EQUALITY IN HEALTH CARE STARTS WITH THE HEART

PLUS:
- Should kids with CHDs exercise as much as their heart-healthy peers?
- Martin Espinoza revs up cardiac care in California by offering rides to rehab

Get your readers out! You’ll need ‘em to see these tiny implantable heart devices
Heartbeat, the national magazine of The Mended Hearts, Inc., a nonprofit organization, is published six times per year by The Mended Hearts, Inc.

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Heartbeat thanks Dr. Phillip Duncan of Virginia Heart Group, Ltd., for allowing us to photograph the January/February 2017 cover in his office.

Letters of inquiry and publication are encouraged. Materials should be sent to Heartbeat, The Mended Hearts, Inc., 8150 N. Central Expressway, M2248, Dallas, Texas 75206, 1-888-632-7899.

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- Cardiac rehab staff
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- Friends and family

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On the Cover:
Kevin Manning photographed Dr. Phillip Duncan and his patient Patricia Brown-Glover at Dr. Duncan’s offices, even though they were undergoing renovations. Mended Hearts appreciates the use of their offices for the shoot so we could tell the important story about disparities in cardiac care.
Welcome to 2017, Mended Hearts and Mended Little Hearts families! Heartbeat is ringing in the New Year by covering some very important topics. Starting small, we highlight some tiny medical devices that are having a huge impact on heart patients: heart pumps, loop recorders and defibrillators that are small enough to be implanted under the skin, through either a catheter or a small incision. Thanks to these types of devices, heart patients can avoid invasive open-chest surgeries.

More patients may now have easier access to new medical devices like these because, late last year, lawmakers passed the 21st Century Cares Act. Mended Hearts was one of more than 700 organizations advocating for the passage of this act, which reduces some FDA regulations for makers of drugs and medical devices. It also boosts funding for the National Institutes of Health. You can read more about this act in the Vitals section of this issue.

We also take a look at an issue that often causes parents of children with congenital heart defects a lot of worry: exercise. If your child is born with a CHD, is it OK for him or her to participate in sports and exercise like their heart-healthy peers? In most cases, the answer is yes, according to the doctors we interviewed.

And our cover story, “One Size Fits All’ Medicine Is Not Fit For All,” sheds light on disparities in health care between different populations. This article helps readers understand how organizations like ours might help narrow the health-disparities gap. In fact, reducing health disparities is one of our Patient Advocacy Network’s legislative priorities for this year. Focusing on this at the patient-to-patient and policy levels will go a long way in helping us all live up to our motto: It’s great to be alive and help others!

Donnette Smith
President
Mended Hearts
Have you had type 2 diabetes for 10 years or more?

If you are a diabetic who has been diagnosed with type 2 diabetes and kidney disease, have been told you have high protein levels in your urine, or have been told by your physician that you are at risk for diabetic kidney disease (DKD), and you are receiving treatment for high blood pressure, you may want to consider the FIDELIO-DKD and FIGARO-DKD clinical research studies.

These studies are recruiting patients with diabetes and kidney disease to evaluate whether adding an investigational medication to regular treatment may be safe and effective to slow the progression of kidney disease and reduce cardiovascular complications, such as heart disease or stroke.

You may be able to join the FIDELIO-DKD or FIGARO-DKD study if you:

• Have been diagnosed with type 2 diabetes mellitus
• Have reduced kidney function as a result of having diabetes
• Are receiving treatment for high blood pressure
• Are at least 18 years old

There are other eligibility criteria that you must meet to participate. The study staff will discuss these criteria with you in greater detail.

To learn more about the studies, call 866-488-7425 or visit print.DKDstudies.com.
Eat Your Greens… & Yellows & Reds & Purples

Our mother was right: You have to eat your fruits and veggies. To drive this message home, the American Heart Association, in partnership with Subway restaurants and Hass Avocados, has launched a new initiative called +color. It’s aimed at the millions of Americans who aren’t already getting their recommended daily amount.

+color is more than just a fun social media campaign. It’s a call to action to get consumers to improve their diet — and for good reason. It is estimated that if Americans ate the recommended amounts of fruits and vegetables every day, approximately 39,900 deaths would be prevented from cardiovascular diseases, stroke and diabetes, and $7.6 billion in medical costs could be saved annually.

“We want to push the perceived limits and perceptions around what people think is healthy to what is actually going to help them improve their diet. It’s about adding colorful, nutritious and vitamin-packed fruit and vegetables to meals instead of choosing unhealthier options,” said Rachel Johnson, Ph.D., M.P.H., R.D., Professor of Nutrition for The University of Vermont. “It’s about showing America how easy it is to get more of these vital foods into their diet each day and how easy it is to share this information everywhere they go with everyone they know,” said Dr. Johnson.

For details on how to start adding more color to your day, visit Heart.org/pluscolor. And if you’re on Facebook, Twitter or Instagram, share colorful selfies using the hashtag #pluscolor.
Cardiac rehab put Martin Espinosa on the road to recovery when he had a heart attack — the day before his 50th birthday. He benefitted from the program in a big way, but when he started visiting patients on behalf of Mended Hearts Chapter 304, he found people weren’t going. Why?

“They didn’t have a ride,” Espinosa says. “Having a father with a handicap, I know what a hassle it is to get to appointments when you don’t have a loved one to take you.”

Espinosa wanted to eliminate that hassle. He noticed that the Citrus Valley Intercommunity Hospital, in Covina, California, where Espinosa had his surgery and volunteers, had a van for oncology and dialysis patients that sat parked much of the time. Why not put that van to work?

Espinosa got permission from the hospital to use the van during its idle hours as a cardiac rehab shuttle. He even found a volunteer driver. Although Espinosa says he still has scheduling issues to iron out, his efforts have allowed otherwise housebound people to attend cardiac rehab.

Espinosa encourages — emphatically — all patients he visits to attend cardiac rehab. “I tell everyone, ‘you’ve got many years to live, but you’ve got to go to rehab,’” he says. “A lot of people don’t even know about it.”

Espinosa knew high cholesterol ran in his family, but like many adults, didn’t focus on his heart’s health until it failed him. He credits Chapter 304 visiting chairman Sandy Labrow and president Fred Sparling for getting him involved in Mended Hearts so he can help others. He thanks Mark Enrico, cardio-pulmonary rehabilitation supervisor for Citrus Valley Health Partners, for restoring his health after his heart attack.

“Mark and his staff put me at ease so I wasn’t afraid,” he says. “He helped me change my way of thinking and my life. Now I see how much better life can be.”

Espinosa directs patients to Enrico when they have questions about the program he can’t answer himself. “I give them my cell phone and tell them to call if they need help,” he says. “Cardiac rehab should be for everyone. It’s what’s going to save your life.”

Thanks to Martin Espinosa, heart patients at Citrus Valley Intercommunity Hospital can get a ride to cardiac rehab.
Improvements In Heart Health Are Stalling

For forty years, rates of heart disease have been declining — until recently. Since 1970, deaths from heart disease and stroke dropped more than 70% in the U.S. thanks to new medications that can lower blood pressure, innovative medical treatments, anti-smoking campaigns and the adoption of healthier lifestyles. But between 2011 and 2014, the annual decline in heart-disease deaths has remained flat. This trend is occurring across gender and ethnic groups.

What’s causing the stagnation? Obesity and the increasing prevalence of Type 2 diabetes, researchers say. Both of these are risk factors for cardiovascular disease.

Though the numbers are sobering, the key to seeing improvements in cardiovascular death-rates is maintaining “healthy weight through childhood and early adulthood,” to prevent risk factors from taking root at a young age, Donald Lloyd Jones, M.D., head of preventative medicine at Northwestern University’s Feinberg School of Medicine told the Wall Street Journal. If this happens, “these problems will melt away.”

Control Your Heart’s Destiny

A recent study involving more than 55,000 participants compared two groups of people who were genetically predisposed to heart disease. The first group had healthy lifestyle habits, while the other had poor habits. Those with the poor lifestyle and unlucky genes had about a 10% chance of developing a heart attack or other cardiac issue over a 10-year period. But those with a healthy lifestyle and unlucky genes had about a 5% chance. So, those with healthful habits basically cut their risk for heart problems in half.

The takeaway? “At least for heart attack, it’s pretty clear that DNA is not destiny,” Sekar Kathiresan, M.D., told National Public Radio. Dr. Kathiresan was the lead author of the study, which was published in the New England Journal of Medicine in November 2016.
Bobby Brown: A Record-Setting Survivor

Bobby Brown likes to compare himself to “Bonnie,” his 1930 Ford Model A: “You have to make adjustments to keep her running well.”

A charter member of Mended Hearts Chapter 379 in Gastonia, North Carolina, Brown holds the Guinness World Record for the longest surviving double heart bypass patient. When he had his first surgery, at age 37, doctors doubted he would live past 40. He surprised them all by running well for more than 40 years.

“I am the vessel,” he says. “I received excellent hospital care and had great doctors, nurses, and a caregiver in my wife. I am fortunate for this care and to survive this long.”

Double bypass surgery was relatively new when Brown entered the hospital in 1975. Doctors knew how to operate, but had little recovery advice. “I went through periods of depression. I didn’t know how to handle it.”

With support from his wife, he found a way. He also persevered through triple bypass surgery in 1985, a pacemaker and defibrillator installation procedure in 2009, and stents in 2003.

Today, Brown stays busy writing, building bird feeders and contributing to his community. As a Mended Hearts volunteer, he reminds patients of their possibilities. “I say, ‘This isn’t the end. This is the beginning. They have repaired you so you can go on with some degree of a workable life.’”

Brown is honored to be a Guinness World Record holder but doesn’t want to keep it long. “If someone else has survived longer after a double bypass, nothing would make me happier than to congratulate them on their long life.”
African Americans have a higher risk and higher mortality rate for cardiovascular disease, and they are less likely than whites to be treated according to evidence-based guidelines.

By Camille Torres

Though the gap in heart health disparities between whites and African Americans is narrowing, there is still much work to be done.

By Camille Torres
There is a lot of denial about existence of the problem.
— Felix O. Sogade, M.D.

When Patricia Brown-Glover was rushed to a Charlotte, North Carolina, emergency room five years after being diagnosed with leukemia, she mistakenly thought she was having an asthma attack. Although the 44-year-old knew heart disease was a potential aftereffect of the chemotherapy that eradicated her cancer, her diagnosis was shocking.

“Heart failure has been more harmful to me and more of a challenge than the leukemia ever was,” Brown-Glover says. She has had three pacemaker surgeries and one open-heart surgery since her heart failure diagnosis 12 years ago. “Heart failure is with me every day. It’s impacted activities I took for granted. When I go places, I have to be very aware of the walking distance. It comes down to energy levels and, psychologically, just getting through life.”

Brown-Glover is a coordinator of special education at a Richmond, Virginia school. She says, “I have a high-energy, high-paced job, and I can’t just say, ‘Slow down. I’m tired.’”

Despite the fatigue, she keeps going. “I am alive because I am informed, tenacious, and I now have a good cardiologist,” Brown-Glover says.

Unfortunately, many other African Americans are not as fortunate.

Differences in Prevalence, Care and Outcomes
According to the American Heart Association, African Americans have a higher risk and higher mortality rate for cardiovascular disease, and they are less likely than whites to be treated according to evidence-based guidelines. These
disparities exist even when the patients’ income, insurance status and other factors are taken out of consideration.

African Americans also develop heart disease at an earlier age and with more advanced heart damage than whites. “Among patients admitted with heart failure in our community and under the age of 50, a significantly higher percentage of them are African Americans,” says Felix O. Sogade, M.D., FACC, FHRS, CEO of Georgia Arrhythmia Consultants & Research Institute and chairman of the board of the Association of Black Cardiologists.

Nationwide, African Americans younger than 50 have a 20% higher prevalence of heart failure than whites of the same age, and black men are more than 30% more likely than white men to die from heart disease.

When researchers study disparities in health care, they often look at two main aspects: quality of care and access to the right medical services when needed. African Americans and other minority populations fare worse in both regards, according to National Healthcare Quality and Disparities Report, which has been published annually since 2003.

And although the 2015 edition shows that many improvements have been made to narrow the gap in both quality and access, there is plenty of work to be done. The report, which includes data on more than 250 aspects of health care, found that:

- In more than half of the health care access measures, blacks fare worse than whites.
- Blacks also receive poorer quality of care for approximately 40% of the quality measures.

In a different report, published in the
Journal of the American Medical Association for Surgery, researchers looked into racial disparities in mortality rates after coronary artery bypass graft (CABG) surgeries. They found that nonwhite patients had 33% higher mortality rates after CABG surgery than white patients.

It’s a clear failure of our health care system. These patients are not being provided a life-saving therapy, and there’s no excuse for it.
— Gary Puckrein, Ph.D.

Drug Works More Effectively in Blacks
Perhaps most alarmingly, a drug that’s clinically proven to reduce the mortality rate in African Americans with heart failure is grossly underused, despite being recommended by the American College of Cardiology and the American Heart Association. The fixed-dose regimen of hydralazine and isosorbide dinitrate (sold under the brand name BiDil) has been shown to reduce mortality for African American patients by 43%. A study in the New England Journal of Medicine showed the treatment improved patient quality of life and reduced first-time heart failure hospitalization by 39%.

Interestingly, the medication does not have the same effectiveness for whites and other ethnicities. Although it’s unknown which genetic marker is responsible for the treatment’s success in African Americans, race is a proxy to identify which patients are likely to benefit from the therapy.

“It’s very complex, as the use of this agent represents a unique situation where a therapy is approved for a particular racial group. Physicians need to be educated more about the science behind the advantages of this therapy in African Americans,” Dr. Sogade says.

Despite the clinical evidence and leading organizations’ recommendations, less than one in four eligible heart failure patients receives the treatment or either of its two components. And less than 10% of eligible patients on Medicare Part D receive the treatment. As a result of the lack of treatment, more than 6,500 blacks die prematurely each year, according to a 2011 report in the American Heart Journal.

“It’s a clear failure of our health care system. These patients are not being provided a life-saving therapy, and there’s no excuse for it,” says Gary Puckrein, Ph.D., president and CEO of the National Minority Quality Forum and executive director of the Alliance of Minority Medical Associations.

The Centers for Medicare and Medicaid Services (CMS) is partially to blame for the underuse of fixed-dose treatment, according to Dr. Puckrein. “The CMS has systematically undervalued the medication and made it difficult by propagating bad information to providers about the value of the medication,” he says.

The CMS’s emphasis on performance measures fails to recognize the need for African Americans to receive the fixed-dose treatment. Instead, it emphasizes a standard treatment for all patients. Because the fixed-dose treatment is effective only for a subsector of the population, it is not included in the CMS’s recommendations.

“I think every American ought to be very concerned about this. When CMS starts
to intervene and push policies that are not aligned with what the clinical evidence says, every patient has to be concerned about that. In that regard, African Americans are like the canary in the coal mine,” Dr. Puckrein adds. “[The CMS doesn’t] recognize patient variability — the differences between men and women, the etiology of diseases between populations, that patients metabolize medicine differently. It’s an utter disaster, and African Americans are losing their lives because of it, and other Americans are too.”

Although the health system is partially responsible for the disparities in care and outcomes, other factors are also at play. Disparities also stem from the fact that minorities often have higher rates of risk factors that contribute to poor heart health. These include high cholesterol, smoking, high blood pressure, obesity and diabetes.

**Role of Advocacy in Narrowing the Gap**

Recognizing the disparities in care is not only a moral issue — one of fairness and equity — but an economic one as well. Racial health disparities cost the U.S. an estimated $35 billion in excess health care spending and $10 billion in illness-related lost productivity, according to the National Institutes of Health.

Addressing disparities in health care is a both a moral and economic issue. Racial health disparities cost the U.S. an estimated $35 billion in excess health care spending and $10 billion in illness-related lost productivity, according to the National Institutes of Health.

Despite these numbers, Dr. Sogade says, “There is a lot of denial about the existence of the problem.” He adds that reducing and eventually eliminating disparities in cardiovascular care will take “dedicated commitment and immediate action from local, state, and national health agencies; professional medical associations, patient advocacy organizations; patients and caregivers and others within and beyond the health sector.”

That’s where groups like Mended Hearts come in. According to Dr. Sogade, organizations like Mended Hearts can begin by developing a long-term plan to support cardiovascular health equity. “This could include a commitment to partner and coalesce in the areas of education, research, advocacy and health policy with organizations like the Association of Black Cardiologists, The
American Heart Association and others to address health disparities,” he says.

Advocacy is key. Often, the patient isn’t aware he’s receiving substandard care, making it imperative for patient groups to intercede. That’s why the Patient Advocacy Network, Mended Hearts’ advocacy program, has made it a priority to advocate on behalf of patients by raising awareness of the health disparities that exist in heart care.

Mended Hearts’ plan is to focus on empowering African American patients to be their own advocates and provide them with the education and tools they need.

“Addressing policies that currently widen the gap in health care disparities will be an important part of this process as well,” says Andrea Baer, Director of Patient Advocacy for Mended Hearts. These policies will include addressing issues with access to care, treatment and cardiac rehab. “African American and other minority voices need to be brought to the table as equal partners in the discussions, and Mended Hearts is dedicated to accomplishing this task.”

For Brown-Glover, the steps toward a solution include personal involvement. “When I had open-heart surgery, that was very traumatic both physically and psychologically. I was just left alone medically,” she recalls. “I later found out there was cardiac rehab I was never offered. I felt very isolated. That could have been a big help.” To connect with other patients and to provide support she didn’t receive, Brown-Glover joined her local chapter of Mended Hearts this year. She plans to undergo training to visit patients.

She emphasizes being deliberate about racial diversity, along with making sure all cardiovascular patients are visited at the hospital and followed up with afterwards. “When a person of color visits another with heart failure, they get a hope from someone from a similar background, especially in this chapter where the people are all white. There are a lot of African Americans and other racial minorities that don't see a lot of people who look like them, and that can make a big impact,” Brown-Glover says. “If there’s a patient who is waking up from heart surgery, they can see my face and say, ‘I can get out of this bed and walk. My life is just starting, not ending.’”

She adds: “I’ve been given these charges in life to remain humble and to give help. Now things are becoming very clear to me on what my next path in life is. This has given me focus. We experience things in life, so it can give us perspective, so we can give service to mankind.”

**VARIABLE QUALITY OF CARE**

Disparities in cardiac care aren’t limited to African Americans. Many minorities face similar lapses in preventative care and treatment. To help drive down these inequalities, it’s essential to provide culturally diverse and competent care to all different types of populations.

Hispanics experience many of the same disparities as blacks, though to a lesser degree. Like African Americans, Hispanics are more prone to develop heart disease than whites and are more likely to die from it. This is due in part to a higher percentage of Hispanics being overweight or obese.

There are also health disparities between women and men. Following a heart attack, 42% of women die within one year, compared to 26% of men. According to a 2009 study, women are more likely than men to experience delays in emergency department care for cardiac symptoms. Women are 52% more likely to be delayed 15 minutes or more reaching the hospital after calling 911. This delay in receiving treatment has been shown to increase damage to the heart.
Miniaturized cardiovascular devices are saving and improving patients’ lives.

By Laura Johnson
The tip of a pencil. A dime. Two matchsticks. A USB drive. These are all phrases used to describe the size of some of today’s most advanced devices being used to diagnose, monitor and treat cardiovascular conditions. Thanks to technological innovations, medical devices are being “miniaturized,” which can lead to lower costs, greater convenience, less invasive procedures and shorter hospital stays.

For Worcester, Maine, resident Dan Wolpert, it was a tiny heart pump — the size of the tip of a pencil — that saved his life. Wolpert suffered a heart attack, followed by several cardiac arrests, at the age of 40. He had a 95% blockage in his left anterior descending artery, which is nicknamed the “widow-maker.” Wolpert’s heart was functioning at about one-sixth its normal capacity. Prior to two stents being placed in his artery, the Impella 2.5 heart pump was placed in Wolpert’s heart to pump sufficient blood to other organs and tissues.

Following a heart attack, some heart muscle is permanently damaged while other muscle is temporarily stunned and requires time to start functioning again. The tiny heart pump bought time for Wolpert.

“The Impella 2.5 was able to give me all the blood flow support I needed while giving my heart a chance to rest and recuperate from the temporary stun from the heart attack,” says Wolpert, a Mended Hearts member at large.

The heart pump remained in Wolpert’s heart for almost 24 hours, allowing his heart to recover and preventing him from needing a heart transplant.

“I have been able to lead such an active life, with autocross racing, skiing and working full time, thanks to the tiny heart pump,” Wolpert says.

“The battery is the largest part of a [cardiac] device, and improved battery chemistry has enabled the creation of smaller devices.”
— Dr. Mark Kremers

At the Heart of Miniaturization
A variety of forces are advancing the evolution of miniaturization in the cardiovascular medical device market. The foundation of technologies developed for other industries, as well as the desire for convenient and functional medical devices, have played a significant role. In addition, demands for lower costs have accelerated the development of cardiovascular devices that are less invasive and longer-lasting.

Mark Kremers, M.D., a cardiologist with Novant Health, Heart & Vascular Institute in Charlotte, N.C., points to the size of batteries as a key catalyst.

“The battery is the largest part of a device, and improved battery chemistry has enabled the creation of smaller devices,” says Dr. Kremers, who is also the chair of the American College of Cardiology National Cardiovascular Data Registry ICD Registry Steering Committee, which establishes a national standard for understanding treatment patterns, clinical outcomes, device safety and the overall quality of care provided to ICD patients.
Little Loop Recorder

For 21-year-old Westerville, Ohio, resident Colleen Myers, a small, insertable loop recorder has helped her avoid emergency doctor visits. Myers has a number of rare and complex congenital heart defects, and while she has always experienced chest pain and arrhythmias, they became worse as she got older. Her physician suggested implanting a loop recorder to get a 24/7 picture of what was happening with her heart.

“My initial thought was, ‘Am I going to look like a robot?’ Myers says. “But I was very surprised by the size of the device. It was skinny and about as long as a USB drive, which was much tinier than I expected.”

The loop recorder, which she can have in her body for three years, records the heart’s rate and rhythm and allows physicians to analyze any abnormalities. “When I’m having any heart issues, I can call my doctors and ask them to look at the recording instead of going in to have an emergency EKG,” Myers says.

Dime-sized sensor monitors CHF

A congestive heart failure (CHF) monitoring device with a sensor the size of a dime is helping Carole Sharp of Placentia, Calif., stay out of the hospital. After extreme shortness of breath and tiredness, Sharp was diagnosed with right-sided CHF a year ago. Her physicians recommended she use a CHF monitoring device that features an implanted sensor.

“It was explained to me that the purpose of the device was to manage the heart failure and keep me out of the hospital,” Sharp says. “That really appealed to me to have more control over my health.”

The implanted sensor wirelessly sends readings to an external patient electronic system. Sharp sends daily readings to her cardiologist who can then recommend medication adjustments based on the data.

So far the device is doing its job; Sharp has not been in the hospital for 14 months.

Smaller Size Means Wider Use of ICDs

The implantable cardioverter defibrillator (ICD) is another device providing...
more benefits to patients as it gets smaller. ICDs are useful in preventing sudden death in patients with known, sustained ventricular tachycardia or fibrillation. An ICD is a battery-powered device placed under the skin that keeps track of heart rate. Thin wires connect the ICD to the heart. If an abnormal heart rhythm is detected, the device will deliver an electric shock to restore a normal heartbeat.

“ICDs used to require open heart surgery so they were only used on patients who were in the worst shape,” Dr. Kremers says. “Now, with the smaller devices, which don’t require an open chest incision, we can implant them in more patients who have a meaningful risk.”

With the miniaturization of both ICDs and pacemakers, they are now usually combined, requiring only one device to be implanted.

Is Smaller Better?
While the shorter hospital stays, less invasive procedures, longer battery lives and greater convenience of miniaturized cardiovascular devices provide health and quality of life benefits to patients, physicians still must consider what is best for the patient.

“One size does not fit all,” Dr. Kremers says. “You have to select the device to use based on the features that best meet the patient’s needs. If it gets the job done, then yes, smaller is better.”

Researchers from the University of Colorado Boulder and Northwestern University are developing a tiny, wearable sensor that can detect sounds of vital organs in the body, including the heart.

The device, which is still in the prototype stage, can stick to any part of the body and pick up sound waves as they move through the wearer’s body. About the size of a small Band-Aid, it is made of sensors and electrodes that are sandwiched between layers of silicon.

How is it different than other wearable devices, like a FitBit? Because this wearable sensor sticks onto the body like a temporary tattoo, there is no air gap between the body and the sensor, which is the case with a FitBit. Furthermore, it allows sweat to evaporate through it, which is not the case with a FitBit. Also, since it’s stuck on the body, there’s no chance of forgetting to put it on every day.

So far, the sensor has been studied on a small group of elderly patients with heart problems. The sensor was able to detect sounds and electrical activity of the heart — a sort of stethoscope-electrocardiogram combination.

Researchers also studied the sensor as it was attached to a mechanical heart pump (a left ventricular assist device, or LVAD) outside of the body in a lab. They purposely introduced a blood clot (using cow’s blood) into the pump, which the sensor detected.

“That’s a life-supporting device,” Howard Liu, a graduate student at the University of Illinois at Urbana Champaign and the lead scientist on the study, told The Verge, a website covering the electronics industry. “If you don’t know whether [the LVAD] is failing, then your life is in danger every second.”

For now, the device must be connected to a computer, but its developers are working on improvements that will allow it to connect to wireless devices via Bluetooth, which would enable it to transfer information to a remote location, such as a physician’s office. The device is still in development and must undergo more testing before hitting the market.
THE Kids ARE ALL RIGHT

For most children with congenital heart defects, exercise can help keep fragile hearts strong. By Heather R. Johnson
Molly Barker of Washington Township, Ohio, watched with pride, excitement and anxiety as her daughter, Brinly, competed in her first swim meet. Barker, of Mended Little Hearts of Dayton, Ohio, had reason to be nervous. Only two years prior, Brinly had surgery to repair a hole in her heart. Now she was swimming for the WTRC Sharks. Would the meet overstress Brinly’s fragile heart?

Many parents of children with congenital heart defects share Barker’s worries. What if their kids overdo it? Will they get an infection? Faint? Get hurt?

The American Heart Association and many cardiologists agree: let the kids play.

“We should be promoting physical activity as opposed to restricting it,” says Nicholas Madsen, M.D., M.P.H., pediatric cardiologist at the Cincinnati Children’s Heart Institute. “Children gain important health benefits with exercise that they would otherwise miss.”

The American Heart Association guidelines support Dr. Madsen and other physicians’ endorsement of physical activity. An AHA 2013 Scientific Statement says, “There is no evidence regarding whether or not there is a need to restrict recreational physical activity among patients with congenital heart defects, apart from those with rhythm disorders.”

**Exercise for Healthy Heart Function**

Exercise not only helps prevent obesity and other conditions associated with inactivity, but also keeps precious hearts strong. “The more efficient a person’s cardiovascular system, the less strain it puts on their heart,” says Gerald Marx, M.D., senior associate in Cardiology at Boston Children’s Hospital.
Three months after Brinly started swimming, her enlarged heart decreased in size. Now, two years later, she has a normal size heart. She swims three times a week for 45 minutes. “She can rest if she wants to, but she makes it look easy,” says Barker. “She’s gone from being the kid that was winded to being one of the faster kids.”

Hollee Stanton’s son Gabriel has to watch himself during soccer games, but not because of his heart. Born with double outlet right ventricle and other defects, Gabriel had surgery at five and six weeks old to repair his heart. And then his kidneys failed.

Because of kidney damage, Gabriel, now 8 years old, has to closely monitor his hydration. “He has 50% kidney function,” says Stanton, who is also a member of Mended Little Hearts of Dayton, Ohio. “So if he gets dehydrated, he goes into kidney failure. He wears a device that buzzes to remind him to drink.”

When he was in kindergarten, Arley Couch would faint if he did too much. After starting physical therapy at Providence St Peter Hospital, his strength and stamina have improved. Now, at 13, Arley enjoys baseball, golf and running.

The benefits of exercise for children with CHD mirror those of the general population:

- Stronger muscles and bones
- Lower risk of diabetes
- Lower blood pressure and cholesterol levels
- Healthy weight
- Stronger heart and lungs
- More energy
- Fewer colds
- Improved sleep
- Less stress
- Improved concentration
He does struggle when it’s hot, though, because he doesn’t have any reserve.”

Despite his limitation, Gabriel plays soccer and other sports pretty much like any active kid. His coach doesn’t have to pull him out of a soccer game anymore when he overexerts himself. Gabriel knows when to walk, rest and drink water when he needs to.

With the exception of certain high-risk individuals, Dr. Marx encourages all of his young patients to participate in physical education and exercise. “They should always be allowed to rest,” he says. “But they should be allowed to exercise with friends and participate.”

**Just How Much Exercise?**

Experts agree that avoiding physical activity does more harm than good for CHD patients. “Traditionally, kids with CHD have been told not to stress their hearts, to engage in less physical activity,” says Dr. Madsen. “But we also know that for the rest of us, to be healthy, we should engage in as much activity as possible. So we were asking kids with vulnerable hearts to intentionally decondition themselves.”

With the exception of conditions such as moderate to severe ventricular dysfunction or arrhythmias, Dr. Madsen says that it’s healthier for kids to stay active. But just how active?

Current guidelines recommend 60 minutes of physical activity a day for children, with at least three days a week of vigorous activity. According to the AHA, physical activity means anything that gets you moving, whether it’s swimming or playing on the playground.

Kids with CHD can generally engage in moderate-intensity activities without risk. A few AHA-recommended

They should always be allowed to rest. But they should be allowed to exercise with friends and participate.

— Dr. Gerald Marx
activities include walking, racquet sports, soccer, baseball/softball, table tennis, dancing, yoga, bowling and cricket.

Kids can participate in swimming, bike riding, ice skating or skiing with supervision, unless episodes of fainting are common. “I’ve had kids participate in high-level baseball, tennis, swimming and basketball,” says Dr. Marx.

They can even participate in a running program if “it’s not a significant dynamic burden,” says Dr. Marx. They may not run at the front of the pack, but they can participate, which is important for confidence-building and social skills. Contact sports, such as football, are not recommended.

In kindergarten, Angie Brown’s son Arley Couch would faint if he did too much. Now, at age 13, he likes baseball and golf and wants to run track in junior high. Brown, a member of Mended Little Hearts of Puget Sound, credits her son’s physical therapy team at Providence St. Peter Hospital in Olympia, Washington, and his cardiology team at Tacoma Mary Bridge Children’s Hospital in Tacoma, Washington, for helping Arley get up and moving after a complicated open heart surgery.

Brown pushed Mary Bridge’s heart center to develop a rehab program for preteens, an age group commonly overlooked in rehab. The program not only helped Arley rebuild his strength, but also gave him and his mom activity options for Washington’s rainy season. “They gave him exercises to do with a stability ball and weights — things I would have never thought of,” says Brown.

Through rehab, Arley improved from zero to 40 pull-ups in the pool, and from doing no activity to running on the playground and playing sports. “His heart function is better now than it’s ever been in his life,” says Brown.

The benefits and risks of exercise vary with every CHD patient. Parents should talk with their child’s cardiology team to determine what he or she can do to stay healthy. By focusing on what they can do, rather than what they can’t, parents can help their kids find plenty of ways to have fun, stay active and thrive."

"His heart function is better now than it’s ever been in his life."
— Angie Brown

Photo courtesy of Hollee Stanton
Your cardiologist is listening
If you have been limiting your work or your activities because of your chronic angina, be sure to talk about it with your cardiologist.

For tips on how to talk with your cardiologist, information about living better with angina, and support and stories from people just like you—including Donnette—visit www.SpeakFromTheHeart.com.

"I realized that by talking only about the number of attacks, I wasn't telling my cardiologist the whole story."

Donnette, angina patient

Watch Donnette’s video

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To stay relevant for more than five decades, a Mended Hearts Chapter has to be willing to adapt to meet its members’ needs.

Mended Hearts Chapter 38, which serves Greater Houston through five satellites, recently shook up its speaker topics to keep members engaged and coming back.

At 55 years old, Chapter 38 is Mended Hearts’ second-oldest chapter. It serves a population nearing seven million. To accommodate members who are spread across an area bigger than New Jersey, Chapter 38 established five satellites. Meetings at some of these satellites often attract as many as 40 people. Recently, however, hosts started noticing a drop-off. Was it time for a change?

Nadia Saiphoo and Donna McFadyen-Taylor, RN, both of Memorial Hermann Memorial City Medical Center, which hosts one of the satellites, decided to find out. After conducting a member survey as part of their involvement with Mended Hearts, Saiphoo and McFadyen-Taylor designed a program that would better educate newly diagnosed heart patients and families. Members wanted more personal discussions. When will I get back to “normal?” How will my heart surgery impact my marriage? What do I do now that I’m out of the hospital? “They wanted to better understand the anatomy and physiology of heart disease and how to live a heart-healthy life,” says McFadyen-Taylor.

Chapter 38 answered the call with a four-part series designed by McFadyen-Taylor and Memorial Hermann Memorial City Medical Center nursing staff. Titled “Rediscover Yourself—Reach for the Stars,” the 2016 series covered “soft topics”: the emotional aspects of recovery, the physical and social aspects of the disease, coping skills, and how to create a healthy lifestyle.

“We’ve had great feedback from those who attended,” says McFadyen-Taylor. “Members really appreciated the information about the emotional aspects of dealing with heart disease.”

Because of the positive feedback, the Memorial City Hospital satellite plans to launch a new series in early 2017.
How to Launch a Great Satellite

Coordinating speakers is one of the many tasks satellite leaders face. Chapter 38 supports its satellite leaders through an open exchange of information and in-person support.

“We always invite the satellite leaders to our monthly board meeting,” says acting president and secretary Dave Westerhaus. “That helps everyone stay on the same page, whether it’s discussions about visiting patients or meeting topics. Currently three of our board members are leaders of their area satellite. Board members attend those satellite meetings, even though for some of us it’s a two-hour drive.”

Joe Rivera, Mended Hearts assistant southwest regional director, advises sponsoring chapters to nurture satellites.

“Remember that you are responsible for the satellites,” he says. “You can’t just organize and forget them.” That means making sure a Mended Heart representative conducts each meeting and filling in if a host can’t attend.

Houston’s Chapter 38 strives to create dynamic programming for its members, but also recognizes its visitor program is key to longevity. “The success of the Chapter begins with the visitor program,” says Westerhaus. “That peer-to-peer support is the heart of the Chapter. Our home in the Texas Medical Center, close to the pioneers of heart surgery, the developing technology, and the support of the hospital community all contribute to our continuing success.”

— Heather R. Johnson
For three years, Mended Hearts has been working with 700 other patient advocacy groups to push Congress to pass the 21st Century Cures Act. And this past December, President Obama signed the bill, making it the largest health reform law since the Affordable Care Act.

The 21st Century Cures Act is a nonpartisan bill that aims to deliver new cures and treatments to patients. It was a top legislative priority during the fall lame duck session of Congress in November 2016. The act will affect cardiovascular health by:

- Helping bring drugs and devices to market more quickly and at a lower cost by making some reforms to the Food and Drug Administration, including an expedited review for breakthrough devices
- Increased patient involvement in the drug-approval process
- Providing $4.8 billion to the National Institutes of Health
- Providing $500 million to the Food and Drug Administration
- House Energy and Commerce Committee Chairman Fred Upton (R-MI) has described the new law as “a once-in-a-generation, transformational opportunity to change the way we treat disease,” and more than 700 patient advocacy groups agree.

What, Exactly, Is The 21st Century Cures Act?
This act started in 2013 as an idea that it was time to boost research and innovation, accelerate discovery, and delivery of new cures and treatments to patients across the nation. Mended...
Hearts has been involved from the beginning, when Andrea Baer, Director of Patient Advocacy, was asked to be a part of the round-table discussion in Pennsylvania’s District 18, with Representative Tim Murphy, in 2013. Other districts also held round-table discussions with key advocacy groups to ask the question: “What makes it hard for your constituents to access medical treatments?”

From there, lawmakers in the House Energy and Commerce Committee got to work. They solicited feedback from patients, patient advocates, researchers, academics, health professionals, and innovators, as well as the FDA, NIH, and White House, in an open and transparent manner to ensure accountability.

The Energy and Commerce Committee stated: “The 21st Century Cures Act brings our health-care infrastructure into the 21st century by catalyzing cutting-edge research and personalized medicine, modernizing clinical trials, updating FDA for the innovation era, and empowering patients to participate in research activities.” The 21st Century Cures Act will help deliver more cures and treatments to patients by embracing incredible advances in science and technology.

Why The Act Is Needed
According to the Centers for Disease Control, there are 10,000 known diseases, 7,000 of which are rare. Yet there are treatments for only 500. The mapping of the human genome and the rise of personalized medicine has the potential to unleash a new generation of health care. 21st Century Cures will allow scientists and regulators to fully embrace these advances and bridge the gap between the number of diseases and the number of treatments.

This law is also expected to create jobs in the U.S. The House reports that the U.S. has long been the leader in medical innovation, but in 2010, more biotechnology companies were formed in China than at home. The investment in, and dedication to, science and research will ensure that the U.S. remains the health-care innovation capital of the world, and will help to keep and create good jobs here at home. The law will also save money by developing cures rather than continuing to shoulder the heavy cost of chronic illness. Chronic illness is a drain on not only the social structure, but also the economic structure of our country.

Containing Cardiovascular Disease Costs
Cardiovascular disease (CVD) is among the most widespread and costly health problems facing the nation today, which is why Mended Hearts so strongly supported this bill. CVD is the leading cause of death in the U.S. and is responsible for an estimated 17% of the national health expenditures.

More than 800,000 Americans will die from cardiovascular disease each year, one in every three deaths. The public health burden associated with CVD is estimated to reach beyond $320 billion annually. As the population ages, these costs are expected to increase substantially. The total direct costs associated with CVD are expected to nearly triple by 2030 to $818 billion.

Mended Hearts’ Patient Advocacy Network was one of more than 700 advocacy groups that submitted a letter of formal support for this legislation. The PAN has also worked closely with industry leaders to help advance it, ensuring that Mended Hearts patients’ voices were heard loud and clear. Supporting bills like this is essential in finding cures.
VITALS

Gifts From the Heart
Special thanks to the following contributors for their gifts to Mended Hearts and Mended Little Hearts from October 1, 2016 through December 2, 2016.

In Memory Of:
Frank Cecco
Lynn Berringer
Catherine Case Larson
Lynn Frierson
Frank Hoehne
Mended Hearts Chapter #126
Mended Hearts Chapter #338
Frank D’Andrea
The Conair Family
Ronald T. Diamond
Paula Granger
Geoffrey Hayden
Mass Team at Voya Financial
Leandro Rizzuto, Sr. and Family
Laura Scinto
Anthony and Charline Shaw
Tileen, Row and Gina

William Ernst
Mended Hearts Chapter #30

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Joseph A. Guest
Thad and Vicki Bechtelheimer

Phyllis Le Page
Raul and Dot Fernandes

Wulma Levi
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Paul Posharow
Diane, Alex and Chris Boyd
Dolores Caughey
Ronald Sisler
Margaret Smarr

Bob Scott
Catherine Case Larson

Raymond Lee Shively
The Grace Fellowship Family

In Honor/Recognition/Celebration Of:
Dr. Dwight Harken
Peter J. Previte

Ethel Raskin
Izchak Kohen

My Heart Beats For:
John K. Ameis, Jr.
Shari Austin - in memory and in honor of Paul Posharow
William and Teresa Bowersock - for my family and other heart patients
Tina Burke - in memory of Paul Posharow
Steve and Floye Burstein - in memory of Paul Posharow
Joseph S. Cincotta - in memory of Frank D’Addario
Paula Coffman - in memory of Paul Posharow
Randy and Sandra Esmay - in honor and in memory of Marion F. Cook (Uncle Marion)
Fannie Mae ERM-Counterparty Risk Group - in memory of Paul Posharow
Philip A. Heinemann - for myself
Betty Johnson
Larry and Mickie Johnson - in honor of Cherie Zavison
John Marchetti
Mended Hearts Chapter #91
Mended Hearts Chapter #221
Philip Michel - for Phil and Ruth Michel
Peter Previte - in honor of Dr. Dwight Harken
Ruth Rosenberg - for my husband, Paul Rosenberg
Dale Sheehan
Barbara Steiner - in memory of Paul Posharow
Michael Toback - in memory of Frank D’Andrea
Joseph N. Todaro
Ingeborg Vilter - in honor and in memory of Frank D’Andrea
Beverly Winther - in memory of Paul Posharow
Bradley and Karen Yeung

Thanks For Giving:
Lynn Berringer
Daniel P. Brady
DeWitt Burns
Michael Capaldi
Karen Chambers
Jane Gravany
Millie Henn - in memory of Frank Cecco, Raul Fernandes and Bob Scott
Leon Kahn
Mended Hearts Chapter #380 – as a token of appreciation for HeartGuides
Paulette Moulos – for Helena Natarelli
Nancy Robertson – in honor of Paul Posharow
Norman Schuminsky – in honor of the Colonel
Catherine “Kate” Stewart – in recognition of Monique Rogers
P. Gerald White

In Lieu Of Expense Reimbursement:
Marcia Baker
Lynn Berringer
Millie Henn

In Lieu Of Shipping Charges On HeartGuides:
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Mended Hearts Chapter #40
Mended Hearts Chapter #51
Mended Hearts of Chapter #179
Mended Hearts Chapter #294
Arthur Thomas Southwell

General Donations:
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Kristin Lunsford
Mended Hearts Chapter #200
Mike and Linda Mussallem
The New Castle Chief Petty Officer Association... Fair Winds and Following Seas
George and Maryann Schnell
Mona Silvey
Rupinder Singh
Peter Stewart
Historical Hearts

Chapter Anniversaries: January/February 2017
5 YEARS

- Boise, Idaho · Chapter 380 · Rocky Mountain Region
- Gastonia, North Carolina · Chapter 379 · Mid-Atlantic Region

No Mended Little Hearts groups celebrated an anniversary in January/February 2017.
Save the Date!

Mark your calendars for the 64th Mended Hearts Annual Conference

**When:** July 3 – 7, 2017 (strategically planned for attendees to see the largest fireworks show in the country)

**Who:** You!

**What (is the theme?):** Let Freedom Ring... Let Your Heart Sing!

**Where:** Gaylord Opryland Resort & Convention Center in Nashville

Colorful architecture, wonderful food and upbeat rhythms will set the stage for what is sure to be an exciting conference. You can reconnect with chapter members and make new friends from across the country, while enhancing your skills as a chapter officer, member, visitor and caregiver. The conference will offer sessions by experienced members and nationally renowned speakers. Whether you’re a patient, family member or caregiver — you don’t want to miss this enriching experience.