

Management of Motor Impairment

Approaches for children with cerebral palsy

by Mauricio R. Delgado, MD, FRCPC and Mary Combes, RN

Once the diagnosis of cerebral palsy is made, the physician and parent must establish a management strategy. The word "management" is preferred over treatment because, for now, there is no cure for cerebral palsy.

The management strategy goal—set as early as possible—is to maximize the child's emotional, intellectual, and physical potential through specific objectives to improve function, develop compensatory strategies, and encourage independence. Since the form and degree of motor impairment caused by cerebral palsy varies from child to child, its management should be individualized after a full assessment of a child's abilities and related problems.

A multi-disciplinary team

Many different professionals—medical, educational, social service—will be called in at different times in the child's life. The family, however, is the one sure constant. Active participation by a child's parent is a very important part of decision making and execution of the management strategies. It is also critical for support. Treatment for a child with cerebral palsy is time-consuming, may be painful, and may seem never-ending, both to the child and the family. With the family at the team's core, there is an underlying physical and emotional foundation.

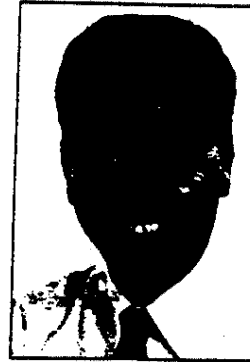
The clinical leader of the team is often the family's primary care physician or pediatrician. But not always. Parents may choose to identify a developmental pediatrician, pediatric neurologist, or a physiatrist through their primary care doctor, or through a special center such as ours at Texas Scottish Rite Hospital, or through their local or state United Cerebral Palsy. (see below).

The clinical leader identifies the other specialists that make up the team, maintains frequent contact with all involved, periodically assesses the child's needs as he or she grows, and coordinates the appropriate timing of different intervention strategies. The choice of person is often dictated by the time available to him or her for coordinating team strategy planning, decisions, efforts, and reviews.

The multiple medical, social, psychological, educational, and therapeutic needs of children with cerebral palsy change as they grow. This requires a well coordinated multi-disciplinary team approach with good communication among the team members. Professional members of the team will depend on the individual child and family situation, but may include a primary physician, physician specialists (neurology, psychiatry, orthopedics, neurosurgery, etc.), therapists (physical, occupational, speech, recreational, etc.), orthotist, nurse, psychologist, social worker, etc.

Goals and objectives

The basic objectives for maximizing the potential of children with cerebral palsy include: 1) developing effective communication skills through techniques such as gestures or signs, assistive communication devices, and oral or written language; 2) improving motor skills by managing abnormal tone and movements, promoting strengthening and coordination, using



Dr. Mauricio Delgado

supportive devices, and preventing and correcting orthopedic deformities; 3) developing independence in daily living activities such as feeding, dressing, and personal hygiene; 4) treating and/or preventing associated problems such as eye-crossing, hearing deficit, malnutrition, aspiration, drooling, gastroesophageal reflux, constipation, seizures, behavioral

problems, and sleep disturbances.

All of these objectives are important and must be addressed on a regular basis. Due to space limitations, it is impossible to discuss all of them in detail. Therefore, we will focus on one of the most challenging problems: motor impairment.

The approach to motor impairment

Movement is the result of a very complex interaction of different parts of the nervous system and the musculo-skeletal apparatus (muscles and bones). A child with cerebral palsy can have abnormalities in: muscle tone (increased or decreased), reflexes; involuntary movements (dystonia, chorea, athetosis, tremor), balance and coordination, sensory responses, and other movement-oriented areas. Even though cerebral palsy is not progressive, the effects on the body may get worse with age, and result in a reduction of function. This is why early identification and treatment of these problems are essential.

Different motor training methods have been used in the past to manage

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the motor deficits seen in cerebral palsy. The methods are:

Conductive Education (developed by Dr. Andras Peto in the 1940s): An educational method where all therapies are integrated. A "conductor" facilitates the learning of the child in a group setting that integrates mind and body activities.

Neurodevelopmental approach using reflexes (developed in 1943 by Dr. Karl Bobath and Bertha Bobath): Based on the idea that the main problem of movement in cerebral palsy is the persistence of "primitive reflexes" that affect posture and movement. The approach is directed at inhibiting these abnormal reflexes.

Sensory stimulation for the facilitation and inhibition of movement (developed in 1962 by Margaret Rood).

Proprioceptive neuromuscular facilitation (developed in 1968 by Dr. Herman Kabat, Margaret Knott and Dorothy Voss): Method to inhibit increased tone using sensory stimulation to facilitate movement.

Sensory integration therapy (developed by Dr. Anna Jean Ayers in 1972): A method used to enhance the way the brain receives and uses sensory feedback—by planning and controlling sensory input and responses—in order to influence movement.

To date, none of these methods have been proven to be superior to the others. But they all have common aspects:

1. Team work
2. Early intervention
3. Repetition of motor activities during therapy sessions and in the daily routine
4. Integration of motor and sensory systems
5. Motivation of the child and the family

Managing abnormal muscle tone

Muscle tone is defined as a muscle's resistance to passive stretching (by an examiner) during relaxation. Muscle tone can be decreased (hypotonia) or increased (hypertonia). Increased muscle tone may be spastic (velocity-dependent), rigid (like a lead pipe),

dystonic (gets worse with excitement or stress). These different types of tone abnormality are due to injuries in different parts of the brain. It is important to identify the type of tone abnormality affecting the child. This will determine the type of treatment used.

Spasticity is the most common increased tone abnormality in children with cerebral palsy, accounting for 65 to 75 percent of all cases. Fixed joint contractures develop more frequently in children with spasticity than in those with other tone abnormalities.

An important question to ask before treating spasticity: Why reduce the

Spasticity is the most common increased tone abnormality in children with cerebral palsy...

increased tone in this child? The answer requires the team to have a very clear understanding of the functional goals of treatment for that particular child.

Treating increased tone has, for some, produced improvements ranging from articulation of speech to activities of daily living to ambulation. Treatment may probably decrease the development of fixed joint contractures, bone deformities, hip dislocations, and pain. Improved function is not the only goal, however. Improving quality of life can be as important. For example, reduction of spasticity of hip adductors may improve a parent's ability to change diapers and, thereby, maintain good hygiene. Or reduced tone in hip muscles may lessen hip pain.

Indeed, increased tone is not always the main reason for a child's disability. Sometimes treating the increased tone will uncover a severe underlying weakness. For example, in

some children, spasticity may be necessary to sustain upright posture.

Managing abnormal muscle tone

Only once the type and location of tone abnormality is identified, the degree of its interference with function or quality of life is assessed, and clear goals are established, it is time to consider the best treatments. Physical therapy is a complement to all treatments and should begin as early as possible.

Treatments for increased tone may be reversible (non-permanent if the treatment is ended) or permanent (the results cannot be returned to the original condition). Reversible treatments include oral medications and botulinum toxin (Botox) injections. Permanent treatments include rhizotomies and orthopedic surgeries. While continuous intrathecal Baclofen (ITB) administration via an implantable pump is a surgical procedure, it is also reversible.

For focal (localized) increased tone, botulinum toxin (Botox) or phenol injections are preferred. When fixed contractures and bone deformities occur, orthopedic surgery such as tendon releases and osteotomies will be indicated. When increased tone problems affect the whole body, oral medications and the Baclofen pump are more appropriate. For children with spastic diplegia who have good trunk control and ambulation potential, selective dorsal rhizotomy may be considered.

Teams will often look for the least invasive and less involved techniques—such as physical or occupational therapy (PT or OT)—"stepping up" to more extensive procedures, if needed.

If the child is old enough and able to participate, it is important to remember to include him or her in decision-making about treatment. This is, after all, the child's body and life. What may be important to the parents—surgically correcting a bent limb for cosmetic purposes, for example—may not be so to the child who will be undergoing the surgery. Including the child in the decision-making is part of enabling him or her to become an independent adult in control of his or her body and life.

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POSITIVE PERSPECTIVES FOR CEREBRAL PALSY PART 4

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Oral medications

Benzodiazepines

Diazepam (Valium[®]) has been an effective muscle relaxant for children with spasticity due to cerebral palsy. Children with athetosis (involuntary writhing movements of the limbs) have also had a favorable response to this treatment. Unfortunately, these types of drugs may cause drowsiness, increased difficulty handling oral secretions (ie., drooling), ataxia (incoordination), and behavioral problems.

Baclofen

Ideally, this drug is administered intrathecally (into the spinal canal) through a small implanted pump (see below). This medication has been disappointing when used orally for cerebral palsy. Then, high doses are required to achieve any significant effect, increasing the risk of side effects such as sedation, dizziness, and decreased ability to handle oral secretions, among others.

Trihexyphenidyl (Artane[®])

This drug improves function for children with dystonia secondary to cerebral palsy. In our experience, its most significant effect is in hand function and articulation of speech. Side effects include: dry mouth (which could help those with excessive drooling), constipation, and urinary retention. Children tolerate this drug better than adults.

Other medications that have been used to treat abnormal tone in cerebral palsy, but with mixed results, include: Dantrolene, Tetrabenazine, Piracetam, and Levodopa. More recently, Tizanidine is being tested for children with spastic cerebral palsy.

Botox

Botox (botulinum toxin) blocks the nerve signal to the muscle at the neuromuscular junction, resulting in muscle weakness. The nerve tends to reconnect to the muscle, however, resulting in a temporary clinical effect that lasts two to six months.

Botox injections are used for the treatment of strabismus (eye-crossing),

increased tone (either spasticity or dystonia) associated to many neurological disorders, and the treatment of abnormal tone in cerebral palsy. It should be noted that Botox was approved by the Food and Drug Administration (FDA) to be used only for people who have strabismus and blepharospasm associated with dystonia. Other uses are off-label, meaning used in treatment of a condition for which it has not been approved, if the physician feels it is clinically indicated.

Children with cerebral palsy under six who have abnormal tone interfering with function and have not developed fixed joint contractures, respond best to this treatment. Since many orthopedic surgeons are hesitant to perform tendon or muscle lengthening at an early age because of the high chance of relapse and need for further surgery, Botox is useful in "buying time." This allows therapy to be delivered more effectively.

It is very important to properly evaluate the child and select the muscles that are considered the primary cause for the child's functional problem. Gait analysis is sometimes necessary in children with a complex gait

Management stages:

STAGE 1: Child selection and evaluation; goal setting, and education/preparation of child and family.

STAGE 2: Injection procedure.

STAGE 3: Follow-up one to three weeks after injection to assess the response to treatment and make recommendations regarding serial casting, orthosis, and therapy.

STAGE 4: Intensive physical therapy to strengthen muscles and maintain range of motion.

The use of orthosis is recommended to maintain the stretched treated muscles and, it is hoped, to induce muscle growth. Serial casting after Botox injections is sometimes necessary to treat children who may have mild, fixed contractures. Children with significant fixed contractures do not respond favorably to Botox treatment.

Side effects include: local pain after the injection and weakness (sometimes

excessive) of the injected muscle. Occasionally, low-grade fever and a flu-like syndrome may occur one to two days after the injection.

The Baclofen pump

Intrathecal Baclofen[™] (ITB) therapy consists of an implanted, programmable pump system that slowly and continuously delivers Baclofen to the spinal fluid via a catheter inserted into the spine.

In contrast to oral Baclofen, intrathecal Baclofen is readily absorbed in the surface of the spinal cord, where it has a direct effect. ITB offers several advantages, such as graduated control of abnormal tone, flexible dosing patterns, and reversible effects.

ITB therapy may benefit children who have moderate to severe generalized spasticity that significantly interferes with function and/or care.

Management stages

STAGE 1: Child selection and evaluation; goal setting and education/preparation of child and family.

STAGE 2: Screening trial.

STAGE 3: Pump implantation.

STAGE 4: Dose adjustment.

STAGE 5: Maintenance: pump refill at least every three months.

Postoperative complications of this procedure include headache, spinal-fluid leaks, wound infection, meningitis, and urinary retention or hesitance. Adverse events include: hypotonia (abnormally low tone), somnolence (sleeplessness), dizziness, hypotension, nausea, and vomiting. Occasionally, seizures have been reported to occur after ITB therapy. Abrupt discontinuation of oral or intrathecal Baclofen may result in seizures, hallucinations, disorientation, psychosis, involuntary movements, and itching.

Selective dorsal rhizotomy

Selective dorsal rhizotomy (SDR) means to surgically cut the dorsal roots (sensory) of the lumbar and sacral spinal cord nerves. By doing this, the muscle stretch arch reflex is interrupted or diminished. Children lose their knee and ankle jerks, and increased tone is abolished. Dystonia does not improve with this treatment

For many with cerebral palsy, becoming an adult will mean taking on the parent's role in the team.

since it is not the result of increased reflexes, but rather an abnormal movement which originated in the brain.

The family must be prepared for a three to four week commitment of intensive rehabilitation after surgery. Weekly physical therapy, at least six weeks before surgery, prepares the child and the family for the intensive physical therapy that will follow the surgery.

The neurosurgeon will cut 20 to 50 percent of the rootlets monitoring the muscle activity. The resulting reduction in tone is significant and long-lasting. SDR has been reported to reduce muscle tone in the lower extremities, to improve gait, reduce the incidence of progressive hip dislocation, and improve gross motor and functional abilities. A recent study from the Children's Hospital in Seattle, however, found that SDR and physical therapy were not significantly different than intensive physical therapy alone in improving independent mobility at 24 months.

Postoperative complications include severe pain, reactive airway disease (bronchospasm) and aspiration pneumonia, spinal fluid leak, wound infection, temporary bowel paralysis, and urinary retention. Immediate and delayed side effects include: hypotonia, unmasking underlying weakness, reduced sensation and a "pins-and-needles" feeling in lower extremities, bladder dysfunction, back pain, spinal deformity, and hip dislocation.

Management stages:

STAGE 1: Child selection.

STAGE 2: Preoperative preparation. Realistic goals established with the family. Family education about the procedure and postoperative hospitalization, pain, and the need for extensive physical therapy.

STAGE 3: Operation.

STAGE 4: Postoperative care.

STAGE 5: Outpatient care. The child continues with physical therapy on a regular basis to improve muscle strength and coordination. Stretching exercises are especially important during times of rapid growth.

Orthopedic surgery

Ideally, we could prevent the deformities caused by the abnormal tone and

weakness that affect children with cerebral palsy. In many children, however, this is not possible, and orthopedic surgery is then necessary.

Orthopedic surgery is aimed at correction and prevention of musculoskeletal deformities. Lengthening, release and/or transfer of contracted muscles due to spasticity, improves the deformities which are the result of spasticity, but does not correct the cause.

The long-term results of orthopedic surgery are considered to be better in adults with cerebral palsy than in children with the disorder. The results of surgery in children are better after the child has developed a stable gait pattern, which by many is considered after 7 years of age. Orthopedic techniques can be used in combination with SDR, ITB, or Botox treatments.

A family affair

The management of a child's cerebral palsy is complex and challenging. This requires a multi-disciplinary team approach which must include the family as well as the child. Each child is different, and the management strategy needs to be individualized. This approach will be critical during the child's growing years, as well as into his adult years. For many with cerebral palsy, becoming an adult will mean taking on the parent's role in the team. For others, siblings or other family members may step in once parents have, by necessity, given up the role.

Eventually, the child with cerebral palsy will grow to be an adult with cerebral palsy. Many will want and will be able to assume independence—part of which will mean taking a central role in the team. While many of the concerns will be similar to when he or she was a child—aging, physical therapy, mobility, medication—new aspects will be figured in, including job security,

independent living, marriage, and creating his or her own family.

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For information on your state or local United Cerebral Palsy, call (800) 872-5827 or check website <http://www.ucpa.org>. For Canada, see Part II of this series EXCEPTIONAL PARENT, APRIL 1999.

Part 4 continues with a closer look at treatments and an introduction to key specialists who are often members of cerebral palsy treatment teams.

Glossary

Orthoses: any device to stabilize or immobilize a body part, prevent deformity, protect from injury, or assist with function (casts, braces, etc.).

Orthotics: The science of orthoses.

Primitive reflexes: reflexes we are born with, but disappear with maturation.

Contractures: permanent muscle and tendon shortening due to spastic tightening of muscles for long periods of time.

Gait: a manner of walking.

Hamstring muscles: muscles at the back of the knee that bend and move the leg and thigh.

Hip subluxation: the ball of the thigh bone no longer fits in the center of its socket.

Tone: amount of muscle contraction when at rest. Too high, it is called spasticity; too low, hypotonia. Both interfere with movement.

Velocity-dependent: the ability to flex a muscle depends on the speed at which you move it. With spasticity, slowly contracting a velocity-dependent muscle may straighten it, but moving quickly may lock it up.

When a child first visits in preparation for Botox injections, we review her history—previous medical, surgical, and radiological evaluations—and ask who thought she might be a candidate for Botox injections—and why?

Most diagnosis procedures of children with movement disorders can be painful or distressing. Visiting a doctor's office is often an anxiety-laden event. But on this visit, nothing threatening is done. The physical exam consists of observing the child's movements and gentle handling, to assess the degree of spasticity, range of motion, and abnormal neurologic findings. Other than that, we just talk.

Discussing goals

Discussing what the family expects to achieve is vital. Goals can be functional (better use of a hand or less toe-walking), management (easier care), or cosmetic (the bent up crooked arm being able to swing more freely in walking). Injections should not be done unless everyone agrees to which goals can be—and want to be—achieved.

We also discuss whether or not to sedate the child. Since as many as eight

Botox Injections

by Martin Diamond, MD

injections may be done at one session, young children do better and have less fear of returning for subsequent injections if they are sedated. We use oral Versed, which tends to not only sedate, but also make the child forgetful of the event.

We also review the time—course of action of Botox—one to three days to onset of effect, peak effect at two to four weeks, and expected duration of effect of three to six months.

Opting for Botox injections usually comes when more conservative measures—therapeutic handling, use of orthotics or other positioning devices, etc.—have not produced the desired results, or if the child has hit a plateau in development. It is preferable for Botox injections to be done in concert with the child's orthopedist.

The injection process during a subsequent appointment is surprisingly simple. Low intensity electrical stimulation identifies an "electroactive" point in the target muscle(s). It

may take only five minutes to inject multiple muscles. A local anesthetic cream is used on the skin to numb the area beforehand.

Possible results

While the effect of Botox lasts only three to six months, lasting improvement is possible, since therapy may be more effective during that time. In that case, the child will not revert to the pre-injection status. Repeat injections may be appropriate to see if that "step-wise" improvement can be continued.

Botox injections tend to mimic the effects of surgical tendon lengthenings. They can buy time until the child is old enough to have a surgical procedure (generally after 5 years old), or, in the older child, to see how the child will respond to tendon lengthenings. It also allows time to see how well the child responds to therapy, and whether or not families are capable of performing the necessary home exercise program.

Dr. Diamond is the Director of Out-Patient Services at Children's Specialized Hospital, New Jersey. Double-boarded in Pediatrics and PM&R, he has a particular interest in multi-modality medical treatment of pediatric spasticity.

The Baclofen Pump

by A. Leland Albright, MD

Many children with cerebral palsy develop spasticity because their brains do not cause the delivery of a chemical (GABA) normally released into the spinal cord. Baclofen is almost identical to GABA, and, in essence, replaces it.

ITB is used to treat severe or moderately-severe spasticity that affects the arms, legs, and sometimes the trunk. Such spasticity is not usually effectively treated by oral or injected medications. ITB is recommended for about 35 percent of new patients evaluated in our Spasticity and Movement Disorders Clinic. Most treated are between the ages of 5 and 19, although some adults (20 to 40) have also been treated.

Treatment goals are:

- a) improving function in the arms and legs by reducing spasticity;
- b) facilitating the care of a child so "tight," that dressing, bathing, and seating are difficult;
- c) preventing the muscle and tendon contractures that develop if spasticity is untreated.

A test dose of ITB is always given before a pump is implanted, to give ITB continuously. A small dose of Baclofen is injected through a small needle into the spinal fluid in the lower back. Effects begin within two hours, are greatest at four hours, and leave by eight to 10 hours. Spasticity in the legs is almost always (95 percent) relieved by

the test dose, although it may not be large enough to relax the arms. Movements and function during the test dose do not predict what function will be like when Baclofen is given continuously and adjusted to the optimal dose.

Implanting the pump

ITB is given continuously from a pump inserted during a one hour operation under general anesthesia. The 3 x 1" pump is implanted under the skin of the abdomen just below the fascia (the outer cover of the abdominal muscles). A small tube is attached to the pump and is tunneled under the skin around to the back, where it is inserted through a needle into the spinal fluid, then upward for several inches. Pain after the operation is usually mild and easily controlled.

Hospitalized for four to six days, children lie flat in bed for two to three of them. Their Baclofen dose is adjusted daily by a portable computer. When they get out

A Botox Experience

by Cara Stout

As a sophomore at St. James School in St. James, Maryland, I love to act, sing, and play field hockey, basketball, and lacrosse. I also have mild spastic cerebral palsy, which has greatly affected my life. My muscles are extremely tight. Problems with my back, legs, and feet all give me difficulty walking. I have had many years of physical therapy to improve my conditions. Receiving Botox injections has been one of the most successful experiments I have ever tried.

On my doctor's advice, my parents took me to the Kennedy Krieger Institute in Baltimore for an examination. My condition was not serious enough for surgery, but the doctor recommended Botox injections. He said it would help the muscles in my legs relax. Then they could become well stretched and strengthened through physical therapy. Though this idea seemed interesting, it did not appeal to me at first—I was not excited about all those shots! The product seemed to have positive results though, with only minor weakness as a side effect.

It was November 13, 1998. I was very nervous. First, they put numbing cream over both of my upper legs and wrapped them in clear plastic wrap. After an hour or so, it was time to receive the shots. They were painful, but I was lucky to have my parents there for support while I lay face down, so the back of my legs were facing the doctor. My Dad sat on the edge of the table and held my hand, and my Mom was right there at my side.

That first month, I was incredibly anxious for the Botox to

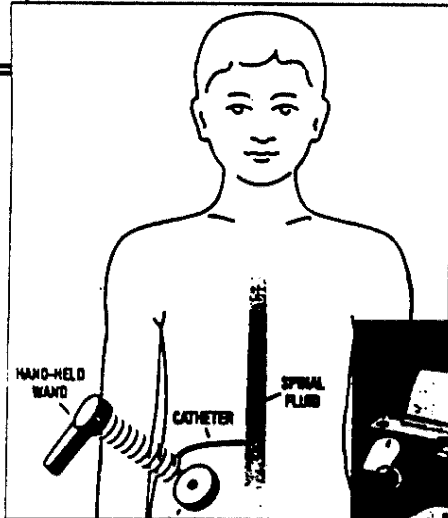
start working. But my legs did not seem looser. Everything felt normal, except that I had small signs of weakness and I needed to be careful walking down stairs. At times I would feel sharp little pains where I had received the shots, but this did not continue through the second month.

Every morning after receiving the Botox, I reached for my toes, hoping to touch them—something I had never been able to do. During the second month, I accomplished my goal! That is when I knew the Botox was working. I nearly cried knowing that now I could do things that I had never accomplished before. As time went on, stretching and physical therapy became much easier and less painful.

Botox has brought me only positive results and I am very thankful for this opportunity. It is supposed to work for only four to six months, but even now my muscles are stronger and looser than ever. When I reach for my toes, my palms hit the floor! The only disappointment has been that Botox did not help make running easier. That is something that I struggle with greatly.

Otherwise, I am completely satisfied with Botox. I would encourage anyone with problems like mine to try it. I would like to thank the Kennedy Krieger Institute, my family, and all of my friends who have contributed tremendously to making my life wonderful.

Cara Stout 16, lives in Hagerstown, Maryland with Mom, Diana; Dad, Gregory; sister, Amanda 14; and brothers, David 12 and Andrew 9.



The Bactrofen pump and its positioning in a child's body.

and accumulating under the skin (10 percent of cases).

Pumps are refilled about every three months, by inserting a needle through the skin over the pump (which can be numbed with EMLA cream), and injecting more medicine. ITB doses may also be adjusted during the refill.

We delay physical therapy for three to four weeks after the pump operation. Its frequency then depends on several factors, including the child's functional goals and motivation.

Currently, the battery for the pump model available lasts four to five years. By June 1999, a newer model pump will be available with a battery life expanded to seven to eight years.

Decreasing spasticity with ITB may allow easier, faster walking, straighter

sitting and better use of communication devices. In our studies, one-third reported better eating/swallowing; one-half, improved speech; and two-thirds, better bathing and transfers. Based on our experience using ITB in about 400 individuals, it is possible to identify general treatment goals, but not yet possible to predict which functions will improve.

ITB has several advantages: it is highly effective in reducing spasticity, often improves function throughout the body, its dose can be adjusted to the desired amount, and it is non-destructive. Its disadvantages are the costs of the pump and its refills, and potential complications of the pump and medication.

Dr. Leeland Albright is Professor of Neurosurgery at the University of Pittsburgh School of Medicine, and Chief of the Department of Pediatric Neurosurgery at the Children's Hospital of Pittsburgh.

of bed, they wear an abdominal binder.

Risks of the operation include: infection (five to 10 percent of cases), catheter problems such as kinking or disconnecting (10 percent of cases), and spinal fluid leaking along the catheter

The ITB Experience

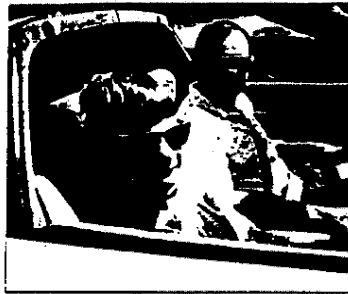
by Larry McClaugherty

Our 16-year-old son, Neal, has quadriplegia cerebral palsy. Spasticity has always been a problem for Neal, who is also non-verbal. In late 1996, a growth spurt triggered uncontrollable muscle spasms and tremendous pain. He could only sleep for about three hours a day, and those in only 15 or 30 minute spurts. Our family was exhausted. This continued on for about nine months.

The ITB test—which requires an IV stick—turned out to be the worst part of the implant process. After five sticks, Neal was so emotionally drained and uncomfortable that the test had to be rescheduled—a terrific disappointment. The second test went much better, and the ITB implant was scheduled for July 3, 1997.

Before the surgery, his Mom, Kathy, and I discussed with Neal who he would be meeting and what would be done. Fortunate to live only 45 minutes from the Texas Medical Center and The Institute for Rehabilitation and Research (TIIR) where the surgery took place, we assured him that one of us would always be with him. Kathy moved in with him during his three-day hospital stay. We also made sure that the nurses and physicians called Neal by name and spoke to *him*, not just to us.

Neal was medicated for nausea and vomiting while under anesthesia, and otherwise all proceeded along the standard ITB route. His hospital recovery period went well. He had to remain flat and quiet, but had no headaches, nausea, or vomiting.



Neal and Dad Larry McClaugherty: two cool guys in a "white Chevy."

Our advice to other parents: ask lots of questions. Find out what the hospital services will be like in all phases: testing, surgery, follow-up visits, and pump refills. Also, talk to veteran ITB families and/or patients. A couple of children who had been through the procedure, visited Neal prior to the testing and pump implant. In talking with other parents, we decided that a neurosurgeon, rather than orthopedic surgeon, should undertake the process.

The pump has been a real gift. The most dramatic benefit for Neal has been the relief from pain and the ability to sleep. The relief from

spasms and a significant reduction in his hypertonicity has also made caring for him easier, both for Neal and his care givers, with greater ease in personal hygiene, bathing, and dressing. An improved seating posture means he can also now be fed more easily.

The "real Neal" has returned. Before the spasms, Neal had a great sense of humor. Now, he laughs a lot again. He is a real pleasure, and truly a teenager. Since the implant, he sleeps between 10 and 12 hours! Now, Neal can enjoy being the great kid he is with all his old favorite pastimes: school, watching his videos, playing "Wheel of Fortune" on the computer, and doing the "guy thing" with his old dad and his favorite toy—buzzing around in the Corvette, better known around our place as the "white Chevy."

Larry, Kathy, and Neal McClaugherty live in Friendswood, TX. Kathy is a registered nurse and Infection Control Practitioner at Texas Children's Hospital and Larry is a Consultant Pharmacist, in Houston.

Selective dorsal rhizotomy (SDR) is a neurosurgical technique used to treat spasticity, especially in children with cerebral palsy. It is based on the assumption that spasticity results from loss of the brain's regulating influences of nerves on the spinal cord's reflex circuits.

There are a multitude of reflex circuits, such as the tendon jerk reflex: tapping the knee with a hammer makes the leg straighten. When the hammer taps the tendon, a nerve impulse goes to the spinal cord where it stimulates a nerve to send a signal back to the thigh muscle to contract and pull the leg straight. Nerves from the brain control these reflex circuits, allowing us to voluntarily move a muscle *without* it reflexively tightening up.

With cerebral palsy, these "control nerves" from the brain can be damaged. The nerves within the spinal cord activate, and numerous muscles throughout the body contract: the

typical picture of limb spasticity.

There are two broad categories of SDR candidates:

- children functionally limited by their spasticity but who have sufficient underlying voluntary power to maintain and eventually improve their abilities, once the spasticity has been alleviated;
- non-ambulatory children for whom spasticity interferes with sitting, bathing, positioning, and general care taking. Spasticity frequently causes them a great deal of discomfort. The goal is to ease the difficulty of daily care taking, to increase comfort, and to enhance stability in the seated position.

Concern should be raised when a child exhibits signs of choreo-athetosis (uncontrolled, abnormal patterns of movement), since the surgery will often worsen this associated movement disorder.

Anesthesia for the surgery must be given in a manner that preserves the ability to elicit muscle contraction when stimulating the sensory roots/rootlets. Most surgeons prefer exposing the nerves in the lower spine between the bottom of the rib cage and the top of the hips. The sensory nerve roots are separated from the motor nerve roots and stimulated electrically while the leg muscles are observed for contraction. Roots that cause abnormal

Selective Dorsal Rhizotomy

by Rick Abbott, M.D.

The Rhizotomy Experience

by Rita Spillane

A veteran mom talks about techniques her family used following her eight-year-old daughter's rhizotomy.

Six weeks past surgery, Megan's casts were removed. It was a treat to see Megan's feet flat on the floor for the first time in four years. Now our work was cut out for us. Physical therapy was of the utmost importance. Our plan revolved around two major goals—to reduce spasticity and to establish a sense of balance.

Because Megan resisted her exercise sessions, we decided to set the alarm clock so she would know when exercise time was over. Her anticipation of the clock ringing seemed to distract her from the discomfort. We also sang songs to accompany certain exercises. "Row, row, row your boat..." matched the one where we sat facing each other on the floor with my legs on top of hers to keep her knees straight and her legs abducted. We would join hands, lie down, and sit up singing as we stretched. When we bicycled her legs, we chorused, "You'll look sweet upon the seat of a bicycle built for two."

My husband constructed parallel bars for Megan to walk through—plumbing pipes, 2 x 2's, and dowels did the trick.

For practice with balance, we tipped a round hassock on its side; Megan straddled it and rocked from side to side, tapping the floor with her foot. At first, I held her hands. Gradually, she could balance without my intervention.

When her brain-leg coordination improved, we thought riding a tricycle would be of benefit both physically and socially. It was almost impossible for her to keep her feet in contact with a pedal. We sawed the wheels off a pair of roller skates and attached the foot pieces to the bike pedals. We slipped Megan's feet into the foot pieces, strapped them in, and off she rode with the other kids. Naturally, she was unable to get off of the tricycle by herself, but her sister or another child would open the straps to free her feet.

Megan progressed to a walker, concentrating on her gait. I would walk behind her using one of my knees to guide her steps. Crutch-walking was made easy and fun. We tied bright yarn bows on Megan's shoes to match the bows we tied to the crutches and taught a four-point method. "Pink crutch, pink shoe," "green crutch, green shoe." Before long, Megan began "zooming" around on her crutches.

muscle contraction are separated into their component rootlets that in turn are stimulated. Abnormally responding rootlets are "selected" and cut. They can never be restored.

Physical therapy is important to rehabilitation. A year after surgery, children who have had SDR average 4.5 hours of physical therapy per week. Three years later, they still receive two to three hours per week, frequently augmented by their parents both in stretching and strengthening activities.

We examine the children six months after surgery and then on a yearly basis: Hip and spine x-rays are obtained as indicated (at least every two to three years), the functional status of the child is reviewed, orthotic devices inspected, and concerns of the treating therapist(s) discussed.

All of the children we have operated on had a statistically significant improvement in the tone of every

muscle tested. Over 80 percent of the time, the preoperative functional goals were achieved. All children who walked or crawled preoperatively—and two of the nine who did not—were walking 60 months after surgery. Other surgical groups have reported similar experiences.

This is not a procedure guaranteed to prevent the need for further surgery. Of 350 children we have operated on, 20 have eventually needed hip operations due to significant dislocation. Over half of these experienced this dislocation after a SDR. Further, 25 have required tendonotomy to treat range limitation in a joint.

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Orthopedic Surgery

by Leon Root, MD

Cerebral palsy affects the way muscles work and can distort growing bones by creating abnormal forces on them. Because standing and walking are often delayed in children with cerebral palsy, the hip joints do not receive the normal weight-bearing stimulation to form properly. Also, spastic muscles can deform growing bones.

Although doctors cannot cure cerebral palsy, we can help to modify its effects by decreasing muscle tone, surgically improving muscle balance, and by preventing and correcting the mal-alignment of limbs to help with standing, walking, or even sitting.

Certain problems are common among children with cerebral palsy. When children with spasticity begin to stand, they often do so on their toes with their knees bent. As they attempt to walk, their legs may cross or scissor so that their progress is impeded. We attempt to align the limbs to facilitate standing or walking, first through physical therapy and the use of orthotics. Orthopedic surgery is often necessary to improve these functions, by releasing or transferring contracted muscles. Operations on several muscles are usually performed at the same time.

Muscle lengthening

The term, "muscle lengthening" may be confusing. The tendon part of the muscle, or in some instances a portion of the muscle itself, is released so that the length of the muscle is elongated, allowing greater movement of the joint. For example, if the child "toe walks," then lengthening the heelcord allows the heel to strike the ground in a more normal pattern. If the hamstring muscles are tight, causing a bent-knee walk, these can be lengthened individually to achieve a desired range of movement. If the hip adductors or groin muscles are tight, these can be lengthened in the inner aspect of the groin.

The actual surgical technique may vary according to each situation or doctor's preference. After muscle lengthenings are done, postoperative care and rehabilitation are very important. The lengthened muscle is always weaker following surgery, so it is essential to get back to moving it again in rehabilitation therapy, to restore joint

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POSITIVE PERSPECTIVES FOR CEREBRAL PALSY PART 4

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mobility and regain muscle strength. I personally advocate minimal casting or immobilization following adductor or hamstring surgery, and limited cast immobilization for heelcord lengthening. I encourage casting and walking two days after surgery, progressing as pain and discomfort subsides. The sooner the child regains mobility, the sooner she returns to her normal level of function.

Tendon transfers

Tendon transfers make the muscle work in a different way than nature intended. For instance, a child walking on his toes and the outer border of his foot, then the heel cord and the muscle on the inner aspect of the ankle and foot (the posterior tibial muscle) are tight. In this instance, the heelcord would be lengthened and the tendon of the posterior tibial muscle would be split longitudinally, leaving a portion attached to its normal site, and taking the other detached portion around the back of the ankle and re-attaching it to a tendon on the outer aspect of the foot. When the muscle contracts, it pulls on the inner and outer aspect of the foot simultaneously, so that the foot is flat on the floor with weight bearing.

Occasionally, the entire tendon is moved so the muscle elicits an opposite reaction to its normal one. An example of this is the middle muscle in front of the thigh (the rectus femoris). This muscle has two functions: 1) to lift the thigh and flex the hip at the same time, and 2) to straighten or extend the knee. In some children with cerebral palsy, this muscle cannot relax while the child walks, so that she cannot flex her knee to advance her leg. This causes a stiff knee gait pattern and makes it difficult to go up steps or curbs.

If a gait analysis confirms this muscle is

not relaxing during the swing or normal knee-bent part of walking, then the muscle's tendon can be detached from above the knee cap and re-routed around the distal thigh to be re-attached to one of the hamstrings. The block to knee flexing is eliminated and the transferred muscle can actually help to lift the thigh and encourage knee flexing. Obviously, careful analysis of the child walking and the range of motion of the individual joints are essential before surgery is considered.

Hip problems

Muscle surgeries do not correct bone deformities. A 3-year-old may have tight hip adductors, hip flexors and hamstring muscles, which in combination, overpower the muscles that would normally spread the hips apart, or extend the hip and the knee. If the situation persists as he grows, the hip joint may become distorted, subluxated, or even dislocated.

Thus it is important to surgically release these muscles early, before the hip problems occur. Once the hip becomes subluxated, however, the muscle lengthenings are not sufficient. The ball at the upper end of the thigh must be repositioned into the socket by actually cutting the upper end of the thigh bone (the femur) and bending the ball into the socket. Occasionally, the socket becomes shallow: more a plate than a cup. Surgery is then done on the socket itself so that it is deeper and can provide better support for the ball of the femur.

Hip subluxation occurs more often in the more severely involved child, and can occur even after muscle surgery. Timely x-rays of the hips should be taken, especially in the child who has quadriplegia.

Scoliosis

Scoliosis is a condition in which the spine begins to bend sideways, either as a long "C" or as an "S". Asymmetrical abnormal muscle tone bends the spine as the child grows. In severe cases, the spine can bend to 90 degrees or more. Most curves begin at puberty, usually at about 10 to 12.

Early bracing is somewhat helpful, but in severe cases, the curvature progresses and surgery is necessary. Surgery consists of straightening the spine as much as possible and placing rods along the spine to hold it straight. At the same time, a bone graft is placed along either side of the back of the spine. When it heals, the spine becomes solid and will maintain its straighter position.

Occasionally, deformities are so severe that to get correction of the curves, the spine must be approached from the front through the chest and/or abdomen as well as the back. These are major surgical procedures that should only be done at medical centers where the necessary expertise and skills are present.

Hands and feet

Muscle and tendon surgeries can be done in the upper extremities to correct a deformity or assist in hand function. Bone operations are also frequently done on the feet, to maintain the foot in a good standing or walking position. Here, the basic principles of muscle surgery or bone surgery are the same.

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At some point, most families of children with cerebral palsy work with a physical therapist (PT). PTs often focus on movement skills such as walking, functional activities such as getting into a chair, strengthening weak muscles, and preventing deformities with stretching, braces and positioning. Therapists also help parents with care issues, as well as with helping build self-esteem and confidence.

Though all therapists learn basic pediatrics in school, an expertise in pediatrics is a specialty certified by The

Physical Therapy

by Meg Barry, MS, PT, PCS

American Physical Therapy Association. These specialists use the initials PCS: Pediatric Certified Specialist.

Children may also see a physical thera-

pist assistant (PTA), who works under a PT's direct supervision, following the treatment plan developed by the PT. A PT closely monitors patient progress. The PTA has an associate degree, and many are very experienced in the treatment of children with cerebral palsy.

A PT evaluation

The PT will ask about medical conditions, surgeries, and medications, so bringing medical records may be helpful.

The PT will watch the child to see how

he moves and holds his body against gravity. For instance, the PT may put a baby in a sitting position to see if he can hold his head up. The therapist also needs to see what the baby can do independently, such as reaching for toys or using hands to hold on, and, in addition, will assess range of motion, muscle tone, and strength. (Many children do not like this part of the evaluation. They may feel restricted or frustrated or wary of a stranger.) Most important, the PT will ask about your concerns. What is difficult for you to do at home? For example, you may find changing a diaper difficult.

A treatment plan will be developed—and constantly updated—from the observations and discussions, along with input from other team members. The key is that it should meet the needs of both you and your child. If you are having difficulties diapering, for example, part of the PT treatment plan may be to show you ways to help your child relax before diapering. Special equipment may also be part of the treatment plan. For the baby who has difficulty sitting, for example, an adapted chair may allow her to use her hands to play.

There is no "ideal" therapy. The amount depends on the situation. Every child and family is different. PTs help set realistic goals for both the parent and the child.

If goals are not meaningful, the child will not be interested. When a child becomes interested in something new, such as getting to the bathroom, an extra burst of therapy may be helpful. After surgery or a new drug, increased therapy often helps a child recover and/or make new gains. For instance, with a drug to reduce spasticity, more therapy may help the child learn new ways to move.

For some families, PT in the home is ideal. For others, school is the best place for treatment. Some children do best with therapy three times every week, others once a week.

To keep in mind

Meaningful activities with active involvement promote learning. Endless repetitions of a meaningless exercise do not.

In addition, because self-esteem is an issue for many children with cerebral palsy, pointing out what a child cannot do, or does "wrong" is harmful. A child who gets up from the floor in an atypical way is

not doing it "wrong," she is doing it in her most natural way. There may be good reasons to teach her other means of getting up. For example, if she gets up only by pulling up on furniture and falls down in an empty hallway, he may not be able to get up. To increase self-esteem and confidence, motivate her to improve on what she can do.

PTs use their best clinical judgment, but they cannot guarantee anything. Though studies show benefits of physical therapy, if promises are made, ask for evidence to support them—and get a second opinion.

Work together with your PT. Plan for your child's whole life, not just the short term. In therapy, it is easy to focus on goals such as walking, but the whole child needs to be considered. Stretching may be important, but learning to communicate is probably more important long-term. Your child is going to grow up, and walking a few steps with crutches will not be as important as communicating, having friends, and enjoying life.

To learn, children explore and interact in their environment. Children who cannot move to explore are at a disadvantage. They may develop a passive, dependent personality. Assistive technology—scooters, wheelchairs, motorized toys—provides means of moving through the world. Children as young as 2 years of age can drive a motorized wheelchair. Further, there is no evidence that children who use wheelchairs are less likely to walk eventually—if they have the potential to do so.

Fitness is important for everyone, including children with disabilities. The habit of exercise is important for children to become healthy adults. But therapy is not the only exercise option. There are many fun activities in the community. Horseback riding and swimming programs are very popular. Dance and karate build strength, endurance, and balance. Older children may enjoy weight lifting in the gym. Remember: There is more to life than therapy. Children need time to play, explore, and even get into trouble. And you need time together as a family. The purpose of therapy is to improve quality of life, not become a way of life.

Meg Barry is a Pediatric Physical Therapist in the Department of Neurosurgery at Children's Hospital, Pittsburgh.

Occupational Therapy

by Annette Majnemer, OT, PhD

Occupational therapy's primary goal is to maximize a child's functional potential in all environments (home, school, community). This enables the child to participate fully in all roles and functions that are meaningful and important to her and her family. Function implies actions—occupations—with a purpose and meaningful to the individual.

Joey, a 21-month-old boy with cerebral palsy, is referred to an occupational therapist (OT), because he has increased muscle tone in his right arm and leg.

OTs focus activities for:

- self-care, such as eating independently, dressing, toileting, grooming and hygiene, and the ability to be mobile;
- contributing to a child's productivity such as learning at school, home responsibilities, and contributing to the community;
- leisure activities and play skills.

As part of the OT evaluation, the therapist determines a child's capabilities and strengths. The family actively participates in identifying areas of concern. The OT also identifies problems that may contribute to functional limitations, such as poor sensation, muscle weakness, spasticity, difficulties with spatial relationships or other perceptual concepts, and short attention span.

The OT's assessment reveals that Joey is a bright, responsive child who enjoys interacting with others. He has an extensive vocabulary and understands simple conversation. He has difficulties changing positions and manipulating objects. His parents are particularly concerned that this limits his ability to do everyday tasks such as eating on his own and dressing.

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The OT has the expertise to evaluate a child's ability to perform routine activities and pinpoint those she has difficulties with, and why. The OT also identifies important roles and functions in which a child is unable to fully participate.

Therapy involves activities to reduce or minimize difficulties or deficits, to prevent disabilities in functional skills, to maximize independence, and to maintain health and a sense of well-being. A variety of approaches are used, such as:

- special handling or positioning techniques;
- seemingly isolated exercises, such as reaching or grasping skills, that together, eventually lead to developing new skills, such as holding a cup and bringing it to the mouth or picking up a pencil to write;
- practicing skills and providing appropriate feedback; per AN
- supplying aids and adaptations to enhance performance and achieve independence.

Treatment is child-centered: goals focus on activities that are most important to

his stage of development. Activities used are meaningful and engaging to him.

For therapy to be most effective, treatment strategies need to be integrated into the child's daily routines with family members, educators, and other health service providers. The team approach is very important, with the OT sharing opinions, knowledge, and expertise.

Together Joey's parents and the OT set the primary intervention goals: encouraging him to spontaneously use his right arm and hand as a stabilizer in everyday functions (eating, undressing and playing, etc.), and to help him get from one position to another on his own. Using special handling techniques, equipment, and age-appropriate activities, the OT greatly increases Joey's ability to learn and to explore his environment independently.

OT for a child who has cerebral palsy is not diagnosis-specific, but individualized based on the ongoing

evaluation of her abilities as well as the family's needs and concerns. A family-centered approach is critical. Families work in partnership with the OT to identify and prioritize goals and to help maximize their child's functional performance. As children with cerebral palsy grow and develop, they are challenged by new tasks and expectations. Ongoing education and support to family members are vital roles of the OT.

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Speech Therapy

by Justine Joan Sheppard, PhD, CCC-SLP

The Speech Language Pathologist (SLP) helps develop and maintain skills for communication, swallowing and eating, and a other oral-movement behaviors including controlling saliva, maintaining normal oral postures, and brushing teeth. Since needs and capabilities change with age, it is not unusual for the child with cerebral palsy to be involved in speech therapy as an infant, during school years, and again in adulthood.

Early on, the SLP may work with those caring for the child, to develop plans for managing daily routines and for advancing skills. Supporting and educating the family to help the child is as much a part of speech therapy as

working with the child. As the child ages, the focus shifts to skills needed for the world outside of the family, first in school and socializing with peers, and then in work settings and the adult's residence.

The audiologist

Since the ability to hear is closely related to communication, most children and adults with cerebral palsy will use the services of an audiologist. The audiologist evaluates and monitors hearing to assure it is normal. When a problem is detected, the audiologist guides the selection of a hearing aid or other amplification, educates the family in its use, communicates with the physician about related medical

needs, and advises the SLP and teachers on the child's special educational needs. Since people with cerebral palsy have a higher prevalence of hearing loss, and early treatment is most effective, infants should have audiological screening tests and children should have an audiological evaluation.

SLPs and audiologists may be licensed by the state or certified by an educational system or by the American Speech-Language-Hearing Association (ASHA). A Master's degree is required to practice. SLPs working in educational settings, however, may have different requirements. In some states, support personnel—who work under the supervision of the SLP or audiologist—are licensed. Ask about the training and qualifications of the therapists with whom you are working.

The SLP's clinical evaluation usually includes an examination of oral struc-

tures, oral reflexes, and breathing movements; functional examinations of eating, pre-speech vocal behaviors, and speech; and oral postural control, control of saliva, and oral play such as mouthing, imitating movements and sounds, and blowing bubbles and whistles. The SLP may suggest that the child have other evaluations by medical and therapy specialists to help determine treatment options and select the best treatment strategies.

Not just speech

A child need not be eating or speaking to benefit from speech therapy. The SLP may suggest exercises and experiences

that prepare him to advance and minimize unnecessary difficulties before skills emerge. If skills are emerging, however, exercises may teach him to chew or drink from a cup, to control his saliva, to use words, to speak more clearly, to listen to and understand what is said, and to speak in sentences.

For the child having difficulty eating, strategies are needed to assure she is adequately nourished and hydrated, can take food and medications safely and comfortably, and can eat as independently as possible. The therapy program will advance eating skills and improve the safety and effectiveness of eating behaviors.

If a child is unable to speak clearly,

therapy will include training in alternative means of communication. For the person having difficulty speaking or using gestures, an augmentative communication system helps him make his thoughts known and helps him maintain social relationships. The system may be as simple as a picture array or as complex as a computer system that can be directed to 'speak.'

The SLP will support you and your child as you work together on these important skills.

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Pediatric Physiatry

by Dennis J. Matthews, MD

Physiatrists (fizz-i-at-trist)—physicians specializing in Physical Medicine and Rehabilitation—are experts in the medical and physical treatment of disabling illnesses and injury.

Pediatric Rehabilitation Medicine training—which includes a three-year pediatrics residency—involves very close collaboration with other medical specialists such as orthopedic surgeons, neurologists, neurosurgeons, as well as physical, occupational, and speech and language therapists. Physiatrists develop a thorough understanding of the physical, cognitive, emotional, and social impact of chronic disabling illnesses.

Rehabilitation includes, but is not limited to, the treatment of neuromuscular disability. Fostering the acquisition of new skills and anticipatory treatment of potential complications are the two fundamental aspects of intervention.

The rehabilitation interventions should begin early, as soon as the impairment or disability is identified. These early intervention programs have been shown to improve infant-caregiver interaction, influence early

development, provide the parents an understanding of the natural history and course, allowing the establishment of a more appropriate and effective rehabilitation program.

A physiatrist can help decide how to focus and prioritize therapies, maximize the efficiency and effectiveness of programs, prescribe specific therapies and exercises, and collaborate with the child, parents, other physicians, and therapists in setting appropriate rehabilitation goals.

In the management team

Physiatrists are experts in the management of spasticity. They can prescribe medications and perform botulinum and phenol blocks to reduce or control abnormal tone. These, however, are recommended only as part of a total rehabilitation program.

The physiatrist's focus on restoring or acquiring functional skills frequently requires the use of durable medical equipment (wheelchairs, walkers, etc.), orthotics, computers, and augmentative communication devices.

Working with the rehabilitation team, the physiatrist evaluates each child's needs

and goals, reviewing the various equipment options (including the advantages and disadvantages of each item) and creating a specific, individualized prescription. This prescription documents the medical need, thereby facilitating the funding authorization process.

The physiatrist sees these devices and equipment as a means to facilitate function and allow successful integration of the child into her community. The selection of appropriate devices should enable function and participation. They are the tools to access the world. These devices should augment the child's skills, compensate for deficiencies, and facilitate inherent potential. Most devices, when appropriately selected, will not inhibit the child's developmental potential.

The physiatrist is an important member of the treatment team. Approaching the child and his family from a unique training background, the physiatrist works to facilitate or restore optimal development, prevent potential complications, and enable full, and meaningful participation in life. **EP**

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