Meet a Patient

Shortly after finishing chemotherapy and radiation treatment for cancer, Mayra was diagnosed with heart failure.

Her symptoms included shortness of breath, retaining fluids and generally feeling pretty bad, but she carried on with her young life in her usual optimistic way. Shortly after her diagnosis however, she became pregnant with her first child and was looking forward to the prospect of motherhood. Surprisingly, she had a beautiful pregnancy with no heart failure symptoms – she felt great!

Soon after giving birth, Mayra’s health took a sharp decline. When her son Gabriel was just nine months old and after weeks of being hospitalized because of her heart failure, Mayra underwent surgery to implant the HeartMate II™ Left Ventricular Assist Device (LVAD). A month later, Gabriel started taking his first steps and Mayra was back on her feet again as well, slowly learning to walk again. “Now we are running together,” she said with a laugh. “It is a great memory.”

Mayra’s husband, Gabriel, Sr. says that they have been able to do many things – like hiking, taking trips and dancing. “We are able to do most all the normal things people do,” he said.

The busy family of three enjoys traveling, and has taken trips to Orlando, Miami and the Grand Canyon, but Mayra’s favorite was their trip to San Francisco. She thought the city was beautiful and they had the most fun as a family. Just recently, the family went to San Diego to share their story at the International Society of Heart and Lung Transplantation (ISHLT) Annual Scientific Sessions & Expo.

“I truly enjoy being able to show what a difference in my quality of life this device has made,” she said of her role as a Patient Ambassador. “I like the feeling that maybe I have helped someone consider this as an option to help manage their heart failure – whether they’re a patient or a doctor. Being a Patient Ambassador is an important role for me to play.”

Mayra says she’s a regular mom. Her typical day consists of getting Gabriel ready for school, housework and taking Gabriel to his many after school activities, including sports and piano.

After nine years of support on the HeartMate II™ LVAD, Mayra shows no signs of slowing down. Dancing is one of her favorite things to do so she enjoys taking Zumba classes. She also does 5Ks, takes hikes and recently signed up for a fitness challenge at her gym. Mayra feels great and is not planning for a transplant. “I love my LVAD. I’m not sure I want a transplant,” she said. “I have many, many more years to go. I can do whatever I want. I have a normal life.”


The stories in this newsletter are the experience of these individuals only. There can be risks and potential complications associated with the use of medical devices including the HeartMate II™ Left Ventricular Assist System. If you are interested in learning more, please consult your physician.

Please see page 4 for indication and risk information for the HeartMate II™ Left Ventricular Assist System.
In 2016, U.S. News & World Report recognized Tampa General Hospital for cardiac care and surgery for the ninth year in a row, and a big part of this nationally recognized program is Lori Anderson RN, MS, Nurse Manager and her team, who currently manage approximately 120 patients on Left Ventricular Assist Device (LVAD) support.

Among the many moving parts of this renowned program, which includes an on-campus outpatient clinic where LVAD recipients are instructed to maintain good, consistent follow-up and communication with their VAD team/Coordinator, is the hospital’s focus on aligning patients with other patients and providing opportunities for patients and caregivers to connect.

“We encourage patients to connect with other patients and start the learning process early, usually before they are implanted,” explained Lori. “We recognize that the only person who can really understand the patient journey on a very personal level is another patient, and making that connection for our patients has been very effective in helping new patients adjust to life with an LVAD, in particular.”

Tampa General also hosts quarterly support groups as a means of building and maintaining connections and relationships among patients and caregivers. “We were really pleased with how the patients and their caregivers embraced having the opportunity to show up for themselves and for each other,” said Lori. “But what really surprised us was how the caregivers seemed to benefit in a very different way.”

Lori explains that the format of the support group is an opening session with a presentation on a popular patient topic, such as travel, followed by a break. Then patients and caregivers are separated into different rooms.

“I was quite amazed to see the patients in one room talking and joking and really having a blast connecting with each other, and then to go into the caregiver area and see a profoundly different experience occurring.”

Lori explained that in the privacy of this breakout session that the caregivers were able to find a place where they could vent or cry or be vulnerable for a period of time with people who truly understood their challenges. Furthermore, it becomes a very cathartic and helpful environment where the caregivers felt an important level of community and support.

Lori encourages all patients and caregivers to seek out support via your center’s program or outside established patient community. She also encourages caregivers to carve out time with other caregivers during those meetings because their need for support is just as important.

“I’ve tried once or twice to augment the program and run the meeting a little differently but no one was happy with that idea. They truly need those breakout sessions, and the unique brand of support and relationship building that they can provide, so I don’t even consider trying to change things around now,” she said.

More than 25,000 people have received the HeartMate II LVAD. Since then, many have celebrated five birthdays – some even 10 or more birthdays. To commemorate these milestone events in our patients’ lives, the team at St. Jude Medical, now part of Abbott, is spearheading a new campaign designed around the celebration of a recipient’s “REBIRTHDAY.”

A HeartMate II LVAD recipient’s REBIRTHDAY date is, as you may have guessed, the anniversary of the date of their implant. While celebrating this momentous date in a recipient’s life is certainly not a new idea according to many of our Patient Ambassadors, the formalizing of a campaign still makes for an exciting time.

The REBIRTHDAY campaign was launched at the ISHLT Annual Scientific Sessions & Expo, with three HeartMate II LVAD recipients who have been on support for five, seven and nine years. Each day a different patient’s number of “rebirthdays” was recognized at the booth. Members of the medical community who were in attendance were invited to come to the trade show booth to meet the Patient Ambassador and hear their story.

We’d love to hear how you celebrate your REBIRTHDAY – please email us at HeartMateAmbassador@sjm.com and let us know. We’ll share some of our favorite REBIRTHDAY ideas in an upcoming issue! Let’s celebrate another wonderful year of your life with the HeartMate II LVAD.
Just for the Caregiver

Expert resources to ensure you’re getting the support you need

LVAD recipients benefit from a strong support system, and this often includes a dedicated caregiver. When a heart failure patient receives an LVAD, the lives of caregivers and loved ones change as well. From the time heart failure starts to progress through the return to a better quality of life, caregivers are there every step of the way as a strong support system. But this often begs the question: is the caregiver being taken care of as well? There are a number of excellent ways to ensure you, the caregiver, are getting the support you need, when you need it. And not surprisingly, many caregivers find that sharing their journeys also support others along the way. Here are a few suggestions to get you connected:

1. **Community Forums on established LVAD-centric networks**, such as myLVAD.com – this website offers tools as well as an ability to connect with other caregivers around the country.

2. **Online resources specifically designed for the caregiver**, such as:
   a. Mended Hearts – when you visit connect.mendedhearts.org you will find a wealth of information including an ability to join communities that allow you to participate in discussions and share resources.
   b. The American Heart Association at heart.org has a robust caregiver section (http://bit.ly/2q3kZY0) that includes a link to a support network as well as printable resources.

3. **Your center and VAD team.** They understand your journey and can help to connect you with other LVAD patient caregivers at the center so that you can hear experiences, ask questions and find friendship and support.

4. **Local Support Groups.** Attending the LVAD support group at your center, or other local area support groups can be a great experience for caregivers as well as patients. Consider asking the support group leader to create breakout sessions just for caregivers as a means to connect with others who can truly understand.

*Based on clinical trial and device tracking data as of March 1, 2017.
**PATIENT ADVOCACY**

**Patient Advocates are sharing their stories to highlight improved quality of life**

Over the past few months, several HeartMate II LVAD Patient Advocates have attended a variety of events, from support groups at their local centers and conferences with local heart support organizations such as Women Heart, to meetings with the FDA and industry trade shows to share their stories. While each patient has their own personal reason why they choose to participate, there is an overwhelming level of advocacy and support that is a result of their efforts.

Just ask George M., who has been on HeartMate II LVAD support since 2010 and recently attended the American College of Cardiology Scientific Sessions & Expo in Washington, D.C.

“Anytime I’m asked, I’ll do everything I can to show up and be there for whoever needs me,” commented George. “I do love sharing my story. If I can help just one person decide to make a change for the better because my story was what they needed to hear, then my time was well spent.”

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**Rx Only**

**Brief Summary:** Please review the Instructions for Use prior to using this device for a complete listing of indications, warnings, precautions, potential adverse events and directions for use.

**Indications:** The HeartMate II™ Left Ventricular Assist System is indicated for use as a “bridge to transplantation” for cardiac transplant candidates who are at risk of imminent death from non-reversible left ventricle failure. It is also indicated for use in patients with New York Heart Association (NYHA) Class IIIB or IV end-stage left ventricular failure, who have received optimal medical therapy for at least 45 of the last 60 days, and who are not candidates for cardiac transplantation. The HeartMate II Left Ventricular Assist System is intended for use both inside and outside the hospital, or for transportation of Left Ventricular Assist Device patients via ground ambulance, airplane or helicopter.

**Risks:** Adverse events that may be associated with the use of the HeartMate II Left Ventricular Assist System are listed below. Adverse events are listed in decreasing order of frequency, except for death, which appears first because it is a non-reversible complication: death, bleeding (perioperative or late), cardiac arrhythmia, local infection, respiratory failure, device malfunction, sepsis, right heart failure, driveline or pump pocket infection, renal failure, stroke, neurologic dysfunction, psychiatric episode, peripheral thromboembolic event, hemolysis, hepatic dysfunction, device thrombosis, myocardial infarction.

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