

December 2016

Dear Myocarditis Families and Supporters,

The following are achievements of the Myocarditis Foundation (MF) this past year, as well as the exciting plans and projects for 2017, all helping to achieve our mission of Education, Funding Research and Emotional Support of those affected by myocarditis. Thank you for helping make this happen.

- We held our first annual Gala/ Awareness /Fundraiser Event in NYC. The event was attended by over 300 people, with help from the re-insurance industry. We were able to raise the bar and expand myocarditis awareness throughout the world. There were corporate executives present from Europe and Asia as well as throughout the United States.
- With the help of the St. Jude's Medical Foundation, we were able to conduct a social media campaign to increase the awareness of myocarditis. From the campaign, we have experienced a robust growth in visitors to our website, especially in the high risk age population of males in the "college age group up to age 34", by 54%. The content sponsored articles that we ran on various aspects of myocarditis also helped drive people to our website to learn more about something that most likely they had never heard of before.
- We were awarded a Google Ad Grant that also helps to direct people to our website when certain myocarditis associated terms are searched for.
- Our monthly visits to our website increased from 30,000 to 55,000 per month.
- Calls and emails from people from all over the world to the Foundation office have doubled. More than 500 individuals or families directly contacted the Foundation to seek answers and direction on myocarditis.
- Dr. L. Cooper, our Medical Director and Dr. D. Fairweather, a Board Member and Researcher of Myocarditis, presented at the International Society of Cardiomyopathy and Congestive Heart Failure in Kyoto, Japan. Cardiologists from around the world were there to learn about the disease and network on myocarditis research. The name of the society was officially changed to the International Society of Cardiomyopathy, Myocarditis and Heart Failure and Dr. Leslie Cooper was appointed Vice-President of the Society. Dr. Cooper continues to travel nationally as well as internationally, educating physicians on Myocarditis.
- We held our 4th Family Support/Researcher Meeting in September, where over 40 families joined us to hear the experts and researchers in the field as well as family member's stories. Attendees had access to speak to the experts which made it a very personal experience overall.
- The MF awarded our 16th Fellowship Research Grant to Dr. Guobao Chen, PhD, at Johns Hopkins University School of Medicine. The title of his research is: "The Role of PDGFRa+ Cardiac Fibroblast in Myocarditis." This is a special grant recipient for the

Foundation as he is being mentored in the lab by our first Fellowship Research Grant Recipient of 2006, Dr. Daniela Cihakova, MD, PhD.

- The Foundation is looking at instituting a Family Advisory Committee, with the chairperson having a seat on the Myocarditis Foundation Board. The strategic focus is to increase communication between the MF Board and our families. Our goal is planned to include: the ability of expanding our programs, suggesting new initiatives, helping to grow our mission into other areas of the country, increasing our volunteer efforts.
- We have big plans for awareness programs in 2017. We realize that the people who most need to learn about myocarditis is the medical community who work as first line caregivers in emergency rooms and pediatrician offices. Texas Children's Hospital (TCH), along with the Myocarditis Foundation, will sponsor such a conference in March 2017 at TCH in Houston. The program will qualify to offer continuing education hours to the professionals attending. Strategically we will expand the program nationally to major heart centers.
- Plans are underway for the 2nd Gala Fundraiser Event this June with the Family Support Meeting to be subsequently held the day after making it a family weekend of sorts. More information will be posted on our website as things become available.
- The Foundation has established a goal to create a Myocarditis Biobank. There currently is not one BioBank for myocarditis specific samples. The Myocarditis Foundation is seeking samples from all areas of the world, races and diverse populations. The BioBank will function to store blood samples from myocarditis patients worldwide. This will make it easily accessible for researchers, who are working diligently on developing an early diagnostic tool and a cure for this devastating disease. The BioBank we feel is a key next step in advancement for a cure. The BioBank is our theme/goal for the 2017 Gala.
- We once again achieved "Gold Star" status. With GuideStar. GuideStar is an organization that monitors non-profits for how well they run their companies and that these companies are appropriately utilizing their funds.
- We achieved an administrative expense ratio of 9.6%. Over 90 cents of every dollar donated goes directly to our mission.

Please consider donating to the Myocarditis Foundation so that we can make 2017 the best year yet. The Myocarditis Foundation is the ONLY organization dedicated entirely for the benefit of myocarditis patients and their families, and ALL our research grants go directly to myocarditis-specific research. We want to save more lives from this disease, and it is only through your support that this is possible.

Sincerely,

Genevieve Rumore
Executive Director

The Myocarditis Foundation