonville Beach,  
FL 32250  
904/247-1966

Caroleann Green  
414 Corvette Street  
Port Hueneme, CA  
93041

805/984-3645

Trudy Forkins  
2705 Henry Street  
Sheboygan, WI 53081  
414/458-4526

Post-Polio Syndrome  
Support Group  
of Fort Lauderdale

*Jan. to June:*  
Rich Rahmey  
Apt. 108

208 Lake Pointe Drive  
Oakland, FL 33309  
305/735-7614

*July to December:*

Sandy Costa  
4333 NW 67 Avenue  
Coral Springs, FL 33067  
305/797-4700  
305/752-0282

*Please make the following changes:*

The Post-Polio Support  
Group of South  
West Florida

Thomas S. Marshall, Jr.  
1846 Powell Drive #38  
North Fort Myers,  
FL 33917  
813/656-1493

Polio Survivors of  
Oklahoma Association

Linda Dickinson  
1423 NW 44th Street  
Oklahoma, OK 73118

Chattanooga Post-Polio  
Support Group

Barbara Tucker  
P.O. Box 368  
Dunlap, TN 37327  
616/949-4480

## Post-Polio Directory 1991

IPN will soon be mailing forms to all clinics, health professionals, and support group leaders listed in the **1990 Post-Polio Directory**. We will ask you to make any corrections in your listing and confirm your willingness "to be there" for polio survivors by returning the form. Please make every effort to return the form by the deadline on the form or January 5, 1991 at the very latest.

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## An informal visit with ... Dr. Arnold R. Beisser

**Dr. Arnold R. Beisser** graduated from Stanford Medical School at 24. After being called to active duty for Korea, he contracted polio, was paralyzed from the neck down, and spent two years in an iron lung with minimal further recovery. Today, Dr. Beisser is a successful psychiatrist who has completed three books — *Flying Without Wings*, *A Graceful Passage: Notes on the Freedom to Live or Die*, and *The Only Gift: Thoughts on the Meaning of Friends and Friendship*.

After reading *Flying Without Wings\**, **Melody Hobson**, President of the Simi Valley/Conejo Valley Post-Polio Support Group, wrote to him asking for an interview. They share their conversation with the readers of *Polio Network News*.

**Melody:** I am interested in why you wrote *Flying Without Wings*.

**Dr. Beisser:** I wanted to get my own thinking straight about how I felt about my disability which has been a very large part of my life for 40 years. My patients also influenced me to write. So often they will ask me questions that are very difficult to answer. "How do you bear not being able to move or not being able to breathe?" At first, I don't have any answer because I don't know. How DO I do that? I then began to realize that the reason it is so hard for me to answer the question is because it is not on my mind. What is on my mind is my patient and not what I can't do. I think about what I might be able to do.

Your physical condition does not matter because where your attention is is more important. If your attention is on something that is valuable to you, something affirming and positive, then it makes no difference how your body is—it is just where you are occupied. There are plenty of times (in particular when things get bad) when my attention is completely occupied with trying to nurse this recalcitrant body along. I do feel disabled. I am disabled.

**Melody:** Your book is so positive. It's not "Ah gee, I've got polio and life is so terrible." It's saying, "I've got a problem, but life goes on." I'm trying to stress in my group that it is OK to have a disability.

**Dr. Beisser:** The most important thing is to have something you value more than your body. Have something that you are committed to that takes precedence over the difficulties of being disabled.

None of us, or very few of us, would have chosen to have a disability, so it's really a matter of what people *can* find in their lives, not what they can't. There are continuously available to us processes of decline, deterioration, or tragedy. There are also conditions of re-birth, growth and development, and affirmation. They are both there all of the time. We need to identify with those positive, affirming, growth-producing processes and to spend as little time as possible on the others.

**Melody:** What I have heard is that polio survivors are a 'dying breed.' I don't go along with that. There are too many people in this world who have polio.

**Dr. Beisser:** We are a 'dying breed,' and we are a 'growing breed.' It's true that old polio survivors are doing amazing things, just as you are doing in the support group by helping people see they have choices to make their life worth living. If there is a choice, they can focus their attention on those processes of decline of the 'dying breed' or focus on things they can value and give them pleasure and meaning. I don't want to imply that the choice is an easy one or one that can be taken lightly. I don't think it's as simple as "think positively and things will be OK." There is a choice and we have to respect each person and what he chooses to do because no person can live in another person's skin. I do think there are times when people's lives are so difficult that it may be time to go. I don't think that's necessary, but what I do know is that if someone feels respected even for his negative choice, that then paradoxically, invites him to consider something more. Have I made this clear? Just to exhort somebody to look at the world positively is far less encouraging to a person than accepting him as he is. Even though he may be in a seemingly negative place, the fact that he has been accepted *as he is*, is a life affirming thing. He then can begin to look that way.

**Melody:** Do you think that older survivors are more negative because there's not much time left, whereas the younger people have a future?

**Dr. Beisser:** I'm one of the older survivors, and I would say that it's true in one sense. We don't have as much to look forward to. On the other hand, the issue has to do with coming to terms with what there is in your life at that moment. The tasks of later life have to do with acceptance and integration.

**Melody:** In my group, I'm trying to point out that we've all had polio and we should consider what we can do.

**Dr. Beisser:** I think one very valuable thing you can do is to ask people to consider what are the things in their lives that make it worth living. Some people will say family, some will say their religious beliefs, some will say their work. If someone says nothing, you have to ask them to think of the things in the past that gave them satisfaction and ask them to find things like that in the present or in the future for themselves.

Sports were the most important thing in my life when I was young. I was a national tennis champion and lettered in three sports in college. I missed sports terribly when I first became disabled, and I couldn't see how it was possible for me to live without them. I fortunately began to see alternative ways of being involved. I really wasn't a fan before because I liked participation. But I found I could get similar kinds of satisfaction just by watching, by identifying with the people and that was important.

Baseball is probably my least favorite sport. When I first got polio, I listened to baseball games and got interested. As a psychiatrist, I began to see athletes in my practice and was a consultant with the Commissioner of baseball. If a person can just hang in there, the things that seem impossible begin to happen.

**Melody:** I was young when I contracted polio and have always had the problem, but you had already lived half of your life. It must be much different.

**Dr. Beisser:** Different? What would you say the differences are?

**Melody:** You were able to do "the normal things" that children and adolescents and adults like to do, and then the wall came crashing down. I was only a year and a half old, so I really don't know any different.

**Dr. Beisser:** So you think that was harder for you or easier?

**Melody:** Harder. I was very resentful. (My Mom says, "I don't see why you are having all those responses now, you didn't show it when you were growing up." I respond, "Because you never asked me what it was like to *be different*.")

**Dr. Beisser:** So for me (people who were older), it's the loss that we feel, and for someone like yourself (people who were very young), it's a feeling of what you missed.

**Melody:** I felt I could not keep up with the "normal things." I did the March of Dimes Walk and they asked us to walk 5 blocks. I walked 105 blocks.

**Dr. Beisser:** It's taken a lot of extra effort to try to be as good as everybody else, and that's true if you are older or younger. That's what so difficult about this "post-polio syndrome." We were able to achieve a certain level of success by extra effort. After we achieve that, we start losing. It seems terribly unfair.

**Melody:** Some of us may look all right, but inside we are fighting this battle.

**Dr. Beisser:** Yes, that's something I've been interested in for some time—the difference between what you would call a "hidden disability" and someone that is obviously disabled. If you walk down the street, no one would notice. On the other hand, there's no question about my being disabled, and the problems are different. The problem for you is that people expect more of you than you can actually do because your disability is hidden. In my case, they look upon me as being different, and so that separates them from me. They may see me as an object of pity, or that they can't relate to me as an equal, or they fear they might "catch it."

**Melody:** Why don't spouses come to our support group meetings?

**Dr. Beisser:** It's not easy for spouses either. When people get married and there is a healthy person or a disabled person, they know what they're getting at the time. But when things begin to change, it's hard because that's not what they bargained for. But you never know who is going to be disabled. When my wife and I got married, I was disabled, and she was anything but disabled. In fact, her incredible ability to manage me made it possible for us to live quite normally. Then a few years ago, she developed rheumatoid arthritis and so she has her own disability. That wasn't her expectation, and it wasn't my expectation, so it creates some real difficulties.

**Melody:** How do you view your life as you grow older? Will you still live in a house and do everything that you want to do?

**Dr. Beisser:** The one thing I am clear about is that you can't look too far ahead for if you do, you know very well where you will end up. You can scare yourself about the future. What we have to do is to take it one day at a time, put one foot in front of the other, and make the most of each day. I don't know what the future holds for me. I do get scared about it sometimes, and that's what motivated me to write *A Graceful Passage\*\**, because I had to come to terms with the fact that I am older. I am getting towards retirement, and I do recognize that my abilities are

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## Dr. Arnold R. Beisser

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diminishing rapidly, and I know I am going to die. I realize that I have to find a way of living until I die, and that's what is important. The important thing it seems to me is to find something *today* that makes it valuable.

**Melody:** You wrote your first book for your own insight. Why did you write the other books?

**Dr. Beisser:** I think the first book really talked about the experience of living with disability. The second was about the fear and anticipation of death. The third book in the series has to do with one of those things that make life worth living, friends and friendship.\*\*\* I would say the most basic thing was to get things straight in my mind. Everybody wants others to understand what it is like. That is why support groups are so valuable. Everybody needs somebody there to see them as they are, to hear them as they are.

**Melody:** I appreciate you taking the time to talk to me, and I know our group is very anxious to hear from you. I'm trying to stress the abilities, not the disabilities. It's not time now for the "Poor Pity Me."

**Dr. Beisser:** Don't be too impatient with "Poor Pity Me," that's a part of it. Everybody wants to be heard, everybody wants people to know how difficult it is. Again, I think perhaps the most useful way to help people is to show that there is a choice at any moment on where they focus their attention—on what they can't do or on what there is available to do. There are times at which someone has every right to see what he only can see. But when he is reminded that there is a choice and there may be something more, I do think it is very helpful.

\**Flying Without Wings* was published in hardcover by Doubleday, in paperback by Bantam in 1989.

\*\**A Graceful Passage: Notes on the Freedom to Live or Die* was published this year by Doubleday.

\*\*\**The Only Gift: Thoughts on the Meaning of Friends and Friendship* will be available in March, 1991, from Doubleday.

### Other Books and Booklets by Polio Survivors

*Through the Storm: A Polio Story* by Robert F. Hall is available from North Star Press of St. Cloud, Inc., P.O. Box 451, St. Cloud, MN 56302 for \$9.95 (pp. 147).

*How to Cope: More Practical Tips for Polio Survivors* by LaVonne Schoneman is available from LaVonne at 16734 - 8th NE, Seattle, WA 98155 for \$7.00 (pp. 80). To also receive her first book, send \$11.

*Surviving It All* by Sylvia Herndon is available from Arkansas League of Polio Survivors, 9010 W. Markham Street, Little Rock, AR 72205 for \$9.95 plus \$1.50 postage. (pp. 57).

## Leaders and Readers Write

### FROM CZECHOSLOVAKIA

"Thank you so much for your kind letter and for your encouraging wish to our First Conference on Post-Polio Syndrome.

"In August, an Association of Polio Survivors was founded in this country. Meanwhile 4000 members are registered. The Association will advocate all interests of our polio survivors, above all a systematic examination of their post-polio syndrome and its rehabilitation treatment. At the same time we shall watch the progress in research and treatment of polio survivors in other countries. Our Association of Polio Survivors has appointed **Dr. A. Wokoun**, Chararovicka 1333, 182 00, Prague 8, Czechoslovakia, for international contacts." **Marketa Fidlerova**, coordinating the Association of Polio Survivors with the Union of Disabled in Czechoslovakia.

### FROM GERMANY

"Whether and when a German post-polio support group for the now united country can be realized depends on the interest shown by survivors in East and West. In general many hesitate to approach other people with disabilities. A small number of survivors in West Germany have been integrated into some associations for individuals with a disability and others into the German Association for Muscular Diseases. Only recently have people with disabilities in the East set up a general organization with the intention of forming groups for various disorders.

"My correspondence and phone calls reveal that the difficulties of polio survivors are rapidly increasing. These include new weakness, musculoskeletal pain, fatigue, breathing problems, and finding technical aids and understanding health professionals.

"Survivors reluctantly accept technical aids and a new life style. However, as soon as it is done, the positive effects give some relief. Although the awareness and knowledge of post-polio syndrome is still much too rare in our country, the diagnosis is indeed being used by some." **Gertrud Weiss**, Ebersbergerstr.33, 8200 Rosenheim, Germany.

### FROM MICHIGAN, USA

"It is the aim of the Polio Network, Inc. serving Michigan to pursue changes in the Social Security Disability (SSD) regulations to assist in designing a more livable system. The proposals we are working on are minimum changes that are long overdue. Our thrust is not just to benefit polio survivors but to give all SSDs the right and the opportunity to better their

current situation which now does not allow many individuals to earn up to poverty level without endangering their SSD as well as a possibility of losing Medicare.

"Basically what we will be proposing are changes that will make it easier and economically feasible to return to work on a part time basis with an eye towards full time. At the same time, it is extremely important that this proposal not cost one cent in additional taxes from any source."

Individuals or groups interested in more information or in assisting in the effort, should contact **Jerry L. Hazel**, Chairman, Polio Network, Inc., 2877 S. Ennis, Ithaca, MI 48847 (616-964-8184).

### FROM MAINE, USA

"In the Spring issue (Vol. 6, No. 2) of *Polio Network News*, I requested people willing to be considered as participants in a research study comparing beliefs and attitudes of polio survivors with those of people who have not had polio. Letters of explanation were mailed with the printed questionnaires to 260 volunteers in September. In addition, 16 support groups were contacted so that polio survivors in all parts of the country would be represented, and an equal number of people who have not had polio were contacted for comparison. Already, many of you have responded, often adding thoughtful questions and comments. Some people have also sent copies of articles which have been published about their own experiences with polio and about their polio support groups. While I very much want to respond individually to the people who took the time to send additional letters and materials, thanking participants as a group is one way of practicing the recommended post-polio behavior of conserving muscle strength.

"The process of data collection will continue until December, 1990. Data analysis should be completed in the spring of 1991, and writing up the results will follow. I hope to have a summary of the findings for the *Polio Network News* with copies in the mail for those of you who requested them by this time next year. Although the questionnaires are still coming in, I have some preliminary impressions, including that polio survivors are even more diverse than I had thought! The level of intelligence and independent thinking illustrated by the questions and comments is impressive. There are still many unanswered questions about how polio and late effects of polio affect our nervous system and muscle function. Many of you expressed concerns related to changes in strength and stamina, and learning to live with an unpredictable future. The impact of late effects of polio on relationships is another recurring issue. Frustration and faith,

courage and perseverance, toughness and sensitivity are all represented in your responses. Specific answers and information of immediate relevancy are wanted.

"I thank all of you who have responded to this research project on change as experienced by people who have had polio." **Dorothy Woods Smith, R.N.**, Project Director Doctoral Candidate, Division of Nursing, New York University

### FROM WASHINGTON, USA

If you live in the Peninsula area and are interested in organizing a support group, contact **Linda Saathoff**, 1930 S.E. Diamond Place, Port Orchard, WA 98366.

### *Do you have this information to share?*

Do you have experience in putting together a "lifecare plan"?

Do you know of any studies in which polio survivors' cholesterol levels have been monitored?

Contact **International Polio Network**, 4502 Maryland Avenue, St. Louis, MO 63108.

## Potpourri...

### IMMUNIZATION INFORMATION

#### National Vaccine Injury Compensation Act Extension

Individuals who suspect their polio was caused by a vaccine and who received the vaccine prior to October 1, 1988 *now have until January 31, 1991* to file their claims. Contact Clerk, U.S. Claims Court, 717 Madison Place, NW, Washington, DC, 20005 (202/633-7257) for the Court Rules to instruct how and where to present a claim or, for more information, contact IPN.

#### p.s.s.s.t.

p.s.s.s.t. (Polio Survivors Standing Strong Today) is concerned about immunization practices. Founders, Kathryn A. Todd, R.N., and Nanette S. Plumley, M.A., have amassed literature and correspondence related to the OPV (oral polio vaccine), IPV (inactivated polio vaccine), the eIPV (enhanced-potency inactivated polio vaccine) and the current and future polio vaccination policies. For more information, contact p.s.s.s.t., RD #2, Box 32, Industry, PA 15052 (412/643-6702).

### GRANTS AVAILABLE FOR NURSE RESEARCHERS

The Rehabilitation Nursing Foundation (RNF) of the Association of Rehabilitation Nurses (ARN) announced that it is now accepting applications for its 1991 research grant award of up to \$5,000.

(continued on page 16)

**G.I.N.I.**  
4207 Lindell Blvd. #110  
St. Louis, MO 63108-2915  
(314) 534-0475

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## **Potpourri** (continued from page 19)

Nurse researchers, regardless of whether they hold membership in ARN, may submit proposals that address the clinical practice, educational, or administrative dimensions of rehabilitation nursing. The grant will be awarded at the Association of Rehabilitation Nurses' annual educational conference, October 23-27, 1991 in Kansas City, MO.

For further information and to receive application materials, call or write the Rehabilitation Nursing Foundation Research Fund Committee, 5700 Old Orchard Road, First Floor, Skokie, IL 60077-1024. The deadline for receipt of applications for the 1991 award is April 1, 1991.

## **GRANT FUNDS LEG BRACE RESEARCH**

National Rehabilitation Hospital, Washington, D.C., has received a \$300,000 grant from the General Reinsurance Corporation to develop a new generation of leg braces.

Approximately 500,000 Americans use some form of leg or foot braces, but the technology has not been significantly updated in the past 30 years. The new brace will be made of non-metallic and resin composite materials used in the nation's defense and space programs. Although metallic braces are effective, the lighter brace will reduce strain and fatigue and allow for greater mobility.

Much remains to be done before this leg brace technology becomes commercially available, but the new brace could offer a 65% decrease in weight, a 40% increase in stiffness, and a 200% increase in overall strength.

Development of the brace was initiated by SPARTA, Inc. an aerospace research development firm located in San Diego. Initial grant funding was provided by National Institute on Disability and Rehabilitation Research (NIDRR).

## **TEXTBOOK ON POST-POLIO SYNDROME**

*Post-Polio Syndrome*, edited by Theodore L. Munsat, M.D., with 15 contributing authors, is now available from Butterworth-Heinemann, 80 Montvale, Stoneham, MA 02180 (ISBN 0-409-90153-9) for \$44.95. Contributing authors include Donald W. Mulder, Robert H. Brown Jr., Lauro S. Halstead, Marinos Dalakas, John J. Kelly, Jr. Neil R. Cashman, Ricardo A. Maselli, Robert L. Woll-

mann, Jack P. Antel, Richard Finkelman, Theodore L. Munsat, Patricia L. Andres, B. Thornell, C. Brussock, Gini Laurie, and Dorothy Woods Smith.

In the preface, Dr. Munsat states, "While we are still a long way from having a definitive etiology for post-polio syndrome, this text provides our current knowledge and treatment for this disorder. It is my hope that physicians and therapists will find it a useful and enlightening resource when treating patients with post-polio problems."

## **NONINVASIVE VENTILATION VIDEO PRODUCED BY LIFECARE**

*Introduction To Noninvasive Ventilation* interviews prominent medical professionals with noninvasive respiratory expertise to discuss the benefits and limitations of noninvasive techniques. It also demonstrates several effective alternatives to invasive ventilation through a unique blend of modern and early technology. The video is available through the 18 district offices and the international network of distributors. Contact **Jim Seeley**, LIFECARE, 655 Aspen Ridge Drive, Lafayette, CO 80026 (303/666-9234).

## **CALENDAR**

*The purpose of the calendar is to notify our many readers, including those who are not connected to a support group, of upcoming conferences. The list includes conferences sponsored by a variety of organizations around the country. We provide this service to prevent duplication of dates in the various regions around the country.*

**January 25,26,27, 1991. First South West Regional Conference on the Late Effects of Polio.** Ramada Inn, Fort Myers, FL. Contact: Thomas Marshall, 1846 Powell Drive Lot #38, North Fort Myers, FL 33917. 813/656-1493.

If you are support group leader who plans to attend the above conference and are interested in participating in a panel discussion about support groups, please contact Joan Headley at 314/361-0475.

**February 1,2, 1991. Bay Area Post-Polio Conference III — Perspectives for the '90s.** Hyatt Regency, Oakland, CA. Contact: Renah Shnaider, 415/832-2574. All attendees must pre-register.

