Any professional who works with children with cerebral palsy (CP) and their families will say the process is not only a challenging, rewarding, and fascinating experience, but also one requiring a long-term commitment from a dedicated multidisciplinary team. The objective is to provide a comprehensive, lifetime treatment plan of individualized care — the ultimate goal is maximum independence when the child reaches adulthood.

No single treatment works for every child. Generally, the earlier the intervention, the more chance the child has of preventing or overcoming many of the secondary effects of this developmental disability. There are also numerous treatment options provided by several disciplines.

This Q&A article focuses on the orthotic management of children with CP from the perspectives of experienced clinicians in the fields of physical therapy, orthopedic surgery, physical medicine and orthotics. It is important to remember that the opinions expressed here do not necessarily represent the opinions of their professions as a whole. This discussion addresses the following topics:

- Essential aspects of CP management for the orthotic practitioners
- New developments in orthotic management of children with CP
- Importance of the orthotist as a member of a multidisciplinary team
- New surgical and pharmaceutical interventions
- Educating the family
- Treating the adult with CP

**News in Orthotic Management**

*O&P Business News:* What is new in orthotic management of CP? What advances have you observed in your field?

**Scott Amyx, CO,** a senior staff orthotist at the University of Wisconsin, Hospital and Clinics, Orthotics Lab, in Madison, Wis.: At one time, the common thought was that we would alter the sensory input patients received when they were standing in their ankle foot orthoses (AFOs). So we'd modify the footplate, unweighting the metatarsal heads or putting in a peroneal arch. The idea was if we could reduce some of the sensory input, we could reduce tone. That theory is becoming obsolete. We now focus on getting good skeletal alignment. Once we obtain proper skeletal alignment, we give the muscles a chance to operate more effectively.

**Beverly Cusick, PT, MS,** the owner of Progressive GaitWays, LLC, in Placerville, Colo.: I allow children with shortened calf muscles to have plantarflexion in their AFOs, and assist them with dorsiflexion (DF) using new joints that are made for that purpose. I rarely stop an ankle from plantarflexing, and more rarely, at 0 degrees. I use a plane-based approach to orthotic design and biomechanical posting principles, drawn from the fields of podiatry and sports medicine, to determine the degree of enclosure that is needed and to adapt the plantar contours of my orthoses to the components of each child’s foot shape and joint mobility.
TheraTogs™, elasticized undergarments and strapping. TheraTogs™ systems are customized for each child and generally reduce the workload for the orthoses. Even with adequate plantar posting, I often can’t get all of the impacts that I want through the closed kinetic chain with just a distal orthosis. For example, the closed chain might be broken by lax knee ligaments. So I also use orthopedic taping to help to restore a more normal patellar alignment or to stabilize a lax knee joint. I try to permit each child to strengthen the weak muscle groups while in his or her orthosis, as weakness is a major problem in CP. Functional electrical stimulation has also found a place in neuromotor and functional training for children with CP.

Marcia Greenberg, PT, MS, the coordinator of the UCLA Orthopedic Hospital, Center for Cerebral Palsy in Los Angeles: There’s been a shift in philosophy over the last several years away from the classic form of physical therapy for CP called neurodevelopmental therapy (NDT). NDT was developed in the 1950s by a husband and wife team by the name of Bobath. They believed that spasticity and abnormal movement were the cause of all the other problems noted in CP patients. So, you didn’t try to strengthen children with CP because that would increase the spasticity.

New theories in adult motor learning and movement have since shown that’s not true. In fact, people with spasticity often have weakness underneath their inability to control their muscles. Interestingly, we often find that some patients who didn’t need braces before treatments or surgery in fact, need braces afterward. Before treatments, they were toe walking. When the spasticity is gone, we find them collapsing into excess dorsiflexion. We make sure that patients have a well-fitting pair of AFOs before they go for rhizotomy surgery.

Dulcey Lima, CO, OTR/L, the clinical education manager for Orthomerica Products, Orlando, Fla.: For the severely involved patient group, more ambulatory sorts of bracing systems are being issued, for example the MkII Hartwalker® (see sidebar on page 28) and the SWASH™ (standing, walking and sitting hip orthosis). Many children with CP who hadn’t been able to walk are ambulating short distances in these devices. There’s still a lot of hardware with them and that can be a management problem for some families.

I could see that in the future we’d be coordinating the electrical stimulation techniques that some therapists are using into the design of the orthoses. Hybrid systems are also available whereby an supramalleolar orthosis (SMO) is made to fit inside a more rigid AFO. It’s a great solution to the battle of whether to choose SMOs versus AFOs.

Allison Scott, MD, a pediatric orthopedic surgeon at Shriners Hospitals for Children, Houston: Children with CP used to be put in the "Forrest Gump" braces. Now we rarely brace these children above the knee. The tone reducing braces with the contoured interior plantar surface have been effective. We also use the wrap around AFO on the youngest kids. These are thin and flexible and they provide better support for the foot and ankle as opposed to the older orthoses that were more like leaf springs. These really didn’t control the foot. Our use of orthotic devices for children with CP is to maintain muscle length while the bones grow. Many clinicians push for less bracing. We don’t believe that is the best decision.

Mark Young, MD, MBA, FACP, a physiatrist and chairman of the department of physical medicine and rehabilitation at the Maryland Rehabilitation Center, Maryland Department of Education, and a faculty member at Johns Hopkins University School of Medicine in Baltimore: Standard of care basically involves serial casting and orthoses. It helps to correct deformities that may exist because of tight muscles. The muscles most likely to develop contractures are those that cross two or more joints, for example, the gastrocnemius muscle. Stretching exercises are critically important. That is providing slow, sustained, passive stretch several times a day and preceding it with moist heat applications — provided the patient doesn’t have decreased sensation in the area.

Moist heat application makes collagen more extensible. Heating can take many forms, such as ultrasound, paraffin dips or warm hydrotherapy. We also use dynamic splints to help push in the direction of a preferred range of joint motion.

Hyperbaric Oxygen Therapy and Cerebral Palsy
Hyperbaric oxygen therapy (HBOT) is a procedure whereby a patient is placed in a closed chamber that delivers oxygen at an increased atmospheric pressure (see *O&P Business News*, March 1, 2002). At the increased pressure, oxygen is more available to red blood cells. Additionally, it is dissolved in the blood plasma thereby saturating tissues with oxygen.

Many parents have reported that HBOT has been successful for their child with cerebral palsy (CP), despite lack of scientific evidence. But a recent study published in *The Lancet.*, found differently.

The double-blind, randomized, controlled study concluded that there were no greater improvements in children with cerebral palsy treated with HBOT compared with the children treated with pressurized air. The primary objective was to determine whether 40 HBO treatments improved gross motor function.

Seventeen children with CP, aged three to 12 years old were referred for the study from rehabilitation centers in Quebec. Of the 111 children randomly assigned, 57 were assigned to the HBO group and 54 were assigned to the slightly pressurized room air. All children received 40 sessions of 60-minute treatments once per day for two months. Parents were kept unaware of which treatment their child was receiving. Children were assessed at baseline, and after 20 treatments, 40 treatments and three months later. Therapists administering the tests were also unaware of the treatment given.

Both groups of children had improvements in gross motor function measure in addition to all other secondary objectives, including neurological assessment, speech and language pathology and functional assessments. The authors concluded that this may be attributed to the participation effect and motivated parents. The study enabled the children to communicate with other children and parents in a positive manner, possibly increasing intellectual, social and emotional development.

For more information:


History of Cerebral Palsy

In the mid-19th century, an English surgeon named William John Little described CP in a series of courses titled “Course of Lectures on Deformity of the Human Frame.” He described CP as “a peculiar distortion which affects newborn children which has never been elsewhere described.” By the end of the 19th century, it was known as “Little’s Disease.”

Little believed there was a relationship between Little’s disease and premature and problematical births. He proposed that the cause of the disorder included asphyxia at birth and direct mechanical injury.

Sir William Osler, a professor of medicine at the University of Pennsylvania, coined the term cerebral palsy in his lecture series titled “The Cerebral Palsies of Children.” Sigmund Freud also did extensive research on CP. He believed a difficult birth might be more of a symptom than a cause.

“Difficult birth, in certain cases, is merely a symptom of deeper effects that influence the development of the fetus,” Freud said.

He also described a correlation between lesions to the brain and degree of spasticity and paralysis in the body, noting that more superficial lesions were more likely to cause problems in the lower extremities.

In the 1980s, scientists analyzed 35,000 births and found that birth complications account for less than 10 percent of CP cases. In most cases, no cause could be found.
Advice for the Non-Specialist

**O&P Business News**: What are the most essential aspects of orthotic management for the practitioner who does not specialize in CP patients?

Amyx: Pay attention to details. Make sure the orthosis is well fitting and that you’re controlling some rotational elements of the deformity in order to get proper skeletal alignment. Listen to the physical therapists (PTs). If they are not happy with the orthosis, it’s because they’re not getting the results from it that they expected. If the child doesn’t have adequate DF range of motion (ROM), and you’re trying to put them into something that is dorsiflexed, the child will have problems with comfort, functional effect, and skin care. Read the literature and attend courses on CP outside of the O&P field.

Gretchen Backer, PT, program coordinator at Children’s Hospital of Michigan, Motion Analysis Lab in Novi, Mich.: CP is a dynamic disorder. The practitioner needs to know how much spasticity there is, what the muscle tone is like, and be able to communicate effectively with parents and other attending clinicians. During the evaluation, I want to know if the high-tone or relaxed muscles I am seeing are typical of that child. The fit in the mold of their foot is extremely important.

It can be a big problem if someone hasn’t attended to relaxing the foot and getting it into a good position that’s reproducible. Make sure the orthoses have enough room for normal movement of the foot, but also protect the normal foot structure — the longitudinal structure, longitudinal arches and the normal alignment of the foot. Make sure the tail is not calcaneus and they’re not being casted in a position that collapses the foot. Team up with someone who has a lot of experience.

Cusick: Discard the outdated idea that one orthosis can meet all management needs for this patient population. They might need different devices for contracture management, for therapeutic exercise, and for community ambulation.

The team members must do a thorough musculoskeletal assessment to identify those components that can or cannot be addressed orthotically and that could enhance or diminish the functional effect of the device. For example, if the femur is excessively twisted, an orthosis that properly aligns the foot might result in increased in-toeing. The orthosis cannot change the torsion in the femur, but an experienced and capable orthopedist can.

I also recommend all team members read *Foot Orthoses and Other Forms of Conservative Foot Care* by Thomas C. Michaud. In the United States, many practicing orthotists are undereducated in the basics of anatomy, kinesiology, physiology and biomechanics, and therefore in the orthotics-related problems of pathokinesiology, pathophysiology and pathomechanics.

In Canada, the orthotist must obtain a bachelor’s degree, attending college classes in these sciences with PTs for the first couple years, after which they split off to their specialty areas. While PTs and physicians are trained in these sciences, they are no better trained in the optimum use of orthotic devices for children with complex neuromotor and musculoskeletal disorders than is the orthotist. Meet the child halfway in your orthotic application. If your solution to their alignment problem is more rigorous than they can handle — you’ll fail.

Lima: Children with CP require a long-term continuum of care. You have to constantly adapt designs to meet individual needs. There are secondary problems related to muscle length and soft-tissue contractures that create bony changes. These have to be addressed. Orthotists should never work with children with CP in isolation from the rest of the team.

Scott: Most importantly, the foot needs to be braceable. It needs to be in a neutral position before bracing. We use serial casting to achieve that. If the child is tight at neutral and you put the child in a brace, they’ll be popping out of it. Then they get a big blister and they blame the brace. They should
blame the person who ordered the brace.

Also, the fit of the brace is important. It needs to control the ankle, forefoot and hindfoot. It needs to be a total contact brace because children with CP have a lot of deviations in various planes. The temptation is to make the brace a little loose because the child is growing. The problem with the child who’s spastic is that their foot tends to move around in a loose-fitting orthosis and the skin breaks down. If you’re not going to make a well-fitting brace, you shouldn’t make one at all.

Young: Recognize an ounce of prevention is worth a pound of cure. Catching these children early and providing families with appropriate stretching guidelines can avert disaster as the child ages. Also be aware if the child is meeting developmental milestones.

Relative Importance

O&P Business News: How important is orthotic management compared to other disciplines in terms of outcomes? Is the expertise of the orthotist fully used?

Amyx: Consider an orthosis a tool that can increase a person’s function. If we put a four-year-old child who can’t walk independently into an orthosis and suddenly he can walk without holding on, obviously the orthosis is impacting his life substantially. The answer to the second question is regional. It depends on the training and fabrication skills of the orthotist.

Backer: The orthotist is an integral part of the multidisciplinary team who cares for a child with CP.

Cusick: The orthotic device is only one of hundreds of coexisting variables. Yet, the foot is our body-ground interface. Appropriate orthoses are essential to promoting a progressive, lifetime course of body care which could be deteriorating if the foot was in malalignment underneath that growing body. PTs value a fine orthotist. Many physicians and PTs lack the information needed to ask appropriate questions about available options in orthotic design and materials.

Many physicians and PTs who apply fad-based or statistical solutions to complex individual problems of orthotic prescription don’t understand the significance of the various elements of their patient’s musculoskeletal constellation. Everybody who cares for this population needs to learn more about matching orthotic designs to their patient’s condition and long-term functional requirements.

Greenberg: It’s not necessarily a choice when there is no team orthotist. It’s more the system. Having an orthotist on the team would be really valuable. There are many times unique issues arise that we would like to discuss with an orthotist.

Scott: Orthotic intervention is important and can prevent surgery or a bad outcome from surgery — in particular Achilles tendon lengthening. It’s an important part of our post-operative regimen. Orthotists are used pretty well in our institution. We have an on-site orthotist and each child with CP gets a full day of evaluation with each team member, including the orthotist. Orthotists will say “yes” or “no” if the patient has a braceable foot. They’ll often recommend to me whether to serial cast first, or use botulinum toxin type A (Botox, Allergan), or whatever, before molding for an orthosis.

Young: Primary doctors need to recognize the importance of making referrals to appropriate clinicians early, involving the physiatrist and the orthotist.

Treating Adults With CP

O&P Business News: How would you address the adult population with CP?
Amyx: Sometimes, I use more rigid materials because of the greater mass. Unfortunately, often older CP patients reject orthoses. They feel they’ve been using them for 15 years and don’t see any difference. They need to be made aware that orthoses are not a cure but an assistive device. Some adult patients have an incredible collapse of their feet. They just wear tennis shoes and use crutches to get around.

Backer: There is a huge adult population that in some ways are more problematic because they grew up during a time when there weren’t many orthotics available. So their feet are in horrendous shape.

Cusick: No child with CP ever graduated from CP. As adults, they still have muscle imbalances, soft-tissue contractures, weakness and bony deformities. They also often have foot deformity and joint pain due to early aging, or degenerative joint disease at the hips, knees and feet after decades of load bearing on malaligned joints. Most adults have miserable memories of their ill-fitting and ineffective AFOs, so they think they are better off without orthotic support.

Yet foot alignment problems can be managed orthotically by using new design techniques, such as the selectively rigid, thin but total-contact R-Wrap© orthosis or adapting from its principles. If needed, they can also be managed by first restoring soft-tissue extensibility with serial casting – with or without neurolytic injections. The adults with CP also need to be trained to engage in a customized routine of positioning for range maintenance and strengthening exercises at home, much like a health club’s thrice-weekly workouts.

Lima: They’re a forgotten population. There are more and more adults with CP because in the past 30 years, we’ve saved more children and premature babies. They have pain management and stamina issues. They may need an orthosis that is more structured and stable. They tell you what they are going to wear, or it’s more of a compromise between orthotist and patient.

Scott: They don’t use orthoses to the same extent. There are some who are really good ambulators who don’t need orthoses and others that weren’t good ambulators in the first place who use wheelchairs. When teenagers are finished growing, I say to them, “Okay, you’re done growing. I’m not bracing you anymore. You decide if you want a brace and what you want it for.” Probably one-third will pick braces — the ones who walk with their knees bent in a crouch.

They find the brace helps them walk in a more upright position and helps with energy efficiency. When I do surgery on the 16- to 18-year-olds, it’s not a big deal because what you see is what you get. On the other hand, surgery on a five-year-old can be wiped out without the right orthosis because six months after the surgery, they may have grown six inches.

Young: Adults are more difficult than children because they’ve acquired lifelong patterns of walking inefficiently. They have learned to compensate to adapt to their disability. Certainly, there are orthotic interventions that help. The pain relief treatments become more of a palliative approach than a preventative one.

Differing Viewpoints

O&P Business News: How does your treatment viewpoint differ from other disciplines or approaches?

Cusick: Our objectives are to protect tissues and joints from injury and to see the child maximizing his independent function in every conceivable way. PTs are usually more family-oriented than the certified orthotists or the orthopedists. Therapists are trying to help their patients learn to solve movement problems with movement training and muscle care. Excellent orthoses that do not interfere with
movement training and protect load-bearing joints from unnecessary wear while permitting muscle strengthening and efficient function are a significant adjunct to these efforts.

—Beverly Cusick, PT, MS

Lima: We’re trying to control movement and PTs are trying to facilitate movement — a conflict between stability and mobility. What it really comes down to is what kind of care and follow-up is the child getting? Bottom line is that both the certified orthotist and PT must be child-centered.

Scott: The biggest problem I see is that the therapists in our community think that every AFO needs to have a hinge on it. While that may be appropriate for adults, it’s not often the best option for kids. A lot of times the children don’t have the range for the hinge. If they don’t have it before they get the brace, they won’t get it while they’re in the brace.

Some PTs tell parents their children should be kept out of braces because it helps them with their transitional movements. That is true to a certain extent. But you have to make a trade-off because if the child has good transitional movements but gets on his feet and is way up on his toes, then maybe that child should have been kept in braces to keep his foot plantigrade. Eventually, they’ll get transitional movements whether they have their ankle locked or not. Maybe the child practices his transitional movements, but the rest of the time he wears an orthosis. There are also children with low tone, who some therapists believe should be braced. I don’t brace children with low tone because I feel they need stimulation to increase their tone.

Young: Physiatrists are involved in the overall formulation of a team strategy. When complications arise, the physiatrist quickly moves in and deals with the complication through nonsurgical means.

Featured Products for CP Management

MkII HartWalker®

According to product literature, the MkII HartWalker® is a revolutionary and progressive system that teaches children with CP how to walk. The benefits include:

- Improvement of body functions from being in an upright position
- Development of bone mass, muscle strength and coordination
- Adjustable frames for growth
- Increased self-esteem

"It is astonishing to realize that one may have a child that can’t talk, feed himself or move while in a wheelchair. Yet this same child is walking upright and racing around the playground with the MkII HartWalker®,” said Patricia Hayston, CO, of Clinical Orthotic Services Inc. in Moncton, New Brunswick, Canada.

For more information:
- visit the Web site at www.hartwalker.com.

R-Wrap AFO©

Designed by Collier Rehabilitation, the R-Wrap AFO© is a new orthotic design that inhibits severe spastic hypertonus and reduces equinus contractures. Company literature states it is a two-piece, ultra-thin, polypropylene, total-contact AFO.

When the orthosis contains the foot and ankle, it fully secures the calcaneus and blocks sagittal and frontal plane motion at the ankle and subtalar joints. It allows small increments of movement in the transverse plane. Comfort is achieved by the combination of maximum surface area for pressure distribution and slight rotary
“We have observed in several cases that after months to years of solid R-Wrap AFO® use, spastic muscles relax and variable measures of voluntary motion of the antagonists around the ankle joint emerge,” said John Russell, the inventor.

He said that in four years of increasing use of the R-Wrap AFO® at Kaiser Vallejo Rehabilitation Hospital, only three surgeries to lengthen heel cords were performed and all patients still wear AFOs.

For more information:

- e-mail arjohn@attbi.com

Latest Advances

O&P Business News: What are some recent advances in surgical and pharmaceutical interventions? How have these interventions helped or hindered your work?

Amyx: The Botox injections, in particular, have made it a lot easier. Let’s say a patient has some severe tone problems and we can’t get them to neutral. They get a Botox injection and a week later, they have more ROM. If the patient has the ROM and you can keep them seated in the orthosis, the orthosis is more comfortable. It’s the same with the intrathecal baclofen therapy (ITB™, Medtronic). The beauty with the baclofen pump is that its use is reversible. It is not like doing a dorsal rhizotomy where once you cut the nerve, that is it.

Cusick: Though Botox can be helpful, the effects are temporary. I’ve been serial casting for nearly 20 years without it. I think it has merit as a preoperative spasm-prevention modality and for casting out shortened hamstring muscles. So far, everybody I’ve seen that has been on a baclofen pump reports they feel less like they’re moving through a swamp. I can’t do that for a child who’s brain damaged.

Greenberg: It is a battle to get reimbursement for intrathecal baclofen therapy and Botox, but more insurance companies are paying. Botox is not FDA-approved for use in CP but that should happen soon. The intrathecal baclofen therapy creates some significant changes in patients’ functioning.

Scott: To provide balance in the muscles, we now do multilevel surgery that addresses all the muscle groups at one time. Most of my children have two big surgeries in their lifetime. In the old days, children would have five to eight surgeries throughout their childhood. They’d operate on one joint a year. This was called “birthday surgery” because it seemed like they had surgery every year on their birthday.

We don’t do the baclofen pump here. It’s too expensive. We use Botox injections. It weakens the muscle substantially and lasts for about three to six months. In that time frame, we work on stretching the tight muscle and strengthening the opposing muscle or both to get things back in balance. Sometimes we use Botox when children are asymmetrical — they have a lot of contractures on one side and have only increased tone on the other side. We’ll do the muscle release surgery on the contracted side and give Botox on the increased tone side.

Young: I’ve had greater success with another version of botulinum toxin (botulinum toxin type B, Myobloc, Elan Pharmaceuticals). Both are botulin preparations and the injections lead to presynaptic inhibition of motor nerve function. The tone decreases in two to four weeks after injection. With intrathecal baclofen therapy, we can carefully modulate the amount delivered. It makes spasticity reduction much easier without encountering unwanted side effects. Generally, the pump is more effective for lower extremity spasticity. Patient acceptance is high. A neurosurgical procedure that is often successful in decreasing spasticity is the dorsal rhizotomy. It is a selective dorsal root clipping.
Common Types of Orthoses

*O&P Business News:* What are the most commonly used orthoses or assistive devices for CP management?

**Amyx:** SMOs, solid ankle AFOs, articulated AFOs and anti-crouch AFOs.

**Lima:** In almost every case, children with CP have a tendency to go up on their toes and you want to block that. You need to give them the ability to bend their knees and move forward over their feet so it’s easier to walk, squat and play. When they go to point their toe, there’s a block in the back of it. It’s very unusual to cross the knee with a CP child unless they’re extremely involved. Below the knee orthoses are standard.

Some children with CP also need spinal bracing. They tend to develop scoliosis and other spinal deformities over time. They may also need hip bracing because the hip doesn’t grow in the right position to begin with. It tends to be shallow especially if one side has a lot of spasticity. It subluxes and makes it uncomfortable for them to walk.

**Scott:** We use two different types of ground reaction, crouch control AFOs. Both of them have a panel across the front of the tibia that pushes the knee back. We use a fixed ankle crouch control AFO for children who walk in a crouch but also have some tone in their gastrocnemius. We use a hinged crouch control AFO for children who have had surgery where their Achilles’ tendon is severely weakened. The hinge is in plantarflexion and doesn’t allow dorsiflexion. It helps strengthen the Achilles’ tendon and helps them get a little more push off.

Family Involvement

*O&P Business News:* How do you involve families in the treatment process? What kind of issues do you encounter?

**Lima:** It’s particularly difficult when we deal with split families — follow-up gets put to the side due to family dynamics. If you can’t sell the parents on why the orthosis is important, it won’t be effective. A lot of times, children will take off their AFOs when they get home from school. They consider this their break from the device. Parents have trouble with the idea of making their child wear braces. That’s not really what should be done, but it’s typical of families. They take them off during summer, too. By the time they go back to school, they may have heel cord contractures.

**Scott:** We spend a lot of time educating the family about why their child needs braces. We have to explain to them that the braces don’t necessarily make the child walk better. That’s hard for them to understand. They’ll say, “He walks worse with the braces.” We tell them the braces are being used to prevent further damage to the foot — to preserve the ligaments in the foot, for example. Some of the things we’re doing are for the future not for the present.

**Cusick:** If the child and family reject the orthoses, there is usually a good reason or a problem that can be solved. They should never “hurt good” or interfere with their functional abilities. Orthoses should be welcomed as a gain by all concerned. If they are a problem, then they must be revised. Most of the commonly used orthoses can meet one of several coexisting needs but certainly not all of them.