

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 fear. 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 inspirational story at Fiesta 2010 in Raleigh, North Carolina.

Special Events

The 4th Annual 5K Walk/Run in Memory of Devin Kravitz will held on Labor Day weekend, September 4, 2010 in Leicester, Massachusetts. Devin was 21 years old when he died in his sleep from cardiac arrest due to viral myocarditis. His family hosts this event annually to raise money for The American Heart Association and The Myocarditis Foundation. All funds go to myocarditis research. Go to Dk5k.org for more information.



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 diseases affecting nearly 30 million Americans.

What are some examples of rare diseases?

There are many types of rare diseases, including autoimmune (**Giant Cell Myocarditis**), cardiovascular (**Myocarditis**), gastroenterologic, metabolic, neurologic, 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 treatment for myocarditis is supportive care. Patients often require hospitalization for treatment for heart failure and arrhythmias.**

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 diseases?

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.

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

Background: In December 2009, I received an email from a high school student from Atherton, California. He explained that he had done a project for his Anatomy class on Myocarditis and decided to raise awareness about the disease by hosting a chamber music concert at his school. In addition, he produced a CD of his piano performances and sold them to raise money. All proceeds have been donated to The Myocarditis Foundation. I asked him if I could interview him via email for our newsletter audience.

Tell me about yourself: "I am 17 years old and go to Menlo School in Atherton, California. My interests include piano, violin, medicine/biochemistry and swimming."

How did you become interested in myocarditis? "I actually came up with the topic of Myocarditis by luck. Everyone in Anatomy class wrote down 5 diseases they are most afraid of getting. Based on this information, our teacher gave each student a different chronic disease. Over the course of the month, we lived as though we actually had our diseases."

How did you choose Myocarditis? "My aunt actually had a very mild version of the disease when she was young. I got some insight from her. Today, she is hardly experiencing any problems."

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 CD's."

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 recorded at home in my own little "recording 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 happen often. But in the end, all the work pays off. I am proud of the product."

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, invitations, etc. At the far-reaching level, I feel rewarded with the opportunity to help those truly in need. I hope my contributions go a long way. Thank you for listening! I will be sure to continue my work. If anyone wants more CDs, I have plenty left." **Please contact The Myocarditis Foundation.**



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 research 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 Moose, Director
March 15, 2010

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 911 though, 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 fireman who lost 2 cousins and fellow FDNY firemen in 911. The widow 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 charities. But 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.



**“Thrombin-PAR-1 Signaling in Viral Myocarditis”
by Dr. Silvio Antoniak
University of North Carolina in Chapel Hill**

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.

THE MYOCARDITIS FOUNDATION

866-846-1600

RESEARCH GRANT RECIPIENTS 2010-2011

**“Discovering and Understanding Virus-Host Factor Interactions
for the Treatment of Viral Myocarditis”
by Dr. David Marchant
University of British Columbia in Vancouver**

I am involved in a program of work with my preceptor, Dr Bruce McManus, that involves studies of particular “worker proteins” called enzymes. The family of enzymes I study are called matrix metalloproteinases (MMPs), and I am especially devoted to understanding their roles during viral myocarditis (inflammation of the heart due to virus infection of the heart muscle). We recently published some work in a prestigious competitive bio-medical journal called Circulation, that demonstrates the beneficial role that MMP-9 plays during viral infection¹. Until very recently MMP-9 was thought to be a nuisance molecule that worsens disease and prevents healing of the heart after virus infection. We have shown that this MMP is in fact a necessary part of the patient’s anti-viral immune response. This research is ongoing and we continue to elucidate new roles for other MMPs during antiviral immunity. Currently we are investigating the role of MMP-12 during virus myocarditis which regulates the antiviral immune response by degrading (chewing up) molecules produced by the immune system. We have found that by inhibiting the function of MMP-12 with a new drug we are able to increase the antiviral immune response during virus 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 myocarditis². 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.

1 Cheung C and Marchant D et al. Ablation of Matrix Metalloproteinase-9 Increases Severity of Viral Myocarditis in Mice. Circulation. 2008 Mar 25;117(12):1574-82.

2 Marchant D et al. Bosentan Enhances Viral Load via Endothelin-1 Receptor Type-A Mediated p38 MAP Kinase Activation While Improving Cardiac Function during Coxsackievirus-Induced Myocarditis. Circulation Research. 2009 Mar 27;104(6):813-21.

**“The Role of Dystrophin in
Enterovirus Induced
Viral Myocarditis”**

**by Dr. Byung Kwan Lim
University of California
in San Diego**



Viral myocarditis is an important cause of heart failure in both children and adults. Little is known regarding the precise processes that are required to allow the virus to replicate in the heart and to cause heart failure. Accordingly, we have focused our attention on a viral protein known as a protease that can digest other proteins. We have shown that this viral protease is able to digest an important myocardial protein known as dystrophin. Dystrophin is the same protein that is missing in patients with Duchene Muscular Dystrophy. The absence of dystrophin is known to cause heart failure in children with muscular dystrophy. Since both hereditary absence of dystrophin occurs in muscular dystrophy and viral infection and both can cause heart failure, it emphasizes the likely importance of the dystrophin complex in both diseases.

In the current studies, we will study the effect of preventing dystrophin disruption during virus infection in a genetically-engineered mouse that has a dystrophin molecule that has been mutated so that it cannot be digested by the viral protease. These experiments will allow us to clearly address the importance of this interaction between the viral protease and dystrophin. A better understanding of this interaction and its importance will facilitate creation of therapies aimed at preventing disruption of the dystrophin complex and hopefully the development of heart failure in viral myocarditis.

Forever Be in Our Hearts

The loss of a child; a road that no parent should have to travel. Unfortunately, many of us do. 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 much 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. That June, the school honored Logan by naming an award after him. Logan was very smart with math and numbers, so this award is given annually to a fifth grade student for their accomplishment in the math programs. My husband and I have the privilege of presenting this award every year at the fifth grade graduation. Next, we had a beautiful bench installed at the school playground, dedicated to Logan by his family. It is a place for anyone to sit and be where Logan loved to "Laugh, Play and Love" – the inscription on the bench plaque.

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 am very excited about this benefit and hope that is it just as successful as last year.

Throughout these past 2 years, I have found that I need to stay



Logan Sweet at 6 years of age

connected to my memories of Logan, no matter how painful it seems at that moment. When something comes up that feels too overwhelming to endure, I have to express my emotions rather than block them. Sharing them with my husband, my family and my friends gets me through the pain. Crying is part of my daily routine; crying has become my connection to Logan. My love for him grows with every good cry. I find I am renewed, and I know that my continued strength comes from him. I have also found peace, peace in the precious eyes of my six month-old daughter. She is proof to me that love never dies and that life does go on.

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

The Myocarditis Foundation Announces Programs for 2010

- Myocarditis Patient Survey**
- Discussion Forum**
- Research**

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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Special Events

"Second Annual Celebrate Logan: Down by the Bay Fundraiser" to raise awareness of viral myocarditis. The event will be held on May 2, 2010, in Bowdoinham, Maine. For more information email: livelife@logansweetfoundation.com

Financial information about this organization and a copy of its license are available from the State of North Carolina Solicitation Licensing Branch at 800-830-4989. The Myocarditis Foundation is also a license charity in the state of New Jersey. For more information, please contact The NJ Office of Consumer Protection at 973-504-6215.



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 decided to name Owen.



Owen, Kristan & Cole

Because of a previous C-section it was decided that I would deliver Owen on November 2nd. On October 20th plans changed a bit when I started to have pain on my right side. A trip to the hospital showed that a cyst on my right kidney had grown and was the reason for my pain. 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 nursery and was given oxygen, but the next day we were told that the hospital we were at could not help him so he was flown to Levin Children's Hospital in Charlotte, North Carolina, for extra help.

Since that day, Owen has had a rough road. What was first thought to be a case of premature lungs turned into a 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 attacking his body. It was confirmed that Owen had a virus called Entero Virus that led to him being diagnosed with Viral Myocarditis. About three weeks

before he was born, I came down with a bad cough and runny nose. I never ran a fever, but I finally went to the doctor and got some medicine. The doctors believe that I passed this "cold" through the placenta to Owen. It has caused damage to Owen's heart, lungs, and liver. He has already overcome extra ordinary circumstances and has proven to be a very special little man.

It is now five months later and Owen is heading in the right direction. His doctors are starting the process of backing 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 received 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 hopeful 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



Owen & Cole



Host: Jim and Candace Moose

Location: Brier Creek Country Club
9400 Club Hill Dr., Raleigh, NC

When: Friday, May 7, 7:00pm

Phone: 732-295-3700

Please gather your friends and join us for

The Myocarditis Foundation FIESTA

featuring
"Twenty Years Gone" Rock 'n Roll Dance Band

Mexican Buffet, Cash Bar, Silent Auction

Award: Dr. Silvio Antoniak, UNC Chapel Hill
2010-11 Research Grant recipient

Speaker: Dr. Leslie Cooper, Mayo Clinic cardiologist
and myocarditis researcher

Speaker: Brian Barndt, medalist, International
Transplant Games in Australia

COST: \$75.00 per person
(\$50 is tax deductible donation)

To confirm Guest Reservation or be an Event Sponsor,
indicate Guest or Sponsor on invite reply
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Paul Kollar- top left

Ken Lundy-top right

Jenny Lyden-bottom left

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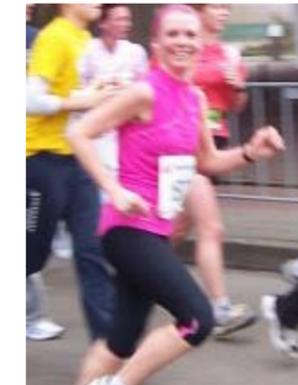
Sister of GCM Victim from the Netherlands Runs NYC Marathon in Her Honor Run for Jolanda

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. My fondest memories of my sister are of the times we shared a horse and our love of horse back riding. Jolanda always was an active person. She loved aerobics, fitness and swimming.

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 there are a lot of practices for mid-wives in Holland. When she became short of breath, she made an appointment with her mid-wife. The midwife explained that my nephew-to-be 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 wrong information. 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 stopped by. When they arrived, they 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, so my mother called my sisters' GP. Same answer as the midwife, so they took my sister home with them for the weekend. She seemed to be doing a little better in their care.

Then, Monday morning my sister felt weird. She was afraid to get out of bed. So my mum called her own GP. Even though my sister was not his patient, he was there in 5 minutes, saying, "You should always attend to a sick, pregnant woman." He looked at Jolanda and



Brenda Heske training for NY Marathon

asked where the phone was to call the emergency services.

My sister was rushed to the hospital and they ran all kinds of tests. The doctors weren'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, because she was so cold and I wanted to warm 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.

We had to wait in the family room. I saw my father who isn't a religious man rocking in his chair and praying. My mother was quietly crying. I can't remember what I did while we waited.

It was hopeless. The doctors had tried everything, but seemed to be only treating the consequences of the disease, not knowing what it was that was killing her. We were all gathered around her bed. Jolanda and her unborn child died at half past five pm on December 3rd 1996.

The doctor requested an autopsy and we wanted to know what killed Jolanda. It was Giant Cell Myocarditis. The doctors had never thought of that because it is so rare and never before seen in a pregnant woman. Her cardiologist showed us a thick book about heart diseases, he called it "the bible of the heart". It only had a few lines on the disease that killed my sister. We gave permission for a university study on my sister's case. It is probably scientifically very relevant, and it might save somebody else someday. But it never answered our biggest question: Why?

Back in 1996, my sister's cardiologist told me there was only one doctor in the whole world who is trying to cure Giant Cell Myocarditis. I later searched the internet and found Dr. Cooper on The Myocarditis Foundation website. Dr. Cooper still can't answer our "why" question but it is good to know he is working hard to do so. And it is good to see he has already come so much further than those few lines in "the bible of the heart".

I cannot help him with his research, but I realized I can do something. I'll be running the NYC marathon this year. I intend to raise as much money as I can for myocarditis research to help Dr Cooper and The Myocarditis Foundation find the answers to the "why-question" and hopefully save many lives.

Please support my run by going to:

<http://www.active.com/donate/runforjolanda>