

Focus on...

Hypertrophic Cardiomyopathy

Seventeen-year-old Sara Landauer, a star athlete from Gainesville, Florida, collapsed at soccer practice in 2011 and died of sudden cardiac death.

Hypertrophic cardiomyopathy (HCM) is the leading cause of sudden cardiac death in young people, including competitive athletes. This genetic heart disease thickens the heart muscle and makes blood flow more difficult. In turn, the heart pumps harder. HCM isn't limited to the young and fit, however; it affects one out of every 500 Americans regardless of age, gender, race and geographic location.

Patients with HCM experience shortness of breath, dizziness, chest discomfort and irregular or palpitating heartbeat. Since these symptoms often overlap with other medical conditions, patients may remain misdiagnosed for extended periods of time.

Not only is HCM difficult to diagnose but treatments are also complex and experts in the field hard to come by. Because of these barriers, there are only a few dedicated HCM centers in the country and none currently in New Jersey.

"Usually diagnosed at around age 40, people live with HCM for a very long time." —Dr. Martin Maron

Morristown Medical Center, however, has committed to caring for this vulnerable patient population. With a \$1 million gift from the Adam R. and Chanin T. Mast Foundation, the hospital is establishing a center dedicated exclusively to the diagnosis and treatment of HCM patients. The Chanin T. Mast Center for the Treatment of Hypertrophic Cardiomyopathy will open its doors in January 2014.

"When our daughter Chanin was diagnosed with HCM in 1987, we were blindsided," says Robert Mast. He and his wife, Terry, lost their daughter to the disease in 1999. "Back then, there was no orchestra leader to coordinate her care. We were lost in a maze of specialists all giving us different advice."

The Mast Center's location within Gagnon Cardiovascular Institute will give patients convenient access to specialists, imaging and diagnostics, and the latest in devices and treatment options. The center will also provide HCM screenings and community outreach to help protect young athletes, like Sara and countless others, from sudden cardiac death.

"We are enormously grateful to the Masts," says Linda Gillam, MD, MPH, the Dorothy and Lloyd Huck Chair of Cardiovascular Medicine at Gagnon. "There are relatively few people who have suffered a tragic loss who really do something about it. The Masts are not only bringing significant financial support but also their willingness to guide this program from its infancy into a world-class center."

Another key factor in moving the center toward interna-

tional stature is Martin Maron, MD, world-renowned expert and director of the HCM Center at Tufts Medical Center in Boston, MA, who agreed to come on board as director of the Mast Center. He will begin seeing patients twice a month in January 2014.

"I want to emphasize the magnitude of Dr. Maron leading this center," says Mr. Mast. "He and his father Barry, who is the director of the HCM Center at the Minneapolis Heart Institute Foundation, are the gold standard in HCM. What we have here is a great coup."

An associate medical director, nurse practitioner and ancillary staff will work alongside Dr. Maron, covering all aspects of care, including scheduling appointments, explaining tests, following up after procedures, and communicating with primary care physicians. The team at the center also includes a social worker and psychologist who will provide essential psychosocial counseling.

This kind of coordinated care didn't exist 25 years ago for the Masts. Not only was shuffling from one expert to the next frustrating for them, but it left Chanin unable to create that necessary bond of trust with her physician.

"This is where Dr. Maron excels," says Mr. Mast. "He has an incredible ability to nurture each patient."

Dr. Maron has worked hard at incorporating all aspects of the patient care experience when treating patients and their families with this disease.



Photo: Courtesy of Tufts Medical Center

"Usually diagnosed at around age 40, people live with HCM for a very long time as opposed to other areas of cardiology where the patients are much older when diagnosed," says Dr. Maron. "It's not only about delivering state-of-the-art procedures but providing the right messages about living successfully with HCM that empowers my patients to make the right choices and gives them the confidence to keep going and not let the disease destroy what is otherwise a long, happy and productive life."

The ability to feel confident about the future is a common problem for many patients dealing with HCM.

"I know Chanin was a young woman who wondered what her future would hold," says Lisa Salberg, CEO and founder of the Hypertrophic Cardiomyopathy Association (HCMA) based in Rockaway, NJ.

Chanin had met with Mrs. Salberg for tea to share her story.

"Chanin needed a clearer pathway. The Mast Center will organize patient care in such a way that will very simply change outcomes for the better."

The Mast Center and HCMA are readying themselves for a long and significant partnership. HCMA is one of the most active patient advocacy and support groups in the country for HCM patients.

"What our partnership will bring to the community is a world-class understanding of an incredibly complex disorder," says Mrs. Salberg who lost five family members to HCM and is a carrier of the disease along with her daughter and two other family members. "We need to learn how to not just get through the crisis but how to live quality lives. The Mast Center will allow each of us to do that."

To support the center or for more information, contact Hyona Revere, director of major gifts, at 973-593-2429 or hyona.revere@atlantichealth.org.



The late Chanin Mast



Robert and Terry Mast

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