The MYOCARDITIS FOUNDATION

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Spring 2009 *Knowledge Nurtures Hope* Vol. 2 No. 1

## The Myocarditis Foundation Announces The Award of A Research Fellowship Grant in 2009

The Foundation awards funds to support research related to all forms of myocarditis. The goal of the Foundation's research program is to advance medical knowledge of the disease and to save more lives.

Candace Moose, Director, states: "We are pleased to support the career development of such an outstanding young physician scientist as Dr. Wollersheim and look forward to the contribution she will undoubtedly make in the field of myocarditis research."

Susan Wollersheim, MD, UCLA Medical Center, PEDIATRIC INFECTIOUS DISEASES FELLOW

**"Cellular and Viral Determinants of Neonatal Coxsackievirus Myocarditis"**

Group B coxsackieviruses (CVB) are a leading cause of infectious myocarditis and have a high mortality rate in newborns. Currently, there is no commercially available specific antiviral therapy for CVB; only supportive care can be offered. My research is designed to identify potential therapeutic targets.

Some variants of CVB are myocarditic, and some are not; this difference in the myocarditic potential has been mapped to a region of the CVB genome called the internal ribosomal entry site (IRES). My research will compare the IRES function from CVB strains recovered in recent fatal cases of neonatal myocarditis to older, prototype CVB strains. We will also plan to use mass spectrometry to identify proteins specifically expressed in cardiac myocytes that interact with the CVB IRES. These proteins may prove to be targets for treatment of CVB myocarditis.

### *Dr. Leslie Cooper Speaks on Myocarditis*

***March 5th,*** *Clinical Immunology Seminar Series,* Mayo Clinic Rochester, MN

***April 9th,*** Hanoi Medical University, Hanoi, Vietnam

***April 22nd,*** *International Society of Heart and Lung Transplantation,* Paris, France

***May 1st,*** *Cardiology Grand Rounds,* Mayo Clinic Rochester, MN

***May 7th,*** *Cardiology Grand Rounds,* The Oklahoma Heart Hospital, Oklahoma City, OK

***May 23rd,*** *17th Asian Pacific Congress of Cardiology,* Kyoto, Japan

***June 4th,*** *Cardiology Grand Rounds,* Medical College of Wisconsin, Milwaukee WI

In these difficult economic times, we are especially grateful for your support.

*Thank you donors!*

*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 license is not an endorsement by the State.*

**Please remember the Myocarditis Foundation in your estate plans. For additional, information contact the Foundation directly.**

*www.myocarditisfoundation.org*

## First Annual Celebrate Logan "Moves and Grooves Fundraiser"

*May 2nd, 2009*

**Carolyn and Jon Sweet, parents of Logan, will host the event which will be held at the Bowdoinham Community School recreation field from 3-5pm. There will be music, dancing, face painting, and informational booths on Myocarditis, routine pediatric health care, exercisie, nutrition and hygiene. There will be a coloring book activity table, entertainment and healthy snacks and a guest speaker - Candace Moose, cofounder of the Myocarditis Foundation and a Myocarditis survivor.**

# Logan's Story

***This is the story of our son, Logan. He died May 9, 2008. He was six years old.***

My sweet Logan was a child full of energy, health and beauty, the most active little boy I have ever known. He loved life and made the most of every moment. When he walked into the room, his smile and laughter filled the room with positive energy. He was loved very much by family, friends and his school.

He loved playing soccer, T-ball, basketball, snowboarding, exercising and dancing, which he called "doing his moves". He also enjoyed climbing trees, going for hikes, swimming, counting with numbers and coins, playing with his friends and making people laugh. He was the best big brother to his little sister and baby brother. They looked up to him and loved him very much.

Logan was a very affectionate boy and loved to snuggle on the couch first thing in the morning to get warm. He was my little cuddle bug.

It was Friday, May 9th 2008, the day that changed my life forever. It began like any other day. Logan was off to school, happy as can be. He was excited about the first T-ball game scheduled the next day. His sister Jaclyn went to preschool, and I was home with baby Ryan.

In the afternoon the bus dropped Logan off at the end of the road along with a neighborhood friend. The boys wanted a play date, so we all headed back to the play set in our back yard. The two boys climbed around like monkeys for over an hour. At 5:00pm, the neighbor went home, and we went inside to get ready for dinner. When dinner was over, I ran upstairs and left Logan and his sister in the den playing.

Moments later I came downstairs and found Logan sitting on the f oor in a very awkward position. His upper body was folded over with his head between his knees. I asked Logan to sit up; he didn't move. I set Ryan down and rolled Logan over. My heart stopped; he wasn't breathing. He was blue around his eyes and mouth.

I scooped him up and ran to the kitchen and dialed 911. I followed the dispatchers instructions. My husband arrived home to find me doing CPR on our son. The doctors pronounced Logan dead at 6:47pm at the hospital. The paramedics were not able to revive him in the ambulance. I truly believe that Logan died at home in my arms.

Two days later on Sunday, Mother's Day, we learned that Logan had an enlarged heart, cause unknown. Almost four months later we were told that Logan died of Myocarditis. A virus had attacked his heart, causing it to become 75% larger than normal.

Logan showed no signs of heart problems. He had no shortness of breath, dizziness, or leg cramps.

Ironically, Logan's annual physical was two days before his death. As with every annual physical since his birth, I mentioned to the doctor that Logan had a heart murmur as an infant. The doctor listened extra long to his heart and said that everything sounded fine. Unfortunately in a lot of cases like Logan's the first and only sign of myocarditis is death.

*Logan Sweet at 6 years old*

After Logan died, I heard more stories of teenagers collapsing in gym class and athletes falling on the fields. My heart breaks for the families of these young people. There must be some way to detect this disease before it is too late.

Please help and donate to The Myocarditis Foundation. The Foundation's hope is that with more knowledge about the disease, physicians will provide earlier and more effective treatment that will save lives. Your donation will help researchers learn more about this heart condition and help spread awareness to doctors, pediatricians and parents.

Thank you,
Carolyn and Jon Sweet, proud parents of Logan Sweet

The last day of February was designated as worldwide "Rare Disease Day" to call attention to the public health issues associated with rare diseases, which affect nearly 30 million Americans and countless others around the world.

"People with rare diseases remain a medically underserved population in every country," said Peter L. Saltonstall, president of the National Organization for Rare Disorders (NORD), which is sponsoring Rare Disease Day in the U.S. "This day was intended to bring together the patients and families with rare diseases to discuss the need for greater awareness, more research, and better access to diagnosis and treatment."

More than 200 organizations, institutions and companies have signed on as "Rare Disease Day Partners" in a U.S. coalition supporting the special observance. The coalition, being coordinated by NORD, includes patient organizations, professional societies, government agencies, medical researchers, and pharmaceutical and biotechnology companies.

Rare Disease Day activities in the U.S. included a nationwide network of online videos, patient stories and blogs; newspaper, radio, and television reports; state and municipal proclamations; a Rare Disease Hall of Fame for researchers; and other activities designed to raise awareness of what it means to have a rare disease.

A rare disease is one that affects fewer than 200,000 Americans. According to the National Institutes of Health (NIH), there are nearly 7,000 such diseases affecting nearly 30 million Americans. **Myocarditis is a very rare disease, affecting several thousand people in the United States each year.**

"People with rare diseases often face challenges that occur less frequently with more common diseases," Saltonstall said. "These include delay in getting an accurate diagnosis, few treatment options, and difficulty finding medical experts. Many rare diseases have no approved treatment, and insurance may not cover treatments that aren't approved. Medical and social services may be denied because those making the decisions are not familiar with the diseases. Also, treatments for rare diseases tend to be more expensive than treatments for more common diseases."

In 1983, the Orphan Drug Act was passed by Congress to create financial incentives for companies to develop treatments for rare diseases. Since then, nearly 330 "orphan" (for rare diseases) drugs and biologics have been approved by the U.S. Food and Drug Administration (FDA). FDA estimates that from 11 to 14 million Americans benefit from these products. However, that still leaves more than 15 million Americans with diseases for which there is no approved treatment.

Rare Disease Day highlighted the unique partnership that exists among the patient community, government entities such as the NIH Office of Rare Diseases and FDA Office of Orphan Products Development, medical professionals, researchers, and companies developing orphan products.

Although this is the first Rare Disease Day observance in the U.S., it is the second globally. The concept was launched in Europe last year by the European Rare Disease Organization, EURORDIS, a sister organization to NORD. This year, Rare Disease Day was observed in other parts of the world, including Canada, Australia, and China. The plan is to have a global Rare Disease Day on the last day of February each year.

NORD, a federation of individuals and patient organizations, was established in 1983 by the patient leaders who worked to get the Orphan Drug Act passed. It provides advocacy in Washington, DC, on behalf of the rare disease community; research grants and fellowships; educational services for patients, the public, and medical professionals; and patient assistance programs. ***The Myocarditis Foundation has been a member organization of NORD since 2007.***

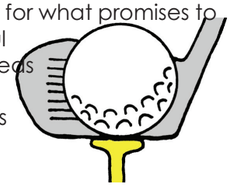
For more information about Rare Disease Day activities in the U.S., go to NORD's website www.rarediseases.org. For information about the global observance, go to www.rarediseaseday.org.

This article was reprinted with permission from NORD.

## 2nd Annual Myocarditis Foundation Joe Rumore Golf Outing

The place to be on Monday, September 21, 2009, will be the White Beeches Golf & Country Club in Haworth, NJ. If the weather is anything like last year, it will be a great day for golf and also your chance to win great prizes, eat good food, have fun and support a really good cause. There will be auction items, tournament prizes and a 50/50 raffle.

Following dinner, Dr. Leslie Cooper, founder of the MF and world-reknowned researcher and lecturer from the Mayo Clinic, will be the guest speaker. If you were unable to attend last year, mark this date on your calendar and be sure to join us this year for what promises to be a wonderful time. All proceeds will benefit The Myocarditis Foundation.



## MYOCARDITIS: A Widow's Perspective

***The Brian Wright Family***

Brian was a very healthy 47 year old father and husband. Our lives were perfect. We were happily married with two beautiful children that we adored, ages 11 and 15. Brian was a very friendly and outgoing person. Everyone who knew him liked him. He was the best father and husband. He loved life and was very optimistic about the future. He had achieved his life-long dream of being his own boss in running his own business. We enjoyed our family life.

Approaching the holidays in 2005, Brian caught a virus and had flu-like symptoms a few weeks prior to suddenly developing heart failure caused by viral myocarditis. On Dec. 23, 2005 he was feeling very short of breath, tired and somewhat ill. He took himself to the emergency room. His heart was in and out of atrial fibrillation. An Echocardiogram was done of his heart; it showed an enlarged heart that was not functioning properly. He was treated with medication and bed rest and later had a procedure whereby they shocked his heart internally to treat the atrial rhythm disturbance. This seemed to help.

That evening 12/26/05 he went into V-fib, a life-threatening rhythm and had to be shocked. Further test showed his heart was failing even more as a pump. They implanted a balloon pump. He went into V-fib 3 more times. The only option left was to implant a dual chamber left ventricular pump machine in hopes that his heart would rest and recover. There was talk of a possible heart transplant. He was worked up medically in the event it was necessary. He was showing signs of heart recovery.

At the same time his red blood cell count was drastically low. He was being treated with blood transfusions and other medications to increase his red blood cell count. This wonderful machine that was pumping his heart and keeping him alive was at the same time destroying his blood cells. All of these medical interventions gave us more time, which was the blessing.

Those days of living on the edge of life and death brought us to the realization of what is really important in life. Family, friends and the love we share with one another.

After being on the LVAD for 8 days Brian suffered a severe stroke and lost consciousness. He died two days later on Jan. 10, 2006. He taught me so much about living.

It is unthinkable that a healthy young person could be struck with such a devastating condition and lose his life so quickly. I am so grateful to the Myocarditis Foundation for their efforts to raise awareness of this devastating disease and to sponsor research in the hopes of discovering new diagnostic tools and treatment options.

Four years later, our daughter is in college, but I worry about where the money is going to come from for her to continue. Due to the current economic climate, I have had to let all of the employees of Brian's company go. I do not know where the money will come from for my son to attend college. It is difficult being a single parent. No one can replace Brian as a role model for my son. This disease has taken away so very much, not only from my life, but from my children's lives.

I pray that the myocarditis research will be so successful that someday, other families will not have to suffer like mine has from the loss of my beloved husband and father to my children.

Cynthia Wright 2009

## Chagas Heart Disease and Chronic Myocarditis

### *A Major World Public Health Problem*

In 1909 Carlos Chagas was assigned as a malaria officer in Brazil where he observed bloodsucking rejuviid bugs infesting the dwellings of the local people. Using crude methods he elucidated the life cycle of a new species of trypanosome (protozoa) and postulated that a human disease might be caused by this agent. He cultured the causative agent from a sick child and described the disease features with cardiac involvement and correctly estimated the high prevalence of the disease years before newly developed medical technology would prove him correct.

Human infection of Chagas Disease is frequent throughout nearly all South America, Central America and southern Mexico. Estimates from the World Health Organization conservatively place the number of infected persons at 18-20 million with 90 million people living in infected zones where transmission is endemic. An estimated 550,000 new cases and 50,000 deaths related to Chagas disease occur annually. However, the true number of fatalities is not known because there is no reporting in most remote areas.

A wide variety of wild animal hosts and domestic animals serve as reservoirs of infection, harboring the infectious agent. The types of housing found in impoverished rural areas of Central and South America facilitate transmission of the agent to humans. Earthen floors, thatched roofs, and cracks in walls provide shelter for the bugs to live and breed in abundance. The infection is most often transmitted to humans when the bug takes its blood meal during sleep.

Host health defenses and environmental conditions are factors in determining the pattern and severity of disease in an infected individual. Factors such as environmental temperature and protein malnutrition alter the host immune response and tissue injury.

Cardiac involvement is the most frequent manifestation of Chagas Disease and is one form of chronic myocarditis. Malignant cardiac arrhythmias and sudden cardiac death are the most frequent causes of death due to focal inflammation in multiple areas of the heart which is replaced with scarred tissue. Death typically results a minimum of 15 years after infection, with most persons dying of Chagas heart disease between the ages of 25 and 45 years of age. Chagas disease is by far the leading cause of death in this young age group in endemic areas, making it a major public health problem.

Public health prevention strategies are the most important means of controlling the devastating impact of Chagas disease. The goal of these programs is to prevent new cases. Spraying of housing twice yearly with residual pesticides coupled with entomologic surveillance is the cornerstone of current control efforts in most countries. Permanent improvement in quality housing in rural areas is a more long-term solution.

As a result of increased global travel, cases have been reported in the U.S. and Europe.

Paraphrased from Myocarditis: Bench to Bedside edited by Leslie T. Cooper, Jr., M.D.; Chapter 20: Chagas Heart Disease by James M. Hagar, M.D. and Shahbudin H. Rahimtoola, M.B. All references available upon request.

# My Miracle

Alex Hall, 15 years old, Massachusetts

**It was Monday**, St. Patrick's day 2008. I was getting ready for work when Alex my 15 year old son came home and said, "Hey Mom, it was weird today. I had chest pains and felt dizzy and short of breath." He said he wasn't doing anything stressful. I called his pediatrician. She said to bring him right in. An EKG and a chest x-ray were negative. The doctor said to take it easy.

**On Tuesday** he complained of a stomach ache. I texted him all day at school much to his annoyance. He assured me he was OK to stay. I called the doctor again to report his new symptoms. She said to call if they got worse.

**On Wednesday** he called to tell me he couldn't walk home from school – his legs hurt and he felt weak. Again I called the doctor to inform her of the new symptoms. We talked for a while. She told me he most likely had a virus, to keep him home from school and call if anything changes.

Alex said he had to go to school because one of his teachers said "You'd have to be dying," as a big report was due. I made a deal: I told him that he could go to school till 2nd period or I'd drop off the report depending on how he felt.

**On Thursday** at 4:00 am, Alex was not breathing well, was pale and weak. I brought him into the ER. It took me about 5 minutes to get there. I think I drove 85 mph. The nurse took us right away. I thought he was having an asthma attack. The doctor came immediately. They started medicines and IV and hooked him up to monitors. They asked me tons of questions.

I stepped out of the room to call my husband and oldest son. Within minutes the doctors tell us Alex will be transported to the University of Massachusetts.

The looks on the faces of the EMT, doctors and nurses made me scared. By 5:00 am we were on the way. There was a medical team waiting for us. Again we answered lots of questions. The monitors were going crazy. At UMass, they put defibrillator pads on him. I told Alex he was going to have to fight.

My oldest son looked like he was ready to collapse. There were tears in my husbands eyes.

Within 15 minutes I'm told Alex should go to another hospital. I was thinking WHAT is going on?! They told me there was a machine out at Children's Hospital in Boston that MIGHT save his life. I was in such shock I asked how to get him there. They told me Life Flight was grounded because of the rain, so a special team was on the way.

He was still talking to us – being so brave. My cousin who is a priest was called to bless him. We all held hands and prayed for Alex.

We all took turns telling him how much we loved him and to be strong. I told him that he was only going to sleep but that while he slept he was to think only happy thoughts. I added, "I promise that I won't leave your side for one minute. I won't go anywhere till you can open your eyes again and tell me you love me."

Boston is an hour away. As the EMT team came through the doors I thought I was in a sci-fi movie. They had jumpsuits and their game faces on. They got to work right away switching over to their equipment.

My son and I were going with Alex in the ambulance. We helped carry equipment. A nurse hugged us and gave us water and crackers. I jumped in the front and buckled up. I kept thinking, "Can't you drive any faster?"

I'd never been to Children's hospital. Alex was hustled away. There were 20 people waiting for him. They wasted no time. I was asked all the same questions. A doctor told me that the machine to my right is ECMO, a heart lung machine for Alex.

I went to the waiting room to find my family. They came in every 15 minutes to update us.

The nurses were wonderful. They told us there were vouchers for food. They insisted I get something to eat. My cell phone was dying. I'd had on the same clothes from Wednesday to Friday. I hadn't taken a shower and left with only 40 dollars, a chap stick and my cell phone.


Alex Hall

I was told Alex had to go for a cardiac biopsy which is very risky. It was necessary so they could know what they were dealing with. We told them if he didn't make it, we wanted to donate his other organs. I found the chapel and went to pray. Then we waited.

The biopsy results revealed myocarditis, a disease we'd never heard of; probably the result of a virus.

The next few days were critical. We didn't get any promising news. Days turned into weeks and Alex was still on ECMO.

One morning, Alex had to be taken off ECMO, as the membrane of the machine had to be switched. Alex did amazing. They decided to take him off completely later in the day. Slowly they let him come around – he looked at us and moved his lips. He knew we were there and began making hand gestures. When the breathing tube came out, he gasped for a breath, looked at me and said, "Love you, Mom!" That was the best gift ever.

We stayed in ICU for 3 more days, finally going home 21 days later.

**One year later**, Alex is doing amazingly well. He is on no medicine at all. He even played soccer this fall. He has a check-up in March almost to the day it happened, with his cardiologist. They call him a legend at the University of Massachusetts Hospital. I call him my miracle. Sue, Alex's Mom.



# Interview: Dr. Dennis McNamara, University of Pittsburgh
## Medical Advisory Board Member

*I had the privilege of speaking to Dr. Dennis McNamara, Director of the Cardiomyopathy Clinic and Heart Failure Research at the University of Pittsburgh. Dr. McNamara serves the Myocarditis Foundation as a one of four members of our Medical Advisory Board. The role of the MAB is to review and score the research fellowship grant applications and to make recommendations to the Board of Directors regarding funding and to serve as consultants to the Foundation board on myocarditis. Future editions of the newsletter will contain interviews with other members of the MAB to give you a better understanding of their contribution to the field of myocarditis.*

*Dr. McNamara is first and foremost a family man, as a father of four children, ranging in ages from 11-20 years. On weekends when he is not on call, you might find him in at a horse show with his daughter Annie, at a contemporary ballet recital with his daughter Maggie, or at a Yale University parents' weekend with sophomore, Harry. Ten year old Joseph at home generally keeps everybody in the household on their toes.*

*Dr. McNamara describes his role as head of the heart transplant program at the University of Pittsburgh as, "Very rewarding". He draws energy from the patients whose names and faces he carries with him.*

*He received his medical education at Harvard University and became interested in myocarditis while a resident at Massachusetts General Hospital under the mentorship of Dr. G.W. Dec, Chief of Cardiology and Heart Transplantation, also a distinguished physician in medical research. Since then, Dr. McNamara's research focus has been inflammatory heart disease, cardiomyopathy and genetics.*

*Dr. McNamara's greatest hope for cardiovascular medicine in general and myocarditis in particular is to find interventions that would stop the disease in its tracks, while retaining native heart muscle function.*

*Dr. McNamara states, "Every myocarditis patient has a different trigger and a different response to the trigger. If only we could figure out the biological signature for each individual patient, we would be able to treat appropriately with much greater success. Over the past ten years, a lot of research has been done on the role of the human genome in determining cardiac health. In the future, treatments will be targeted to individual patients and many more lives will be saved. "*

*Thank you, Dr. McNamara, for your contribution to the field of myocarditis, for your contribution to your patients and their families who you serve, and for your contribution to the Myocarditis Foundation and the patients and families we together serve.*

**Candace Moose, Director, February 16, 2009**



## The Myocarditis Foundation Is Pleased To Announce The Appointment Of New Board Members

### Board of Directors

***Clement (Clem) Weinberger,*** a PhD in Celluar Biology from NYU, who is recently retired from Sanofi Pasteur in Lyon, France, as Director of Medical Communications and Training, in the department of Medical Affairs International. Clem and his wife Eva spend six months each year in Prague, Czech Republic, and the other six months in New Jersey. Clem brings extensive expertise in medical writing and personal expertise in website development as well as an international perspective.

***Liz Kravitz***, a television reporter for a North Carolina station, graduated with a Bachlor's degree in Broadcast Journalism from Emerson College. Liz's 22 year old brother died suddenly from myocarditis in spring 2007. Liz has served the Foundation as a celebrity speaker at our Vintage Celebration fundraiser in Raleigh, NC, last year. She brings media expereince and a youthful perspective to the board as well as a deeply personal committment to improving the outcome of those affected by myocarditis.

### Volunteer Consultant to the Board of Directors

The Myocarditis Foundation is grateful to acknowledge ***Sherry Mordecai*** as a volunteer consultant to the board. Sherry is a retired professional fundraiser with over 24 years expereince , most recently as Director of Development for Pediatric Endocrinology at Yale School of Medicine.

### Medical Advisory Board

The Myocarditis Foundation welcomes ***Steven D. Colan, M.D.***, to our Medical Advisory Board. Dr. Colon is a Professor of Pediatrics at Harvard Medical School and is Chief of Noninvasive Cardiology at Boston Children's Hospital.