



HAPPY HOLIDAYS



- **2011 Virginia Transplant Games**
- **Celebrating 100 Million Registered Donors!**
- **A Life Shared & A Life Saved**
- **DLVA & DMV Partnership**
- **Trivia Time Contest**

A LIFE SHARED

AND

A LIFE SAVED

In the April 2011 issue of Commonwealth Beat, we brought you the story of Amanda Key, a young lady who was on the waiting list for a life saving kidney transplant.

“I am lucky enough to have a few special people that are willing to give me that special gift, but they don’t match, so I wait to see if that miracle phone call will come sometime soon.

I understand it still could be years before a match is found. I know that when one is found another chapter will start in my life; one with less hospital stays, doctor visits and hopefully with more happy endings.

So I wait every day, just hoping.”

----Amanda Key

Here is the story of what happened next.....



My name is Amanda Key, I am 32 years old, and I am waiting for an organ transplant to save my life.

My story starts in October of 1998. I had never been sick except for an occasional bout of bronchitis once a year. At the time, I was working 2 jobs, 7 days a week; living as a typical 20 yr old. It started with migraines, and after months of no relief, weight loss, and extreme fatigue, one day I passed out at work. I was immediately taken to the local Emergency Room. From there I went to my primary care physician, and from there I went to the hospital for admission. I had several blood transfusions, spinal taps, kidney and liver biopsies and numerous blood tests.

After my second admission into the hospital within 2 weeks, I was diagnosed with a rare autoimmune disease, Good Pasture's. I was in End Stage Renal disease. My life was not my own anymore. For the next 8 1/2 months on Mondays, Wednesdays and Fridays I went to dialysis and on Tuesdays, Thursdays and Saturdays, due to my disease I had to undergo other treatments. Sunday was my only day off.

On August 20, 1999, I received a kidney from my Mom. She was discharged in two days and I was discharged in three. Unfortunately, within a year of my transplant, I was diagnosed with chronic rejection. This meant multiple hospital stays for tests and medical procedures for the next 7 years. I was still grateful not to be sitting in dialysis 3 days a week, for 3 hours per day. I could travel and work. Seven years went by and it seems it was so fast.

On January 3, 2006, I found myself back to square one. I was in the hospital barely conscious and having to make one of the hardest decisions of my life. Decline all treatment, or go back on dialysis and wait. After 3 days of back and forth decisions and not knowing if I could handle dialysis and waiting again, my youngest brother convinced me that I had a lot to live for. That clinched my decision. I immediately went to surgery and had a dialysis catheter placed. My life once again revolved around dialysis, and everything that goes with it.

So, what is it like to wait? My situation might be a little different. I am now waiting for that second transplant. It has been 5 years so the allure and hopefulness isn't as grand as the first go around. The first transplant I knew I had a living donor, my Mom, so my wait wasn't as long and painful. This time I am going on year number 5+ and no luck so far.

I am lucky enough to have a few special people that are willing to give me that special gift, but they don't match, so I wait to see if that miracle phone call will come sometime soon.

I understand it still could be years before a match is found. I know that when one is found another chapter will start in my life; one with less hospital stays, doctor visits and hopefully with more happy endings.

So I wait every day, just hoping.



“Stories from the Field”

A young lady visited DMV requesting a duplicate license. She stated she had lost it while in the hospital. The representative asked if she wanted to remain an organ donor. Eagerly she replied, “Yes, Yes, Absolutely Yes!” It turns out she had just had a heart transplant, and immediately following her release, she came to DMV! She gave a great testament concerning the importance of organ donation and expressed her appreciation to DMV for taking the time to ask all customers their preference in participating in the Organ Donation program.

—Hilltop DMV, VA Beach

If you have a similar story or situation you would like to share, please let us know, and we will feature your DMV in our next edition of Commonwealth Beat.

My name is Lisa Stanzione. I have worked in the field of organ donation since 1990 and have witnessed firsthand the healing power of donation for both the donor family and the recipients of the gifts. I've always thought living donation was a wonderful thing to do, but like most people I never took any steps towards making that happen.

My name is Amanda Key. I am 32 years old, and I have been waiting for a kidney transplant to save my life.



My story starts in October of 1998. I had never been sick except for an occasional bout of bronchitis once a year. At the time, I was working two jobs, seven days a week; living as a typical 19 year old. It all started with migraines, and after months of no relief, weight loss, and extreme fatigue, one day I passed out at work. I was immediately taken to the ER. I had several blood transfusions, spinal taps, kidney and liver biopsies and countless blood tests.

After my second admission into the hospital within two weeks, I was diagnosed with a rare autoimmune disease: Good Pasture's. I was in end stage renal failure. My life was not my own anymore. For the next 8 1/2 months on Monday, Wednesday and Friday I went to dialysis; and on Tuesday, Thursday and Saturday, I had to undergo other treatments. Sunday was my only day off.

On August 20, 1999, I received a kidney from my Mom. Within a year of my transplant, I was diagnosed with chronic rejection. This meant multiple hospital stays for tests and medical procedures for the next seven years.

On January 3, 2006, I found myself back to square one. I was in the hospital barely conscious and having to make one of the hardest decisions of my life: decline all treatment, or go back on dialysis and wait. After three days of back and forth decisions and not knowing if I could handle dialysis and waiting again, my youngest brother convinced me that I had a lot to live for. That clinched my decision. I immediately went to surgery and had a dialysis catheter placed. My life once again revolved around dialysis, and everything that goes with it.

I met Amanda's mother, Robbie Key, about five years ago when she began working for LifeNet Health. She is someone I admire greatly for a multitude of reasons: she is hard working, passionate about donation, smart, funny, kind and caring. I learned early on in our working relationship that Robbie's daughter Amanda was diagnosed with Good Pasture's disease at the age of 19, which shut down her kidneys and weakened her lungs. Over the last five years Robbie's coworkers, myself included, have closely followed Amanda's deteriorating health.

Robbie and Amanda shared their story at our first collaborative meeting at Natural Bridge in 2009. Amanda shared with everyone in the room that at one point she had wanted to die, and that she was not going to go through another transplant since the rejection of her mother's kidney had nearly killed her. She told us that her chance of getting a matching kidney was like finding a needle in a stack of needles, and that she knew she could die waiting. Robbie shared with us how difficult it was as a mother to have your child give up on living and she tearfully urged the hospital staff attending the conference to picture Amanda as that “someone” on the waiting list when they refer potential donors to LifeNet Health.

Story Continued ...



Donate Life America Announces Significant Milestone Achieved with 100 Millionth Organ, Eye and Tissue Donor Registered in the U.S.



New national goal set to register 20 million more by the end of 2012

A key goal set by the donation and transplant community in 2006 was achieved this October. The United States can now boast that **100 million Americans** -- roughly **42 percent** of the adult population --are now registered as organ, eye and tissue donors in state donor registries!

Growth in the number of registered donors is vital because the need for transplants continues to rise. More than 112,000 people are currently waiting for lifesaving organ transplants. Thousands more await tissue transplants to resume their normal lives. Last year, more than 28,000 people received organ transplants, more than 40,000 received corneal transplants and hundreds of thousands received tissue transplants, yet 6,590 died awaiting organ transplants. A surge in the number of donors is necessary to save more lives. Therefore, as the donation and transplant community celebrates the accomplishment of registering 100 million people, work has already begun to reach the new national goal of registering 20 million new donors by the end of 2012. Twenty million additional donors would result in saving thousands more lives each year. Donate Life Virginia encourages you to share this good news and read more about how you can save lives by visiting: www.DonateLifeVirginia.org.

“At a time when we as a nation have difficulty finding common ground on many important issues, 100 million people have agreed on their desire to save lives by registering as donors. They are hope for all of the men, women and children in need of lifesaving transplants today. For that, we say thank you,” says David Fleming, President & CEO of Donate Life America. “While this achievement speaks volumes about the generosity of human beings, more work needs to be done to motivate Americans to register and save the lives of those in need.”

On average, nearly 8 million people nationwide join a state donor registry each year; a majority (98 percent) joins through state DMV’s. Therefore, DLA builds strong relationships with many DMV officials throughout the nation to encourage education and training of their staff to help them better advocate for organ, eye and tissue donation.

As the DDC works to increase the number of donors, the high percentage of registrations through DMVs poses a new challenge to overcome. New designated donors come from only three sources – first-time drivers, new residents, and current residents who previously elected not to register. Given that in Virginia, residents renew their license every eight years, with the option of doing so online every other time, some individuals can go 16 years between DMV in person visits. These infrequent visits make it even more important to ask every Drivers License new applicant and renewal; “Would you like to register to become an organ, eye and tissue donor?”

“As we lay the foundation to register an additional 20 million people by the end of 2012, we are developing strategies to overcome the obstacles presented by maturing registries. We are not deterred by the challenges ahead,” says Donate Life America Chairperson, Helen W. Bottenfield. “Our primary goal is to preserve human life and improve the quality of life for those in need of organ, eye and tissue transplants. We will remain focused and find creative ways to reach, educate and motivate those who have not yet registered as donors.”

To learn more about how you can become involved, visit: www.DonateLifeVirginia.org.



Join the 100 million registered organ, eye and tissue donors.
Register today.

Saturday, October 1, 2011 was a crisp, cool fall day in Richmond – the perfect setting for the first ever Virginia Transplant Games held at Clover Hill High School. The opening ceremonies didn't leave a dry eye in the stadium as donor families, recipients, family, and friends stood together to celebrate life.



The games were established for two reasons:

- to illustrate how organ, eye, tissue and bone marrow donation and transplantation works; allowing recipients of these precious gifts to live, full, healthy, and more active lives than they ever imagined; and
- to reinforce how these gifts are generously given by Virginia citizens who can designate their decision to donate on the Virginia donor registry, www.DonateLifeVirginia.org.

Attending the event was an emotional experience for everyone – including donor families, organ recipients, and supportive friends and family. Knowing that so many people in attendance had either experienced the loss of a loved one who had donated life-saving tissue and organs, or had been a recipient of another person's selfless giving and generosity, was overwhelming.

Let the Games Begin!

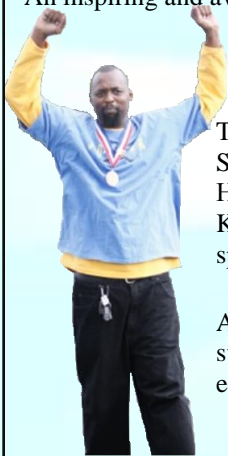
The opening ceremonies began with the Color Guard and National Anthem which was a stirring rendition by Reverend David K. North. As the athletes marched in, cheers arose from the crowd and were sustained for what seemed like forever. Virginia's First Lady, Maureen McDonnell spoke at the opening ceremonies and praised the brave families of the organ donors, along with the recipients who have overcome so much to reach the point where they are today.



An inspiring and awe-striking moment occurred with the ceremonial dove release and the games began!

Special Thanks to the DMV Mobile Unit & Staff who came out to support the games!

Olympic Events



The day was filled with fun, laughter, and excitement. LifeNet Health, Bridge to Life, University of Virginia Health Systems, VCU Medical Center, HCA Virginia Health Systems, Old Dominion Eye Foundation, Cytonet, Sentara Health, Henrico Doctors' Hospital, Washington Regional Transplant Community, Bon Secours St. Francis Medical Center, King Pin Lanes, Sports Backers, Uncharted Pixels, Chesterfield County Public Schools, and the YMCA were special sponsors and supporters of the Transplant Games.

A powerful message was sent by recipients who participated in a 5K walk/run, track & field, basketball, bowling, swimming, and table tennis. They participated alongside family members of donors making it even more dramatic and emotional.

The Closing Ceremony

The closing ceremonies were equally matched with the opening ceremonies. Watching the donor families and recipients share in such incredible accomplishments was humbling.



Andrew Mullins, Transplant Games Planning Committee Chairman, spoke of the bravery, selfless giving, and courage of all of the participants. Jill Stephenson gave a heart-wrenching account of what it was like to lose her brother at the age of 11 to a car accident, and her own young son at the age of 21 in the fight against the Taliban. Both young men donated their organs so that others could live and it has had a profound effect on Jill and her friends and family.

A surprise highlight occurred when Brad Ellis of TV's hit show *Glee*, a heart recipient himself, joined the stage and performed with piano and singing. He is the incredibly talented pianist on *Glee* and was awarded the 2011 *Donate Life Hollywood Person of the Year* award for his work in donation. In addition to solos, he also performed with the Clover Hill High School's New Dimensions Show Choir, sharing with us an awe inspiring performance. Seeing how Brad has taken his life to new heights — thanks to a heart donor who gave him a chance to live – was a shining example of what the day's events were all about.

The next Virginia Transplant Games will be in two years and with the success of the first-ever annual games in 2011, the 2013 games are sure to be even better!

Congratulations to all of the brave donor families and recipients who participated in the 2011 Transplant Games – you are an inspiration for thousands of other people.



We will see you again in 2013!

Article by Rhonda Day

Robbie shared with me that every morning she and her husband Ted take turns going into Amanda's room because they both fear they will find that she had died in her sleep. As a mother, Robbie had done everything she could to keep her child alive. I knew I would do the same for my children. Robbie was waiting for someone to help her daughter and I felt pretty strongly that I wanted to be that person. As a Mother I would want someone to help my child. I knew that there was a strong likelihood that I would not match, but perhaps at least I could offer hope.

I called Robbie a few months after hearing her and Amanda speak at the 2009 collaborative, and told her that I wanted to be worked up as a living donor. In February of 2010 I met face to face with Amanda, it was only the second time we had met. She tearfully told me that it meant a lot to her and for the first time in many years, she had hope.

On July 7, 2010 I contacted the Virginia Transplant Center at Henrico Doctor's Hospital to begin my donor evaluation. As part of this work up I have had every possible test and scan known to man. I even passed a comprehensive psychological exam which in a surprising turn of events did not find me to be crazy. The good news was that I was found to be in excellent health and suitable for kidney donation. The bad news was that Amanda and I did not match. Her only hope now was that we could find her a matching kidney through the National Kidney Registry. What this meant was that if we found a match, I would donate to a stranger so that she could receive a transplant.

On March 3, 2011 Amanda and I joined the National Kidney Registry and both of our DNA were entered into the system. Amanda has a lot of antibodies in her blood from having had a prior kidney transplant and from the many blood transfusions she's had over the last five years. This measurement is called Panel of Reactive Antibodies (PRA) and it's measured in a percentage. Her PRA was 99%. This meant she would have only a 1% chance of not reacting with a potential matching donor. We knew the wait would be long and that it might not come in time.

Over the past 5 years I have grown accustomed to waiting. It's a difficult thing knowing that your life is not your own, that your future rests on the hope that someone out there, whom you have never met, will be a match to save your life. Having my family and friends by my side throughout has been comforting and a strong reminder each day of what it is I have to keep fighting for and to live for. When Lisa called and told me that she wanted to be worked up to see if she was a match, my first thought was "really?" It's difficult to express the emotions and thoughts I felt. Someone you have met only once, telling you they are willing and wanting to literally give you a part of themselves is no small thing.

I felt thankful for her generous offer, excited for the chance to get my life back, fear for the coming months of even more tests and waiting, but more than anything else, I felt hope for the first time in a long time. I knew that we only had a 1% chance of matching, but when you're waiting for your life to be saved, that 1% is everything. But, we didn't match. The next step was now to be added to the National Kidney Registry, in addition to the UNOS waiting list I was already on. It was an all too familiar process for me. Yet, this time felt different. Perhaps it was the hope given to me from Lisa, or the continuing love from my family, but I had a feeling that things would soon be different.

On July 10th I received a call from the Virginia Transplant Center at Henrico Doctor's Hospital telling me that they had a match and the targeted donation date was July 21st. I was stunned, happy, scared and panicked over the short amount of time I had to prepare for the surgery and recovery. There was vacation to reschedule, a speaking engagement to cancel and on and on. Amanda and I were part of a large chain and because of this the surgery date changed a few times. The final surgery date was set for August 10.

The day before our surgery, Amanda, Robbie, my oldest daughter Ellen and I met at the Virginia Transplant Center. Amanda and I had a chance to talk late Tuesday night after all our visitors and family had gone home. She was anxious about the surgery but mostly afraid that the kidney she was about to receive would not work. I joked with her that all I could think about was how hungry I was. I'd been having clear liquids all day and the grumbling in my tummy was driving me crazy. I don't do well with hunger.

I was taken to the operating room around 6:00 Wednesday morning. I was the first of six surgeries performed that day at four transplant centers across the country. My husband John made his way to the surgical waiting area where he was joined by the rest of our family. Robbie never left his side as they anxiously awaited word from the recovery team. The surgery took about four hours and my left kidney was packaged up along with a GPS tracking device for the commercial air flight across the country to a recipient at USCF in San Francisco.

My kidney, nicknamed "Squirt" by my youngest daughter Abbey, arrived in California late Wednesday night and was transplanted into a thirty-something year old man. "Squirt" began to function immediately and he was discharged from the hospital the same day I was with better kidney function labs than mine. He is still doing great!

Amanda's new kidney worked amazingly well. She was texting me a week and half after surgery telling me how she was out shopping and had just bought size six pants. I was still laid up at home feeling pretty awful. This is to be expected as the kidney recipient goes into the hospital sick and comes out well. The reverse is the case for the donor. Amanda continues to do well, her dialysis catheter has been removed and she is on the lowest dose of medication.

Story Continued ...

Since receiving my new kidney, my life has significantly changed. There are no more nightly visits to the Emergency Room. No more continuous vomiting. No more listless days lying in bed with my dogs, Reese and Foxy, simply trying to muster enough energy just to walk them outside. The change I felt after the transplant was almost immediate. I am alive! I am healthy! I am here! It's as though I was in a sleepless daze for all those years, and now I have awoken, and am able to continue with my life. It has only been a few short months since transplant, but I am already undertaking all the things I have wanted to do and dreamt about for all these years.

I am able to drive myself without the aid of others. I have found a new love in shopping, and trying on new clothes. I am renewing friendships, now that I am actually able to go out. I am even in the process of moving, and am remodeling an old farm house to start my life on my own. And amazingly, I am now able to offer help to all my friends and family who have carried me through all these years.

I don't yet really know much about the person who donated their kidney to me, other than he is doing well and was able to return to work quickly. I hope to one day thank him in person. It is Lisa, however, that has made all this possible. Her gift of life, and that is truly what it has been, has allowed me to return to being me, something I haven't known for a long time.

In addition to putting my life back together, and having a little (or a lot) of fun in between, I am doing everything I can to share my story and my struggles with others. I want to let people know the difference they can make by simply signing up online, or at the DMV, to become an organ, eye and tissue donor. I want to share my story of hope, and success, with all those who are still waiting for that life-saving transplant to happen. I want to give others hope, the same hope that Lisa gave to me, that one day their life can be their own again.

I am thankful every morning I wake up, with all the promise of a new day, and tomorrow. After all these years of waiting and hoping to be saved, I have now been granted that gift, and I plan to live every moment of my life enjoying every day I have with my family, my friends, and myself.

In addition to being a mother, wife, nurse and transplant professional, living donor is now part of my identity. Organ donation creates a life of greatness. It was an honor and a privilege to have participated in Amanda's life of greatness. And I am looking forward to being a part of her life for many, many years to come.



Lisa Stanzione & Amanda Key

Donate Life Virginia & DMV Partnership

On October 3rd, 2011, Donate Life Virginia began directly supplying pens, pencils and highlighters for all 74 DMV Customer Service Centers throughout Virginia.

These simple office supplies are being offered as a way to give back to the department for all the hard work and effort that is put into saving lives through organ, eye and tissue donation registrations.

These items are in addition to the newly designed clipboards that were distributed to all Customer Service Centers at the beginning of 2011.

If you haven't yet received an order form, or have any questions, suggestions, or ideas on how we can continue to better serve you, feel free to contact us at any time.

Thank you for continuing to spread the important message of organ, eye and tissue donation.

Over 98% of signups take place at the DMV. Your role is crucial to saving lives!

DMV Pen, Pencil & Highlighter Order Form

Beginning Monday, October 3rd 2011 all pens, pencils and highlighters will be ordered through Staples Promotional Products, provided for by Donate Life Virginia. **STAPLES Promotional Products**

DMV Location: Person Submitting:
 E-Mail Address: Phone #:

For each item, designate the number of "packs" you are ordering. Each pack contains 25.

Item	# of packs	total # being ordered (# of packs x 25)
Pens:	<input type="text"/> x 25 =	<input type="text"/>
Pencils:	<input type="text"/> x 25 =	<input type="text"/>
Highlighters:	<input type="text"/> x 25 =	<input type="text"/>

You can submit this form by clicking "Submit" above, or e-mail to: Adrian.Smith@StaplesPromoProducts.com

Please double check your order before submitting. You will receive a confirmation reply that this order has been received.

Please submit any questions or problems to:
 Brian Sullivan
 Chair, DLVA DMV Committee
Brian_Sullivan@LifeTextHealth.org

Thank you for continuing to spread the important message of organ, eye and tissue donation. Over 98% of signups take place at the DMV. Your role is crucial to saving lives!



TRIVIA TIME!

Do you know which recent dancer from "Dancing with the Stars" received a transplant, and what type of transplant he or she received?

—The first 5 correct answers win a 2011 VA Transplant Games Tumbler!—



Do you have an idea of other ways that Donate Life Virginia can help to educate and spread the message of donation

in your DMV? [Let us know!](#)



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