

2003

<from a promise and a vision:[THE_MIAMI_PROJECT]

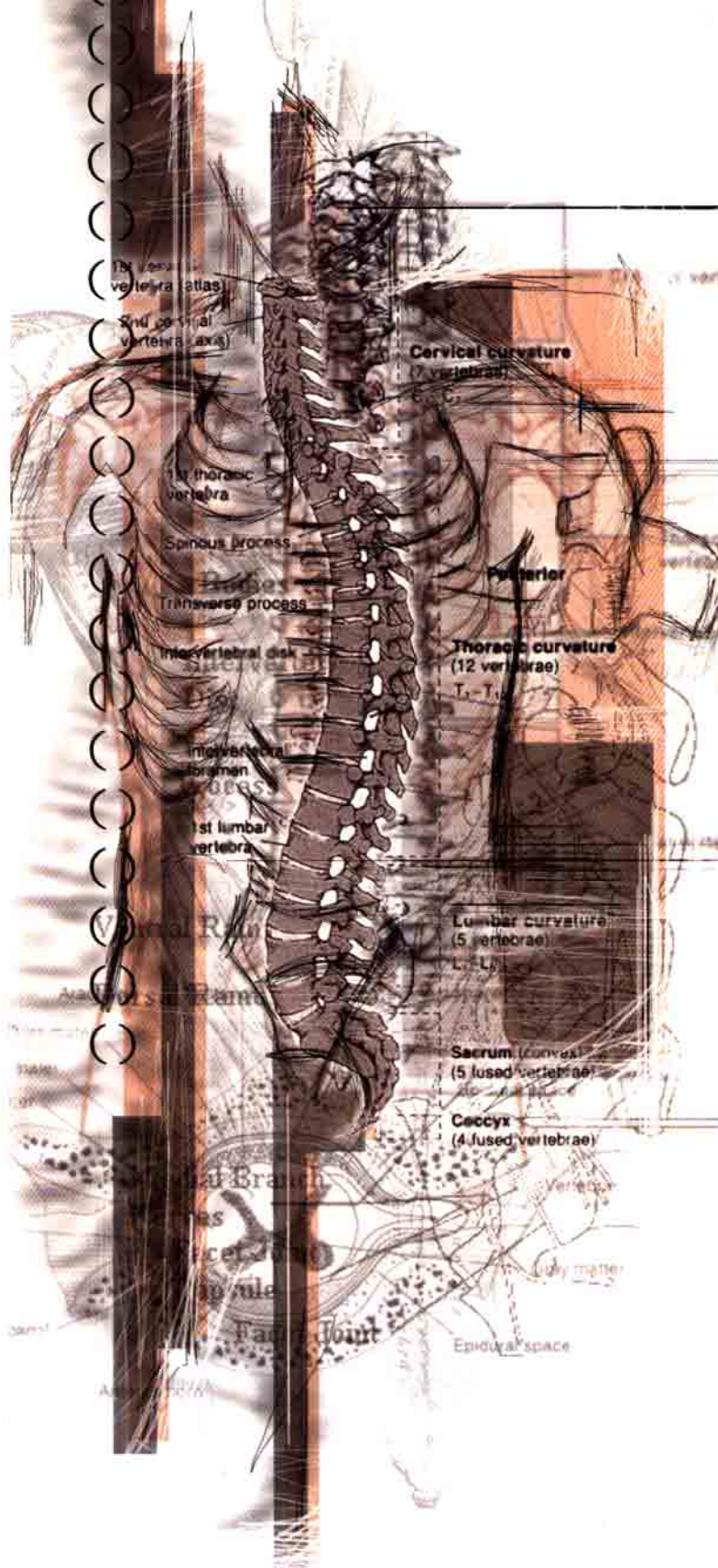
We've all seen the movie: Tom Cruise playing the role of Jerry Maguire, passionate sports agent holding on to his one rogue football player, Rod Tidwell. Impossible to forget is one of the film's more pivotal scenes which depicts Tidwell, vibrantly portrayed by Oscar award-winning Cuba Gooding, Jr., as the recipient of a fierce

tackle by an opposing player. In one swift movement, Tidwell is hurled into the air and comes crashing to the ground, his neck and back accepting the brunt of the force. He lies motionless. A deafening silence grips the arena. In the distance a lone fan is heard yelling, "We love you, Rod!" As his wife watches the game from the safety of her living room couch, her children start to whimper. With all eyes on the downed player, Tidwell begins to blink. His eyes flutter open. And, in the dramatics that only Hollywood can offer, he slowly lifts his head and looks around. As the throng of coaches, doctors and teammates gingerly help him to his feet he takes a few tentative steps and the arena erupts into a thunderous show of support—the scene culminating in a gleeful victory dance.

Had this been a scene from real life, the arrogant-player-turned-affable-sportsman might not have been so fortunate. In fact, Rod Tidwell might very well have become one of the 11,000 Americans who incur a new spinal cord injury each year. Instead of performing a victory dance to the delight of his fans, we might have watched instead as he was whisked away to the closest trauma facility—doctors in a fight to save his life. "Show me the money!" possibly replaced by the mantra, "Show me the cure!"

Football Hall of Famer, former Miami Dolphin Linebacker Nick Buoniconti, has been challenging doctors and researchers to do just that—show him the cure. In 1985, his son, Marc Buoniconti, was playing college football when a single tackle changed the course of Marc's life, and his family's. "It was October 26, 1985, and I was 19," remembers Marc. "I was playing for The Citadel against East Tennessee State when I made a tackle like I had done a thousand times before. This time, the guy flipped around and hit the back of my neck. In one second I went from being in the best shape of my life to lying paralyzed on the ground and fighting for my life.

"Because of my injury, I had the wind knocked out of me and I was having difficulty breathing. I laid on the field for half an hour, they really didn't know what to do. Luckily I made it to the hospital in time; I didn't lose consciousness or go into distress. When I got to the hospital, I felt very helpless. I was fortunate to have my family at my bedside."



As doctors worked feverishly to stabilize Marc, his father began what would be a long stream of phone calls. Wanting only the best care and treatment options for his son, Nick researched facilities from one coast to the next and then took his hunt overseas. In the end, all roads led to Dr. Barth Green at the University of Miami School of Medicine. "My family searched around, not just within the United States, but throughout the world looking for the No. 1 doctor. They were prepared to transfer me to New York, California or anywhere. The name that kept coming up was Dr. Barth Green of the University of Miami," adds Marc. Little could his father have known of the impact this new relationship between the Buonicontis and Dr. Green would have on the future of spinal cord injury research.

One night, shortly after his accident, Nick stood by Marc's hospital bed and promised his son that he would dedicate his life to finding a cure for spinal cord injury (SCI). While Marc turned his focus to getting off the ventilator—a task which would ultimately take almost seven months to accomplish—Dr. Green began sharing with Nick his own vision of bringing together the best scientists in the world focused on finding a cure for SCI. Thus, born from the bedside promise of a father and the dream of a visionary, the Miami Project to Cure Paralysis began to take shape.

Dr. Green envisioned a multi-disciplinary approach that brought together different fields such as neuroscience, biology and chemistry. "We modeled The Miami Project after the Manhattan Project and the Moonshot Project," explains Dr. Green. "We wanted to get the best minds and put them together under one roof to focus on a common goal until they come up with a solution."

"The Miami Project was founded to focus research efforts on improving the quality of life after spinal cord injury. Our research in basic sciences is aimed at understanding and reversing the neurological consequences of the injuries. Our research in clinical sciences is aimed at evaluating and improving strategies that maximize function in persons living with spinal cord injuries today," adds Dr. W. Dalton Dietrich, the Miami Project's Scientific Director.

What started as a promise and a vision has escalated to create the world's leading SCI research facility. As you walk through the doors of the Lois Pope Life Center, the building that houses the Miami Project to Cure Paralysis aptly named after its benefactor, it is as if you are instantly transported to a place where the word *never* has no meaning and a cure is only a matter of when, not if. It was no accident the lobby was designed in such a way that the first images are that of people who have quadriplegia walking—assisted by the very latest in state-of-the-art technology—or working out in an accessible weight room. "This building was built like that on purpose. When you walk through the front door, on both sides, you see what we're about. You see the people.

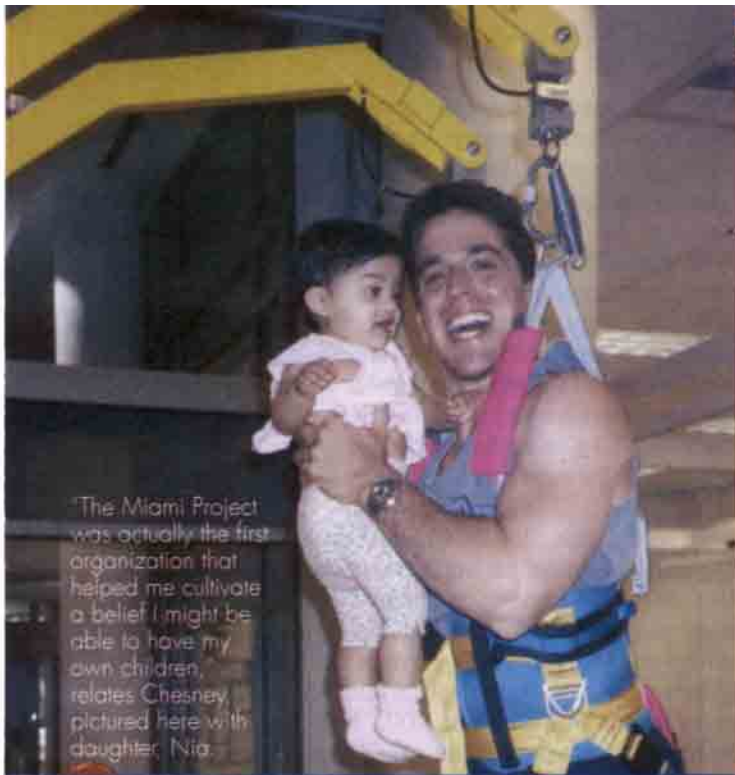
You can't just go look under a microscope—it's a human problem. Whatever we do upstairs in the labs, we want to apply it directly to what's going on downstairs in the therapy or weight rooms," says Marc.

What can't be seen by walking through the front doors are the relationships that have formed over the years between a team of dedicated staff, doctors and researchers and those with SCI and their families. Walking the halls of the building there is an undeniable camaraderie; each doctor, research participant and person with SCI a valuable member of a team taking research to the next level.

Now volunteering for the Miami Project full-time, Marc continues to spread encouragement and an ever-positive attitude to all he comes in contact with. Although he takes no paycheck from the Miami Project or the Buoniconti Fund (the fundraising arm of the Miami Project), Marc is seen making his way around the office almost every day. "I'm walking at 3:00," he tells a group of reporters. "Come watch me walk." By the time 3:00 rolls around, a large group of curious observers has formed to watch Marc walk, assisted by the Lokomat, one of only three in North America. Carefully harnessed to a precise support system, he is gently lifted to the standing position atop a treadmill as the Lokomat begins to replicate a natural walking motion. While Marc has no feeling below his neck, this type of therapy may prove crucial in an effort to keep his bones from calcifying and his muscles from atrophying, allowing him to maintain the best possible physical condition for the time a cure is found. Always positive, Marc sees himself as an ambassador, and finds the opportunity to share his experiences with people a gift. "People are told when they have an injury they may never walk again.



Former Hall of Famer Nick Buoniconti, with his son, Marc.



"The Miami Project was actually the first organization that helped me cultivate a belief I might be able to have my own children, relates Chesney, pictured here with daughter, Nia."



The devastation on people, on their faces, it's so difficult to see them go through the early emotional changes. SCI can happen to someone you love, and it's very difficult for a family to deal with. I have seen people who have struggled for their life turn out to be productive, very independent confident people. It's great to see that side. It's so important for all of us to give them another chance."

The majority of the world will never experience the initial devastation of an SCI, and possibly never be intimately acquainted with a person who does. In fact, the odds of never incurring an SCI are in our favor. Because of this, when it comes to supporting SCI research, we often look the other way. After all, avoiding an SCI is relatively simple: don't get involved in a wild car chase, avoid dangerous football tackles and stay off horses or unsecured high platforms. Right? Not exactly.

What if you could undergo a spinal cord injury by just laying your head down on your pillow? Scott Chesney's real-life story perfectly illustrates no person is exempt from potential injury. At the age of 15, Chesney was in great shape and an avid basketball player. One night after a long game, Chesney went to bed and woke the next morning to a feeling of numbness in his left big toe. Within only 48 hours, the numbness had traveled up both legs and paralyzed him from the waist down. Caused by a malformation of blood vessels that had been lodged in his stomach muscles from birth, Chesney's injury was the result of the vessels rupturing and placing pressure on the spinal cord.

"In the hospital, I was basically told I would never walk again and I would never be able to father my own children. At that time, I was both stunned and shocked. The next set of doctors told me I was very lucky," recalls Chesney. "I said, 'How can you tell me that I'm lucky? You've just shattered my dreams.' Of the eleven known similar cases prior to mine, seven of the malformations occurred in the brain and the individual did not survive. In my case, it started in the spinal cord and went down. At that moment, I felt like it was a blessing that I was still here. It pretty much set my life in a different direction and one that has been truly rewarding and truly inspiring."

Since the occurrence of his injury, almost 18 years ago, Chesney has become a motivational speaker and traveled the world researching alternative medicines as they relate to paralysis. To date, he has looked into nearly 70 alternative forms of medicine and believes there is practicality and benefits to all of it. One particular treatment he vested time and energy in is called Ayurveda, a 5,000 year-old holistic approach to healing, which focuses on the body's ability to heal itself when at complete rest. During treatment, all stimuli is reduced to the lowest possible degree. Food intake is limited to a small breakfast, television viewing is prohibited, reading and writing is limited to one hour per day. Shaving or trimming fingernails are small examples of forbidden "exertion." Deciding to completely dedicate himself to trying Ayurveda, Chesney elected to live in total silence for the first 13 days. On day 28, he

began to wiggle his left big toe on command. Up and down. Up and down. While the ability to move his toe only persisted for about two and-a-half hours, he was rejuvenated and returned to the states with a new outlook on his future and an internal belief he will someday walk again.

What attracts Chesney to the Miami Project is a like-minded philosophy that many avenues of research may prove beneficial. "I don't think there's going to be one cure, but a number of treatments that are going to benefit people. One example being their male fertility program. I think the pursuit, their open-mindedness and expansiveness is demonstrated by the researchers and scientists they've brought from different parts of the world. It's not about egos; it's about coming together and bringing in the best scientists and researchers who can work together as a team. I don't think there's a more unified team in the entire world than the Miami Project to Cure Paralysis. As a person who wants to get out of the wheelchair, I'm encouraged by their commitment to explore all different avenues such as stem cells or primate research cells. Their intention is just to get this done—to help people walk again," notes Chesney.

"It is more and more clear to me that one simple discovery is not going to directly lead to a cure for paralysis," concurs Dr. Dietrich. "The concept that one study will uncover the "silver bullet" that will lead to successful regeneration and a cure for paralysis is not likely to materialize. On the contrary, a number of small steps, each bringing us closer to a cure, are most likely the means by which our goals will be met. This is exactly why the Miami Project to Cure Paralysis is such a special and important program. Here, a broad spectrum of researchers, clinicians and therapists have been brought together to attack the problem of spinal cord injury. Expertise in the fields of electro-physiology, transplantation, surgical interventions, regeneration, and molecular biology are all needed to successfully position the many parts of the puzzle together for successful therapy."

Since its inception, the Miami Project's goal has been to advance the basic understanding of spinal cord injury and the processes needed to promote regeneration. By bringing together researchers studying both human injuries and animal models, the Miami Project is striving to accelerate the translation of laboratory successes into clinical applications. The project works to simultaneously develop techniques to better evaluate the natural course of tissue damage and recovery after human injuries, to study similar injuries and innovative therapeutic strategies in clinically relevant animal models, to isolate and grow human cells for transplantation, and then to apply results of animal studies to studies of the human injury. This can only be accomplished by rigorous and objective evaluation of the functional results of new therapies.

To date, the Miami Project's successes are numerous. Groundbreaking pathology studies of the human spinal cord after injury have been conducted and researchers have developed new intraoperative monitoring techniques and neuroprotection strategies. Incisive physiological studies



have located spinal circuits that coordinate human walking and researchers have been successful in identifying new reflexes that develop after injury, confirming the adult human spinal cord can be functionally rewired.

Also coming from the Miami Project has been the development of methods to isolate and grow large populations of adult-human Schwann cells (growth supporting cells) that promote regeneration of nerve fibers from human central nervous system tissue as well as exciting new work showing various combinations of grafted cells and growth factors which promote unprecedented spinal cord regeneration.

In addition to striving for a cure, researchers at the Miami Project also focus on various quality of life issues faced by people with SCI. The Project's male fertility research program is one such study offering new hope to those that dream of being able to father their own children. The intent of the male fertility program is to learn more about what happens to disrupt male fertility following SCI. Studies so far indicate that problems are not caused by lifestyle factors, but may be related to abnormalities in chemical factors within the seminal plasma. Other possible sources of infertility caused by SCI and treatments to reverse the problem are currently under investigation.

"The Miami Project was actually the first organization that helped me cultivate a belief I might be able to have my own children," relates Chesney. "When doctors originally shared with me that I was not going to be able to walk or sire my own children, that was a scar and a wound I didn't think was ever going to heal. But, seeing is believing. I saw babies of research participants from the Miami Project. Eventually, I had research done on myself, and they helped me to refocus and to believe that this was possible." Today, Chesney and his wife, Pat, are the proud parents of young Nia, a life which represents the culmination of years of dedicated research.

"The Miami Project has been called the Mecca of SCI research, because it really is. People come from all over

the world, just to come through these doors, to hear about the research and see what's happening because they really want to be a part of something. They have to be a part of something. When I was first injured, nothing like the Miami Project existed and it left us with very little," Marc notes.

For many who have an SCI, the onslaught of new *cures* or treatments that are coming from around the world can become overwhelming, and ultimately even discouraging. In the end, the majority of medical *breakthroughs* are impossible to replicate in the clinical setting. Under-scoring the validity of their research and the integrity of their findings, the Miami Project was recently designated as a Facility of Research Excellence in Spinal Cord Injury by the National Institute of Neurological Disorders and Stroke (NINDS). Furthermore, the Miami Project was awarded \$2.6 million by NINDS to specifically support the instruction of new researchers in the field of SCI with the aim of promoting consistency of procedures and practices across laboratories. Another component of the program is to review and replicate novel treatments for SCI. To those involved, this is but the latest in a series of events that confirms they must be doing something right.

"There's been new cures announced every year for the last five years and it's all a lot of hype. People know they can trust what they hear from the Miami Project and that the information will be real. People are so appreciative that we're doing something toward a cure. Everyday we go to work and we know why," Marc says with a smile.

■ ABILITY

by Romney Snyder

For additional information about these or other Miami Project research programs, call 1-800-STANDUP and leave your name and telephone number or visit www.themiamiproject.org www.thebuonicontifund.org

For more information on Scott Chesney, please visit www.d2motion.com



Technician J.P. Brunshwig looks at cells on the electron microscope.