Why Are Intestinal Transplants Such A Secret?

I have been very saddened by a series of emails I have been receiving recently. Some of these messages have been left in the comments, but I felt that their stories deserve more attention. Many people are suffering and dying because of the lack of information concerning intestinal transplants. If you have never heard of intestinal transplants, don’t be embarrassed, as most doctors are unaware of them. This is due to a lack of media attention on the procedure and the fact that most doctors feel no need to learn anything new after they graduate medical school – except what the pharmaceutical companies pay them to learn.

In a way, the comments and emails has had a positive side, because the information I have provided has found its way to some people in need. Unfortunately, it was far too late for one reader, Jan, whose courageous mother, Marlyn, lost her life in a battle with intestinal necrosis. The doctors were refusing to remove the necrotic bowel for some unknown reason – most likely due to the fact that they had no knowledge of the success of intestinal transplants. It is in her mother’s memory that I am writing this most important post that I hope you will take to heart.

The doctors here in Orlando had made a similar decision in my case following the first resection of bowels. I was left with three feet of jejunum, but the tissue was necrotic and killing me. The surgeons refused to operate again. Because they had no knowledge of intestinal transplants, they had decided that I could not live on less than three feet of small bowel and would be better off dead. They made that quite clear. Fortunately for me, I was transferred to another hospital for a vascular procedure and the surgeons there did remove the necrotic tissue, even in spite of the fact that they did not know of intestinal transplants either and also felt I would die without the three feet. My wife was able to plead enough to guilt the doctors into doing the surgery, but they were reluctant and told her I would have a miserable existence and die a slow agonizing death. They were wrong, but surgeons are making these decisions strictly based on the lack of publicity concerning the success of intestinal transplants.

Whenever I tell someone that I was the recipient of a full intestinal transplant, I rarely get what I call the "Shock And Awe Reply.". I had never heard of intestinal transplants and was very shocked to find out it was possible. So by way of the "False Consensus Effect", I thought that this would be the typical reaction to this news. Instead, I am usually extended what I call, "The Gesundheit Reaction".   This is when the person reacts as though I had my tonsils taken out and say something like; "well I hope you feel better" or any other casual response as if someone sneezed. It is not the type reaction I might expect if I were to tell them I was a cancer survivor – even though there are many more cancer survivors than intestinal transplant survivors. Losing your intestines is considered a death sentence to more than 90% of the doctors in the U.S..

If I were to tell someone that there is a cure for cancer, the news would spread like wildfire, so why hasn't the information concerning intestinal transplants? It's quite frustrating, but I am beginning to see why. It seems that most people do not want to admit that they are unaware of a medical treatment. Many people I have encountered since my transplant simply smile and nod as if they have known many people who have received intestinal transplants. It is only if I specifically ask them, "have you ever heard of an intestinal transplant?", that they will admit that they haven't. It's either a lack of curiosity or too much pride that causes this complacency.

Most people have heard of transplants. Kidneys, livers, heart and lung transplants have been possible for many decades, so most people assume that intestinal transplants are as common and this is very far from the truth. Intestinal transplants are the rarest of organ transplants and its outcome was not very promising until recently. The intestines presented a very large problem when it came to transplants. The intestines are considered the largest lymphoid organ in the human body. Because the intestines are a “dirty organ”, filled with thousands of different strains bacterial and fungal colonies, the human immune system reacts more rapidly and aggressively when defending the intestines than any other organ. We had to develop this system or we couldn’t have survived as a species.

We eat a tremendous amount of bacteria and fungus everyday. Much of these microbes colonize in our intestines and many of them are beneficial to our digestion and help us to break down foods that would otherwise be indigestible. But any of these microbes can become lethal if they enter our bloodstream. For this reason, the largest part of our immune system is located in our gut. When bowels from a donor (with different DNA) are placed within the recipient, the immune system cannot tell the difference between the new bowel and the pathogens within, so it unleashes an attack on everything and ultimately destroys the new intestines. A slow, horrible death is soon to follow.

The first intestinal transplants were attempted in the 1960s, with a 0% survival rate. Even though there were great strides being made with kidneys, livers and even hearts and lungs over the next decade, all intestinal transplants attempted resulted in severe organ rejection and the patients died in a short period of time. There really was no success in this type of transplant until the 1990s, when the transplant program at the University of Pittsburgh had some level of success by first transplanting some of the donor’s bone marrow into the recipient. This made the recipient’s immune system accept the foreign organ better. Some of the recipients survived for the first year or so, but overall survival rates were still dismal. There was less than a 25% chance that a recipient would survive the first year after the transplant, so these transplants were only reserved as a desperate effort. The patient had to literally be at the point that all of their access arteries were gone and they could no longer receive TPN and were waiting to die of dehydration before a transplant would be attempted.

It wasn’t until a drug called “Campath” was introduced to the process that the survival rate began to doubled. No one really understands how Campath works to make the body accept the organ – it just does. I did not have to go through the painful process of a bone marrow transplant prior to the intestinal transplant. Because I was given an IV infusion of Campath, my body accepted the organ and I had no signs of rejection.

Dr. Andreas Tzakis (pictured on the left), the surgeon that performed my transplant, was working at the University of Pittsburgh at the time of the first successful intestinal transplants. He was the first doctor to use Campath. There is little doubt that I had the best surgeon that you could hope for working on me. Dr. Tzakis has performed more transplants than any surgeon in the world. He has performed over 2,000 liver transplants and has the highest record of success in intestinal and multivisceral transplants. Dr. Tzakis was actually successful at first transplanting a baboon liver into a human.

There are so few hospitals that can perform intestinal transplants, that I was able to get an organ after only 6 days on the transplant list. Most people in need of a kidney can be on the list for years, because kidney transplants are so common and nearly every hospital can perform them. A kidney transplant is less than a week stay in the hospital at Jackson

Memorial. But most intestinal and multivisceral recipients can spend up to 6 months in the hospital recovering or longer.

There is a huge difference in the severity of these transplants. A liver transplant can still carry great risks, but no other transplant is as rare or complicated as an intestinal or multivisceral transplant (which include intestines). Less than 3,000 intestinal transplants have ever been performed and since few people survived them in the first 20 years they were attempted, there are probably less than 1,500 survivors walking around today. So, the chance that you have met someone else who had an intestinal transplant is highly unlikely. I wish people would stop acting as if they were aware of them, when 90% of doctors don't know that they are possible and that includes specialists in GI medicine. Not one gastroenterologist that worked on me here in Orlando had heard of these transplants.

I believe that this is the explanation for the "The Gesundheit Reaction". Most people feel a transplant is a transplant, so it's not a big deal. If you were to ask most doctors, they would tell you that intestinal transplants are impossible and no one survives them. Many people are going to die this year based on that information from their doctor. When Jan first contacted me, her mother was still alive, but her bowels were necrotic and she was dying. The doctors were refusing to remove the dying bowels. I wrote back and told her that the doctors were not aware of transplants and had made the decision that she would be better off dead – just like they did with me. I provided her with the contact information to the doctors in Miami that performed my transplant.

Jan wrote back the next day and told me she had relayed my story to the doctor and he replied something like, "yeah,it would be nice to believe in magic.". Asshole! This is the arrogance of most doctors. Does he think I'm making this shit up? I am living proof that they are successful and it wouldn't take him 15 minutes of research on the internet to confirm that this procedure is not only possible, but hundreds of people will be saved by intestinal transplants this year. Even more could be saved, if the news about them could spread.

I have tried to get media attention on this life-saving procedure, but these type of things are never sexy enough for the mainstream media unless a celebrity has been afflicted. Had a celebrity ever needed an intestinal transplant, it would suddenly become a national crisis and everyone would know about them from the countless reports following the celebrity's recovery. So far, no celebrity has needed an intestinal transplant, so the fact they exist has remained a secret. Can we wait until a celebrity needs an intestinal transplant to make this procedure common knowledge? In her last email, Jan not only informed me of her mother's unfortunate passing, but also told me of a 34-year-old man who also lost his life at the same hospital, because the doctors did not know of these transplants.

If you read of my story, please do not keep this information to yourself. If you believe that my story is common and that doctors know what to do when someone loses their intestines – you are mistaken. I implore you to spread the word to as many people as possible. Email others, tweet about it, blog about it, mention it on Facebook or anyway you can think of to let everyone know that this procedure exists – it could save thousands, if not tens of thousands of lives. According to the statistic that Jan left in the comments, over 145,000 people are dependent on TPN. Many of these people will die, because a human can not live on TPN indefinitely . If you read my post on "The Effects Of Sugar On Arteries" and "The Truth About Soy", you will understand how TPN will keep someone alive, but is also killing them at the same time. People requiring full-time TPN will usually die within two years.

These people will die never knowing that there was a realistic option to live out their natural life. Living on TPN is a very poor quality of life – I know because I lived that way for more than six months. Besides the knowledge that it would ultimately destroy my liver and arteries, I suffered two systemic infections that nearly killed me. TPN is high in sugar and feeds both bacteria and fungus. The human body will not defend a plastic catheter, so the lines colonize with pathogens quickly – pathogens that are then flushed through the heart with the TPN infusions. An intestinal transplant is the only realistic long-term option for someone suffering with Short Bowel Syndrome.

These deaths are not just limited to adults and elderly. When I was at Jackson Memorial Hospital, there was an entire floor dedicated to the pediatric intestinal and multivisceral transplants. There were more children receiving these transplants than adults. There are children who are born with a birth defect known as "Short Bowel Syndrome". Some are born without much of their GI tract and some are born with their intestines outside of their body, which die and have to be removed. I seen toddlers who were getting full multivisceral (multi-organ) transplants. I met one young woman who was 18 years old when I met her, but was born without intestines and received a multivisceral transplant at the age of 8. Without the transplant, she would have never lived to the age of eighteen and she is still going.

I really don't get a tremendous amount of traffic at this site, so it is up to everyone to spread this vital information – information that could have saved Jan's mother's life or the 34-year-old man, had they found my site sooner. I have tried to contact a variety of talk shows, such as Ellen and Oprah, with absolutely no response. One letter rarely gets a response from these shows. If you have read my story and were amazed that someone could survive a full intestinal transplant (both small and large), please take the time to write a letter or email to some of these talk shows about it. Maybe if they were to receive a volume of letters they would feel this warrants some media attention. Feel free to send a link to my story (found here). I know of several other intestinal and multivisceral transplant survivors that would be willing to share their stories.

Even smaller internet venues seem to scoff at this story. I had contacted Jimmy Moore, who first agreed to interview me on his podcast over 6 months ago, but never followed up on his promise. I guess the 150th interview with someone who lost 20 pounds on a low carb diet is a more compelling account to Jimmy than someone who survived an intestinal transplant. He may be underestimating his listening audience – or maybe not. It's sad to believe that another Tom Naughton interview about "Fat Head" the movie, could be more vitally important than the news about someone left for dead being resurrected. News that could have easily saved a life, like Marlyn's, if we could get the information out there. Good luck Jimmy – hope you never need a transplant. I guess I'm not a big enough internet star to warrant his time. Funny how even a small amount of internet fame can go to someone's head real fast and to the point where they only want to suck up to other celebrities.

It's this starfucker mentality that keeps this type of information in the dark. Because I'm not famous, my story is irrelevant, because after all, only celebrities suffer, feel pain and need our help. Only a celebrity can be the arbiter of what the rest of us should be concerned about. Global warming myths and animal rights far out-trump the fact that people of little fame and wealth are dying unnecessarily. None of the doctors, in two separate hospitals here in Orlando, had heard of intestinal transplants. As much as we'd like to believe that it is their responsibility to provide that information, they have chosen to ignore the call, so it is up to the rest of us.

It was my wife's tenacity and exhaustive research that led us to Jackson Memorial Hospital in Miami (one of a handful of hospitals in the world that have successfully performed this procedure). Most of the doctors here told me I was a fool for considering undergoing these transplants and that I had a small chance of survival. Actually, Jackson Memorial has over a 65% first year survival rate, so the odds were in my favor. I received my transplant over 2 years ago and am doing well – the doctors were giving me less than 2 years on the TPN, so I would have already been dead by now had I not have opted for the transplant. The fact that I suffered two deadly systemic infections during the time I was on TPN would certainly support the claim that I would have been dead by now. I was only approved for the transplant because I had nearly died twice from sepsis, due to the TPN line colonizing pathogens.

The longest living intestinal transplant patient is a woman who had her transplant over 20 years ago – and the medication and post operative treatments have been greatly improved since her operation, so my chances of living more than 20 years are better than hers. She is still alive and well. The young woman I met at Jackson in Miami, who was born without intestines, has now been alive for more than 11 years – that's 11 years more than she would have had without the transplant. She just graduated High School this year – amazing. Some other 8-year-old will not be so lucky and never see their graduation without your help. Any child living on TPN will die without a transplant – a senseless death strictly based on the doctors lack of knowledge about the success of the intestinal transplant programs at several hospitals across the United States. Here is a list of the hospitals that I know of that have successful intestinal and multivisceral transplant programs.

University of Pittsburgh	Pittsburgh Pennsylvania
Jackson Memorial Hospital	Miami, Florida
Cleveland Clinic	Cleveland, Ohio
Georgetown University Hospital	Washington D.C.

UCLA Hospital Los Angeles, California

University of Nebraska   Omaha, Nebraska

There may be others, but these programs have a high survival rate, especially The University of Pittsburgh, Jackson Memorial (in Miami) and the Cleveland Clinic. the University of Pittsburgh is where the first successful intestinal transplants occurred. Dr. Andreas Tzakis was one of the pioneers at the time and was working at the University of Pittsburgh. He has since established the intestinal and multivisceral transplant program at Jackson Memorial Hospital in Miami, so their program is equally as good as Pittsburgh.

It is easy to assume that the doctors know about this procedure and inform TPN patients of this option, but that is not the reality. Somehow, this life-saving procedure remains a secret to most doctors and hospitals. If you are reading this, you now know of a medical procedure that few doctors know are possible. It would seem irresponsible for doctors treating TPN patients, especially those who are failing to thrive, not to know about intestinal transplants, but for some reason, that's the reality. This is why I simply shake my head when people believe that their doctor is up on the latest research concerning any disease and why doctors continue to spout outdated advice concerning heart disease, diabetes or any other modern disease. Never trust that your doctor has all the answers. I know that many of you feel that's what you pay the doctor for and just look to them for answers – that'll get you dead!   You have to invest your own time in doing the research concerning your health. If my story, Jan's mother's story or the 34-year-old man's story is not enough to convince you not to place all your options at the discretion of your doctor, then you could well end up deceased long before your time.

The doctors were fine with letting me die on TPN, believing there was nothing more they could do. It was my wife's relentless research that discovered that the doctors were wrong or I wouldn't be writing this post. Not one of those doctors invested any time into doing the research. Even after my wife made the contacts in Miami, the doctors that were treating me attempted to talk us out of undergoing the transplant. While we were in Miami, the husband of the nurse manager told us of a dialysis clinic where the doctors hand out published pamphlets scaring patients away from getting kidney transplants, by exploiting all of the rare risks. Their motivation was strictly money. There is more money to be made by daily dialysis treatments, than curing the disease with a transplant. At over $200.00 a bag, TPN is also very profitable to the pharmaceutical companies, because a person with no intestines needs a bag everyday. While I was on TPN, the cost of medication, TPN and hydration infusions were costing over $500.00 per day! You can see why there is a motivation to keep those people on TPN.

Let's not wait until your favorite pop star, actor or politician needs a transplant to finally consider it interesting enough to tweet about it. You could help save countless lives by simply spreading my story. By all accounts, I shouldn't be alive. I am the closest thing to a walking miracle that you will find. Jan lost her mother due to complacency, please don't let the next person or child on TPN die because this subject is not sexy enough to pass on. The only way that the nightmare I lived through will have any reason is if it can help someone else who is dying on TPN. Don't casually dismiss my story and think that this could never happen to you. You could be in an accident tomorrow and lose your intestines or you could be injured by a colonoscopy, like I was, and require an intestinal transplant to live. I am not selling anything at my site and I make no money from links sent out to my story – it's about saving lives. I would love to see more traffic come to my story, so I will know that the word is spreading and lives will be spared.

This deed will only cost you a few minutes of your Twitter time, but could certainly save a life or two. Trust me when I tell you that many doctors do not know about this procedure and are letting TPN patients die prematurely. Just take a minute and Tweet my story around. Better yet, take a minute to go to any talk show’s website and shoot off an email with a link to my story. Making these transplants common knowledge will save lives of both adults and children.

Thanks,

Wolverine