Kyle Williams' **Survivor Story**

Location: Syracuse, NY **Profession: Environmental Engineer** Diagnosis: Dilated Cardiomyopathy, August 2011 (Age 29) Transplanted: December 10, 2014 (Age 32)

In the Beginning...

It was the summer of 2011, and I could sense something was off. I noticed some labored breathing. I was an active 29-year-old, going to the gym, playing sports and working full-time as an environmental engineer. "It must be some sort of lung infection," I thought. I went to a doctor and told him my symptoms. He took some chest x-rays and sent me on my way; prescribing an inhaler, telling me it should improve my symptoms. It did not. After a CT scan and a trip to the local urgent care, it was discovered that I had an enlarged heart and needed to get to the hospital immediately. I met my cardiologist, Dr. Joseph Battaglia, in the emergency room at Crouse Medical Center in Syracuse, New York and was given a diagnosis of dilated cardiomyopathy. The cause was likely some sort of virus that attacked my heart. The virus was already out of my system, but once the damage was done, it was done. During my hospital stay, I had abnormally fast heart rhythms, known as ventricular tachycardia (VT). When I left the hospital, I was given a life vest to wear (which can deliver a lifesaving shock, if needed). To top it all off, a week prior to going into the hospital, Sara and I found out we were going to be parents for the first time – talk about a life-changing seven days.

Post Diagnosis

I had a hard time after I was diagnosed. Physically, I felt okay. The hardest part for me was mental. A few months after leaving the hospital, the life vest gave me a life-saving shock in the early hours of the morning while I was asleep. I was taken to the hospital by ambulance and implanted with an internal implantable cardioverter defibrillator (ICD) later that day.

In April 2012, my daughter Ella was born, which gave my life new meaning and perspective. From that point on, I managed to live with my condition without too much trouble. In April 2014, Sara and I welcomed our second daughter Eva. In September 2014, I came down with a fever and a hacking cough. One afternoon, while watching football, I was shocked

by my ICD numerous times. I was brought to Crouse Hospital for a third time by ambulance. My heart function had dropped dramatically. Over the years, Dr. Battaglia and I had talked about the possibility of needing a heart transplant, but I never dreamed the need would come this quickly.

Shipping Up to Boston

As fate would have it, Dr. Battaglia's daughter was a cardiology fellow at Tufts Medical Center in Boston, one of New England's premier heart transplant centers. Once I arrived, I went through a barrage of tests and was told I would need an LVAD (left ventricular assist device) as a bridge to transplant. Dr. Duc Pham performed my LVAD surgery. Then, after some serious training on how this "thing"- which now was essentially keeping me alive – works, I was discharged. In mid-November, two days before I planned to return to work, I was readmitted to Tufts Medical Center because of blood clot concerns. I spent Thanksgiving in the hospital. December arrived and I was preparing to settle in for the long haul in my hospital room. Encouragement came when I was notified I was the "backup" for a donor heart. Then, on December 10, a little after midnight, I was awoken by a group of wonderful nurses. They said, "Kyle, we have a heart for you."

How is Life Post-transplant?

December 10, 2014 is the beginning of a new story for me, one that I am still writing. I look at life a little differently now. How could I not? I've been given a great gift and consider myself very lucky. I take time to thank my donor and family every single day. The support of my beautiful wife along with the rest of my family, friends and co-workers and medical staff was overwhelming. Beyond that, getting to know members of Team HeartBrothers and talking to people who have been through it all before made such a difference in my attitude and outlook. We all share a common bond. It will always connect us and I will forever be grateful for the kindness and generosity shown to me.



Patrick Sullivan Co-Founder & Transplant Survivor

> Leslie Sullivan Co-Founder & Caregiver

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BROTHERS FOUNDATION

IS AT THE HEART OF ALL WE DO.



64 million people worldwide suffer from Heart Failure.

Heart Failure. Two words that sound devastatingly hopeless. So imagine being one of the 6.7 million adult patients in the U.S. facing this potentially fatal condition. Where do you turn for help? How can you get support? Who can offer you hope?

We Are The HeartBrothers Foundation

Established in 2014 by Pat Sullivan and Bob Romer, two Heart Failure survivors and now best friends, The HeartBrothers Foundation is a 501(c)3 non-profit foundation that serves as a beacon of help and hope for patients and their loved ones trying to navigate the complex world of Heart Failure (HF), ventricular assist devices (VADs) and heart transplantation. With more than 30 years of combined experience living with the overwhelming challenges of Heart Failure, Bob and Pat have a unique perspective on the condition and a deep understanding of what patients and their loved ones go through every single day. As survivors, they decided the best way to pay it forward was to give back. A true sense of gratitude and an opportunity to fulfill a need for HF patients and their families inspired Bob, Pat, and their wives to create The HeartBrothers Foundation.

HeartBrothers Programs

Launched in Boston, at a renowned medical center for cardiovascular care and heart transplant surgery, our assistance programs currently serve patients throughout New England, upstate New York and beyond. We coordinate with hospitals to help fill the financial gaps that exist between a patient's medical insurance and comprehensive, compassionate hospital care.

We also assist families in covering costs that exist in that "gap" including transportation, parking, lodging and meals associated with long-term medical stays.

Types of Programs Include:

- lodging, food, transport, parking, and critical travel expenses.
- hopeless.
- patients and families through the duration of their hospitalization or clinic care.
- centers.
- schools and companies.



More than 900,000 new cases of Heart Failure are diagnosed each year.

Approximately one in four Americans wi develop Heart Failure in their lifetime.

• Patient Assistance: Financial support for the costly Heart Failure burden of hospitalizations,

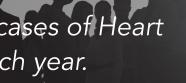
• Team HeartBrothers: Our 80+ Team HeartBrothers Ambassadors—survivors of VADs, heart transplant, and beyond—who provide emotional support and education. In person and virtually, they visit hospitalized and homebound patients-delivering hope when all seems

• HeartBrothers House: The first lodging option in downtown Boston dedicated to Heart Failure patients. Offering fully furnished upscale one-bedroom apartments to Heart Failure

• Patient Support Group: Our free monthly virtual meetings that are a gathering space for all Heart Failure patients and loved ones to listen or share first-hand knowledge, experiences, and strategies on living life with Heart Failure. Featuring Team HeartBrothers Ambassadors, fellow Heart Failure patients and caregivers, and social workers and staff from partnering transplant

 Organ Donation Awareness: Virtual and in-person outreach & presentations to raise awareness about organ donation to the national HF community as well as local organizations,

HEART BROTHERS FOUNDATION



Though certain conditions and behaviors increase the risk for Heart Failure, anyone—at any age can develop Heart Failure.

Our Sole Mission

"We bring resources together to help patients and their loved ones survive a life with Heart Failure and all its challenges."

Through grass roots fundraising efforts and generous donations from individuals and corporations, we've been able to continuously expand our efforts to help Heart Failure families in need. Essential support includes financial assistance, informative stress-coping resources and connections with the global Heart Failure community. What's more, we've been able to increase awareness about Heart Failure and the progress being made today to offer more people the promise of more tomorrows.

Submit a "Heart Prayer"

If you know someone struggling with Heart Failure, or anything else for that matter, The HeartBrothers Foundation welcomes you to submit a "Heart Prayer" on his or her behalf. Simply go to heartbrothersfoundation.org and click on the "Submit a Heart Prayer" button in the homepage footer.

Failing Hearts Need Helping Hands

No matter how big or how small, your donation can give someone living with Heart Failure today the promise of more tomorrows. Please consider donating. Your generosity is truly appreciated. For more information or to make a donation, please visit our website at heartbrothers.org and click on the DONATE tab. To donate by check, make a check payable to: "The HeartBrothers Foundation" and mail to:

> The HeartBrothers Foundation 225 Cedar Hill Road, Suite 200 Marlborough, MA 01752

To contact us directly, please call (800) 262-0931 or email us at us@heartbrothers.org.