

Transplant News

Summer/Fall 2009 Volume 2, Number 1

Inside

In this issue of Jefferson *Transplant News*, we will shed a little light on the subject of cardiac transplantation. Just imagine being told that you will need a new heart, and soon. Inside you will read the story of one such patient, how she coped with her sudden illness and went on to receive the precious gift of life.

We are also introducing a new addition to *Transplant News* called **People Behind the Scenes**. Here, you will meet people that are part of the transplant team but rarely seen by our patients. These are people who perform a vital function that improves the care and services that we provide to our patients.

Finally, our transplant pharmacist will tell you how to protect yourself from the sun and its harmful rays with his summertime safety tips.

We hope you are having a wonderful summer with lots of fun and excitement.

Be safe and be well.

We welcome your comments and suggestions for future issues.

Kim Phillips RN, BSN, CCTC
Managing Editor
Jefferson Transplant News
215-955-6734

Heart Transplantation

A Viable Option for End-Stage Heart Failure



Paul Mather, MD

*Professor of Medicine
Director of Advanced Heart Failure and
Cardiac Transplantation*

The first heart transplant was performed by Dr. Christiaan Barnard on December 3, 1967, in Cape Town, South Africa. Dr. Barnard's transplant was made possible by the work of two giants in the field of medicine, Drs. Norman Shumway and Richard Lower. These scientist-physicians began their research in human heart transplantation at the University of Minnesota in the 1950s and then helped perfect the surgical techniques and immunosuppression that made heart transplant possible in the 1960s and 1970s at Stanford University in Palo Alto, California.

The therapy of heart transplant, however, did not become a viable option for patients suffering from end-stage heart failure until the late 1970s and early 1980s, when immunosuppressive regimens with medication such as cyclosporine were approved for general use.

One of the most difficult questions facing practitioners in the field of heart transplant is: when is a patient considered a suitable candidate for heart transplant? This is a very difficult and complex question that takes into account many factors that affect the patient's health and well-being.

When a patient's symptoms can no longer be managed by optimal medical therapy, and there are no surgical options that would offer better long-term survival, transplantation becomes an option.

The evaluation process is designed to analyze whether a patient would do better with currently available standards of care or whether an intervention such as a heart transplantation would be the best pathway for their long-term survival and quality of life.

Every year, approximately 3000 heart transplants are performed throughout the world. America accounts for over 2000 of these 3000 heart transplants. Currently, patients are doing extremely well post-heart

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A Return to Life

Loretta Mather

Cardiac Transplant Recipient

I enjoy spending time with my family. Every moment has a special meaning for me, and now, even more so. Not too long ago, the family all got together for some fun at the Jersey shore. It was a beautiful week and my five kids and seven grandchildren all found a way to be there together at the same time, traveling from as far as California.



Loretta Mather, pictured here with Kazoo.

We spent time at the beach, laughing, playing in the sand, taking in the warm sun. We had our fair share of ice cream too! For some reason though, I was unusually wiped out by midday. I wasn't able to join the group for a stroll on the boardwalk or play any of our usual games. I found myself resting and just not feeling quite right. We had one last delicious seafood dinner before leaving the shore, but I didn't realize at the time that it could have been my last.

We went home and returned to life as normal, but after few days, I found myself in the hospital in Philadelphia. It seemed that my lungs were filling up with fluid, my blood pressure was high, and despite being exhausted and generally not feeling good, I just couldn't rest well. As you might

imagine, the heart failure team prescribed test after test to try to figure out what was going wrong. It turned out that my heart was not functioning well. To top it off, I was told that it was not going to get better, even with the best medication available.

I heard the shocking news that I needed a heart transplant. What can I say to describe that feeling?

I guess that when you don't have any other options, you just have to go for it. From the time that you find out that you need a transplant to the time that you are put on the waiting list is a trying one. I was in the hospital for the duration, and I was happy to have many visitors to keep my spirits up. My grandson wrote me a wonderful poem. My cousin wrote a great poem as well about the "skateboarding granny." Someone also made me a special piece of heart jewelry that I cherished. The recent picture of the whole family at the beach that summer remained in my room for me to look at every day.

At last, after every test known to man, I was put on the waiting list for a heart transplant. As I laid there with wires attached to me and IV's dripping, we collectively gave a sigh of relief that there might be some hope after all. I realized that I wasn't in good shape and I needed to improve physically before the big procedure. I worked hard at the hospital gym and did as many walking laps as I could every day. Again, I had visitors just about every day to keep me going strong. As extra company, I was given a fish. I had to name him Cardio, of course.

I made many friends in the hospital. The hospital staff was terrific and the other patients were a joy too. Since there were a bunch of us waiting for our transplants together, we spent a lot of time together and made some very special bonds. We watched movies, played dominos, made crafts, and even bowled on the Wii.

I was getting ready for the big day.

As I waited, I wasn't worried as much as my family. My granddaughter even worried that I might lose my love for her because I was going to have a new heart and it wouldn't recognize her. That surely wasn't going to be the case!

On September 16, 2008, I was told that a heart was going to be available for me and to get a good night's sleep. I said my prayers and was at peace that night. I woke up the next morning with my daughter curling my hair. She wanted to make me pretty for my surgery. It was so sweet of her! So, I finished getting ready and we got the call. My family paraded with me down the hall and towards the prep room. It was time.

Three days later, I was up and walking. The doctors, the nurses, friends and family were all there to support me. There was a lot to learn. I was home not long after that and so very grateful to the family that gave me new life. Just think, I could actually be back in my own house and bed! I was able to see my little Chihuahua, Kazoo. I missed him a lot.

There have been a lot of follow-up visits and procedures since then, but they are getting less frequent now. The Jefferson

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Find your voice, share your story and encourage one another.

Share your story with others. Write a short story about your transplant experience, and submit it to:

Kim Phillips, RN, Education and Community Outreach Coordinator
Thomas Jefferson University Hospital Transplant Services
833 Chestnut Street, Suite 610, Philadelphia, PA 19107
or e-mail to: Kim.Phillips@jeffersonhospital.org

Returning to Work After Your (Heart) Transplant

Elizabeth Shore, MSW, LSW

Heart Transplant Social Worker

For many patients facing heart transplantation, establishing disability via Social Security can be an uphill battle. Once confirmed, related benefits, such as Medicare, follow. So when your transplant team “clears” you to return to work, how do you re-enter the work force without upsetting the fragile construct of income and benefits? **For many, staying a step ahead can be the answer.** Once you and your transplant team have discussed the conditions under which you may return to work, consider some of the options available to you. For patients who need a new skill set after their transplant, most states offer **Vocational Rehabilitation** free of charge. Vocational Rehabilitation (VR) is a federal-state program that works with people who have physical or mental disabilities to prepare them

for employment. VR is committed to helping people with disabilities find meaningful careers. Engaging in VR should not affect your SSDI/SSI benefits. Social Security also offers a program called the **Trial Work Period** which allows you to test your ability to work for at least nine months within a 60-month period. During your trial work period, you will receive your full Social Security benefits regardless of how much you are earning as long as you report your work activity and continue to have a disabling impairment. In 2009, a trial work month is any month in which your total earnings are \$700 or more. If you are self-employed, you may earn more than \$700 (after expenses), and you must spend more than 80 hours in your own business. Other benefits related to the

Trial Work Period, Extended Period of Eligibility, Expedited Reinstatement, Continuation of Medicare and Work Expenses of your Disability are all part of this benefit. You can access these benefits at www.ssa.org under the Heading of “Working While Disabled – How We Can Help” or by calling **1-800-772-1213**.

As always, you can contact your Transplant Social Worker who will be glad to guide you through this process. Remember that there are so many benefits to returning to work after your transplant; proceeding with caution but staying a step ahead can be the key to a seamless transition from being disabled to gainful employment!

Summer Safety

Mark Chabala

Clinical Pharmacist

Sun exposure is a major factor in the development of skin cancers in both transplant and non-transplant patients. Transplant patients require the long-term use of immunosuppressive medications to prevent organ rejection, and they may impair the capacity of the immune system to repair or destroy sun damaged cells, allowing damaged cells to develop into cancers. It is also possible that the immunosuppressant medications directly cause cancer-

generating changes in cells. Some non-immunosuppressive medications that transplant patients receive to treat other diseases are also associated with increased risk of sunburn, skin sensitivities and even skin cancers.

Preventing skin cancer in transplant patients requires being sun-smart. The following measures should be followed by all patients.

Always wear sunscreen. Sunscreen should be rated SPF30+ and should be broad spectrum (blocking both UVA and UVB radiation). You should apply sunscreen 15 to 30 minutes before going outside. Sunscreen needs to be reapplied regularly during the day. Daily application to the face and hands regardless of your intended activities should be considered.

Avoid sun exposure, especially important during the middle of the day, between 11 a.m. and 4 p.m., when UV radiation levels are at their highest.

If you are outdoors during these times, stay in the shade.

Cover up well. Wear long sleeved shirts and pants. Dark-colored, tightly woven material provides the most UV protection. If possible, try to wear sun protective clothing that has an Ultraviolet Protection Factor (UPF) rating of 40 to 50+.

Always wear a hat when outdoors. Choose a hat with tightly woven material that shades your face, nose, neck and ears.

Wear sunglasses. Sunglasses provide the best protection to the delicate skin around the eyes. Choose glasses that are close fitting with large lenses. Wrap-around style glasses provide the best protection.

Just follow these steps and have a safe and happy summer. If you have any questions about summertime safety, please call your transplant office and speak with your coordinator.





People Behind the Scenes

Chad Gorn

Transplant Information Systems Manager

Transplant Data and You

As the Data Manager for Transplant at Jefferson Hospital, I have learned how critical updated and accurate information is to the transplant program, as well as to transplantation worldwide. We are always trying to improve care to

our patients. By studying every transplant performed, we can develop improved methods of treating patients in need of organ transplantation. Everyone is involved in the data collection of our transplant patients. We begin collecting information from the first phone call and visit, through the surgical procedure, and on and on throughout the recipient's life.

Transplant centers must also report a variety of important information to outside organizations, such as UNOS (United Network for Organ Sharing) and SRTR (Scientific Registry for Transplant Recipients), to ensure that the best care is given to recipients and donors. Not only do we report medical history, diagnoses, and details on the operation itself, but we also are required to submit annual forms on the current health of all patients.

Graft survival and patient survival rates are reported by every center. This information is available to the public at the SRTR web site (www.ustransplant.org).

The information we collect is also used for research projects designed to create and improve practices and to enhance technologies which will help improve the care of the patient. For example, by comparing the type of organ (deceased donor or living donor) and the function of the donor kidney, we can determine if there is a common thread that contributes to graft survival (how long a new organ may last). This, in turn, will help surgeons select the best-quality organs for future candidates.

How can you help? By contacting Jefferson's Transplant Service team:

- if you have been admitted to the hospital
- if you have any change in your medical condition
- if you have been transplanted at another center
- if you have started dialysis or changed your dialysis center
- if you or your donor has a change of address or phone number

Keeping annual appointments and staying in touch with Jefferson's Transplant Service will ensure that we provide the best care and support to all of our patients.

A Return to Life

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Transplant team follows you very closely after surgery to make sure you are progressing well. It has been just over six months since the big day, and I appreciate everyone's love and concern and special talents.

I went to the Donor Dash in April. It was a 3k walk and I walked with a smile. I look forward to giving back to the community of friends and families that gave so much to me. I intend to volunteer at special events in the future. I am feeling great and awaiting another wonderful summer filled with precious moments with my family at the beach. Thank you, Dr. Mather, Colleen and all of the Jefferson Cardiac Transplant team for your love and support. I chose a great team and a great hospital!

Editor's Note: Loretta Mather bears no relation to Dr. Paul Mather.

Heart Transplantation

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transplant. The one-year survival is between 84 to 90%, the five-year survival is reaching 75 to 80% and the 10-year survival is nearing 60 to 70%. We now have patients who have been living longer than 20 to 25 years with their heart transplant. Patients have been able to return to an excellent quality of life and, hopefully, the type of lifestyle they wish to continue.

Thomas Jefferson University Hospitals' Advanced Heart Failure and Cardiac Transplant Center serves a rapidly increasing volume of patients with congestive heart failure. Nationwide, fewer donor organs are available, increasing numbers of patients are waiting for organs, and waits for transplant are longer. Newer, sophisticated technology has helped to support patients with end-stage heart failure.

The Jefferson Center provides aggressive programs tailored to patients with heart failure. These programs are designed to help improve cardiac function and quality of life. Jefferson offers a full range of medical and surgical options, including promising investigational treatments.

The ultimate goal and philosophy of the Jefferson Advanced Heart Failure and Cardiac Transplant Center is to provide a comprehensive, multi-disciplinary and holistic program that provides state-of-the-art care for the whole person. After all, life is precious and we are all given only one to live.

Did you know...

Transplant recipients from all over the country consult the **National Transplantation Pregnancy Registry (NTPR)** located at Thomas Jefferson University Hospital when they are considering parenthood after transplantation.



Jefferson transplant surgeon **Dr. Vincent Armenti** started the NTPR. Since 1991, the NTPR has collected information from nearly 2000 women who have become pregnant after their transplant and men who have had a transplant and then fathered a pregnancy. Along with the advice of their transplant physicians, this information has helped many couples make family decisions.

If you would like to enroll in our database or to speak to one of our registry nurse coordinators, **Lisa Coscia** or **Carolyn McGrory**, please contact the NTPR toll-free at **1-877-955-6877** or by email at **NTPR.Registry@jefferson.edu**. We are also available to meet with you in the transplant clinic.

Additional information is available on our website: **www.jefferson.edu/ntp**.

Living Well

Organic Produce....Is it worth the money?

It's summer and fruits and vegetables are abundant so enjoy. They are low in fat and so delicious this time of year. Many fruit and vegetable stands often offer organic produce as well as conventionally grown produce. The question isis organic really worth the extra money?

When you grocery shop, you have the choice to spend more money on organically grown foods or stick with the cheaper conventionally grown foods. We are all watching our budgets, but we also want to be healthy.

What does "Organically Grown" mean?

The "organic" label refers to the way food is produced, processed and handled, typically with little or no synthetic fertilizers or pesticides. But when it comes to your grocery list, not all organically grown foods are created equal.

When shopping, look for the USDA white and green labels on organically grown foods. Organic produce such as apples, grapes and tomatoes may be worth the extra money because you are eating the skin that could have been exposed to pesticides. When it comes to produce like oranges, bananas or any food where the skin is removed before eating, you might want to save your money.



Please join us in celebration of the 25th Anniversary of the Delaware Valley's First Liver Transplant

Jefferson Liver Transplantation Symposium October 2, 2009

8 a.m. to 4:45 p.m.
Bluemle Life Sciences Building
Room 101
Philadelphia, PA 19107

For more information, please visit
<http://jeffline.jefferson.edu/jeffcme/>
or call 1-888-JEFF-CME.

Nationally Renowned Speakers:

John J. Fung, MD, PhD
Cleveland Clinic

Bruce E. Jarrell, MD
*University of Maryland
School of Medicine*

Willis Maddrey, MD
*University of Texas
Southwestern Medical Center*

Anthony P. Monaco, MD
Harvard Medical School



Jefferson Hospitals held a celebration this spring to commemorate the first liver transplant performed in the region. Michael Donahue, our first transplant patient (third from left), and many other transplant recipients also took part in the festivities. Also pictured are: TJU President Robert Barchi, MD, PhD; Cataldo Doria, MD, PhD; R. Anthony Carabasi, MD; Hospitals President and CEO Tom Lewis, Victor Navarro, MD, and Charles Yeo, MD.

Contributors

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*Managing Editor
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Paul Mather, MD

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Chad Gorn

Transplant IS Manager

Fall 2009 Events

Hepatitis B and the Korean and Chinese Community

Hepatitis C: State of the Art for You

For more information, call
Karen Pine, RN, at 215-955-7675.

October 4, 2009

NKF Kidney Walk at the Philadelphia Zoo

Contact NKF at www.kidney.org
or 215-923-8611.

November 14, 2009

American Heart Association Heart Walk

Citizens Bank Park

Registration at 9 a.m.

Walk begins at 10 a.m.

www.start.kintera.org/philly

Links to Education

Heart Transplantation Links

www.chfpatients.com
www.transweb.org
www.transweb.org
www.transplanthealth.com
www.lifeaftertransplant.com

Liver Transplantation Links

www.liverfoundation.org/patients
www.transplantliving.org

Kidney Transplantation Links

www.kidney.org
www.nkf.org
www.pkdcure.org

Need an appointment?

Kidney Transplant Program

215-955-7625

Jefferson Support Group for Kidney Recipients meets every third Friday of the month. For more information, call Cheryl Boyd at 215-955-2585.

Heart Failure and Cardiac Transplant Program

215-925-2050

Hepatology and Liver Transplant Program

215-955-8900

