Transplant Swimmer Shows a Lot of Heart

Paraphrased from article written by Teri Saylor and published in North Raleigh News, January 20, 2010

Brian Barndt, age 42, a Wake Forest, North Carolina, resident knows something about heart failure. He suffered from heart disease for nearly two decades before receiving a heart transplant in 2005. As a student swimmer and polo player at UNC-Wilmington in 1990, Brian contracted a virus that damaged his heart. The doctors were able to control his disease with medication, but he knew a heart transplant was in his future. “My body did well 10 years after the virus, but in 2000, I started to decline”. First, he had a defibrillator implanted in his chest, a device designed to deliver a shock to his heart if a life-threatening rhythm occurred. The once athlete water polo player could not even swim the length of the pool. He fought his fear of transplant surgery, and got in line for a new heart. Six weeks after the surgery he was back in the pool. Less than a year later, he competed in the US Transplant Games, winning four gold medals. In 2009, he competed at the World Transplant Games in Australia, and brought home more medals. Come hear his inspira-

RARE DISEASE DAY FEBRUARY 28, 2010
FREQUENTLY ASKED QUESTIONS

What is a rare disease?
In the United States, a disease is considered rare if it is believed to affect fewer than 200,000 Americans. Myocarditis is considered a very rare disease as fewer than several thousand people are diagnosed in the US each year.

How many people have rare diseases?
According to the National Institutes of Health, there are almost 7,000 rare dis-

eases affecting nearly 30 million Americans.

What are some examples of rare diseases?
There are many types of rare diseases, including autoimmune (Giant Cell Myo-
carditis), cardiovascular (Myocarditis), gastrointestinal, genitourinary, neuro-
logic, ophthalmologic, pulmonary, renal, and skeletal diseases. Some, such as hemophilia and Lou Gehrig’s disease, have names that are familiar to the public. Others bear the names of the physicians who first identified them.

Who is affected by rare diseases?
Nearly one in 10 Americans has a rare disease. More than half of the people known to be affected by rare diseases at this time are children.

How many rare diseases have treatments?
Many rare diseases still have no approved treatment. The foundation of treat-
ment for myocarditis is supportive care. Patients often require hospitaliza-
tion for treatment for heart failure and arrythmias.

And many rare diseases are not even being studied by medical researchers, at this time. The Myocarditis Foundation has funded research into Myocarditis for three years. To date, the MF has awarded 6 Research Fellowship Grants totaling $195,000, to guarantee that new and innovative research avenues are thoroughly funded and explored.

What are some of the problems experienced by people who have rare diagnoses?
Difficulty in obtaining an accurate diagnosis (Myocarditis is poorly understood and often under diagnosed which can rapidly progress to heart failure and death.)

Limited treatment options
Little or no research being done on the disease.
Difficulty finding physicians or treatment centers with experience in treating a particular rare disease. Treatments that are generally more expensive than those for common diseases.
Reimbursement issues related to private insurance, Medicare, and Medicaid.
Difficulty accessing medical, social, or financial services or assistance because those making the decisions are not familiar with the disease.

What did you learn that propelled you to raise money for The Myocarditis Foundation?
“I learned that Myocarditis is not well understood due to lack of research. Because all research requires money, I decided to incorporate my personal interest in music by selling CDs.”

Tell me how you went about producing a CD of your music?
“I actually have spent a couple of years making this CD. I gradually add on to it as I complete new pieces. I practice about one hour a day on both piano and violin. This practice time varies however depending on the amount of school work I have. This CD was re-
corded at home in my own little “record-
ing studio”. It is really just a computer with some microphones and recording equipment. I spend hours some days to record just one or two pieces. The work is very intense because mistakes hap-

What kind of feedback have you received from this project?
“I mainly received feedback from teachers and adults. They were amazed at the work I put into making the CD and planning/performing a little concert to raise awareness for Myocarditis. My friends also thought I did a great job.”

What aspect of the project did you find most rewarding? I feel that the project was rewarding at both personal and far-reaching levels. At the personal level, this project helped me take greater initiative. I did all the planning, reservations, CD sales, invi-
tations, etc. At the far-reaching level, I feel rewarded with the opportunity to help those truly in need. I hope my continued interest in music will help those for whom I am working. I have plenty left.” Please contact The Myocarditis Foundation.

THE AVALON OPEN
Sixteen years ago a group of guys got together at the Jersey shore to play golf for the weekend. Their occupations were as diverse as their handicaps. Over the years the number of golfers increased, the weekend got longer, and jokes got worse. After 11th hour, things changed. The event remained the same but the guys decided to add philanthropy to their recreational agenda. One of the golfers was a FDNY firefighter who lost 2 cousins and fellow FDNY firefighter in 9/11. The wife and children of the married cousin, who were having a tough time financially, became the focus for the group as they chipped in and donated money to help them out. Since 2001, the golfers have donated every year to a variety of very worthy charties. In 2009, The Myocarditis Foundation became the recipient of their generosity with the receipt of a $5,000. gift. Thank you, fellas; we are so grateful for your support. Keep up the good work.

Miles Shen, 17 year old Piano and Violin Virtuoso, Myocarditis Foundation Activist

Dear Miles,
On behalf of the Board of Directors of The Myocarditis Foundation, I would like to thank you for your efforts to raise awareness of this terrible disease and to raise money for re-
search to find answers and to save more lives.
You will likely never know how many lives you have touched by this project, but rest assured that you have touched ours. You are a rare, altruistic, generous and focused young man that is a credit to your generation. Thank you for your contribution of time, energy and talent.

Candace Moore, Director
March 15, 2010
Our laboratory is interested in the understanding of the cross-talk between coagulation and inflammation in different diseases. Tissue factor is the major cellular initiator of blood coagulation and is essential for hemostasis. Tissue factor-dependent activation of the coagulation cascade leads not only to clot formation but also to the inflammatory response by activating protease activated receptors (PARs). PARs are G-protein coupled receptors with 4 known members. Our group has shown that activation of PAR-1 and PAR-2 during myocardial infarction contributes to cardiac inflammation, fibrosis and hypertrophy. Furthermore, during my PhD thesis I investigated the impact of the tissue factor expression in myocarditis. I observed that the coxsackie virus B3 (CVB3) infection leads to local and systemic coagulation activation by increasing tissue factor expression within the heart. Thus, was not associated with a left ventricular stasis and dilatation.

Animal experiments showed that anticoagulant treatment with heparin before CVB3 inoculation reduced myocardial inflammation, collagen deposition and fibrosis in the heart. Furthermore, it was observed that herpes viruses can promote thrombin generation and PAR-1 activation which may increase the susceptibility of host cells to infection. Thus, PAR-1 may provide a link between infection and vascular diseases. To date, the role of PAR-1, the primary thrombin receptor, in virus-induced myocarditis has not been investigated. Preliminary data showed that PAR-2 deficient mice were protected in CVB3 induced myocarditis. This protection was associated with reduced cardiac virus load and replication and less cellular infiltrations in the heart.

During my fellowship I will investigate if the role of PAR-1 deficiency in CVB3-induced myocarditis in mice. Further, I will determine if a pharmacological inhibition of PAR-1 could be a new therapeutic approach in the treatment of virus induced myocarditis.

Another part of my research program seeks to explain the signaling queues triggered by virus, in the host cell, during virus infection. I have found that a molecule called p38 MAP kinase is required for infection of the heart by virus during viral myocarditis. Treatment of mice with an inhibitor of p38 blocks heart infection and halts viral myocarditis. We have also found that this inhibitor helps heart function during virus infection and so may prove to be an effective therapeutic drug for those with existing viral myocarditis. Finally, in addition to the above, we have shown that some drugs prescribed during viral myocarditis, help heart pump function, can actually activate p38 and increase virus infection of the heart. This research finding may prove to be of immediate use given that physicians can avoid these drugs that activate p38 in favour of those that prevent p38 activation.

Forever Be in Our Hearts

Logan Sweet at 6 years of age

The loss of a child is a road that no parent should have to travel. Unfortunately, many of us do. On May 9th, 2008, at 6:47pm, was the beginning of a journey that would change my life forever. Logan, our 6-year-old son, collapsed in our den and, despite my efforts to revive him, died instantly in my arms. He was a healthy boy who lived a normal, active life. The autopsy report indicated that his heart was 75% larger than normal; later we found out the cause of his death was Viral Myocarditis. This was a total shock to all of us. For months I walked through life in a fog. How would I continue to live?

It has been almost 2 years since that devastating moment. I am proof that you can continue to live after the loss of a child. In my case, I had to...for many reasons. I had 2 other children, ages 1 and 5, who needed my care. I had a shocked husband who needed me to help him stand. I had to be strong, not just for them, but for Logan too. One of my biggest fears after Logan died was that people would forget him; that his friends and neighbors would forget how fun he was and how much he made them laugh; that his family would forget the love and excitement he had for life, that his teachers and school would forget how enthusiastic he was to learn and explore all that they had taught him. So for the first year after he passed, my goal was to make sure that Logan would be remembered.

My first task was to make a large quilt that friends and family could see when they came to our home. With help from a friend, I made a quilt that has 110 squares of pictures, artwork and his favorite shirts, all sewn together. This beautiful memory quilt sits on our bed right now, a constant hug from Logan.

Lastly, to keep Logan’s memory alive, we created a foundation, the Logan Sweet Foundation. The foundation’s mission is to raise awareness of Viral Myocarditis, and to promote good health and eating habits, as well as, the importance of living a healthy and happy lifestyle. Last year we held the First Annual Celebrate Logan “Moves and Grooves” fundraiser. It was a huge success, and we were able to donate thousands of dollars to the Myocarditis Foundation. We were also able to give back to our community by using some of the funds to teach local children about nature, the outdoors and the importance of healthy eating. This year, we are hosting the Second Annual Celebrate Logan: “Down By The Bay” fundraiser. This will be a fun concert at the waterfront in our hometown of Bowdoinham, Maine.

I hope Logan is looking down on us with a “huge heart” at all that we have done, and continue to do, to keep his memory and love alive. I miss him more than words can say. I think about him every day, and I know that he will be Forever in Our Hearts. I love you Logan.

Carolyn Sweet
Logan’s Mom
Bowdoinham, Maine

For Patients:
Click the Myocarditis Patient Survey tab on our Home Page and complete the online form. The purpose of the questionnaire is to try to capture the impact that myocarditis has had on your life. Your perspective is vitally important to others who are trying to understand the seriousness of the disease.

For Patients and Families Who Have Lost Loved Ones to Myocarditis:
Click on the Community Discussion Forum tab on our Home Page to receive your authorization for your online Support Group.

For Physicians:
We are accepting applications for Research Fellowship Grants. The stipend will be $35,000 for the 2011/12 academic year. The deadline for application submission is December 1, 2010. Click on the Research tab on our Home Page to access online Research Fellowship Guidelines and Application Form.

www.myocarditisfoundation.org
1-732-295-3700
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Owen & Cole

The MYOCARDITIS FOUNDATION

Owen Lee Cardwell, Cole’s Little Brother

After having our first son, Cole, in 2007, Daron and I knew that we wanted to have at least one more child. We wanted Cole to have a sibling to grow up with. In February of 2009, we found out that we were pregnant. We soon found out that we would be blessed with another little boy who we decid-

It is now five months later and Owen is heading in the right direction. His doc-

trators are starting the process of back-

down some of his medications. Owen has started to smile and to talk. Every day he is doing more and more. Owen loves to watch his big brother, Cole, who garners the biggest smiles.

We are so thankful to God for the gift of our little Owen, and we have re-

ceived amazing support from friends and family. Many prayers have been with him and we know that we would not be able to do this without all of the love and support. We are so thankful for every prayer. Owen definitely has a long road ahead, but we are hope-

ful and know that God will lead us through this journey.

“Do not fear, for I am with you; do not anxiously look about you, for I am God, I will strengthen you, surely I will help you, surely I will uphold you in my righteous hand”. Isaiah 41: 10

Kristan Cardwell, Mom

March 2010

Albemarle, NC

Sister of GCM Victim from the Netherlands Runs NYC Marathon in Her Honor

My sister Jolanda and I grew up in a typical Dutch family. My father had a small business and my mother worked part-time in an office. We were loved and looking back at it, maybe a bit spoiled. She was afraid to get out of bed.

In 1996, Jolanda was 27. She seemed to have it all: a loving husband, a home of their own, two cars, a big dog, a job she liked and she was pregnant with their first child. It was going to be a boy. I was looking forward to becoming an aunt. Jolanda was about six months into her pregnancy, when she fell ill. She was short of breath, extremely tired and was turned off by food. In Holland babies are mostly born at home, it’s a tradition. You only go to the hospital to deliver if there is a high chance of complications. So my father, who was a big fan of his wife’s friends in Holland. When she became short of breath, she made an appoint-

ment with her mid-wif e. The midwife explained that my sister’s heart had grown so much that he pressed against her lungs and that there was nothing to be worried about. It sounded logical, but it turned out to be the opposite. Her shortness of breath became worse and worse. Even walking the dog was a strain.

She was home alone for the weekend because her husband was traveling for work in England. My concerned parents called the midwife. The next day Owen made a grand entrance at 37 weeks and 5 days. He was 7 pounds, 4 ounces and 20 inches long.

After about an hour, it became clear that Owen was having problems breathing. He was taken to the nur-

sery and was given oxygen, but the next day we were told that the hospi-

tal we were at could not help him so he was flown to Levine Children’s Hos-

pital in Charlotte, North Carolina, for extra help.

Since that day, Owen has had a rough road. What first thought to be a case of premature lungs turned out to be much more complicated case. Owen’s lungs became worse as the days passed and the doctors felt that he may have a virus that was attack-

My fondest memories of my sister are looking back at it, maybe a bit spoiled. My concerned parents were very worried about the way Jolanda looked. My mum called the midwife who said my mother was overly concerned. My mum got angry. The midwife was too busy for a house call. The next day we were told that Owen was a giant, white spot turned off by food. In Holland babies aren’t saying a lot, but Jolanda saw an x-ray of her chest with a giant white spot on it. “That can’t be good”, she said to my mum. But how bad it really was, she never got to know. The giant white spot later turned out to be her enormously enlarged heart.

In the hospital she got some medicine and seemed more calm. My parents went home for the night. I had a bad feeling about it. The call came, in the middle of the night. It was my mum, in tears. Jolanda had an attack of some kind that night. It was bad. My sister’s husband tried everything to get home but missed the last flight out of England the night before, but he would be on the first one that morning. He would never talk to his wife again.

When I arrived at the ICU, I asked where my sister was. When I walked into her room I thought it was the wrong one. The person lying in that bed with all those tubes sticking out of her looked nothing like my sister. When I looked closer, I saw it was Jolanda. I lay next to her, be-

cause she was so cold and I wanted to war-

m her. I knew things were very wrong and I realized she might not survive. Her doctor said her organs were failing. I asked him if he could take some of mine and make her chances better, but he said no.

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Run for Jolanda

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