

A Presentation Scott Made to The Kidney Foundation Conference, 1998

This evening I'd like to take you all on a journey. A journey through my life. I hope that this journey can show you how important your work with the Kidney Foundation is. I think that sometimes we don't really realize the impact we make on people's lives by volunteering for the Kidney Foundation, and furthering its mission. The work you do is extremely important and I hope I can emphasize that tonight.

I want to start this journey by telling you about the first time I fell in love. Now I'm sure you can all remember the first time you fell in love how exciting it was. Well I was 5 years old and boy I remember it like it was yesterday. My first experience with love was maybe a little different than yours.....you see it wasn't a girl that I fell in love withand no it wasn't a guy either. My first love was the game of hockey.

I will never forget my first hockey practice at the age of five. I can still see how crisp the painted blue and red lines looked on the ice and how the white mesh of the nets was glistening at each end of the arena.

It was magical!

As I skated around the rink tightly holding my stick with my brand new gloves I imagined that the seats were full of wildly cheering fans. It sure didn't take me very long to fall in love with the game of hockey.

About a year before that first hockey practice of mine I was diagnosed with Cystic Fibrosis, a very serious genetic lung disease. At that time my doctors told my parents that if I lived to be twelve years old I would be very lucky.

You can imagine how my parents must have felt watching me at that first hockey practice, wondering how long I would be able to play a game I so obviously loved.

Well as it turned out I was able to play for quite some time. Thankfully my doctors' prediction of only living until the age of twelve was a little off. CF didn't begin to seriously affect my lungs until my late teens.

My childhood was really indistinguishable from any of the "normal" kids. I didn't miss too much school, I was as rough on the playground as the rest of my friends, and on the ice.....I could skate like the wind.

As a youngster hockey was a fun game to play but when I turned thirteen, it became something more..... Hockey became my life. It absolutely consumed me. I was either playing the game, thinking about the game, or dreaming about the game.

The highlight of my career came when I was sixteen years old. I was playing for the Hamilton Huskies, the All Star team for Hamilton Ontario. We played in a league comprised of the best players in the province. Boy we had a great team that year.

I remember how hard my teammates and I worked in practice that season. Our coach would skate us until we dropped. I also remember how good that felt, my legs striding furiously as my lungs filled with the cold arena air. It felt so good to be in peak physical condition.

All our hard work paid off. My team made it to the Provincial Championship finals. It was a grueling tough series against Windsor which went down to the final game. We won! I'll never forget the unbelievable sense of jubilation as my teammates and I dove all over each other our sticks and gloves hurled into the air in celebration.

I was on top of the world after that championship game. I was so excited where my hockey career might take me. The future looked so bright.

When I think back to that time it seems inconceivable that that future, the future that held so much promise, could so quickly fall to pieces.But it did.

You see it wasn't long before playing hockey became a tremendous struggle. Cystic Fibrosis began to take its toll. I remember one of my last hockey practices at the age of eighteen. Working harder no longer felt good. The cold arena air now assaulted my lungs making me cough violently. Instead of skating like the wind.... I was winded. It was too much for me. I gasped for breath, desperately trying to keep up with my teammates, but I soon knew it was hopeless.

My hockey career was over!

You know, it was so hard to have to give up playing. Remember hockey was much more than a game to me. My identity and self esteem was tied to the game of hockey. When I quit it was like a part of me died.

During my early twenties my lung function continued to decline and soon hockey wasn't the only part of me that was dying. Long walks were replaced by short ones, stairs were replaced by elevators and soon any physical activity was replaced withwell nothing really.

At the age of twenty-five my doctor sat me down. He told me that my lungs would probably only keep me alive for another year and a halfif I was lucky. He suggested I think about having a double lung transplant. I wasn't ready to hear that. When I looked in the mirror I still saw Scott Young, the "Hockey Player" even though that person had been gone for so long. It took me a while, but eventually my denial was replaced with the shocking terrifying truth.

The mirror image of the strong fit athlete disappeared, and for the first time I saw the thin... pale...breathless Scott Young. It was now very clear to me that my doctor was right. I was dying and a transplant was my only hope for survival.

I made arrangements to be assessed as a candidate for the Toronto Lung Transplant Program and thankfully was deemed to be a suitable candidate. In March of 1991 I was put on the waiting list for a pair of lungs. The thing I remember most about being put on the list was the incredible sense of desperation that I had.

Not knowing when, or more importantly, if a suitable donor would be found for me. There were about 25 other patients waiting for lungs in Toronto with me. Every Monday we'd get together for a support group meeting. We'd share our thoughts and feelings, and really just try and help each other through that very trying time. We became a very close group.

Those meetings were wonderful as they played a large role in helping us to maintain our sanities and I am very glad they were a compulsory part of the Toronto Program at that time. But I have to tell you, some Mondays were pretty tough. We'd arrive to find one of us missing from the group. One of us had died before a donor could be found. On those Mondays our tears were of sorrow and fear. We missed special friends and we were terrified that we would be next.

While I was waiting I endured two false alarms. False alarms are when you get called for a transplant but then for one reason or another the lungs turn out to be unsuitable for transplant and the surgery has to be cancelled.

My second false alarm occurred in the middle of the night. I was called in and told that a potential donor had been found for me. After being prepped for surgery and waiting until about 5 in the morning I'll never forget when my surgeon Tim Winton came to tell me the lungs turned out to be unsuitable. He told me to hang in there... that they would find another set... but I had my doubts.

I mean this was the second donor for me that did not turn out. Maybe there was going to be a third but I wasn't sure if I could last long enough to find out.

When I came home after that second false alarm I was lying in bed trying to get some sleep when I was suddenly hit with quite the realization. My having a false alarm meant that somewhere a family was grieving over the death of a loved one.

I felt very guilty. I mean here I was hoping for a set of lungs to live but that meant someone else's life had to end. I thought about it a lot and finally came to the conclusion that donors were going to die regardless of my needs and if given another opportunity I would accept my lungs as a precious gift.

My days of waiting turned into months which turned into a year. The oxygen tank that had been my companion for the past year wasn't helping like it used to. I was constantly out of breath and very close to being out of time.

But then fourteen months after being put on the waiting list something truly amazing happened. A family who knew nothing of my situation decided to donate their son's organs after he was suddenly tragically killed. You can imagine their grief during such a trying time, yet they had the courage and compassion to think of complete strangers. They wanted their son's organs to give others a chance to live.....I was one of those others.

The morning I received the "CALL" for my transplant was a dark and stormy one not the kind of day you want to be going in for major surgery. You really want one of those bright cheery days with birds singing and all of that, but boy it looked like there was going to be a tornado or something.

I really expected that the whole thing was just going to be another false alarm, but after waiting a few hours I finally heard that the donor's lungs were great.

There was another problem however. My donor was in Northern Ontario and the weather there was also very bad. So bad in fact that the plane carrying the retrieval team and my new lungs couldn't take off. I couldn't believe it! After all I had gone through finally a suitable set of lungs and I still might not get my shot at a new life. Time is a crucial factor after an organ has been removed from a donor. Time was running out. I was living a nightmare.

The transplant team eventually brought me down to the O.R. They put me on the table, started a few IV'sand then we waited. We waited for word the plane had taken off. They didn't want to start taking out my old lungs until they knew for sure my new ones were on the way. So there I was, laying on the operating table, desperately hoping that the weather would clear enough for the plane carrying my new lungs to take off.

Well the plane did take off, and I later heard it was quite the white knuckle trip for the retrieval team.

Tim Winton came in and told me the tough part was over. I had survived long enough to get my chance at a new life. In fact, I probably only had weeks to live had I not had that chance. He said, "Scotty, go to sleep and leave the rest to me"and I did.

Well the rest as they say is history. Today life after transplant is so wonderful. Just being alive would be enough but there has been so much more. Long walks are a joy, and stairs have replaced elevators. My future looks so bright again. One of the most amazing results of my transplant is that I am back playing hockey. For eleven very long years I had not stepped foot on the ice, and I thought I never would again. For eleven very long years I dreamt almost every night about what it would feel like to play hockey again. For eleven very long years part of me was missing.

Well I am whole again. I no longer dream about hockey, I play it. The joy felt by that five year old boy at his first hockey practice is duplicated every time I play. You would not believe how awesome it is to be once again skating hard, my lungs effortlessly filling with that cold arena air.

Each time I walk from the dressing room and head out onto the ice I think about my donor and his family. I quietly thank them for their strength in adversity and for giving me the opportunity to once again live life to the fullest.

I also think about the Kidney Foundation. You know it might seem strange for a lung transplant recipient to be volunteering for the Kidney Foundation but it actually makes perfect sense. We are outdistancing every other health care organization with respect to our Organ Donor Awareness initiatives. And organ donor awareness is so important to me. You know, I don't want to lose any more friends because a donor could not be found in time. And I certainly don't want to accept the present state of organ donation in Canada.

Finally I also think about people like you. I am alive today because of the synergy or the force of energy created by people just like you. You see Organ Donation is incredibly powerful but it needs energy to be put in motion. Each of you provides that energy. It's easy for me to be involved with the Kidney foundation because of the personal tie I have to transplantation, but boy do I ever admire those who don't have that tie and give so generously of time and effort.

You see by volunteering with the kidney Foundation you give much more than just your time and effort. You give children the opportunity to grow and parents the opportunity to see them grow. You sustain friendships. You give memories and fun and joy and laughter. You give life, and I for one believe there is no greater gift than the gift of life.

Thank You!!