

POLIO NETWORK NEWS

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Sixth International Post-Polio and Independent Living Conference The Battle with Bracing, Part II: Choosing an Orthotist

Glenn Ham-Rosebrock, CO, Downey, California

An orthotist specializes in orthopedic appliances, also known as orthoses. Orthotists study anatomy and physiology, mechanics of movement (kinesiology), as well as fabrication of orthoses and prostheses.

Prosthetics deal with replacing missing limbs, while orthotics provide bracing. A certified orthotist can suggest how to best duplicate mechanically what is functionally missing anatomically.

Choose a board certified orthotist. In 1948 the American board of certification required that orthotists be certified. Anyone already practicing was automatically certified under the "grandfather clause." Those new in the field were required to take a two-hour written quiz. Today an orthotist must have a bachelor's degree and several years of work experience prior to his or her exams. The exams consist of a day of written, a day of oral, and a couple of days of practical fabrication. In the future a master's degree will be required. There is now a mandatory continuing education program requirement.

A certified orthotist, or a CO, also referred to as a practitioner, deals directly with patients and assists physicians in evaluating orthotic needs. Orthotists are not doctors and cannot diagnose or prescribe, so have a prescription in hand when approaching an orthotist about an appliance.

Another form of certification is that of the certified technician. Technicians do not see patients but fabricate braces.

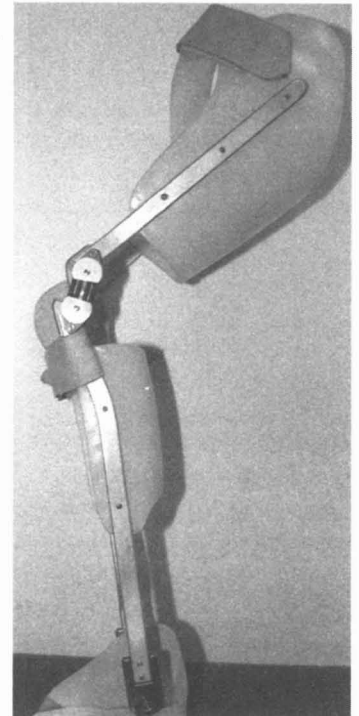
Images of orthotists vary. Initial impressions are very important. Individuals who have never worn braces can have a variety of anxieties or expectations. One should expect a facility with examination rooms allowing for privacy. Also expect to see parallel bars in the walking room for initial gait evaluations if lower extremity problems are present. Parallel bars are not used when evaluating upper extremity or spinal difficulties.

Orthotists should perform muscle tests, range of motion, and gait analysis to confirm a prescription. A muscle test determines muscle strength and what loca-

tions are having problems — ankle, knee, hip, even upper extremity. Range of motion detects joint deformities. Gait analysis is done both before and after lower extremity bracing.

An orthotist should explain what the options are and discuss the types of materials available to fabricate the orthoses. The approximate weight of the different approaches should also be discussed. It needs to be determined whether weight and/or strength is the priority.

There are lightweight, sturdy plastics such as polypropylenes or polyethylenes. Some braces are made out of exotic materials such as epoxies and graphite with or without metal bars for reinforcement. They can be any color of the rainbow, which surprisingly can present individuals with additional anxiety. Depending on the need and the physical limitation, metal materials such as aluminum, steel, stainless, or titanium are available as well as different cosmetic approaches, leathers, and velcro closures.



A free motion brace with an offset knee joint with roller bearings and a rubber band type extension assist mechanism. The brace accelerates the lower shin portion forward extending the knee during swing phase of gait.

Different diagnoses require different designs.

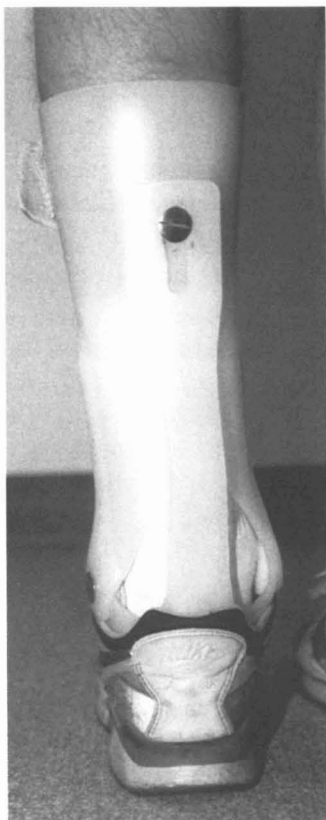
For example, the needs of a person with a spinal cord injury as opposed to a sports injury differ tremendously from the needs of an individual who is post-polio.

An individual with a low level spinal cord injury needs to have flail extremities stabilized and aligned to bal-

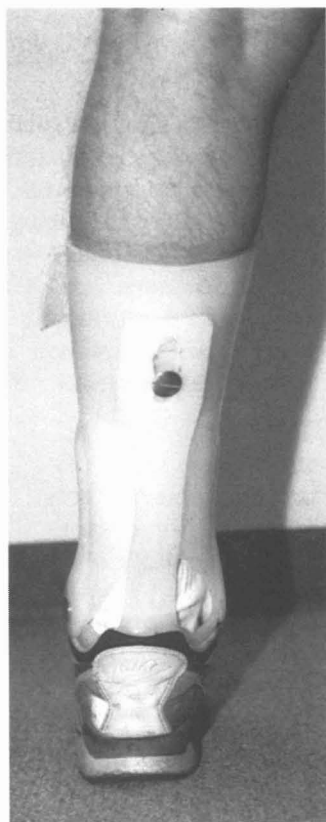
Choosing an Orthotist

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ance the body when standing with locked knees and locked ankles. SCI individuals have to see where their body is in space because they have no proprioception. That is, there is no ability to know where the body is in space when eyes are shut or while looking away from the extremities. The bracing goals are simple: Lock up all the joints.



A plastic floor reaction brace which stabilizes the knee (without crossing the knee) and picks up the foot via a spring action. Note position of screw in each channel in each photo.



A sports-related injury is usually an isolated injury on an otherwise intact body. Individuals need the injured area protected from re-injury while continuing with their usual activities. Sports bracing leverage is too short for polio survivors' flail extremities, and the limbs will not tolerate the circumferential restrictions that usually accompany the sports brace.

An athlete works out three to four times a week, resting in between days to prevent burnout or getting fatigued. During this resting period they go about their activities of daily living (ADL). Polio survivors need to recognize that ADLs for them may really be EDLs — exercise of daily living. A prescribed or a "ritual" exercise will be unnecessary for a polio survivor whose energy is depleted from "doing hurdles" over the

telephone cord in a carpeted area. The challenge for the orthotist is to recognize the functional needs of the polio survivor just as the needs of an athlete are recognized.

Orthotists need to be aware that post-polio individuals have been overcompensating with every step or movement. During my internship some years ago at Rancho Los Amigos Hospital, I also doubled as a professional patient for the benefit of orthotists in training in gait analysis. As I walked back and forth in front of the class without my braces, the instructor noted the control of my hip, knee, and ankle joints totally void of any muscle power and commented, "If you had that kind of control and regained all your muscles, you would be greater than Nuryev." Polio survivors proprioception is intact and heightened and that makes us different from all other diagnoses.

Consider follow-up and finances. An orthotist should appreciate the value of a six-month follow-up appointment. I mentioned this at the '87 G.I.N.I. conference, and at the '89 conference, a gentleman told me that he showed up for a six-month follow-up with his orthotist and was greeted with, "What are you doing here? There's nothing broke."

Brace joints need resquaring and lubricating; straps and rivets need checking. Joint bushings and bearings should be changed prior to a failure which can create financial and time burdens. One does not wait until the engine blows to change the oil. Our bodies change and braces need to be adjusted.

An orthotist should discuss the financial aspects of bracing so there will be no surprises at the time of delivery. A well-trained orthotist can put technique, material, and design to the test and keep polio survivors functionally active. □

RELATED RESOURCES

American Orthotic and Prosthetic Association, 1650 King St., Suite 500, Alexandria, VA 22314 (703/836-7118).

Northwestern University's Prosthetics Research Laboratory and Rehabilitation Engineering Research Program phone help line: 312/908-8565; e-mail: reiu@nwu.edu; web site => <http://www.repoc.nwu.edu/>

The Whole Crutch and Wheelchair Catalog compiled by Thomas Fetterman, Inc., P.O. Box 174, Southampton, PA 18966-4514 (215/355-6941).

House of Canes and Walking Sticks, 767 Old Onion Mountain Rd., Wilderville, OR 97543 (800/458-5920). Call or write for a catalog with extensive collection of shafts made of walnut, oak, ebony, birch, lucite, covered with fabric; handles and knobs made of sterling silver, silver plated, brass, etc.



Sixth International Post-Polio and Independent Living Conference Post-Polio Corrective Surgery: Then and Now

Jacquelin Perry, MD, Pathokinesiology, Rancho Los Amigos Medical Center, Downey, California

Then... Most of the surgery done in the past still is applicable today, however, there is some limitation in response due to aging of the muscles and tendons.

The purpose of surgery is to improve function. The first reconstructive surgery ever conceived was heel cord (Achilles tendon) lengthening which actually was done with a simple snip in 1821 even before anesthesia was developed. The back of the ankle became tight, and if the heel cord was lengthened, a flat foot resulted. The benefit did not necessarily last unless the surgeon transferred muscles to the front of the foot. On a positive note, the residual return usually was less severe than the initial problem.

Another early surgery to provide a stable foot, for one without muscles, was to fuse everything and was called a pantalar arthodesis. More commonly, the surgeon fused just the foot (a triple arthodesis) leaving the ankle free to provide early knee stability for optimum weight bearing. Total fusion got rid of braces and was considered a great success in the early '40s and '50s. Now it is a disadvantage because the total foot fusion is creating increased demand at the knee. My recommendation is not to get it done if you have not had it done.

Tendon transfers to the heel were also done. One obscure but critical problem was a weak calf which secondarily led to foot deformities and unstable knees. Transferring the tendons of other muscles to the heel restored posterior ankle control and made both the foot and knee more stable. The common growth deformity from a weak calf was a very vertical heel and high arch which resulted in a great deal of instability. Muscles were transferred to the back of the heel. In just three years, the growing foot would respond with a flatter arch and better heel and much more stable foot. By changing the pattern of muscle force we actually influenced bone growth. Obviously, once the foot has finished growing that would not be an outcome. One can use the same procedure for stability in an adult today but it will not change the shape of the foot without an accompanying osteotomy.

Another early surgery was done on the upper extremity. Both a problem and a salvation for polio survivors is paralysis of the muscles controlling the shoulder joint with the shoulder blade muscles preserved. The result is a flail arm and inability to use a functional hand. These areas have a different nerve supply than the muscles to the shoulder joint. A solution was to fuse the

shoulder blade and the upper arm bone, i.e., a shoulder fusion which gave a stable arm for hand function as well as reach. Many young girls who had polio in their upper body could flip their arm up on top of their head and fix their hair and did not choose the shoulder fusion. A shoulder fusion was a great advantage if one could not control the hand and use it. It is still a good procedure. I actually did one about two years ago on an adult woman, and now she is able to place her functioning hand in useful positions.

A tendon transfer in the hands to make a pinch by bringing the thumb across is an old procedure. Today, I have found that people substitute so well there are no candidates.

If one did not have any muscles in the hand and wanted stability, we grafted a bone between the first finger and the thumb. This was excellent for people who were fully ambulatory or wheelchair users, but was not good for people who used their hands for transferring because the hand could no longer be flattened for weight bearing.

A challenge to orthopedists then and now is the polio survivor who has no quadriceps and uses hip or calf muscles to lock the knee back in a recurvatum to walk. In the late '50s I designed a procedure which transferred every available tendon and the iliotibial band and put them behind the knee and called it a triple tenodesis. It worked great in the growing child and resulted in a straight knee, because while they were growing this surgery was kept tight. Once the child stopped growing the surgery gradually loosened. It is not recommended in adults. The reason is there is nothing to keep it tight, and the person still does not have a quadriceps. Surgery, of course, cannot create a quadriceps, it can only stabilize the knee. If you have no quadriceps today, and your recurvatum has become painful or unstable, a protective brace which still allows free knee flexion for swing is the best answer.

Mary Ann Keenan, MD, Albert Einstein Medical Center, Philadelphia, Pennsylvania

Now... The procedures for polio now are the same as then, but fewer are done. The goals for surgery are very much the same — rebalance the muscle forces. Even a weak muscle, totally unopposed across a joint with nothing to balance it on the other side, needs to be in balance. Surgery aims to correct limb deformities, improve function, and to stabilize the spine or limb.

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Previously the goal was to eliminate braces. But now the goal is to improve bracing options. Older individuals have less muscle power and polio-affected muscles have been working extra hard.

Surgery cannot increase muscle function or make people as if they never had polio. In fact, when transferring a muscle a little bit of strength is actually lost. Limb surgery can lengthen a tight ligament; eliminate the deforming muscle forces; redirect muscle force for better function or balance; stabilize joints or the spine. When dealing with older individuals, resurfacing arthritic joints with a joint replacement technique or correcting malalignments may be needed.

The Albert Einstein Medical Center experience based on the first 200 consecutive people.

Lengthening the heel cord (Achilles tendon) is the simplest and the most common procedure done. It was recommended to 25 patients; nine refused; two required additional procedures. The procedure was done on 16 patients with three having both sides done with no complications. Before surgery they had an average of a 25 degree toe-down or equinus position. The mean age was 54 years. The Achilles tendon turns as it attaches from the calf to the heel of the foot. If it is too tight a foot is held with the heel off the floor. Three or four partial cuts in the tendon release the fibers and the body fills in the gap. The result is a foot that is flat on the floor and can be more appropriately braced.

The second most common surgery was lengthening the iliotibial band, a tendon on the outer side of the thigh running from the hip. When tight, it can tilt the pelvis, and, even more commonly, cause valgus or knock-knee. When contemplating surgery for knock-knee, the bones need to be relatively healthy because no matter what is done to the tendons or ligaments it will not correct the deformed bone. If the bones are relatively adequate, then releasing the iliotibial band will correct the deformity and hold the leg in a more appropriate position with a brace.

We recommended this for nine people, two declined. Of the seven patients, four had surgery on both legs. The mean age was about 53 years and approximately 40 years after the onset of polio. Before surgery there was an 18 degree average knock-knee deformity, and after surgery a 10 degree alignment. Normal is seven degrees. If the leg is straightened out, the brace can be a lot simpler. Again, there were no complications.

A bent knee or flexion deformity is caused by the hamstring muscles in the back of the thigh overpulling weak or absent quadriceps muscle in the front of the thigh. Releasing the deforming forces, which are the hamstring muscles behind the knee, is the solution.

But rather than letting relatively good muscles go unused, surgery can move them to the front and hook them into the quadriceps tendon around the knee cap. A non-helpful muscle is now very useful. This procedure has been done without any complications. After healing in a cast a brace is prescribed. Before surgery the mean muscle strength of the quadriceps was grade one; after surgery, grade three which means the person's leg could be lifted against gravity. This is not enough to go without a brace, but it improves the bracing choices. For example, a knee joint that is light weight, hinges, and is offset protecting against hyper-extension could be used.

A very high-arched foot, or cavus foot, is difficult to fit into a shoe. The first decision is whether or not there is a bone deformity. If not, and the foot has some flexibility, the ligament on the bottom of the foot that is holding the arch so high is released. This was done on eight patients, all of whom were women; two had both feet done. The foot is painful because it has got to stretch out after surgery and then the arch will come down. Before surgery average degree of arch was about 21 degrees, and after surgery it was six degrees. Zero degrees or neutral alignment is normal. Three people had scar pain for several months after surgery primarily from the stretching.

When the bones in the foot are deformed resulting in a high arch, releasing the ligament on the bottom of the foot will not be sufficient. One solution is to cut a little wedge in the top of foot or do an osteotomy (cutting bone). Held with a few staples, walking in a cast is recommended immediately after surgery to stimulate healing. We performed this surgery in six patients who had an average high-arch deformity of about 24 degrees and after surgery a two degree. One person had complications of a sore on the bottom of the foot.

Tendon transfers to the heel to improve calf strength are done usually in combination with other procedures. A variety of tendons that run in a calf can be hooked into the heel to improve the pull of the calf. This surgery does not eliminate the need for a brace but it does improve strength and makes the bracing less complex and lighter weight.

We performed miscellaneous procedures on several individuals such as correcting toe deformities which are very painful inside of a shoe; a bad knock-knee with bone deformity which required cutting the bone to realign the leg to be able to brace it; and one hip replacement. Good muscle strength is needed to hold the hip stable and *must* be considered in recommending total hip surgery for a polio survivor. We also did a total knee replacement.

Overall, of the first 200 patients, we recommended surgery for 79 and 46 had surgery with 58 different procedures done. □

Post-Polio Corrective Spinal Surgery

Irwin M. Siegel, MD, Associate Professor of the Department of Orthopedics, St. Luke's Medical Center, Chicago, Illinois

Roughly one-third of all patients who have had poliomyelitis develop scoliosis (spinal curvature). This usually occurs early in the acute disease. No other scoliosis group benefits as much from spinal surgery as paralytic polio survivors. This is because they require a stable spine, balanced over a level pelvis, in order to stand and walk. A progressive curve of 50-60 degrees may indeed be an indication for correction and surgical stabilization. However, as with any operation, one can always make a patient worse if close attention is not paid to the specific conditions that must be met before surgery is undertaken. Among other things, these include cardiac and respiratory status adequate to survive the surgery, with close attention given to the special considerations of these operations in the post-polio patient.

The scoliotic curve in a polio survivor is usually long and may involve the thoracic as well as the lumbosacral spine. Trunk imbalance can cause an uneven pelvis, and the pelvis itself is often regarded as just another distal vertebra. Curves can increase after maturity, becoming painful if they have not been fused. Also, the patient can experience pain at the ends of a spinal fusion, where movement is usually increased to compensate for the loss of motion in the arthrodesed (fused) area of the spine. Ill-advised or overzealous spinal correction can cause serious loss of function, such as the ability to walk.

One alternative to surgery is bracing. The Milwaukee Brace (*Polio Network News*, Vol. 11, No. 2, p. 5) is an active orthosis requiring muscle strength and therefore usually not prescribed for a patient with neuromuscular disease. The TLSO (thoracic-lumbar-sacral orthosis) passively supports the back, usually producing better results.

Bracing is often indicated in the younger patient, but is also useful in the post-polio patient experiencing mechanical back pain. Light mesh garments (such as the Hoke garment) with stays are usually well tolerated. The fabrication of such a garment (which requires much patience and skill) is fast becoming a lost art. Consult your doctor, surf the network, search the Yellow Pages, or seek out an experienced orthotist who can provide you with a comfortable, functional appliance. For individuals using a wheelchair, various seating arrangements and spinal containment systems are available for back support. Modern techniques of vacuum molding can provide a custom-made seating system which should support the back and provide relief of pain. Seating assessments and recommenda-

tions are usually made by a physician working closely with an orthotist who specializes in seating.

The benefits of surgery include maintaining an upright posture, decreasing trunk fatigue, and freeing the arms from a supporting role for more functional tasks such as dressing, eating, personal care, or using a computer. Surgery may stabilize pulmonary function, avoiding respiratory compromise secondary to spinal deformity. However, one has to be cautious of increasing "dead space" with over-enthusiastic correction of spinal curvature. All of us have to push air in and out of our lungs from an area called the "dead space." This includes the trachea and the bronchi. We need muscle power to accomplish this. Straightening the spine too much can increase the "dead space." When this occurs, the patient experiences difficulty moving air in and out of the additional space and may require mechanical ventilation to do so.

In planning for a major operation on a post-polio patient, there are some serious matters to be considered. Most important is a thorough respiratory examination (particularly in a patient with a history of bulbar polio). This workup should include blood gases and sleep studies. All prospective patients should have a good cough. Coughing requires the use of all respiratory musculature. Those patients with a poor cough may be unable to clear the pulmonary secretions that accumulate post-operatively.

In general, if the vital capacity is less than 30-35%, a patient will require post-operative respiratory aid. Where the vital capacity is somewhat above 60-70%, he or she should tolerate surgery well, except for obese patients or those with severe sleep disorders. The nutritional state of the patient is too often overlooked. Remember that protein depletion directly correlates with increased morbidity, compromised healing, impaired immunity, and a greater risk of post-operative infection.

Finally, post-operative pain has to be considered. One theory holds that post-polio patients have increased sensitivity to pain, and some researchers feel that this is due to virus-induced brain lesions, as well as the anti-metabolic action of glucocorticoids on the brain produced during stress. Pain can be managed with anodynes, PCA (patient controlled anesthesia), and NSAIDs (non steroidal anti-inflammatory drugs), with care taken not to use medications which depress respiration.

Patients who have had polio are at more risk during surgery than those without such a history. Temperature has to be monitored because its decrease (hypothermia) can trigger cardiac arrhythmia. Hypotensive anesthesia coupled with blood loss may seriously lower blood pressure. Patients with neuromuscular disease undergoing surgery on their spines lose more blood than the average patient because they do not have

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Post-Polio Corrective Spinal Surgery

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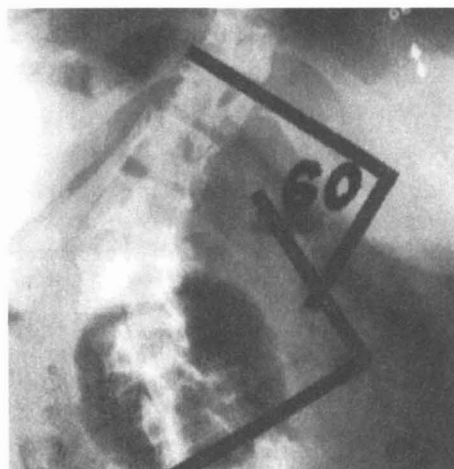
muscles which can contract to block off small bleeding blood vessels. Their bone is often osteoporotic and will bleed copiously. Many people are overdosed on aspirin or other drugs which increase bleeding. These should be discontinued at least two weeks prior to any anticipated surgery.

Monitoring the spinal cord during the operation is important. Somato-sensory evoked potentials can be observed so that in straightening the curve further damage to the cord is avoided. Finally, at the time of surgery other contractures such as those of the hips, knees, and ankles, can be released.

All of these matters should be taken into account prior to surgery as part of a detailed risks/benefits evaluation. Where the conditions as well as the indications for these operations are present, spinal stabilization performed by a skilled and experienced surgeon can often

Measuring Scoliosis Curves

The technique most often used to measure a curve was described by Dr. J.R. Cobb. The Cobb measurement is made by identifying the vertebrae at the ends of a scoliosis curve on an x-ray of the spine taken front to back, or back to front.



A line is drawn along the upper border of the upper end vertebra, and along the lower border of the lower end vertebra. The angle between these lines is the Cobb measurement. An angle of 0 degrees means the spine is perfectly straight, while an angle of 90 degrees means that the two vertebrae are at right angles to each other, signifying a severe curvature.

Excerpted from *Back Talk*, Vol. 17/Number 3/December 1994, published by The Scoliosis Association, Inc., P.O. Box 811705, Boca Raton, FL 33481-1705 (800/800-0669)

OTHER SCOLIOSIS RESOURCES

Scoliosis Research Society, 6300 N. River Rd., Suite 717, Rosemount, IL 60018

The National Scoliosis Foundation, 72 Mount Auburn St., Watertown, MA 02172 (617/926-0397)

offer the post-polio patient correction of deformity, relief of pain, increase in the ability to perform tasks of daily living, improved mobility, and enhancement of lifestyle. □

Ensor E. Transfeldt, MD,
Twin City Scoliosis Spine Center, affiliated with
Abbott Northwestern Hospital, University of
Minnesota, Minneapolis, Minnesota

The Twin City Scoliosis Spine Center works in conjunction with the Sister Kenny Institute at Abbott Northwestern Hospital where Richard Owen, MD, has a special interest in post-polio problems.

A surgeon's job of actually doing surgery requires technical skills, but those technical skills are worth nothing without the team of people that assist in the care of the patient. We are treating people, not treating spines, so we need to consider other factors such as pelvic obliquity, limb deformities, ability to walk, pulmonary function, general medical condition, and nutritional, immunologic, and health status.

We also consider the mental and emotional well-being of a person undergoing surgery. Most deformity surgery is major surgery, and we cannot overemphasize that people need to be ready for the physical and emotional onslaught.

Patients with poliomyelitis are subject to the same conditions of degeneration as everyone else. They may undergo disc degeneration and even develop stenosis which may produce neurologic compression and confuse the diagnosis of a post-polio syndrome.

Scoliosis is a side-to-side curvature, but also a three dimensional deformity. Persons who from the side have an exaggerated hump have what we term a kyphosis. Persons who have an exaggerated hollow in the low back region have a lordosis.

Many times a rotation of the vertebrae is associated as well. The vertebrae do rotate on top of each other and on an x-ray may appear to show a straight spine, but, from another view, the rotation shows up. Attached to the vertebrae in the thoracic spine are the ribs, and as the vertebrae rotate the ribs rotate. The ribs produce the characteristic prominence, not the spine.

Another problem that develops is that the whole trunk gets shifted to one side. The body is not centered over the pelvis and the legs. This requires a great more energy to stand or to walk.

The curve types resulting from polio do vary according to the area of the spine affected — the cervical, thoracic, or lumbar. The long C-shaped curve is very common. The original curve, called the primary curve, is usually due to an imbalance of the muscles. If that was the only curve one would lean over to one side. There are muscles that are not paralyzed which try to compensate for this so the body is centered over the pelvis.

This results in compensatory curves usually on either side of a primary curve.

Sometimes compensatory curves will progress and become fixed or structural curves. Frequently, it is important to operate early in a young person before the compensatory curves become structural curves.

Not a great deal is known about the natural history of scoliosis and poliomyelitis except that all curves progress. The pattern of progression in polio is certainly very different to idiopathic scoliosis in that the progression frequently occurs after skeletal maturity into adulthood. Early surgery is generally recommended in scoliosis for younger patients, but in adults there are other complicating factors.

Spinal surgery is considerably more difficult in polio than idiopathic scoliosis. For example, cosmetic correction tends to be successful in young patients. In adults the results tend to be much more variable. The only way to produce any significant correction cosmetically is to remove the prominent ribs which are associated with rotation. This is associated with a higher morbidity, and patients need to be aware of that fact.

The indications for surgery are curve progression, pain associated with bad curves, and, if spinal stenosis or spinal compression is evident, decompression. The goals are to correct the deformity, stabilize the spine, and produce a vertical torso or a body centered over the level pelvis.

Surgery of putting in implants and rods in patients with severe scoliosis is difficult. Disc spaces frequently become narrow and vertebrae become coalesced making it difficult to move them and create a correction.

Because pelvic obliquities and muscle contractures are common and complicate surgery, one needs to evaluate the presence and cause of pelvic obliquity. One must ask if the pelvic obliquity is because of the scoliosis or is it a result of something in the pelvis or something below the pelvis. Muscles go from the spine to the pelvis; from the spine to the lower legs, spanning right across the pelvis not attaching to it; muscles run from the pelvis to the lower legs. Any contractures, or imbalance, of any of the above muscle groups can result in a pelvic obliquity. One has to evaluate where the problem is — above the pelvis, in the pelvic region, or below the pelvis. One test is to lay the person on an x-ray table and move the pelvis to see how flexible the spine is at that level. If one can tilt the pelvis and create a level pelvis then the spine is flexible. One gentleman was recommended for surgery and this bending test showed a possible level pelvis. The problem was a muscle contracture of the iliotibial band below the pelvis which was corrected surgically by a simple release of the muscle.

Ambulatory status needs to be evaluated. Long fusions down to the pelvis could limit someone who walks

with crutches and needs the mobility of the lower lumbar spine.

Pulmonary function needs to be evaluated. Pulmonary dysfunction may be due to respiratory muscle paralysis or mechanical obstruction. Decreased lung volume can be caused by the collapse of the thoracic spine, the rib cage pushing in on the pelvis, or the abdominal contents being pushed upwards. Breathing ability does not equate to the ability to tolerate surgery. Certain tests do indicate whether or not surgery may help. There is some controversy about pulmonary function studies, but a study done at Twin City Scoliosis Center showed that patients with severe cor pulmonale or severe pulmonary dysfunction can be considerably improved by pre-operative traction. The thoracic cage is pulled away from the pelvis and the diaphragm is allowed freer excursion.

There are several methods of instrumentation including newer methods using segmental instrumentation. Fixation at multiple levels of the spine really does eliminate the use for braces which in fact restrict chest expansion and affect pulmonary function. The type of instrumentation is not as important as the technique of the surgery and the judgments considered before surgery.

Complex problems need the team approach and that includes the physicians, the surgeons, the physiatrists, the therapists, the nurses, and a program of intense rehabilitation. The family is an integral part of the team and should be included during the decision-making process and fully understand what is going to occur. □

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

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Recovery from Orthopedic Injury

Sunny Roller, Ann Arbor, Michigan

Having just finished a strenuous two-day training program and carrying a heavy book bag, my crutch tip hit some water and I hit the ground, smashing the wall, clanking a wastebasket, knocking the wind out of me, fracturing my leg.

At the emergency room, I learned that my health care institution did not easily accommodate a person with a disability. The physicians on duty did not understand why I should be admitted as an in-patient for a broken leg. They wanted to send me home by myself to my wheelchair inaccessible apartment. I felt I needed nursing care and rehabilitation. They suspected me as being homeless with nowhere to go, wanting to use the hospital like a hotel room. They felt my problem was a social one, not a medical one.

My experience as a person with a disability obtaining appropriate treatment was not a matter of common sense and need, but a matter of common practice and standard insurance reimbursement policy. Fortunately, my physiatrist advocated for me.

From the first day in the hospital I set goals for my recovery. Through the ten days of rehabilitation and hospitalization, the three months at home in a wheelchair, and the five months of daily physical therapy, I applied what I have learned as an adult polio survivor — to make my own decisions about my care.

In my apartment a door had to be removed, cupboards had to be rearranged, and I learned how to take our city's accessible bus service (when they could fit me into their schedule).

I worked full time at home and the office. At the same time, I managed physical therapy to regain strength and walking ability, the paperwork for worker's compensation, and I purchased new shoes and a wheelchair seating system. One of the best decisions I made during that time was to swim twice a week after work. Swimming gave me stress release from an old fear of never being able to walk again.

During my recovery I received support from my physician who made house calls, friends, family, neighbors, and I was able to attend a meeting in Germany.

Even with the finest of care it took nine months for me to recover from the injury. It was a time to learn about the medical implications of what was happening to me, to relearn to be open to new ideas, and to take control of the situation.

I learned that polio survivors should have an injury control checklist with two categories: intervention and prevention.

Injury Control Check-List

Intervention:

- Post-polio physician to contact for consultation
Name _____
Telephone _____
- Advocate who will meet me at the emergency room or treatment facility
Name _____
Telephone _____
- Post-polio literature collected and collated for health care professionals.
- Organizations to call for support and information:
 - Local post-polio support group
Telephone _____
 - International Polio Network
Telephone: 314/534-0475
- Local Center for Independent Living to contact for information about financial, medical, and other support services and products available.
Contact Person _____
Telephone _____
- Optimism and flexibility available on demand!

Prevention:

- Energy conservation and pacing a part of my routine.
- Home safety inspection and upgrade completed.
- Assistive devices checked and upgraded regularly.
- Safety precautions considered before traveling outside the home.
- Personal wellness/fitness needs considered and addressed.
- Positively focused on living every day in strength, health, and wellness and never really plan to use this list!

A Summer Plague: Polio and Its Survivors (ISBN 0-300-06292-3) by Tony Gould published by and available from Yale University Press, P.O. Box 209040, New Haven, CT 06520, or from your local bookstore (\$30). *Polio Network News* is pleased to excerpt from *Part I: The Rise and Fall of Epidemic Poliomyelitis*. In *Part II: Lives of the Polios*, polio survivors from England and America tell their own stories. The book concludes with *A Civil Wound*: an autobiographical coda. Gould's own story was placed last in the book as he explains in the introduction:

“ For what I discovered in the process of researching and writing this book was that I, too, had been so busy ‘mainstreaming’ and ‘denying’ my disability over the years that I had simultaneously both overvalued and undervalued it. I had overvalued it in the sense of regarding my experience of polio as somehow unique (hence my original intention of giving it pride of place here), and undervalued it by not allowing that it had made any substantial difference to my way of life and thinking. Certainly, I’d always regarded this as a pivotal episode in my life, one that had changed its direction; but I had also thought of it as over and done with.

... Yet I have learned that, however impressive a recovery you make, you don’t ‘conquer’ or ‘overcome’ polio in any meaningful sense, you merely adapt to the limitations it imposes and — if you’re fortunate — discover within yourself resources you might not otherwise have found.”

Excerpts from *Part I: The Rise and Fall of Epidemic Poliomyelitis*

“ Cats and dogs were suspected of being carriers of the disease; strays were rounded up and pets put down. In early July animals were being destroyed at a rate of ‘300 to 400 a day.’” *New York 1916*, Chapter 1

“ As his presidency would demonstrate, FDR was a past-master of the art of ‘divide and rule’; he would habitually set up two individuals or departments in opposition to one another, leading both to believe that they had his personal backing. People often made the mistake of imagining that he agreed with them when he was merely being agreeable and keeping his real thoughts to himself.” *FDR*, Chapter 2

“ In 1925, when the first ‘polios’ (as I shall continue to call them for convenience) were drawn to Warm Springs, regular patrons of the Meriweather Inn resented their presence in the public pool. They complained ... that it exposed them to the disease (regardless of the fact that these were ‘old’ polios long past the infectious stage). As a result, Roosevelt had another pool constructed nearby, so that ‘he and his “gang” ... could continue their unsupervised, unregulated, groping efforts to reduce their afflictions in the warm water of the Springs.’” *Warm Springs*, Chapter 3

“ The upshot was that, in 1939, Basil O’Connor announced, on behalf of the National Foundation for Infantile Paralysis, that it had decided ‘to grant the sum of \$161,350 to Tuskegee Institute (in Alabama, half a day’s drive from Warm Springs) to provide the first polio center for negro people.’” *Polio Crusaders*, Chapter 4

“ ... Sister Kenny’s attempt to persuade the hospital doctors of Brisbane to abandon their splints and plaster casts set the pattern for many future encounters with officialdom: her words were greeted with at best incomprehension and, more commonly, derision; her demonstration of her method — until she became adept at it — with embarrassment.” *An Angel Abroad*, Chapter 5

“ ... In the Summer of 1954, when Salk, the members of the vaccine advisory committee and the staff of the National Foundation could do little more than hold their breath and hope or pray that no disaster would overtake the largest mass experiment in the history of medicine, O’Connor took an amazing gamble with money he did not have but was confident he could raise, and ordered twenty-seven million doses of vaccine at a cost of \$9,000,000 so that the pharmaceutical companies would continue to manufacture it pending the outcome of the field trial. If the vaccine failed to obtain a licence, it would be nine million down the drain; but if, on the other hand, the field trial was a success and no vaccine was available, there would be hell to pay.” *A Planned Miracle*, Chapter 6

“ Everything to do with polio in Britain — not least the disease itself — was on a minor scale. Outside Scandinavia, no one in Europe had been unduly concerned about polio until after the Second World War.

... In Britain, despite the continuing prevalence of polio, a campaign launched in 1958 to encourage the take-up of Salk vaccine made little headway against public apathy. It was not until the Spring of 1959, when the Birmingham City and England international footballer, Jeff Hall, died of polio, that the message got through.” *The Quick and the Dead*, Chapter 7

“ Many respiratory centres produced mimeographed newsheets in the Fifties. They had punning titles like *The Croaker’s Chronicle*, *The Res Parader*, *The Rocking Report*, *The Rock ‘n Roll*, *The Vital Capacitator*, *The Weakley Breather*, and *Gulpers’ Gazette*. The one that outstayed them all was originally known as the *Toomeyville Gazette*. By 1957 it had been ‘shelved and forgotten’, but it was revived under a new name, *Toomey j Gazette*, in 1958 (providing Dr. John Toomey with a measure of the posthumous fame he deserved for being right about polio in the Thirties — even if he could not prove it — when almost everyone else was wrong).

... In 1958, when Dr. Robert Eiben, Medical Director of the Cleveland centre, asked Gini Laurie* and the only other surviving volunteer in the Toomey Pavilion to revive their newsletter — ‘because each polio outpatient who came in for a checkup or a bout with pneumonia plied him with questions about all the other outpatients’ — they wrote to the medical directors of the other fourteen respiratory centres and drew in polios from all over the country.”

Born Too Soon, Chapter 8

*Founder of Gazette International Networking Institute, publisher today of *Polio Network News*, *I.V.U.N. News*, and *Rehabilitation Gazette*, formerly known as *Toomeyville Gazette* and *Toomey j Gazette*.

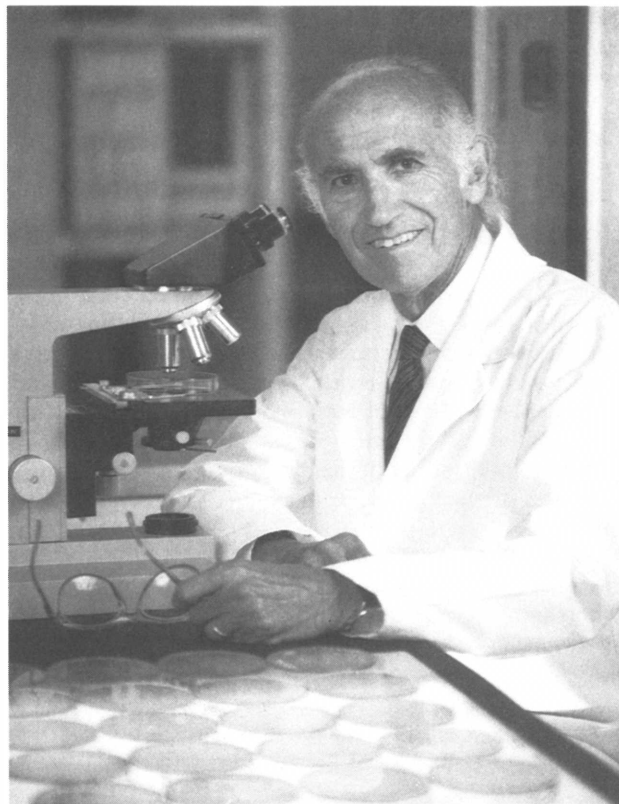
Adapted from *A Summer Plague: Polio and Its Survivors* by Tony Gould, to be published August 31, 1995 by Yale University Press. Copyright ©1995 by Tony Gould. Reproduced by permission.

IN MEMORIAM



Jonas E. Salk

1914-1995



Photograph courtesy of the Salk Institute

U.S. Polio Vaccine Policy Under Review

Joan L. Headley

A recent joint meeting of the Vaccine Safety Forum of the Institute of Medicine (IOM) and the Centers for Disease Control and Prevention (CDC) discussed possible changes in polio vaccine policy in the United States. Neither has authority to implement recommendations. Immunization policy for the U.S. is established by the Advisory Committee on Immunization Practices of the U.S. Public Health Service and the Committee on Infectious Diseases of the American Academy of Pediatrics.

◆ **Why consider changing polio immunization policy now?** There are several factors which have caused officials to debate the issue. The last naturally occurring case of polio in the U.S. was 1979, and the last naturally occurring case of polio in the Western Hemisphere was in September 1991. With the risk of wild poliovirus in check, the usually 10 or fewer cases of paralytic polio associated each year with the live virus vaccine (OPV) have become a concern for public health officials. Additionally an enhanced potency IPV (inactivated polio vaccine) has been available in the U.S. since 1987. It will not cause vaccine-associated polio (if properly produced) and is recommended for use in immunodeficient individuals and their family members.

◆ **What new schedule is likely to be implemented?** Experts at the meeting who support change in policy recommend the use of IPV for the first two or three doses, followed by one dose of live oral polio vaccine (OPV) at 18 months, and another between four and six years of age.

Currently, the United States recommends OPV #1 at two months; OPV #2 at four months; OPV#3 at six months (with OPV #3 at eighteen months as an acceptable alternative). Some recommend OPV #4 between 4-6 years. The IPV is available and is recommended for immunocompromised individuals and their close contacts, as well as for adults who have not had a primary series, or who are at a greater risk of exposure to wild poliovirus because of international travel or an occupation in the health profession.

◆ **What concerns were expressed about the U.S. introducing IPV into the polio immunization schedule?** The IPV is administered by injection, whereas OPV is given by mouth. The easier the vaccine is to administer the more likely parents are to have their child vaccinated. There is a substantial difference in price. In the private sector, IPV costs \$5.50 more per dose than OPV. The CDC is concerned that the increased cost may reduce funds available for other programs. Some are concerned about reports which indicate that the producers of IPV have been overly active

in the discussion which would change the policy in their favor.

A switch by the U.S. to IPV could affect the worldwide polio eradication program because the U.S. is considered a world leader in public health. Concern was expressed that other nations where polio is still endemic might also switch to IPV from OPV. The use of the OPV is vital to the worldwide effort to eradicate polio because it is easier to administer, it costs less, and is more effective in stopping the spread of wild poliovirus because it stimulates immunity in the intestines and reduces the risk of spread to other children.

According to the World Health Organization, the U.S. now spends about \$230,000,000 a year on polio immunization. Once polio is completely eradicated worldwide that \$230,000,000 could be spent on other health programs.

◆ *When will a new policy be presented?*

The Advisory Committee on Immunization Practices will review policy options during an October meeting with a goal of reducing cases of vaccine-associated paralytic polio.

◆ *What are the polio immunization policies for selected other countries?*

Australia: The National Health and Medical Research Council recommends OPV at the ages of 2 months, 4 months, 6 months, 5 years, and 15 years.

Canada: The National Advisory Committee on Immunization reports that both the IPV and the OPV are licensed for use in Canada. Both have successfully controlled poliomyelitis in various parts of Canada. Primary vaccination with three doses of IPV will confer immunity in more than 99% of recipients when the first two doses are administered at least six weeks apart and the third dose is given six to 12 months later. A primary course of three doses of OPV, the first two being given at least six weeks apart, and the third given six to 12 months after the second, will give long-lasting immunity to more than 95% of recipients. Some authorities recommend administration of a three-dose course of IPV prior to giving OPV. OPV must never be given to patients who are immunodeficient, those on immunosuppressive therapy, and to persons who will have household or similar close contacts with such individuals in the following four weeks.

Denmark: The Danish vaccination plan recommends diphtheria, tetanus, polio (IPV) at five months; diphtheria, tetanus, polio (IPV) at six months; diphtheria, tetanus, polio (IPV) at 15 months; OPV at two years; OPV at three years, and OPV at four years.

France: The vaccine policy for France is first injection (IPV) at two months; second injection at three months; third injection at four months; boosters at 15 months,

5-6 years, 11-12 years, 16-20 years. After 21 years a booster is recommended every 10 years.

Germany: The Permanent Vaccination Commission of the Federal Health Agency (STIKO) recommends OPV #1 during the third month; OPV #2 not earlier than six or eight weeks later (it may be postponed to 10 weeks in case of illness); OPV #3 at 24 months which completes basic immunization (OPV #3 can be given somewhat earlier, but never before 15 months); OPV #4 ten years later, repeated every ten years. IPV used only in special cases or health situations respectively.

New Zealand: The New Zealand Ministry of Health Immunisation Handbook, 1993, recommends OPV #1 at three months; OPV #2 at five months; OPV #3 at 18 months; booster at school entry. Boosters are recommended for travelers to countries where polio is epidemic or endemic. An IPV is recommended for use in an individual with a suppressed immune system or living with someone immune suppressed.

Switzerland: The Federal Department of Health, the Swiss Society for Pediatrics, and other medical groups, recommend OPV #1 at two months; OPV #2 at four months; OPV #3 at six months; OPV #4 at 15-24 months; booster five to seven years; booster 12-15 years; booster every 10 years (if going to endemic regions or contacting persons with poliomyelitis in or of endemic regions). IPV is given under certain circumstances, e.g., a never-vaccinated person after age 20, persons with suppressed immunological status, persons with AIDS, etc.

United Kingdom: The Department of Health recommends OPV #1 at two months; OPV #2 at three months; OPV #3 at four months; booster at 3-5 years; booster at 15-19 years.

◆ *What recourse does one have in the U.S. if polio is vaccine-associated?* The National Childhood Vaccine Injury Act of 1986 (PL-99-660) created a no-fault compensation alternative to suing vaccine manufacturers and providers when injured or killed by the DPT (diphtheria-pertussis-tetanus), MMR (measles-mumps-rubella), or polio vaccines.

The compensation was divided into two parts. One part dealt with injuries or death prior to October 1, 1988 no matter how long ago the injury occurred. The deadline for filing these claims was January 31, 1991. The National Vaccine Information Center, who supplied information for this article, knows of no claims admitted since that deadline date. A total of 4,095 pre-88 claims were filed. One thousand and twenty eight (1,028) cases were dismissed and awards have been paid to 1,241. Because of the large number of claims filed, there are many which have not yet been reviewed by the Claims Court, and many continue to receive extensions.

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U.S. Polio Vaccine Policy Under Review

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The other part, for injuries or deaths occurring after October 1, 1988, requires a citizen to apply for federal compensation prior to pursuing a law suit. Further provisions include: the system will offer to pay up to \$250,000 for a vaccine-associated death; the system will offer to pay for all past and future unreimbursed medical expenses, custodial and nursing care; up to \$250,000 for pain and suffering; and loss of future earned income; if a citizen rejects the award, or is turned down, a law suit may be filed (restrictions apply to law suits); claims must be filed within 24 months of a death and 36 months of an injury. The system is funded by a sur-charge on each dose of vaccine sold (e.g., polio vaccine — \$0.29).

The law also created safety reforms. The law requires physicians to record the date, manufacturer's name and lot number, the signature and professional title of the person administering the vaccine, the address where the vaccine is administered, as well as provide parents with information about childhood diseases and vaccines prior to vaccination. The law requires all physicians who administer vaccinations to report vaccine reactions to federal health authorities. The FDA and the CDC have developed a "Vaccine Adverse Event Reporting System" (VAERS). The national toll free number to receive VAERS forms is 800/822-7967. If a physician or health official does not report the "event," parents are allowed to file their own report. The law further requires physicians to record vaccine reactions in an individual's permanent medical record.

Individuals who want to file a claim for a vaccine injury or death may write to U.S. Claims Court, 717 Madison Place, NW, Washington, DC 20005 (202/219-9657) and ask for a copy of "The Vaccine Rules." This publication gives specific directions for filing a petition for a claim.

The National Vaccine Information Center (NVIC), 512 West Maple Ave., Suite 206, Vienna, VA 22180 (800/909-SHOT) has published a booklet, "The Compensation System and How It Works," which is available for \$10.00, as well as other related information and resources.

◆ **How do adult polio survivors react to the discussion?** Some feel very strongly that the OPV should continue to be used to wipe out polio worldwide, ultimately sparing the children of the world acute paralytic polio and the late effects of polio.

Other polio survivors feel that if OPV can cause even a few cases of polio (one in 2.5 million doses), it should not be used exclusively and spare individuals from vaccine-associated polio. There is no documented scientific evidence to support any claim that the OPV can cause post-polio syndrome. By current definition, a case of acute paralytic polio must precede any diagnosis, and it is generally accepted that the severity of post-polio syndrome depends to some extent on the severity of the initial paralytic polio. □

SOURCES AND CONTRIBUTORS:

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MOVING??

Please send your old and new addresses to:
International Polio Network
5100 Oakland Avenue, #206
Saint Louis, Missouri 63110-1406 USA