

SPRING / SUMMER 2014

APRIL IS ORGAN DONOR AWARENESS MONTH

#### **Mission Statement**

Raising awareness of the critical need for organ transplant donors through public education and advocating for donors and their families.

122,836

PEOPLE ON THE NATIONAL ORGAN TRANSPLANT WAITLIST

THAT IS OVER

100,640 OF THEM WAITING FOR

A KIDNEY

OF THE NATIONAL ORGAN TRANSPLANT WAITLIST

#ELIMINATE THE WAIT

THERE ARE 100 MILLION REGISTERED ORGAN DONORS

IF JUST BECAME

DONORS

THOUSANDS OF LIVES CAN BE SAUED

# #ELIMINATETHEWAIT

As you can see from the infograph on the front page, there are over 120,000 people on the transplant waitlist. Of those people, 80% are waiting for a kidney. You can help The Living Bank by spreading the message that living kidney donors can eliminate the wait and save lives. Please participate in our tweet campaign.



**Tweet:** #ELIMINATETHEWAIT for over 99,000 people on the kidney transplant waitlist. Learn about living kidney donation and spread the word!

## ADVOCATE FOR CHANGE

Help Thousands of Transplant Recipients Get the Medication Coverage They Need

Imagine waiting for over a year on the transplant waitlist for your life-saving organ. You receive the transplant and for the duration of your life you are required to take immunosuppressive (anti-rejection) medication to prevent your body from rejecting the new organ. Now imagine that those critical anti-rejection drugs cost anywhere from \$10,000 to \$14,000 a year (National Institutes of Health Study). This financial burden is what many transplant recipients face.



In order to alleviate this issue, members of the U.S. Congress have proposed the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act (H.R.1428/S.323).

The congressional bill will help transplant recipients obtain immunosuppressive medications necessary to preserve the viability of their new kidney.

Currently, those impacted with kidney failure or End Stage Renal Disease (ESRD) are covered through the Centers of Medicare & Medicaid Services (CMS) for dialysis treatment. Elderly and disabled populations receive lifetime coverage. Unfortunately, CMS coverage for ESRD patients, who are not aged or disabled, is terminated 36 months post kidney transplant. This bill will extend CMS coverage solely for immunosuppressive medications.

Please consider signing The Living Bank's petition and let's work together to get this bill moving through Congress and on to the President's desk.

SIGN OUR PETITION at: <a href="http://goo.gl/xzBzJ4">http://goo.gl/xzBzJ4</a> and visit our advocacy webpage at <a href="http://www.livingbank.org/advocacy">http://www.livingbank.org/advocacy</a>

## **A GIVING FAMILY**



Stefanie Plotkin and Marc Plotkin, living kidney donors

My name is Stefanie and my husband, Marc, and I are both living donors.

My husband donated a kidney to his father in April of 2005. My husband was 37 and my fatherin-law was 63 at the time of donation. My father-in-law's kidney disease was caused by chronic hypertension which he was diagnosed with in his late 20's. Fortunately, my husband was able to donate a kidney to his father before he went into full renal failure and never had to get on dialysis. As of this April, it will be nine years since the donation and both Marc and his father are doing great.

I donated a kidney to my friend David on September 20, 2013 at St. Luke's with Dr. Wesley A. Mayer of Methodist Urology performing Associates the surgery. I was 46 years old and David was 65 at the time of donation. David's kidnev problems started 10 years ago and he first got diagnosed, I did tell him I would be his kidney donor. As much as he appreciated the gesture, he declined my offer. As the years went on however, David's kidney disease got worse. In May of 2013, David was going into renal failure and was put on the transplant waitlist. I once again offered to donate a kidney. David once again respectfully declined. I did decide to go for testing to

see if I was a match so he would at least have an option if it turned out I was, indeed, a match.

I started my testing at the end of June and on August 28, 2013, I received the phone call that I was a match and that David's surgery could be scheduled. Needless to say, it was an emotional moment for both David and me.

In my case, for whatever reason, I always knew I was going to be David's donor. I wish I could explain how I came to my decision, but all I can say is that I felt to the core of my being that this was something I had to do.

I did know that donating a kidney is not a decision to be taken lightly. I weighed all of the pros and cons in making such a life changing decision. I have two young sons, who were 10 and 14 at that time and they needed their mom and that was honestly my biggest

concern. However, having gone through the experience with my husband's donation I had the fear element taken out of the equation because I knew what to expect. I knew everything was going to be fine.

In the nine years since my husband's donation I am amazed at the advances that have been made to remove a kidney from the donor. It is absolutely amazing!

To know that I have been able to give my friend David his old self before kidney disease is absolutely the most priceless feeling of joy next to the birth of my sons. This has been such an indescribably amazing life changing experience for me. I wish I had more kidneys to give!



David Bowers, kidney recipient (left) Stefanie Plotkin, kidney donor (right)

## LIVING DONORS SAVING LIVES



Photo Courtesy of J.Patric Schneider

Memorial Hermann Hospital transplant surgeon, Dr. David Hobeika (pictured center) and his Houston transplant team worked tirelessly with transplant centers in North Carolina and Minnesota to provide three organ recipients with

three kidneys from living donors.

Jimmy Walker (pictured right) needed a new kidney. His brother, Danny Walker (pictured left) was tested to see if he was a match. He was not a match, but all was not lost. Danny was matched to another recipient in Charlotte which sparked a three-chain kidney organ exchange that ultimately allowed Jimmy to get his life-saving organ from a living donor in Minneapolis.

Kidney donation from deceased donors has not been able to keep up with the need for kidney transplants. Living kidney donation revolutionized kidney transplantation and helps eliminate the wait for transplant candidates.



Dr. Richard Knight, Surgical Director at the Houston Methodist J.C. Walter Jr. Transplant Center, and his staff were diligent in their efforts to open a satellite center in Lubbock, Texas.

On January 1, 2014 the Lubbock clinic officially opened. The clinic serves transplant and living donor candidates in the west Texas area. The candidates are evaluated and tested at the clinic and undergo their transplant at Houston Methodist.

The Living Bank's transplant social workers implement the assessments of the candidates in the Lubbock clinic.

## INDEPENDENT LIVING DONOR ADVOCATE NETWORK (ILDAN)

ILDAN is an online networking community of social workers, professional counselors, psychologists, physicians, nurses and clergy who work as independent living donor advocates











Thank You to Series II Presenters

Patrick Hansen, MA, BC Mayo Clinic Arizona

Gigi Spicer, RN Henrico Doctors' Hospital

Helen Matthis, RN Memorial Hermann

Gwen McNatt, MS, RN, CNN, FNP-BC Northwestern Memorial Hospital

Miriam F. Weiss, MD, MA, FNKF Case Western Reserve University

Sarah Stone, LCSW The Living Bank

> Funded by: The Brown Foundation, The George & Mary Josephine Hamman Foundation

# Dr. Michael C. Braun, The Living Bank Board Member, Educates ILDAN Participants about Pediatric Donation

Currently, over 900 children are waiting for a kidney transplant in the U.S., many of whom will be waiting 1 to 3 years for a new life-saving organ. Living donation among this population is low and the likelihood of non-white children receiving living donors is even lower.

Dr. Michael Braun addresses issues of disparity within pediatric donation and how it is a challenge to find healthy, willing living organ donors for such a vulnerable population. You can view a recording of his February presentation at: <a href="https://www.livingbank.org/calendar-of-live-recorded-webinars">https://www.livingbank.org/calendar-of-live-recorded-webinars</a>



Dr. Michael C. Braun Texas Children's Hospital Chief, Renal Section

# **CELEBRATE LIFE 2014**

Celebrate Life 2014 will be held on Friday evening, October 24, 2014, at The Junior League of Houston. The theme for the night will be *Small Miracles* to focus on pediatric transplant.

The honorees for this special event are Mary Ann and David McKeithan. The McKeithan's are beloved, dedicated volunteers in the Houston community for over 40 years. They are the proud grandparents of ten children.



## THE LIVING BANK INTERNS

Jessica Wight (left), MSW Intern with Mindy Norris (right), Living Donor



The Living Bank is a field education agency through the University of Houston Graduate College of Social Work (GCSW).

GCSW Masters of Social Work (MSW) students gain direct insight on the operational, administrative and management side of a non-profit organization.

The students access clinical knowledge in the Houston transplant hospitals and learn a wide range of assessment and counseling theories and techniques from The Living Bank's living donor advocates.

Jessica Wight, a Utah native, is interested in the impact of living donation among diverse populations. She can be seen in the picture to the left giving a Nancy's Knit shawl to a living organ donor.

Kaitlin Throgmorton, Texas native, has shown great interest in the area of research. She is tech-savvy and has developed the #ELIMINATETHEWAIT

infograph and design materials for the social media campaign.

We wish them continued success on their educational journey.



Kaitlin Throgmorton, MSW Intern

# TRANSPLANT GAMES OF AMERICA COMING TO HOUSTON

JULY 11-15, 2014

The Transplant Games of America is a celebration for everyone connected to organ donation and transplantation.

If you are an organ or bone marrow recipient, or living donor who is at least nine months out from transplantation or donation, you can register to participate in the games and a host of other fun activities such as ballroom dancing, poker and trivia.

Register at: www.transplantgamesofamerica.org









### **Competition Categories:**

Badminton, Basketball, Bowling, Cycling, Golf, Racquetball, Swimming, Tennis, Track, Volleyball and more.

### **Venue Sites**

BBVA Compass Stadium

George R. Brown Convention Center

Discovery Green

Hilton Americas

Memorial Park

Palace Lanes

Rice University



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### **Independent Living Donor Advocate Network**

The Living Bank's Independent Living Donor Advocate Network (ILDAN) is an online networking community of social workers, professional counselors, psychologists, physicians, nurses and clergy who work as independent living donor advocates. ILDAN offers professional development, solutions, collaboration and peer support through live webinars, videos of instruction and forums.

ILDAN has been generously funded by:

- · The Brown Foundation
- The George & Mary Josephine Hamman Foundation

CEU credits available for Nurses, Professional Counselors & Social Workers



Public Education & Outreach

The Living Bank Programs

Living Donor Advocacy

(assessment , counseling and

resources for living donors)

Independent Living Donor

Advocate Network

If you would like to participate, please register with us at livingbank.org/ilda-network

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If your employer matches your donation to nonprofit organizations, please provide your company's matching gift form with your contribution.