



**Julian E. De Lia, M.D.**  
**2010 Pacesetter Award Recipient**

Julian De Lia is the founder and medical director of the International Institute for the Treatment of Twin-to-Twin Transfusion Syndrome (TTTS), located in Milwaukee, Wisconsin. He is being honored for his outstanding contribution to maternal fetal medicine and for his pioneering work in the development of fetoscopic placental laser surgery.

Twin-to-twin transfusion syndrome (TTTS) is a rare condition affecting approximately 10% of identical twin pregnancies. In the United States, that is about 2,400 pregnancies a year; worldwide, about 200,000 cases. The syndrome, which has no primary prevention, is considered one of the most challenging problems in modern obstetrics.

TTTS has a complex pathophysiology. It occurs when twins share a single placenta containing abnormal blood vessels that connect the twins' circulations. It is 200 times more common than conjoined or Siamese twins, where the twins' bodies are joined. In most cases of twin pregnancies, the blood is shared equally between the twins, but in TTTS, the abnormal blood vessels cause the blood to pass disproportionately from one twin to another. One fetus, the donor twin, pumps blood to the other fetus, the recipient. Without intervention, the recipient receives too much blood and may develop fluid overload, heart failure, and die. The donor twin may also die from not having enough blood.

TTTS can develop at any time during pregnancy, right up to the delivery at term. It is estimated that 80% of these fetuses will die without treatment. "The tragedy," says Dr. De Lia, "is that the babies are developing normally. The problem is with their placenta."

In the early 1980s, the outlook for twins with TTTS was relatively hopeless, because there were no tools to diagnose the syndrome and no effective treatments. Studies showed a twin death rate of more than 90%, while more than half of those who survived experienced significant handicaps, including cerebral palsy.

In the first part of the '80s, advances in ultrasound significantly improved the ability to diagnose TTTS. At the same time, Dr. De Lia began to study the problem under America's leading pediatric pathologists, and to develop a surgery to treat it.

On October 3, 1988, Dr. De Lia performed the first fetoscopic laser occlusion to destroy the abnormally connected blood vessels. Shortly thereafter, he received the Research Award for Innovations in Gynecologic Surgery from The American Congress of Obstetricians and Gynecologists, and in 2003 he was named by the International Fetal Medicine and Surgery Society as one of the four "fathers of maternal-fetal surgery."

Today, Dr. De Lia's placental laser surgery is the most commonly performed intrauterine surgery to benefit the fetus throughout the U.S. and abroad.

There are currently a number of treatments for TTTS, depending on when in the pregnancy the syndrome develops and is recognized, and on its severity. Dr. De Lia's team has identified two factors in TTTS mothers that impact fetal well-being: the presence of

Since 1988, Dr. De Lia has treated patients from 43 states and two Canadian provinces. He has consulted with patients and physicians from 48 states and 55 countries.

maternal protein-calorie malnutrition in most cases, and a shortening of the uterine cervix in 25% of cases, with a threat of premature delivery. Most alternative treatments address the symptoms, and only the laser surgery treats the primary problem.

Dr. De Lia points out that the laser surgery is not needed in all cases. When appropriate, however, and if combined with treating the maternal factors, it dramatically increases the odds for TTTS babies, achieving the highest survival rates with the highest number of healthy survivors and the lowest rates of prematurity.

In 2000, Dr. De Lia founded the International Institute for the Treatment of Twin-to-Twin Transfusion Syndrome, where he performs lifesaving surgery to correct this problem. Since 1988, he has

treated patients from 43 states and two Canadian provinces, and in addition, has consulted with patients and physicians from 48 states and 55 countries. In 90% of the cases in which the operation is performed, at least one twin survives; in two-thirds, both twins live. Less than 5% of the survivors have any disabilities or birth defects, compared with up to 25% of those who have had other treatments.

New York Hospital Queens is honored to be associated with the brilliant and inspiring work of Dr. Julian E. De Lia and proud to present him with the 2010 Pacesetter Award.



## Letter From a Mom

For any woman facing the frightening diagnosis of twin-to-twin transfusion syndrome, Dr. Julian De Lia is known for his ability to provide comfort and counsel and to help achieve a successful delivery.

He has personally performed 300 laser surgeries at his Institute for the Treatment of Twin-to-Twin Transfusion Syndrome in Milwaukee. But he has also provided support and guidance to many others, in his continuous commitment to encourage parents and to save babies.

He offers hope — and help — to these very vulnerable patients, as this letter from Meghan Dolan, the mother of Connor and Kieran Laffman, describes.

“I have never met Dr. De Lia in person, but he is always in my heart. Without his guidance during my pregnancy, I truly believe my twins would either not be here today, or would have serious health issues.

“At 21 weeks, I was advised by a well-known specialist to let go of my boys altogether, or to do selective reduction, because it was highly unlikely that I would carry to 28 weeks. And if the boys did survive, I was told, they would have severe neurological issues. When I asked what I could do, I was told ‘nothing.’

“As one could imagine, I was devastated by such news and felt completely helpless. Fortunately, I was given Dr. De Lia’s contact information and called him immediately. I still remember the day I was sitting in my bed, talking to him on the phone for the first time following the appointment that had left me shattered. I was crying between each word that I spoke, and could barely get them all out. Dr. De Lia was so patient with me. And it was clear he was really listening and even taking notes on the weights of my babies and their fluid levels.

“He assured me that my diagnosis, mild TTTS, was not as rare as I had been led to believe, and that there had been cases in which the babies did survive and grow to be healthy children. Such news was completely contrary to what I had been told, and gave me hope that my boys did have a chance. Any bit of hope meant everything to me at that point in time.

“Dr. De Lia was upfront with me, telling me I had a tough road ahead and would need to take it one day at a time. But he said that he would be right there with me every step of the way. He recommended that I remain on side bed rest and drink three to four protein/vitamin drinks each day, which I did religiously.

“I had weekly appointments with my local OB/GYN and specialist, and reported back to Dr. De Lia after each visit. If too much time seemed to pass between communications, Dr. De Lia would call or write, inquiring as to how I was doing. He even called to wish me well on the Sunday night preceding my scheduled Tuesday delivery. I have never come across a doctor who was so caring and giving of his time.

“My husband and I feel truly blessed that we were able to announce the healthy arrival of our twin boys, Kieran



Connor and Kieran Laffman, healthy and strong at six months.

Thomas (5 lbs., 1oz.) and Connor Matthew (6 lbs., 6 oz.), who were born at 37 weeks, on August 25, 2009. Both Kieran and Connor left the hospital with me three days after they were born, and remain in good health today.

“I am forever grateful for Dr. De Lia’s expertise, and for his unwavering commitment to me and the other families out there that are affected by TTTS and/or unequal placenta share.

In his years of practice, he has touched so many people’s lives. I can’t tell you how many times I think of Dr. De Lia when I see my boys’ faces light up with a smile, or hold their little hands. Thanks to Dr. De Lia several times over for not giving up on me or my boys when the other doctors clearly had.”

— Meghan Dolan