Before having Peter, we had an unusually unfortunate reproductive history, with four lost pregnancies. We were always encouraged to try again, as these were all classified as "random" events. We thought that we had lost Peter also when Donna started hemorrhaging early in the pregnancy, but it turned out that there had been two fetuses, and that one had survived. Right to the end of the pregnancy, Peter always had top scores on all of his biophysical tests. We were told that he had an unusually strong heart and could be quite an athlete. Our first possible hint of trouble came when, four months before he was born, he was found to have clubbed feet. However, as this does run in part of my family line, and is easily repairable, we weren't overly concerned. One week after the due date, Peter still did not start moving out in the birth canal, even in response to induction. His obstetrician then decided to do an emergency C-section on December 19, 2003. Much to our surprise and dismay, he came out extremely floppy and in respiratory distress. He needed oxygen via a nasal canula. Peter was transferred (accompanied by me) overnight out of NYU to the Mount Sinai Neonatal Intensive Care Unit, the reason given to me by one of the doctors at the NYU NICU being that there were "too many babies in distress, and that was unfair to the NYU staff". Donna was meanwhile left to recover at NYU while worrying about what would happen to Peter. I promised her I would take care of him. It was very hard on the three of us, but I shuttled between the two hospitals, catching occasional naps during the cab rides.

It soon became apparent that Peter had a very serious condition. His lungs collapsed twice, and he had to be intubated. The wonderful team at Mt. Sinai included neonatologists Dr. Ian Holtzman and Dr. Michael Green, geneticist Dr. Judith Willner and neurologist Dr. Alan Aron. Within a couple of weeks, they confirmed via muscle biopsy and genetic testing Peter's diagnosis of X-linked Myotubular Myopathy, resulting in extremely weak skeletal muscles, and for which there was no known cure. They said that, while they could do nothing about the diagnosis, something in Peter's rapid improvement gave them great hopes for him. Peter stayed at Mt. Sinai for seven weeks, during which time he had a tracheotomy and a g-tube placed. He was transferred to Children's Specialized Hospital in February 2004, where he stayed until July of that year, when he came home with us, having improved even further. We were told that he would likely remain ventilator dependent for the rest of his life. We read all the literature on XLMTM, in particular the heroic efforts of the Joshua Frase Foundation to find a cure. Peter's improvement after coming home was remarkable. On June 17, 2005, he gave me the best possible 40th birthday present by coming off the vent for the first time ever for three hours. We celebrated with a lunch at Panera's. He started "cruising" (walking while holding on to walls and other sturdy objects) and even took four unassisted steps in January 2006. Unfortunately, that would be the high point of his physical abilities, and he has been gradually declining ever since. His respiratory status, on the other hand, continued improving for one more year, so that by age three, in December 2006, he was off the vent for 24 hours when well. Also unfortunately, that too declined, especially after he contracted the RSV virus in 2009. After that, he had to always be ventilated when asleep. At present, he is able to be off the vent anywhere from 5 – 8 hours total during the day, but only when he is well, and often needing ventilation and/or oxygen for various periods in between. During the period in which he was doing relatively well, he loved riding on a specialty bike, in which he could peddle and steer, with a push bar used by one of us or his nurse for support.

Peter had a stomach hemorrhage in December 2010, and a very bad liver hemorrhage in March 2012. Amazingly, he pulled through both events, but after the liver event, he was no longer able to ride his bike. His mobility is now very limited, except when he is in the bath, where he is helped by the buoyant force, and can last over two hours. In 2012, we set up the Peter Khuri Fund for Myopathy Research to support the work of Dr. Martin Childers in search of a genetic cure for XLMTM. This research gives us the greatest hope for finding a cure for Peter and other affected children, as does the enzymatic approach. With the help of family and friends, we were able to raise over $170,000. In all these efforts, the role of the JFF has been overwhelming, providing 80-90% of the funding for the entire field, including the single largest contribution to Peter's fund. Tragically, Joshua Frase himself passed away on December 24, 2010, two months shy of his 16th birthday. In his all too short but tremendously inspirational life, he was destined to have an enormous impact on the search for a cure, and it is a great tribute to him and his wonderful family that their efforts to find a cure have not slowed down at all with his passing.

Peter recently celebrated his 10th birthday, a significant milestone for a boy with his illness. He has been relatively stable recently, without any hemorrhaging events. However, he is subject to vasovagal reactions when having a bowel movement. These lead to rapid oxygen desaturation. He has lost consciousness twice as a result and had to be hospitalized briefly in November 2012. Despite all these problems, Peter is always in good spirits, and has a very sweet smile. He enjoys company and watching videos, especially those with a hero with a great heart beating the odds ("Hercules", "Tarzan", "The Hunchback of Notre Dame"). I always tell Peter that he is my hero. I was recently found to have 99% blockage in a major artery, and had to have two stents placed. When I asked the doctor why I didn't feel worse with such a horrible blockage, he said that I was "a really tough guy, who does what he has to do". The real reason I was able to carry on, of course, is Peter. We knew Peter had a very strong heart before he was born, and he is alive, as am I, and hopeful today because of his great heart.