

**Written Testimony of  
Peter Loss**

**March 7, 2012**

**In Support of House Bill No. 5333  
Public Health Committee**

**Testimony in Support of HB 5333,  
An Act concerning Organ and Tissue Donation Awareness**

**Representative Ritter, Senator Gerratana, and Members of the Public Health  
Committee:**

Thank you for the opportunity to support House Bill 5333.

My name is Pete Loss. I am a volunteer with Donate Life Connecticut and a caregiver and spouse to an organ recipient. I am an organ donor.

My wife Maria was diagnosed in 1996 with Alpha 1 Antitrypsin Deficiency, a genetic lung and liver disorder, that causes Chronic Obstructive Pulmonary Disease. Maria was a teacher for 28 years, and struggled with this progressive disorder, until she came home from teaching one day in 2006 and said "I can't do it anymore". She was forced to a disability retirement. In the space of one year, she weighed 93 lbs, couldn't walk more than a few feet, couldn't get dressed, needed oxygen 24/7, and could barely get out of bed.

In 2008 Maria received a double lung transplant at Brigham and Women's Hospital in Boston. While she was still asleep, I watched her take her first full breath in 20 years! 36 hours later she was walking around the ICU pulling her equipment with minimal staff assistance. It was enough to make this grown man cry. Today she walks on the treadmill every day, attends rehabilitation classes, receives follow-up monitoring, and has a vibrant and healthy life.

The donor family showed courage and selflessness that I still cannot fully fathom, and there is no question Maria would have died if she didn't receive the lungs. Their generosity saved her life, and that of our whole family.

Over 1 million citizens in Connecticut are registered donors, putting us at about the national average of 40% registration. DMV, Donate Life, and other organizations have

worked hard to register donors. While this places CT in line with other states, **it's not enough**. About 1200 adults and children in CT like Maria are waiting for organs. Many who are waiting will die and deteriorate - this is the statistic that requires this Bill.

We need the Advisory Panel and motorist funding this Bill will bring, to advocate for all of those on the waiting list. Each single donation saves and helps so many, with lungs, liver, heart, cornea, skin, and more. While I know it takes a tragic loss to be able to donate, so many more could see the miracle that my family has witnessed. Please make sure other Connecticut families like ours can be saved with the awareness that could result from your vote.

Thank you.

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# MARIA'S STORY

Life is sweet, the world miraculous, and living a treasure.....

Walking more than 25 feet; climbing up stairs and inclines; eating; taking a shower; dressing; driving, grocery shopping - all routine tasks the average person takes for granted. I could do none of these without the greatest of effort, followed by complete exhaustion. By the time Alpha-1 Antitrypsin Deficiency, a genetic form of COPD, ravaged my lungs at age 52, I couldn't contemplate even the simplest jobs around the house. As I fell behind my family in trying to walk to fun family activities, always trailing, oxygen in tow at later points, I thought the only vocabulary words my children knew were "Mom, are you alright?" I never gave up, but I was so frustrated, so tired, and wondering if I would see my daughters' graduations and weddings.



My name is Maria, I am 56 years old, and live in southeastern CT with my husband and two adult daughters. I began having breathing problems at age 39, and at 42 was diagnosed with Alpha-1 Antitrypsin Deficiency, a genetic lung and liver disorder where a missing blood protein allows the lungs to deteriorate. I worked for 29 years as a teacher, and continued to do the work I love, but in 2006, my lungs became so compromised I had to leave on disability. By 2007, I couldn't eat well, had no energy, rarely got out of bed, and weighed 93 lbs.

In 2007, the lung team at Brigham and Women's Hospital in Boston strongly recommended lung transplantation immediately because my condition had so worsened. I was listed, and two months later received a double lung transplant on 2-1-2008.

36 hours after surgery I was walking in the hallways with confidence and determination; during the first week I started regaining my appetite; with time I took a shower with much less strain than before; in the weeks and months after I climbed stairs, inclines; after a month I was driving and shopping for groceries! Months later I was travelling and taking an active role with my family, doing cooking, wash, driving, and resuming activities I hadn't been able to do for years. Today I walk 3 miles a day on a treadmill/incline, volunteer my time, and **feel like I have a second chance at life.**



I simply can't believe the transformation I have gone through. I never thought that I could feel this good after 17 years of gasping for air. The oxygen hoses are gone. I can draw a full and healthy breath with no effort. I am so grateful for the full life I have been given through the courage and pain of the donor family. What must have been their emotionally wrenching decision to generously give, at a time of such sadness, has given an indescribable second life to me. I have written to them, and they have yet to respond. It must be a bittersweet moment, the wonder of the enormous gift they selflessly gave, yet a poignant reminder of their loss. I hope we can meet someday to personally thank them and tell them what kind of awe inspiring change this has been. My husband and daughters can tell them that they no longer say "Mom, are you alright", because I am usually walking ahead of them faster and leaving *them* behind

# PETE'S STORY

My name is Pete, I am 56 years old, father of two adult daughters. I am a correctional social worker by trade. My 56 year old wife Maria had a double lung transplant on 2-1-08 at Brigham and Women's Hospital in Boston. We live in southeastern Connecticut.



Maria had breathing problems since age 39, and was diagnosed with a genetic form of COPD called Alpha-1 Antitrypsin Deficiency, in 1996, at 42 years of age. She was able to continue working as a teacher, take medications, and had two surgeries to remove lung obstructions. In 2006 she was no longer able to work due to her deteriorating lung function, weight down to 93 lbs, resulting in disability status. Her doctors advised transplantation in 2007.

As Maria's condition deteriorated, my role as a caregiver quickly changed my life into a double full time job. I worked full time in prison, and at home cooked, cleaned, did the wash, everything. Had my children been younger, it would have quadrupled the effect. I always did my fair share, but now was an overwhelming responsibility surrounding Maria's obvious and visual deterioration. Managing my own anxiety and depression about Maria's fate and mine, and that of my daughters, soon stole most of my waking time. Even with family and Alpha-1 community support, it was a marathon.

Since the transplant, she has had a few hospitalizations due to minor complications with her airways, but no rejection. She has regained her original weight. She walks on the treadmill everyday, has resumed normal activities, household, family travel, exercise, driving, walking, in other words, NORMAL LIFE. It is nothing short of miraculous to see her perform tasks with ease that had dogged her for years, such as walking up a simple incline. She volunteers her time now to the COPD Help Line and a local charity, and we are active in the Alpha-1 and Donate Life communities.

Life after transplant has been an earth-shaking change. One day Maria couldn't breathe, and within 36 hours of her transplant she was walking around the hospital with two new lungs. We are so thankful to the donor family for the deep personal sacrifice they made. In an instant, they returned Maria's life to her, a dream come true. While there are complications and maintenance, and we are advised that we could always face unexpected diversity, Maria has been to hell and back, and there is nothing that could come that could be as worse as her condition before the transplant.

I know as a caregiver, husband, and parent, that my entire family was overwhelmed by Maria's illness. **Yet in some way the donor family gave us all a transplant.** My wife received lungs, but we all received our lives back. We have written to the donor family through the organ bank, but to date have not heard from them. There must be so much emotion and pain involved. I often wonder if the donor family hesitated at first about the prospect of donation, and that the thought of saving someone else as they grieve must be so bittersweet. If only they could know how completely and selflessly they have transformed our family from despair to joy, and how the pain of one person's passing could become so immortalized in another person's beginning.