

Rooted in Philanthropy, ARVD/C Program Thrives 20 Years Later

When John Campanella was diagnosed with early symptoms of arrhythmogenic right ventricular dysplasia/cardiomyopathy (ARVD/C) at Johns Hopkins 20 years ago, the only hospitals with specialized ARVD/C centers were in Padua, Italy, and in Arizona. Campanella was concerned because his father, a former linebacker and general manager for the Baltimore Colts, died of the condition (then thought to be a heart attack) in his mid-30s. His sister Carrie, also an athlete, died suddenly of the condition after riding a horse. She, too, was in her mid-30s.

Campanella and his wife, Kathy, visited both ARVD/C centers and proposed that Johns Hopkins establish a program in Baltimore. The Campanellas leveraged family funds and contacted investor Jack Bogle, an ARVD/C patient who founded and served as CEO of The Vanguard Group. Bogle provided funds to help launch the program. The Campanellas also garnered support from others, such as the family of supermodel Niki Taylor, whose younger sister Krissy died from ARVD/C.



John and Kathy Campanella garnered funding to launch the Johns Hopkins ARVD/C Program.

Thanks to such support, electrophysiologist **Hugh Calkins** opened the Johns Hopkins ARVD/C program for research and treatment of the rare, inherited heart muscle condition that can cause sudden death in young athletes. Calkins hired cardiology fellow Hari Tandri and a genetic counselor, while Kathy Campanella linked the program to a patient support website she had started, arvd.com.

John Campanella says he took advice from the late Johns Hopkins geneticist Victor McKusick, who told him to leave no rock unturned to support the program. “What we learned is that patients can come together and work with their friends and families to raise money through smaller events,” he says. Many embraced the philosophy. The Healing Hearts Foundation, founded by nine friends of a deceased ARVD/C patient, has held several events including bull and oyster roasts and golf tournaments, raising more than \$119,000.

Funding for rare diseases is difficult, says Tandri, now the center’s co-director. “It’s the motivation and the commitment of people with the disease, and their families, that really drives this engine forward.”

Donors Andrew and Sandra Cohen of the Cohen Family Fund find the experts in the ARVD/C program help to attract donor support. “Dr. Tandri is a superior doctor not only in terms of his technical skills and medical knowledge, but also in his equally important compassion and understanding of the unique impact of ARVD to the patient and the

family.”

The Johns Hopkins ARVD/C program, which has become the biggest of its kind in the world, will celebrate its 20th anniversary in May 2019. The program has evaluated more than 2,500 patients from all over the world and provides information through its website, newsletters, annual reports, an annual patient and family conference, and via Feeling the Beat, which is a blog of patient stories. Physicians affiliated with the program have published more than 150 research papers about the condition. All these efforts have been made possible by donations.

“It’s been unbelievably successful,” says Calkins, ARVD/C program director. “From a terrible tragedy came this program that has saved thousands of lives all over the world.”

Current research priorities for ARVD/C include identifying the genes responsible for the 30 percent of patients who have unexplained ARVD/C; further understanding the impact of exercise on disease progression; promoting disease prevention for families who are at risk; and developing more advanced treatment regimens. Through the support of grateful patients, families and friends, the Johns Hopkins ARVD/C team will have the necessary resources to continue this research and persist in their efforts to achieve the ultimate goal: finding a cure for this rare, devastating disease. ■



The Johns Hopkins ARVD/C team says, “Thank you!” From left to right: Crystal Tichnell, Hugh Calkins, Brittney Murray, Hari Tandri and Cindy James.



To make a gift to the ARVD/C program, visit bit.ly/hvigitf.



Jennifer Lawton, M.D.
Chief of Cardiac
Surgery

The Division of Cardiac Surgery at Johns Hopkins is thriving! I have been in Baltimore for just two years now, and I am honored to be at Johns Hopkins, which celebrates its 29th year ranking among the top five hospitals in the country. Johns Hopkins is currently ranked #3 in the nation and #1 in Maryland by U.S. News & World Report. Cardiology and Cardiac Surgery rank #11 in the nation.

In the Division of Cardiac Surgery, our motto is **We CARE: We** are conscientious, accountable, respectful and engaged. By modeling these values, we have successfully begun to establish stability and continuity in the division. We have 12 faculty members, and eight are clinically active. We are especially delighted to have three new adult cardiac surgeons in our division: Ahmet Kilic, Stefano Schena and Dan Choi.

Our mission in cardiac surgery is to provide the highest quality, compassionate care to our patients. We have seen growth in our structural heart program, reinvigoration of the heart transplant and mechanical circulatory support programs, and enhanced structure and standardization of our extracorporeal membrane oxygenation program. We are also fortunate to have robust basic science and clinical research programs led by our nationally recognized faculty.

Our division's ability to provide the best patient care, foster innovation, promote education and encourage scientific inquiry would not be possible without the help of our donors and appreciative patients. We are extremely grateful for your generous support.



Watch a video about a patient who underwent a complex emergency surgery by Jennifer Lawton at bit.ly/DrLawton or scan the QR code.

The Mirowski Legacy: One Family's History of Tenacity, Ingenuity and Generosity



Anna and Michel Mirowski

Today, about 800,000 people in the U.S. rely on implanted defibrillators to protect them from potentially fatal cardiac arrhythmias. They might not know that Michel Mirowski, the inventor of the lifesaving devices, barely escaped the Holocaust with his own life.

While his name is now associated at the Johns Hopkins Heart and Vascular Institute with a professorship, lectureship, award and fellowship, his influence in cardiology is recognized worldwide.

Mirowski was born in Warsaw, Poland. The Nazis invaded in 1939, imprisoning him and his family and others. At 15 years old, Mirowski escaped the Warsaw ghetto and fled to the Soviet-occupied region of Poland. Daughter Ariella Rosengard shares that her grandfather's last words to his son expressed hope that he become a physician.

When Mirowski returned to Warsaw at the war's end, he learned that his family had been killed, including his 8-year-old brother. He honored his father's wish and enrolled in medical school in Lyon, France, where he met his wife, Anna.

The two moved to Israel for Mirowski's medical residency. There, says Rosengard, he met Harry Heller, chief of medicine at Tel HaShomer Hospital, who became his mentor. At one point Heller recommended that Mirowski complete a fellowship with Helen Taussig, a pioneer in pediatric cardiology at The Johns Hopkins Hospital, which he did.

Mirowski returned to Israel from Baltimore in the early 1960s. Soon thereafter Heller began suffering from ventricular arrhythmias. Unfortunately, Heller chose not to use an external defibrillator, resisting the inherent limitations of being hooked to the machine and remaining in a hospital interminably. He soon succumbed to ventricular fibrillation.

The death of his key friend and mentor prompted Mirowski to search for another treatment option for

patients like Heller. He began to conceive of how to miniaturize the external defibrillator and make it completely automatic, thus permitting patients to survive outside a hospital. Unable to find support for his invention in Israel, he returned to Baltimore.

In 1968, Mirowski became the first director of the coronary care unit at Sinai Hospital of Baltimore. He devoted great effort and nearly two decades to developing his invention. "He was lucky to have my mother by his side because I am not sure he could have developed the implantable defibrillator without her. She always cheered him on and encouraged him," says Rosengard.

Bringing the implantable cardioverter defibrillator to patients was not easy. Funding was only part of the problem. Convincing the cardiology community was even harder; manuscripts were routinely rejected by specialists in the field, and experts scoffed at the idea. But eventually, Mirowski found financial support and a close team to help him, including Morton Mower, Alois Langer and Steven Heilman, all of whom were named to the National Inventors Hall of Fame in 2002.

Prior to Mirowski's death in 1990, he was able to see his device implanted in thousands of people, many of whom thanked him for saving their lives.

To honor her husband's contributions to cardiology, Anna Mirowski established the Michel Mirowski, M.D. Professorship in Cardiology in 1998, as well as the annual Michel Mirowski M.D. Lectureship in Cardiology, which will be held on Dec. 7, 2018.

The Mirowskis' daughters, all physicians, established the Michel Mirowski, M.D. Discovery Award in honor of their parents, to support a physician-scientist doing early research in the specialty.

continued on page 4

Make a World of Difference

We all want to find that balance, a means to give back to the Heart and Vascular Institute and still meet our own financial goals. A charitable gift annuity enables the next generation of cardiologists and cardiac surgeons to advance treatments for cardiovascular conditions and provides lifetime income to you or a loved one, along with significant tax benefits. Take advantage of recently announced higher payout rates for a new charitable gift annuity. Contact the HVI Development office today for more information, or visit www.jhu.planyourlegacy.org/calc.php to calculate your income and benefits.

Make Your Gift Today

We want to hear from you. Contact Lisa Hamman or Adrienne Rose in our development office at **443-287-7384** or hopkinsheart@jhmi.edu if you have questions or need additional help.

To make a contribution to the Heart and Vascular Institute, use the contribution envelope enclosed or give online at <https://secure.jhu.edu/form/heart>

Giving from the Heart

Meet Richie and Kathy Amato

When Richie Amato was 50, he and his wife, Kathy, asked Richie's physician about doing a baseline stress test just to check things out. The test revealed some issues that required follow-up. Richie, CEO of O.S.T. Trucking in Baltimore, decided to seek care at Johns Hopkins. After seeing cardiologist **Roger Blumenthal, M.D.**, he was referred to cardiac surgeon William Baumgartner, M.D., who performed a double bypass operation in September 1994.

Now living in Crofton, Maryland, the Amatos say they developed close bonds with both physicians and have been loyal supporters of the Johns Hopkins Heart and Vascular Institute since 1995, donating in recent years directly through their individual retirement accounts. They spoke recently with *Pulse*.

Q: Can you tell us about your experience with the doctors and staff members at Johns Hopkins?

Kathy: We came to Johns Hopkins because we knew its reputation. We were very fortunate to be introduced to Roger Blumenthal, who we developed a great relationship with, and we were more than fortunate to have Dr. Baumgartner do Richie's surgery. Dr. Baumgartner was absolutely wonderful. He was a skilled doctor and so humble, with a wonderful bedside manner. He made us feel so comfortable.

Q: How did you become donors to Johns Hopkins?

Richie: Roger Blumenthal at the time was involved with a yearly fundraiser called Heartfest. That's what actually started our giving. We went to the first Heartfest in 1995. From there, we graduated into donating every year.

Q: What has inspired you to continue giving, year after year?

Kathy: We have a great rapport with Dr. Blumenthal. He is Richie's cardiologist to this day. Through learning about the heart center, we realized the importance of research. We made a decision to put our charitable donations each year toward the Johns Hopkins Ciccarone Center for the Prevention of Heart Disease because of the great service we received, and continue to receive, at Johns Hopkins. Without heart research, a lot of folks, my husband probably included, wouldn't be here today.

Q: How do you feel that your gifts have made an impact?

Kathy: We feel that without contributions like ours, the research wouldn't happen. For example, it took a lot of research to develop the implantable defibrillators that have saved so many lives. Without research, there wouldn't be implantable defibrillators. (See related story on page 2.)

Q: What would you tell others considering a gift to the Heart and Vascular Institute?

Kathy: For the last several years, we have asked our family, in lieu of gifts, to give to the Ciccarone



Center. They have done so, because we believe so much in Johns Hopkins and the research and the care that they provide.

Richie: I would tell them that, one day, I think researchers at Johns Hopkins are going to cure cardiovascular disease. ■

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SNAPSHOTS OF SUPPORT



 **Cardiac Surgery Leaders Honor Bill Baumgartner**

Pioneering cardiac surgeon William Baumgartner was honored in June for his 36 years of exceptional service to the Johns Hopkins Medicine community. Many of Johns Hopkins' past and present leaders in cardiac surgery joined Dr. Baumgartner at his retirement dinner on June 1. From left to right: Robert Higgins, chairman, Department of Surgery; Jennifer Lawton, chief of cardiac surgery; Bill Baumgartner, former chief of cardiac surgery; Vincent Gott, former chief of cardiac surgery; and Bruce Reitz, former chief of cardiac surgery.



Dash 4 Dowd Memorializes Classmate, Supports ARVD/C

Students from Holmdel High School in Monmouth County, New Jersey held a 5K fundraiser to honor the memory of their classmate, Jack Dowd, and to support the Johns Hopkins ARVD/C Program. Jack tragically passed away in September 2017 from ARVD. Front row, from left to right: Jess D'Agostino, Shelley Merhav, Jess Kaden and Casey Dowd. Back row, from left to right: Jordan Gilbert, Alec Licato, Arun Movva, Alok Malhotra and Evan Smith.



Board Members and Faculty Convened at the Fall Meeting

Members of the Cardiovascular Advisory Board and faculty from the Heart and Vascular Institute met on October 5 for their fall meeting. Front row, from left to right: Fritzi Hallock, Loretta Downey and Jennifer Lawton. Second row: Jonathan Myers, John Darvish, Sharon Akers and Michael Brodsky. Third row: Chris Helmraht and Thad Shelly. Fourth row: Ron Berger, Dick Nielsen and Ed Kasper.

A Reinvigorated Heart Transplant Program

Cardiothoracic surgeon Ahmet Kilic is sharply aware that he stands at the midpoint of a see-saw, one tilting downward.

Kilic was hired in 2017 as the Director of Johns Hopkins' Heart Transplantation and Mechanical Circulatory Support Program for his art and skill in transplanting hearts and expertise in matching recipients with donors. If an organ is unavailable in a timely manner, the decision can be made to pursue surgical therapy



through a ventricular assist device (VAD) or other mechanical circulatory support system.

Kilic is confident that soon, surgical therapy will level the see-saw of outcomes for sicker patients and start its tilt in the other direction. LVAD design is steadily improving, for example. Also, Kilic says, there's research on new materials.

He ticks off other changes: "We now see our advanced patients earlier as a team," Kilic explains, "and we're more often introducing the pumps earlier, when people are less sick."

"As we solve the shortcomings of device therapy, guided by our outcomes research, we can expect procedures to become more routine," he adds. "So far, I like best care as opposed to most care, and that is absolutely what we strive for at Hopkins—it's our bottom line." ■

The Mirowski Legacy: One Family's History of Tenacity, Ingenuity and Generosity

(continued from page 2)

"This is the best way to keep our parents' memory alive," says Rosengard. "It honors our father's mission of bringing a novel idea to the patients and recognizes our mother's invaluable support."

"The Mirowskis' legacy of personal, professional and philanthropic contributions to the Heart and Vascular Institute cannot be overstated," says **Ronald Berger**, interim director of the Division of Cardiology at Johns Hopkins. "Their collective commitments continue to encourage the kind of innovation in cardiology for which Dr. Mirowski was so well-known." ■

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NEWS FOR FRIENDS OF THE JOHNS HOPKINS HEART AND VASCULAR INSTITUTE



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Inside

1

Rooted in Philanthropy, ARVD/C Program Thrives 20 Years Later



2

The Mirowski Legacy: One Family's History of Tenacity, Ingenuity and Generosity



3

Giving from the Heart: Meet Richie and Kathy Amato