

## Dean Goldschmidt's Interview with Marc Buoniconti

April 25, 2008

**PJG:** The Miami Project to Cure Paralysis is probably one of the most extraordinary projects that ever took place in the medical field and the neuroscience field. The Project was launched by Barth Green and his vision, initially, was to create almost a Manhattan Project. Then when you and your family came in to The Project, it simply took off. Again, as far as I am concerned, I have never seen [in the biomedical field] the intensity and the concept that was invented to find a cure for paralysis. I'm just curious -- I have had the pleasure and opportunity to get to know you for about two years, and actually we met the very first time I came for an interview when you were at a restaurant in Miami and I came for an interview with Luis Glaser and we were introduced -- and I wonder if you could describe how you became aware of The Miami Project and what your role was then. Now you are president of the Project Foundation and I just wonder if you could explain to us how it happened and what it means to you. I have a couple of specific questions, but I would like to hear it from you.

**MB:** Sure. First, I want to thank you for inviting me here to spend a little time with you. This is a different forum than I'm used to, so it's nice to be here, hanging out with you in your office.

**PJG:** We usually talk business.

**MB:** It's really nice, yeah we're usually at the table — we're at the couch here so that's really nice. You know, when I think back to The Project and my involvement and the involvement of my family, from where we've come and where we've grown and how it started, I have to give the initial credit, of course, to Barth Green. You have to take a step back and see his roots, where he came from and his life as a neurosurgeon. I always talk about the frustration that he had to go through and he still goes through having to tell loved ones every day that they will be paralyzed, that they will never walk again -- having to deal with that on an everyday basis. You know, I don't envy his job or other physicians' jobs that have to tell these traumatic stories to their loved ones, that, specifically spinal cord injury, they will never be able to walk again. That was the message that he had to tell these families, and I think that frustration just grew and grew, to a point where he couldn't take it anymore and he was either going to quit medicine or do something about it -- and you know Dr. Green never is going to quit anything. It was, I think, a

choice, to try to do something about it, try to come up with a solution, and in 1985 to say that we are going to create a center that is going to cure paralysis and get people out of wheelchairs. It was not only a bold announcement by Barth, but something that put his reputation on the line. You know, people really started to ridicule him as someone who was giving false hope, but when you think back about all these success stories in medicine and not just in medicine, in human endeavor over time, it's people who are taking risks, and people who are going against the grain and sometimes doing things that are not the norm and I think that's what Barth did. He said, "You know what, I'm putting my foot down now, I'm standing up for those who can't and saying that we have to take a stand on paralysis." He had the vision, he had the enthusiasm, he had the commitment, but he didn't have the resources.

**PJG:** Yes.

**MB:** He didn't have the resources and it's all about timing -- you know, life is all about timing in so many different ways. At about that time I had my injury and a few other soon-to-be high profile people had an injury all around the same time, and it was a pulling of resources and it was Barth Green laying out his vision as eloquently as he does with that passion. For me it was a bedside promise that my dad made to me when Dr. Green talked about The Project. My dad made a commitment to me that he would do anything, everything in his power to raise the money necessary to start this new, fledgling Miami Project to try to help his son.

**PJG:** Unbelievable. I do remember, I think I told you I was in Charleston, South Carolina, when you had your accident.

**MB:** Yeah, at MUSC [Medical University of South Carolina].

**PJG:** I recall there was a cloud of sadness around the city when it happened. It was such a dramatic event that even those who did not know you at all felt very strongly, but then you brought that incredible hope with you which is that "I'm not going to give up, I'm going to fight the fight, we're going to find a cure." Everybody got up with you in that town, in that fight. I can only imagine being a very young man at the time and looking ahead; it's difficult when you're 20 to see three years ahead, not to mention 20 years ahead. Did you ever think that you would become the incredible personality and actually superstar that you have become because of your work, your courage, your energy and steadfast commitment to help everybody who has experienced your condition?

**MB:** I appreciate that. You're talking about the other Buoniconti superstar. Sometimes I still don't believe what I've gone through and whether it was a metamorphosis or just growing up real quick, having to mature and become an adult really quick. I joke that at 19 and playing football, all I cared about was sports, girls and having a good time, and in a split second my life changed. That energy that I utilized so much on the field in doing those types of things, I had to re-channel it really, to first of all fight for my life and then to try to again re-focus it on something completely different. My life was about being physical, everything about my life was being physical, and now I had to turn on the intellectual and emotional and it was not easy for me. But I had unbelievable guides. I had unbelievable mentors in Barth and in my father and in my family, so going from a football player in the best shape of my life to fighting for my life but then being able to experience the things I have and to be a part of something that was greater than I ever would have imagined in my life, to be part of a world-changing movement, a revolution toward a cure, I found myself in a unique position to be able to try to make a difference. I went from rehabilitation in a hospital to a position as Ambassador of The Miami Project, which meant that I was dedicating my life, just like my father and Barth, to do whatever it took to raise money to find a cure. So I went from a football player and a little bit of a mischievous young man to now growing up very fast, slapped in the face with reality and now having to be part of something that was extraordinary, was going to change lives. To see how I have grown as an individual over time — miracles do happen. I owe everything, I would not be here today, if it wasn't for my family and Dr. Green, who saved my life, and the University of Miami, which had offered us the opportunity to create a Center of Excellence, again just as bold as Dr. Green. The University of Miami put their head on the chopping block as well, I mean their reputation, to open up the doors to The Miami Project. I look back at my life and say, "You know what, it's going to be all worth it because the things I've been able to do and experience and to see I never, ever would have been able to do in my previous life." That's why I really appreciate my life and my position as a fund-raiser and an advocate for spinal cord research because I have seen the most unbelievable things in my life. And you know we're going to see one more unbelievable thing real soon.

**PJG:** Tell me a little bit about your mom, your dad and your sister.

**MB:** And my brother.

**PJG:** And your brother.

**MB:** He's in Orlando -- we forget about him sometimes.

**PJG:** I see the other ones all the time.

**MB:** You know, I'm going to try and not get too emotional but it's hard — it's hard not to when you think about ...

**PJG:** Don't worry about it.

**MB:** ... When you think about our family was always close knit and we always relied on each other. It took a whole new turn when I had my injury from the moment that I had the injury to them being by my bedside that night, where my sister and my brother refused to leave the hospital room — they wouldn't leave. That night my parents tried to go out in the hallway and the nurses and doctors gave them another patient room so they could at least lie down a little bit. When you think about what they had to go through initially -- I could only imagine what I would feel like if it happened to my brother or sister. My parents have never left my side. My dad basically gave away his career to help me. I mean he was working as a president and COO of a Fortune 500 company and just was not able to give enough time to his son, and he made that promise to me. My mom is the backbone, sometimes the silent backbone, but she is the foundation of our family and even though they are not together anymore, it's just that she is such a strong and caring person. Her name is Teresa and we call her Mother Teresa, cause she's just that type of person and anyone who knows her is a better person for that because she is just really incredible. And my sister and brother, when we were young they used to torture me to death. They are the older brother and older sister and they used to pick on their little brother, me, but it made me tougher and, you know what, now I really see the true love they had for me. And my brother runs the largest chapter for the Fund — you know we have chapters all over the country -- he raises a quarter of a million dollars a year for his little brother and he does that out of love, and my sister too and her husband and the extended family. It's a family affair, just as it is for Dr. Green and the Sayfies. I mean you look at Suzie Sayfie and the Sayfie family, half of the family has either volunteered or worked for The Project and the same with Dr. Green. Jenna Green is now going to be working at The Project as well. It's passion, you know how it is: You get involved in something like that and it's all about relationships and people who care.

**PJG:** You have an absolutely extraordinary family you know, and it's a pleasure, I must tell you, when I see your sister or your mom or your dad in a group of people. They always know where you are, they always kind of cover you. The love is transparent, it's totally there, there is

no limit to it and it's really extraordinary. I've learned a lot from your family and I've learned a lot from you. I love the "American way" of getting things done that your father has — you know, the next ten yards approach to life, which is not accidental, it's just a very organized way that only people in the United States are excelling at: deciding that there is a longer goal but this is how we are going to go to the next step. The effectiveness that is being accomplished is totally remarkable. It is also fascinating to see the partnership between a family foundation which is really, you know we have tremendous support from everybody on the planet, the powerhouse, and then also the Sayfies, who are incredible organizers of fund-raising as well, and the association of that powerhouse of individuals capable of creating resources for the science and the scientific world and this opportunity that developed where very often you and Suzie have become the interface between the work that has been done in the laboratories and the clinics, in the world of science, and the factory of fund-raising that was developed around The Project, very rare effectiveness. Nothing is wasted -- it's just a very tight, very disciplined organization and I believe it's a model for the future of science. If you think about it, there was not much science in Miami 55 years ago [the Miller School of Medicine is 55]. I say it kiddingly, but it's true: If somebody had an issue of *Science* or of *The New England Journal of Medicine* it would have been a tourist from Boston who had dropped it on the beach while taking a week's vacation. For both the University of Miami Miller School of Medicine and also for The Project to be able to succeed in an environment that did not have a lot of science, like Hopkins and Harvard who have been there for 200 years, the ability to come in, plant and grow is just a formidable experiment and quite significant for the future of medicine. It goes even beyond paralysis quite frankly, it is just a successful way of getting things done in science and I am thinking a lot about it.

Hope is becoming more concrete. We already know that in rodents and small animals, paralysis has been resolved substantially. I was interviewing Mary Bunge, and her work with Schwann cells has been extraordinary. Sometimes you need people with inspiration to get science done, and certainly Mary and Dick had a very unique vision for what would repair the spinal cord, but we see more and more evidence with stem cells and their ability to repair tissues that we are not far away from a solution. I was talking to Dalton a couple of days ago, and I'm always a pain in the neck — I'm always asking him when the first patient of that trial is coming in, and by the time September comes we will have patients in clinical trials and there are going to be stem cell

trials and the Schwann cell trials. I really believe, as I told you, within four years we are going to be in a very different place and then we will look back and I hope 20 years from now we will look back and we will be walking somewhere. You'll be next to me and I'll be next to you and I may be the slow one then.

**MB:** I hope so — we'll both be moving and shaking.

**PJG:** And we'll think back about this. I feel blessed for the opportunity to be a small part of this, but particularly for the opportunity of knowing you. You are such a wonderful individual and I am so proud of you, what you do and just of knowing you.

**MB:** Well, I appreciate that.

**PJG:** The only thing I wanted to say was that when I studied medicine, I thought honestly that repairing a damaged spinal cord was probably the most difficult project that anyone could ever encounter, and now I see it as a clearly feasible project that will require some additional steps but it's not an infinity of steps, it's a definable number of steps. I don't think that it will be completely resolved at once, but it will be a series of steps that will progressively improve the reconstitution of the connection of the nervous system between the brain and the limbs and it's going to be in your lifetime, certainly yours, I hope mine.

**MB:** Or less. Let me just first say that I have really appreciated your friendship over the last two years and I have said it privately to you and publicly that we are very fortunate to have your leadership here in the School and the campus, and it goes beyond the Medical School. You have brought a lot of enthusiasm and a lot of vigor and have brought tremendous change to make our Medical School a better place. From someone who's been here for a long time, it's great to see that spirit and passion that come from you. I thank you for your hard work and being there -- yes, for The Project, but I see what you do for all the departments and everybody and everything here at the Miller School. You have done great work. I applaud you for your work. Let me just try to address some of the things that you mentioned. Yes, it's a very lofty goal to cure paralysis, there is no question about it. You mention it may be the most difficult medical condition or injury to overcome, but maybe it had to take one of the most determined families to be in the role to do that. You know my father, he is "join us or get out of the way because we are not going to wait for you." That's how he was taking on offensive linemen and huge players -- my dad is 5' 11, 220 pounds, one of the smallest football players that ever played in the NFL, he played 15 years, a Hall of Famer. You know he's a tough guy and so maybe paralysis needed a tough guy

and a tough family to take it on. I really think that was part of it. My father was not going to let paralysis beat us and our family, and the prognosis to me was unacceptable. We're going to fix it no matter what it takes. That's why I think in 1985 and before 1985 you didn't hear anything about paralysis or research or anything like that and it took my dad to put his foot down and to pound the table and say, "We're going to change the situation," and The Project really came out from nowhere. Like you say, Miami, the University of Miami wasn't really known for discovery, and here is a world-class facility coming out of the ground. It's 22 and you think, 22 years, but in research that's like a split second. In research years that's nothing and here comes this center, out of the ground. Before The Project was all about hope, there is no question about it, and by now it has surpassed the hope message and we're talking about realistic feasibility and hope for people to have recovery. And I think you talked about the uniqueness of The Project. I think The Project is so unique in so many ways. Unique in that it took a private individual along with a determined neurosurgeon, someone who really didn't spend a lot of time in research, just was really motivated by wanting to help his patients — not motivated by anything other than trying to help people -- and then a private individual who made a commitment to their loved one that, let's just team up and let's just work this from different angles and different ends. You know, he had the fund-raising component of that, and then you had Dr. Green, through the University, working with the medical and research component and they merged and that's really what they did. My father really took the initiative as a businessman -- again, he ran a Fortune 500 company -- to say, "We're going to run this like a business, we're not going to fund 20 different research centers all around the country cause you're not going to be able to keep an eye on these people. Where's the accountability, where are the results, where is the camaraderie, where is this collaboration of minds that Dr. Green so eloquently talked about?" That's the vision of The Project, making people work together and getting it done efficiently and effectively, and that was really what was different. Not just working together; let's combine basic scientists with clinicians, let's put them in the same room. You know clinical scientists are asking way different questions than basic scientists, and then let's put the neurosurgeons in there too, people who are actually working on humans to make sure that this whole strategy worked. Now what I see that really pushed us forward in a way is that we know that we both rely on each other — our fund-raising relies on the science. You know, for us to be able to tell the scientific

story to our donors sells that science, but the science also has to realize that they rely on the fund-raising to get the job done.

**PJG:** Absolutely.

**MB:** So here we are, meeting with Dalton and Suzie and a lot of times with you to package our science in a way so we can sell it to a lay person so they can understand our vision, but also the other way around. When we are talking about putting together a fund-raiser, we want to make sure that we present our science, because most recently our science has been what's selling The Project. That is the best way to raise money, to be able to sell the science because we no longer have to just invent ways to convince people to give money — here we are in clinical trials. We have taken people's investments over this time and you know these people want to see results and finally -- we say finally and it has only been a short period of time -- we are, imagine from the beginning of starting something 22 years ago to be on the verge, four years, six years, eight years, who knows when, but to be working in humans in only a couple of decades, I think, is nothing short of miraculous.

**PJG:** Extraordinary. And you mention Nick your father and his ability to, with you, convince people that it's the right thing to do is extraordinary and the force he brings to his comments explains why, year after year, you have some of the most substantial benefactors in the world gathering together with you and your father to decide this is what we're going to put in this year.

**MB:** He's a hell of a speaker.

**PJG:** It's exceptional. You know, I have a German Shepherd at home and I've always been fascinated by these dogs because they never truly sleep, there is always a little fiber in them that is vigilant and they always have their ears standing like antennas.

**MB:** They sleep with one eye open always.

**PJG:** Yeah, and I must tell you that the way I feel is that at the Miller School of Medicine, we will never be resting. Even when we are supposed to be resting, we're still going to be thinking about how to find a cure for paralysis, not just when we are fully awake. Nobody will sit down, nobody will relax on their heels until we find a cure for paralysis. The opportunity that a group of talented individuals as we have here brings to destroying the barriers between us and the cure for paralysis is one of the most extraordinary aspects, if not the most extraordinary aspect, of humanity. It is really what makes humans such an amazing and blessed species on earth, and I can feel it. The motion is untouchable — it is steadfast, determined and unattackable.

**MB:** It would be safe to say it would be one heck of a medical endeavor to be part of curing paralysis. I mean, you are here at the helm, and I give the credit to our two leaders, between Barth and my dad. You know, these two are both amazing. You get in a room with these two and I don't think there is a more strong Type A personality than either of those two. They are like race horses with their blinders on and they just go. It's true -- they are just so passionate about what they feel for and like you said, my dad bringing together people from all walks of the world, not just celebrities and entertainers and business people, and Dr. Green being able to do the same thing from his consortium of friends, all coming together for one cause. You have been to our events and you know that my dad commands a presence that I've rarely seen in other people. I have seen presidents speak, I've seen amazing people speak, but I put my dad up against anybody — that guy, he's amazing.

**PJG:** I agree.

**MB:** You know, you're in the Waldorf and there are 1,300 people and you can hear a pin drop in there and people are on his every syllable. It's a magical night — it really is.

**PJG:** And so are you.

**MB:** No.

**PJG:** You get that from him.

**MB:** Oh no.

**PJG:** Oh Marc, I've heard you speaking.

**MB:** Well I appreciate that, but that's a magical night and we are very fortunate. I personally am fortunate and people say, how can you say you are fortunate, you're in a wheelchair for 22 years. You know, it's because I have seen an ignorance crumble before my very eyes. Not so many people can say that, a whole ignorance of paralysis forever and I see this whole thing happening before my very eyes. It's amazing to be able to see a medical miracle like that in front of your eyes and so I am very fortunate. I'm going to live three lives — I know this for sure.

**PJG:** I know you will.

**MB:** Before, and I have this one, and one more to go, and I look forward to walking on Old Cutler in the morning. My mom says she sees you exercising in the morning. She says she waves at you but you're right in the middle of your exercise so.... No, we are very optimistic, very excited — our clinical trial is going about as good as expected. When I know that we are

doing well is when I have scientists that are very conservative sounding optimistic about our results. You know, when you have Dalton Dietrich and you have Mary Bunge and other scientists leading the way, it's just a matter of time.

**PJG:** We are very lucky for the people we have working on The Project -- the scientists, Mary and Dalton and the entire team.

**MB:** But you know, you have to give yourself credit too. You helped us fan the flames. You really need to do that, and science is wonderful but you are not going to do science for the sake of science, it's got to take you somewhere and you know sometimes people need a little enthusiasm, a little kick in the butt. I think that's healthy and I appreciate the support of the University.

**PJG:** We'll give ourselves a tap on the back when you are standing to do it.

**MB:** That's right.

**PJG:** Until then, I'm not going to take anything for granted and it's going to be hard work all the way. You can count on me.

**MB:** Good. Well, thank you again.

**PJG:** From the bottom of my heart, thank you for being you and for all that you do.

**MB:** Likewise. Thank you, man.

**PJG:** You are the hero and I will be proud and delighted to work with you until we get it done, and we will — we'll get a cure for paralysis.

**MB:** Thank you very much. And then we'll go on to something else, right?

**PJG:** Plenty of things to do.

**MB:** No, but thank you. It was my honor to be here, my honor, thank you.

**PJG:** All right my friend, thank you.