

# Brachial plexus palsy

## Chicago families get the word out on a little-known birth injury

By Karen Olesch-Williams  
Photos courtesy the O'Rourke family

**F**ifty-one years ago, a perfectly normal and healthy 10-pound, 4-ounce baby boy was briefly stuck in the birth canal because he was too big. The doctor reached in and grabbed tightly onto the infant's arm and pulled him out. Something went wrong.

Each year for the next 17 years Michael Turano made the trip to a hospital in Brooklyn for an annual evaluation of his injured arm. As he recalls that time in his life, Turano still shudders, remembering the doctor asking him to "walk the wall."

"They made me place my fingers on the wall and I had to walk them up like a spider to see how high I could get my arm up," says Turano. Apart from this annual visit to the hospital, nobody but his family talked to him about his birth injury.

It wasn't until Turano was 17 and applied for a spot in the army that he learned there was a name for his condition: brachial plexus injury (also known as ERB's palsy, Klumpke's palsy, brachial plexus palsy, or Erb-Duchenne palsy). The army turned him down, telling him that as far as they were concerned, he only had one arm.

Turano copes with this birth injury every day of his life. He has to make sure his belt is on before he pulls on his pants because he can't reach behind to pull it through the belt loops. At parties, he balances his plate of food on the back of his left hand because he can't turn his palm towards the ceiling and he can't use his left hand to eat. He has never seen his left palm without the aid of a mirror. Incredibly, there was no treatment for Turano as he was growing up—no surgery, no physical therapy, no chance for him to gain more control over his arm.

In January of this year, through a random meeting on the Internet, Turano encountered a woman named Kathy O'Rourke, the mother of a child with a brachial plexus injury. This meeting would change his life. Turano had never known of anyone else with an injury

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*Emma O'Rourke wears a temporary cast prior to surgery.*



similar to his. As he read O'Rourke's message, he thought, "My God, there are others out there. I am not alone."

**W**hile most two-year olds are learning their colors, Emma O'Rourke, Kathy's daughter, is working hard at physical therapy three times a week so that she can continue to use her arm. Emma also suffered a brachial plexus injury at birth—one that may have been preventable. But even now, 51 years after Turano's injury, very few people have heard of this type of birth injury. If parents do, typically it is because their child has been injured. Most likely information came to them from another parent, an operational or physical therapist, or the Internet, rather than from their obstetrician or pediatrician. Often, parents must rely on their own research to help them find ways to help their children lead as normal a life as possible.

Yet more children suffer from brachial plexus injuries sustained at birth than from Down syndrome or muscular dystrophy. Between two and three children are affected out of 1,000 births. Nonetheless, if you are like most people, you are still not sure what brachial plexus injury is.



*Emma with mom, Kathy; dad, Dan; and sister Maeve.*

The most common form of brachial plexus injuries occur during the birthing process as a result of excessive traction or force being applied to the infant's head during delivery. The excessive force can cause severe nerve damage, a fractured clavicle, and dislocation of the shoulder. Injury to nerves of the

brachial plexus can result in full or partial paralysis of one or both arms.

The injury affects children differently. Some have no muscle control and no feeling in the arm or hand. Some children can move their arms, but have little control over the wrist or hand. Other children can use their

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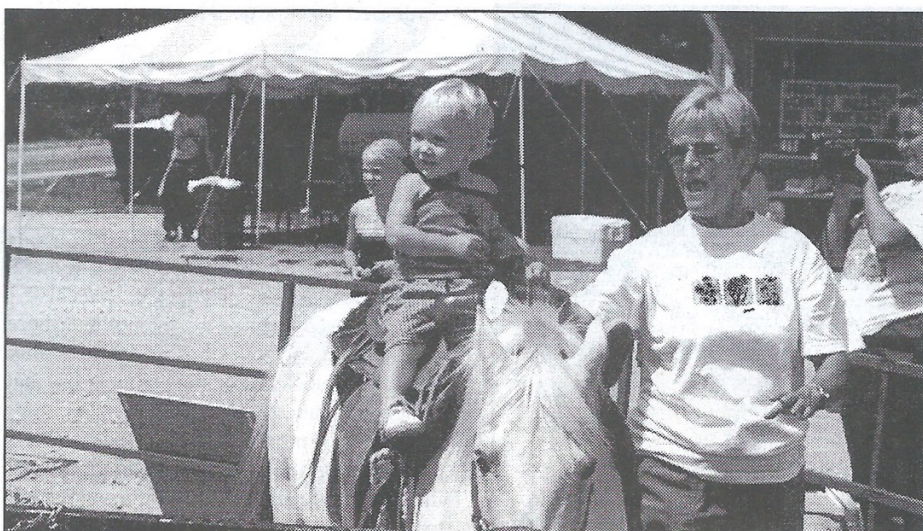
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hands well, but cannot use the shoulder or elbow muscles. Most children can recover and obtain partial use of their arm, but, for the best outcome, brachial plexus injury needs to be spotted right away and treatment started immediately. The two forms of treatment are physical therapy and, for more severe cases, muscle transfer surgery. Before and after the surgery, range of motion exercises need to be done daily to keep the muscles and joints moving.

Many physicians receive little training regarding brachial plexus injury. Parents are often sent home from the hospital without knowing that something is wrong with their infant. Infants who are visibly injured at birth, those suffering from a fractured clavicle or dislocated shoulder, are typically sent home with their arm pinned to their sides, and parents are told to follow up in six weeks. In many cases the injury may be healed in that time, but the infant may still not be moving his arm. Parents may be told to "wait and see" if the problem resolves itself. In some cases it may, but in others the "wait and see" approach can be devastating to the infant's recovery potential, and the consequences can be permanent.

Had it not been for Kathy O'Rourke's persistence, her daughter Emma would not be able to use her arm today. Seven weeks after Emma's birth, when she still couldn't use her arm, her physician suggested that the O'Rourkes start Emma on physical therapy. It was at her first physical therapy session that Kathy O'Rourke found out what was wrong with her daughter. "The occupational



*Emma's arm is locked in place before surgery.*

therapist said to me 'Emma has Erb's palsy.'" O'Rourke left in a daze, and after researching the condition on the Internet, was devastated to learn that it was possible that her daughter might never use her arm.

As she found more information and talked to other parents of children with Erbs, O'Rourke realized that she was not alone. She found that other parents had not received any information or had been misinformed by their physicians and left to their own devices. Many parents were advised to take the "wait and see" approach.

**R**ahul Nath, M.D., director of the Brachial Plexus Center at Texas Children's Hospital, strongly disagrees with this approach. "For the best results, [in situations where surgery is indicated] the surgery needs to be done before these children are a year old. The purpose of the surgery is to improve how well the arm functions, and after one year the surgery may not be as successful."

The Texas Children's Hospital has one of the largest and most comprehensive brachial

plexus centers in the country, with a team made up of pediatric neurologists, neurosurgeons, plastic surgeons, neuromuscular specialists, physical therapists and occupational specialists. While other hospitals may see two or three cases of brachial plexus each year, the Texas Children's Hospital sees about 1,200 children annually.

Nath believes that physicians take the "wait and see" approach because they are not exposed to the volume of cases he sees. On a daily bases, he observes the positive results the center's treatments have had on these children. "These are not trivial injuries; they are long term permanent disabilities," says Nath. He believes that education and aggressive training of physicians will help increase awareness of the treatments available. Nath makes scientific presentations worldwide, and frequently meets with parent groups to get the word out.

Like Nath, Kathy O'Rourke believes education is the key to success, and is determined to help other families become aware of the surgical options that made such a difference in her daughter Emma's life. Together with

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*Emma and her dad on the day of her surgery in Texas*

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*Surgery and physical therapy help Emma regain flexibility in her arm.*

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Michael Turano and two other local families, she has started a group called Chicago's Brachial Plexus Injury Support Group. Their main goal is "to inform people, learn from people, and more importantly promote awareness of brachial plexus injuries," says O'Rourke. "The need is definitely out there. After we ran an article in the local paper, several families contacted me to seek out more information, and four of those families only lived a few blocks from me. For an injury that is tagged as rare, it sure is common.

"One of the most important things we do is provide information to newly diagnosed families. We can tell them the questions they need to ask their doctors," says O'Rourke. The support group educates people through the media and mass mailings. Turano, through contacts at work, was able to get Governor George Ryan to make International Brachial Plexus Awareness Week official. It will be held October 15th through the 21st. The support group also has a web site which provides information (see below), offers suggestions on activities that can be done during play time and bath time to exercise the arm, and recommends other helpful web sites.

In addition to increasing awareness of

brachial plexus injuries, prevention is among the goals of the support group. Some women, particularly if their babies are likely to have a high birth weight, may be at higher risk of delivering a baby that will suffer from a brachial plexus injury at birth. If they are aware of brachial plexus injuries, they will have the opportunity to discuss it with their obstetrician before delivery. The support group would like to see literature about brachial plexus injuries in physicians' offices so that information is readily available to their patients.

The support group meets from 7 to 9 p.m. the third Wednesday of each month at Hope Children's Hospital, 4440 West 95th Street in Oak Lawn. A summer picnic will be held on August 18 at Brookfield Zoo. It begins at 9:30 a.m., and will feature an instructional slide presentation and question and answer session with Dr. Nath of the Brachial Plexus Center at Texas Children's Hospital.

For more information, e-mail the Chicago Brachial Plexus Injury Support Group at [chicagobisupport@aol.com](mailto:chicagobisupport@aol.com). Additional information is also available through the Texas Children's Hospital, [www.texaschildrenshospital.org](http://www.texaschildrenshospital.org); and through the United Brachial Plexus Network at [www.ubpn.org](http://www.ubpn.org).

*Karen Olesch-Williams is a freelance writer from Algonquin.*

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