Wythenshawe ICD Support Group

DEFIBBER NEWS

October 2012

Come and Join us at the October meeting

Wednesday October 24th 2:00 – 4:00pm

Education & Research Centre
Wythenshawe Hospital
Tea, Coffee & Biscuits from 1:00pm

Jeanette Hornsey

Will be speaking on Inherited Cardiomyopathies.

Inherited cardiac conditions include primary electrical, myocardial, and structural heart diseases, in addition to vascular conditions. The presentation, diagnosis, and management of the different categories of inherited cardiac disease vary greatly.

Cardiomyopathies can lead to sudden death as a result of fatal ventricular arrhythmias. Disease of the heart muscle may also progress with age and lead to heart failure. Early diagnosis and modification of risk factors for premature death may prevent such outcomes and are important. The diagnostic process has improved in recent years, with advances in clinical cardiological evaluation.

Lindsay Waddell

Will be speaking on Long QT and Brugarda Syndrome

Future Meetings

All held at :

Education & Research Centre Wythenshawe

2:00 – 4:00pm

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Wednesday

20th February 2013

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Wednesday

10th July 2013

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Wednesday

16th October 2013

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If you are going to attend the meetings, please email Jeanette at:

jeanette.hornsey@uhsm.nhs.uk

or ring her on:

0161-291-5076

Jeanette's Corner

It is so strange writing this corner to you all as it is the last one of this year and it is only August! So official still summertime! I know, I can hear all the groans re ; SUMMERTIME!

However the reason for my eagerness in putting type to paper is because I am going to be off for a while, as I am having an operation on my foot. Also as you are aware, there was no newsletter in June, prior to the Support Group Meeting. I was very sad that, for the very first time due to circumstances beyond our control we were unable to put a Newsletter together and despatch it in time for the 4th July meeting. I am therefore trying to ensure that we are well prepared this time.

The 4th July meeting was very well attended; in fact Susan and I could take up furniture removal in our spare time, as we have to bring so many extra chairs in to the lecture theatre. I believe most of you enjoyed the pharmacist's talk; you certainly were very enthusiastic with your questions.

Unfortunately one of the reasons for the missed issue of the Defibber News, was George did not have enough material to put a Newsletter together, I know you all have a story to tell, something to share with your fellow patients. I have said this before; you do not need to be a Charles Dickens or William Shakespeare, just write a few lines and share your story with us all please. I am told by so many how much they enjoy the Newsletter so come on give it a go! New ICD patients this includes you too!

Understanding Stem Cells

This is a story taken *WEB*MD in the USA and is for information. The website can be accessed by following the link below:

http://www.webmd.com/heart/features/stem-cells-heart-failure-heart-disease?ecd=wnl_day_082212&ctr=wnl-day-082212_ld-stry

Jim Dearing of Louisville, Ky., one of the first men in the world to receive heart stem cells, might have helped start a medical revolution that could lead to a cure for heart failure. Three years after getting the experimental stem cell procedure, following two heart attacks and heart failure, Dearing's heart is working normally. The difference is clear and dramatic -- and it's lasting, according to findings now being made public for the first time.

Dearing first showed "completely normal heart function" on an echocardiogram done in 2011, says Roberto Bolli, MD, who is leading the stem cell trial at the University of Louisville. Those results have not been published before. That was still true in July 2012, when Dearing again showed normal heart function on another echocardiogram. Based on those tests, Bolli says, "Anyone who looks at his heart now would not imagine that this patient was in heart failure, that he had a heart attack, that he was in the hospital, that he had surgery, and everything else." It's not just Dearing who has benefited. His friend, Mike Jones, who had even more severe heart damage, also got the stem cell procedure in 2009. Since then, scarred regions of his heart have shrunk. His heart now appears leaner and stronger than it was before. "What's striking and exciting is that we're seeing what appears to be a long-lasting improvement in function," Bolli says. If larger studies confirm the findings, "potentially, we have a cure for heart failure because we have something that for the first time can actually regenerate dead tissue.

Rare Opportunity

Jones, 69, first learned about the heart stem cell trial in a convenience store. He was buying diet soda when he saw a newspaper headline about the proposed research. Other scientists had tried using bone marrow stem cells to rejuvenate damaged hearts, but the University of Louisville researchers would be the first to use a patient's own heart stem cells, harvested during bypass surgery.

For the first time in a long while, Jones felt hopeful and excited. Already, he was pondering his mortality. He was drastically weakened from a heart attack in 2004 that had led to congestive heart failure, a problem in which the heart pumps blood inadequately. Heavy exposure to Agent Orange during his military years contributed to his heart disease, he says. The Department of Veterans Affairs recognizes heart disease as "associated" with exposure to

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Agent Orange or other herbicides during military service.

Walking had become difficult. His ashen color and frequent sweating alarmed his wife, Shirley, a 67-year-old retired nurse. "I was very concerned," she says. "I knew that I wasn't going to have him long if something didn't happen." Often, Jones relied on nitroglycerin to ease his chest pain, which struck after even a little exertion. Before the stem cell trial, he says, "I wasn't capable of doing much of anything. I could be playing a game of Internet checkers and get chest pain. There's not much to moving the mouse and clicking."

After seeing the article, he called the University of Louisville right away to volunteer. At first, his wife had mixed feelings, since this specific type of stem cell experiment had never been done in humans. But she came to trust her husband's judgment, she says. Both grasped the seriousness of his heart disease. "I knew things were winding down, so it just came at the right time," Jones says.

A Former Athlete Struggles

Meanwhile, Dearing, 72, a standout football player in his youth, struggled to understand his weakness and shortness of breath. "My first inkling of having heart problems was when I couldn't breathe very well. I thought I was out of shape," Dearing says. Often, he felt wiped out, "as if I had run wind sprints," he says. "That's how you feel. Your legs are gone, you're bending over, leaning on your knees, you're out of breath and you're tired."

After he fared poorly on a treadmill stress test, doctors performed a cardiac catheterization and found four blocked arteries. "That's when I first knew I had a big heart problem," he says. Heart disease runs in his family, having affected both of his parents. Three of his siblings have already had bypass surgery or stents. Doctors told Dearing that they also saw evidence of a couple of previous heart attacks, although he wasn't aware of them. He also had heart failure.

When he told his wife, Sharon, 69, the news explained a lot. During 46 years of marriage, Sharon had always known Jim to be a vigorous man. But lately, he had seemed much more tired. "He always did a lot of work around the house -- yard work, painting, and that kind of thing -- and it got so that he would put it off," she says. "I thought it was just age." When a cardiologist asked Jim if he wanted to enter the university stem cell program, he replied, "Yes, I'll do it if it's not [using] embryonic [stem cells]," he says. "I'm a right-to-life person. I'm very active in it."

Public controversy has surrounded research using embryonic stem cells. Dearing had educated himself by reading magazine articles on stem cells. Once he heard that the trial would use his own adult stem

WHAT'S YOUR STORY

We would like to hear from you. We are interested in how you are dealing with your Heart Condition and the impact it has made on yours and your families life. Why not put pen to paper and send your story in so that we can all share your experience and perhaps learn from it.

DEFIBBER NEWS

If you would like to submit your story and experiences, please send them to :

George S Davies

103 Redearth Road

Darwen Press Lancashire

BB3 2AR

e-mail to:
george.davies1@virgin.net

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cells, he signed on.
His wife wasn't so sure at first, but became confident as she learned more. "I was a bit hesitant, I have to say, because I had not read anything about it, like he had. I was anxious because it was a new thing," she says. "But he was ready to go."

Renewed Lives, New Friendship

In 2009, Jones and Dearing met by chance after striking up a conversation at a local Veterans Affairs hospital's cardiac rehabilitation program. Both had recently undergone bypass surgeries -- but with a bold scientific twist that could expand medicine's frontiers. During the bypass operations, surgeons cut off a small section of the right atrium, an upper chamber of the heart.
Researchers isolated cardiac stem cells from this tissue and then expanded them in the laboratory until they numbered about 1 million. Four months after bypass, these multiplied cells were infused back into the men's scarred heart tissue through a catheter inserted into the femoral artery in the leg. Jones and Dearing received only their own stem cells back, no donor cells. "That's one thing that's so unique about this: There's no rejection." Jones says. "They're my stem cells."

For the Joneses, high school sweethearts, the stem cell procedure took place on July 17, 2009. "That was a very special day, the anniversary of our first date," Shirley Jones says. "We went to see a movie and we went to the Dairy Queen. I was 15, he was 17. We had a double date -- Mother's rules." While Jones received the stem cell infusion, his wife and adult daughter waited in a nearby room. Both women caught sight of medical staff carrying a plastic cooler that contained the stem cells. "I saw this container, and I got so excited," Shirley Jones says. "I said, 'Those are your dad's stem cells!' They were carrying it like Fort Knox, just carrying gold." She felt a wave of "fear, concern, and excitement," she adds. "I was thinking of what this was going to do for him."

Encouraging Results

Unlike bypass surgery, the stem cell procedure did not require a long recovery period. After the stem cell infusions, doctors followed Jones, Dearing, and 18 other patients in the trial for two years. They published the one-year results in *The Lancet* in November 2011. Since then, Bolli's team, along with their research partners at Brigham and Women's Hospital in Boston, are still elated with the highly promising results in follow-up tests. All of the patients who received stem cells have shown improved heart function and less heart scarring, compared to a control group that showed no improvement. Researchers believe that the stem cells might be regenerating heart muscle -- a step toward disproving a long-held belief that scarred heart tissue remains dead forever.

Jones and Dearing are convinced, too, that they've benefited. Follow-up tests have shown dramatic improvement in the pumping ability of both men's hearts.
Through echocardiograms, doctors tracked their ejection fraction, a measure of the percentage of blood that leaves the heart with every contraction. A normal ejection fraction from the left ventricle ranges from 55%-70%. A measurement under 40% may point to heart failure.
Jones' ejection fraction rose from 26% before the stem cells procedure to 40% two years later; Dearing's went from 38% to 58%.
"Jim didn't have as much heart damage as I did, so he's coming through marvelously," Jones says. During follow-up, imaging tests showed that scarred regions of Jones' heart had gotten smaller. "The areas where the muscle had died, some of that has been regenerated," Jones says. Overall, his heart, which had become enlarged from heart failure, appeared leaner and stronger. "It was oversized and it had gotten smaller," he says.

Typically, patients who develop scarring and heart failure after heart attack don't get better, Bolli says. "They don't get better because a scar is

a scar; it doesn't change, it doesn't go away. The best you can hope for is that [patients] don't get worse." He's hoping that stem cells will change that, for good. "Obviously, that's what we're looking for: a permanent improvement, rather than a transient one."

The findings from Dearing's latest echocardiogram, Bolli says in an email, "support[s] the notion that the benefits received from our stem cell therapy are sustained over time." But Bolli does not consider Dearing to be "cured" of heart disease. He explains that Dearing probably still has scarring on his heart from the heart attack, though his heart is functioning normally. Still, the stem cell procedure isn't ready for prime time. Jones and Dearing took part in a phase I clinical trial, which means that researchers were mainly assessing safety and initial effectiveness. Only 20 patients were enrolled -- too few to gauge full effectiveness.

Before cardiac stem cells can become an approved treatment to regenerate damaged hearts, scientists must do larger clinical trials. That could take three or four years, Bolli says. Bolli's team is applying for permission to continue studying Jones and Dearing. The researchers also want to start phase II studies -- the next step forward -- but funding is not yet in place. Meanwhile, Jones and Dearing, now close friends who chat by phone about twice a week and occasionally double-date with their wives, hope the procedure will prove helpful to other patients. But they are reluctant to entertain the notion that they might be making history. His own part in the stem cell trial may have played a small role, Dearing finally allows. "It's one cog in the wheel, going forward," he says. "It's like the race to the moon."

Life "Falling Back Into Place"

Jones, who couldn't even play online checkers without chest pain, can now work outdoors at his home, set on nine acres of countryside. Not only can he "brisk-walk" on a treadmill for 30 minutes, he says, but "I can pretty much mow nine acres on a tractor. I'll take lopping shears and cut down those little aggravating things along the creek that you don't want growing up. I don't work as fast as I used to... but I can generally do anything I want to do."

"It's been amazing," his wife says. "He had no hope, and after he started feeling better, things just started falling into place. The look in his face -- his color is better. He isn't ashen. He could do things with the grandkids, and our quality of life together is just so much better."

Dearing, who couldn't manage to walk up a short hill before the stem cell procedure, still has trouble walking around a nearby park -- but not for health reasons anymore.

What's the distraction? Stopping to tell people his story. He loves to talk about being a "guinea pig," he says. "That's why I can't hardly make it around the park, usually. I tell everybody I meet about the stem cell program."

The same thing happens when he chats with people at the grocery store. "If they have any heart condition, he's telling them all about what he has been through," his wife adds.

To date, neither man has noted any ill effects from the procedure, and the researchers have deemed the technique safe. Jones and Dearing continue to see their own primary care doctor or cardiologist for heart treatment, which includes standard medications for heart failure, high blood pressure, and high cholesterol.

Any downsides or regrets about the stem cell procedure?

"Not at all," Jones says. "It just was the right thing to do, when you listen to that little voice in your head. I was very comfortable, very at ease. I never second-guessed myself. I just knew that was what I was supposed to do."

WebMD Senior Health Editor Miranda Hitti contributed to this report.