

FOTA TRANSPLANT LIFE QUARTERLY

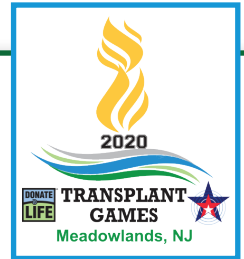


LATEST NEWS FROM FLORIDA ORGAN TRANSPLANT ASSOCIATION

INAUGURAL ISSUE: FALL 2019

Transplant Games 2020 | Everything You Need to Know

Next summer, the New Jersey Meadowlands will welcome its most inspiring event – the Transplant Games of America— July 17-22, 2020. Celebrating its 30th anniversary, the 2020 Donate Life Transplant Games will be like none other, with an expected 12,000-15,000 transplant recipients, living donors, donor families, transplant professionals, caregivers, supporters and volunteers expected to attend.



Produced by the Transplant Life Foundation, the six-day event will feature 20 competitions and more than 40 special events and programs. The Games are open to transplant recipients, living donors, donor families and family, friends and supporters.



Sporting events highlight intense competitions among 44 teams who pursue gold, silver and bronze medals. Competitions include a 5K Run/Walk, Badminton, Ballroom Dancing, Basketball, Bowling, Cornhole, Cycling, Darts, Golf, Lyrics for Life (singing competition), Pickleball, Swimming, Table Tennis, Tennis, Texas Hold'em Poker, Track & Field, Trivia Challenge, Volleyball, Virtual Triathlon and Youth Olympiad.

An array of special events and activities designed to honor the gift of life will be held concurrently with the competitions, including an Opening Ceremony, Donor Tribute, Workshops/Seminars, Welcome Reception, Quilt Display, Live! From the TGA broadcasts, Living Donor Celebration, Quarter Century (continued on page 5)

All FORE Adam | Organ Donor Family's Commitment to Transplant Community



The Adam Straub Memorial Golf Tournament began in 1998 at Eagle Watch Golf Club in the small town of Woodstock, GA., after Bill Straub Sr.'s son, Adam, died suddenly at 43 years old. Adam was stricken with a cardiac event, was declared brain dead and placed on life support until his organs, bone and tissue could be harvested for waiting patients. Adam was an organ and tissue donor who saved 27 lives.

This was the beginning of Bill Straub's quest of over 20 years to heal the pain of losing a son and keep his spirit alive through organ donation awareness and educating people who do not understand the dire need for donated organs.

Bill and Louise moved to Fernandina Beach in 2003 where they worked tirelessly to continue the tournaments to raise money. As the tournament grew, Bill and his crew of volunteers continuously worked to keep the Adam Straub Memorial Golf Tournament going and thriving. To date more than \$800,000 dollars has been raised to benefit the transplant community.

Bill will be 90 years young this year and although he is still very involved with raising money for FOTA he has handed over the torch to his daughter, Betty Ann Straub Ruotolo, who will continue his legacy by holding the tournament in Palm Beach County.

The Florida Organ Transplant Association 2nd Annual South Florida Adam Straub Memorial Golf Tournament, is set for Saturday, October 26th, at the Delray Beach Golf Club, in Delray Beach. Single player rate is \$150, and foursomes are \$500. Fee includes a round of golf, cart fees, light breakfast, hot buffet lunch following play, tee gifts, and more. Free drawing for 50" Flat Screen TV for (continued on page 4)

Executive Director's Message



Dear Friends,

Welcome to the Inaugural edition of the FOTA Transplant Lifestyle Quarterly—a publication designed to connect the South Florida transplant community with information, and opportunities to come together. Thankfully, transplant is becoming more mainstream and understood. According to the Donate Life Florida website, 10.9 Million Floridians have signed up to be an organ/tissue donor. Celebrities like Tracy Morgan and Selena Gomez are expressing their gratitude for life-saving transplants. However, the need continues to rise with roughly 115,000 individuals on the wait list, of which 5,000 are fellow Floridians.

In this edition, you will find local support group information for both pre and post transplant patients, families, living donors, donor families and the like who are all welcome; information about upcoming events around the community that bring transplant to light and celebrate it; and ways to get connected and involved.

Florida Organ Transplant Association's (FOTA) mission is to support the transplant community through forums to provide information and financial support for patients, caregivers and organ donor families, educate the community at large on the importance of organ donation, and fund transplant research.

Our main focus is to provide support for pre and post patients through social workers at all local transplant hospitals. We have just concluded visiting with all hospital groups to gather feedback from the front lines on how we can make the journey of transplant a little bit easier. We are hard at work developing additional outreach opportunities, like our recent trip to Marlins Park for a day of fellowship and fun. With 100 attendees, patients and families got to enjoy America's favorite pastime.

Please make sure to save the date and join us at our upcoming events: Saturday, October 26th for the 2nd Annual Adam Straub Memorial Golf Tournament (Delray Beach); and Saturday, December 7th for the 6th Annual Holiday Celebration of Life Luncheon (Davie).

We can only do what we do, thanks to our members and supporters! Please consider joining our membership, beginning at \$25. More details on the opposite page. Also, a shout-out to a few of our supporters including the Straub family, Global Reach Health, Linares family and Miami Marlins. Please know that if you have ever made a donation, big or small, you have made a large impact—it takes a village and we are grateful that you are a part of ours.

Sincerely yours,


John Venezia
Executive Director



is to become a central hub of resources and fellowship for the transplant community



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JOIN THE FOTA FAMILY

Whether you are a transplant recipient, living donor, organ donor family, or just beginning your pre-transplant journey, you have a place with us at Florida Organ Transplant Association (FOTA). And the first stop is to join the membership.

By becoming an annual member, you are investing in the mission and supporting transplant families every day. We work tirelessly alongside the social work departments at all South Florida transplant hospitals to offer emergency support and resources to families in need. Membership begins at \$25—and all levels include entrance to the annual Holiday Celebration of Life, so save the date and check out which level is best for you:

\$25: Individual Member

- One (1) complimentary member admission to annual Holiday Celebration of Life.
- Invitations to upcoming FOTA events and seminars.
- Subscription to quarterly newsletter.
- Monthly email with upcoming transplant support group information, and resources for the transplant community.

\$75: Family Membership (2 Adults and up to 3 Children at the same address)

- Complimentary admission to annual Holiday Celebration of Life for a family of 5 (2 adults and up to 3 children, at the same address).
- Invitations to upcoming FOTA events and seminars.
- Subscription to quarterly newsletter.
- Monthly email with upcoming transplant support group information, and resources for the transplant community.

\$150: FOTA Professionals

- Complimentary admission to annual Holiday Celebration of Life for a family of 5 (2 adults and up to 3 children, at the same address).
- Invitations to upcoming FOTA events and seminars.
- Subscription to quarterly newsletter.
- Monthly email with upcoming transplant support group information, and resources for the transplant community.
- Listing in the monthly email with your company name and website (if applicable).

\$250: Celebration of Life Membership

- Complimentary admission to annual Holiday Celebration of Life for a family of 5 (2 adults and up to 3 children, at the same address) with reserved seating.
- Invitations to upcoming FOTA events and seminars.
- Subscription to quarterly newsletter, with company listing and website (if applicable).
- Monthly email with upcoming transplant support group information, and resources for the transplant community.
- Listing in the monthly email with your company name and website (if applicable).
- Recognition in FOTA's online Annual Donor recognition page.

\$500: The FOTA Society

- The opportunity to restrict your membership specifically toward our mission work of patient services, education or research.
- Complimentary admission to annual Holiday Celebration of Life for a family of 5 (2 adults and up to 3 children, at the same address) with reserved seating.
- Invitations to upcoming FOTA events and seminars.
- Subscription to quarterly newsletter, with company listing and website (if applicable).
- Monthly email with upcoming transplant support group information, and resources for the transplant community.
- Listing in the monthly email with your company name and website (if applicable).
- Recognition in FOTA's online Annual Donor recognition page.

To sign up, please visit www.floridaorgantransplant.org or return the enclosed envelope.

Thank you for your consideration!
See you Saturday, December 7th at Signature Grand for the Annual Holiday Celebration of Life!

Transplant Support Group Information

All groups are open forums to express your ideas and concerns about transplant issues. Meet with transplant recipients, pre-transplant patients, donor families, medical staff, families & guest speakers involved in the transplant experience.

Cleveland Clinic Hospital (Weston) Transplant Support Group Meets the 3rd Thursday of every month 1:00 PM- 2:30 PM at 2950 Cleveland Clinic Blvd., Weston, FL 33331, 3rd Floor Conference Room (Clinic Building) For more information, please contact Randi Swersky at 954-659-6750.

Memorial Transplant Institute Adult and VAD Transplant Support Group Meets 2nd Wednesday of the month at 11:00 AM at the Memorial Regional Hospital's Medical Office Center at 1150 N 35th Ave, Suite #390, Hollywood 33021. For more information, please contact Janet Delgado, LCSW (Direct) 954-265-6810 (Main) 954-265-7465 or via email at Jadelgado@mhs.net.

Miami Transplant Institute Transplant Support Group Meets every 3rd Monday of the month from 2:00 PM-3:00 PM at the Highland Professional Building 1801 NW 9th Avenue, 7th Floor Conference Room, Miami 33136. For more information, please contact MTI Group Support Phone: 305-355-5000 E-Mail: MTI-TransplantSupportGroup@jhsiami.org

South Florida Transplant Group COMING SOON. Meets the 3rd Thursday of every month at 7:00 PM at LifeCare Specialty Clinics, 3880 Coconut Creek. For more information please contact John Venezia at 954-328-4751 or via email at venez40@comcast.net.



All FORE Adam Organ Donor Family's Commitment to Transplant Community

(continued)
all paid entries for a chance to win! And a \$25,000 HOLE IN ONE prize!! The tournament is open to golfers at all levels who wish to play in solidarity for the gift of life.

Adam was a son, a brother, an uncle, a father, a grandfather a great grandfather and an Air Force Veteran. Adam is missed every day, but his family knows a part of him lives on in those he helped.

Betty-Ann Straub Ruotolo with her Dad, Bill Straub, Sr. at the Inaugural South Florida Adam Straub Memorial Golf Tournament

Message in a Bottle | By: Joyce Bacon Griffin

Several years ago, I was placed on the kidney waiting list and I decided to commit to getting the word out. I was inspired by the idea of a message in a bottle and cast one into the South Florida waterways. It was incredible, a bottle was found by someone who had a nurse-friend working at Cleveland Clinic inside of the kidney transplant unit.

Approximately a year later a potential kidney match was found, but was not accepted by physicians, and so the journey continued. Same story with the second kidney and was declined. Finally, a third potential kidney match came my way and I proclaimed it as mine!!

Finally, the call came in on June 30th and I didn't pick up! I was out with some girlfriends bowling, and the number wasn't recognizable, so I ignored it thinking it was a spam call. My friends insisted I called back and all the while it was "the call"...this was it and my kidney was ready. I had my kidney transplant surgery on July 3rd and while everyone was celebrating the Fourth of July holiday, I was celebrating a new kidney.

Everything happens for me in the increment of threes: the third kidney worked, with the surgery on July 3rd, and it took three months' post-surgery to ensure that all was well. I realized it was the work of the holy trinity: Father, Son, and the Holy Spirit.

I am truly grateful, and continue to encourage others never give up, keep the faith, and believe.



Transplant Games 2020 Everything You Need to Know

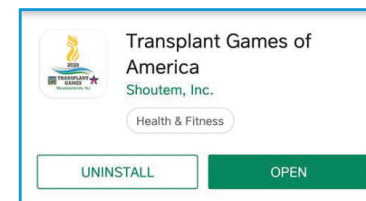
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Club Dinner, Transplant Expo, TGA Village, Quilt Pinning Ceremony, and the 2020 Awards and 2022 Launch Party.

"Hosting the Transplant Games, 'live from the Meadowlands,' home of world-renowned major sporting events, will not only showcase the incredible competitors but it will elevate the awareness and importance of organ, eye and tissue donation advancing the Donate Life cause. The countdown is on, we are extremely honored and proud to be a partner of the 2020 Games and excited that we are now less than a year away," said Jim Kirkos, President and CEO of Meadowlands Regional Chamber.

TRANSPLANT GAMES HAS GONE DIGITAL

You can download the Transplant Games app for free by searching "Transplant Games of America" in the Apple App Store for iPhones or the Google Play Store for Android phones. The app is intended for everyone, but is specifically tailored to current Transplant Game's participants, and to attract a new audience interested in organ donation awareness and life after transplant.

The app will be a useful resource leading up to the 2020 Games, during the Games and even after the Games. Be sure to check it out and download it now!



TEAM FLORIDA

Florida's Team Managers are:
Denise Simpson, denisesimpsonTM@gmail.com
Josie Flores-Centrella, josieflores16@gmail.com
Adrian Monsalve, monsalve.adrian@gmail.com

Stay in the know with Team Florida! To be added to the Team Florida listserv, please email: TeamFloridaTransplantGames@gmail.com. Also, check the Team Florida Facebook page for inspiring stories, team updates and more: <https://www.facebook.com/teamfloridatgagames/>.



World Transplant Games Message from Team USA:

The 2019 World Transplant Games are over and will be remembered as one of the best-run in Games history--congratulations Newcastle-Gateshead and all of the people who made this possible!

Recipients who have received lifesaving organ transplants from more than 55 countries worldwide will gather in two years in Houston, Texas, USA--the first time in over 40 years--and will compete in various sports in the hopes of winning Gold, Silver and bronze medals for their country! The games celebrate the triumph of the human spirit and the hope that is behind every transplant.

Stevie Wonder to Receive Kidney Transplant

Courtesy of Associated Press



Stevie Wonder surprised concertgoers in London over the summer by announcing that he will take a break from performing so that he can receive a kidney transplant this fall. He said he was speaking out to quell rumors and sought to reassure fans that he would be okay.

"I'm going to be doing three shows then taking a break," he said. "I'm having surgery. I'm going to have a kidney transplant this year." He said a donor has been found and that he would be fine, drawing cheers from a devoted crowd of tens of thousands that stretched out from the stage as far as the eye could see.

He did not provide additional information about his kidney illness. There had been a recent report that Wonder was facing a serious health issue. Wonder seemed in top form throughout the concert and performed a stirring rendition of the latter's "Imagine" near the end of the show.

EVENTS CORNER



2ND ANNUAL SOUTH FLORIDA ADAM STRAUB MEMORIAL GOLF TOURNAMENT

Saturday, October 26th | Delray Beach Golf Club, Delray Beach

Join us for the 2nd Annual Adam Straub Memorial Golf Tournament, slated for Saturday, October 26, 2019 at the Delray Beach Golf Club, with a shotgun start at 8:30. A single player is \$150 and foursomes are \$500. Entry fee includes light breakfast, golf & cart, hot buffet lunch, tee gifts, prizes and complimentary beer, plus \$25,000 Cash Prize for Hole in One! For more information: Betty Ann Straub Ruotolo at straub1951@gmail.com or via phone at 561-870-2720. To register, visit: www.firstgiving.com/FOTA/golf.



KIDS NEEDING KIDNEYS AT BUILD-A-BEAR WORKSHOP

Every April, for Donate Life Month, FOTA partners with Laura Kowalczyk, founder of “Kids Needing Kidneys”, and host a Build-a-Bear-Workshop event for children pre and post organ transplants. This is not just an ordinary day for these children. This is a day where they can just be kids, and not have to worry about the struggle to survive. It’s not just the children who get a day of fun and happiness, but the whole family all enjoy the event, where they watch their kids laughing, and playing with other children who are in the same boat.

The day is a magical experience that begins with choosing a trending stuffed animal to make entirely custom with sound choice for the paw, a special heart and kidney plush especially made by Laura and family that goes inside the new friend. They make a wish, kiss the heart and kidney, and put them in the bear while they step on the pedal, bringing their stuffy to life!

Then the children go to pick out clothing for the bear. From sports, to fairy princesses, these kids dress up their bear however they please. Finally, it’s time to name the new furry friend! Volunteers assist them in putting the bears in cardboard houses, with their certificate, to be sent home to snuggle with. Children who could not attend the event due to them being in hospitals, get the bears delivered to the hospital the next day by the volunteers and Laura herself. We are so grateful to have a partner like Laura and everyone who supports Kids Needing Kidneys.

UPCOMING COMMUNITY EVENTS

SOUTH FLORIDA WALK FOR PKD
Sunday, November 3, 2019
TY (Topeekeegee Yugnee) Park, Hollywood. For more information, please contact: Georgina Haberman, Volunteer Walk Coordinator, at southfloridawalk@pkdcure.org.

LIFE ALLIANCE RUN FOR LIFE
Saturday, November 16, 2019
TY (Topeekeegee Yugnee) Park, Hollywood. For more information please visit: <http://surgery.med.miami.edu/laora/>.

NKF KIDNEY WALK
Saturday, November 23, 2019
Check-in time: 8:00 AM with a Start time: 9:00 AM at Plantation Central Park, 9151 NW 2nd St, Plantation. For more information, please contact: Barbara Chatman at bchatman@kidneyfla.org or via phone at 954-947-4033.



Holiday Party 2018

HOLIDAY CELEBRATION OF LIFE LUNCHEON

Saturday, December 7th | Signature Grand, Davie

Come together as one transplant community at the annual Celebration of Life Holiday Luncheon on Saturday, December 7th from noon to 4pm at Signature Grand in Davie. The celebration features a toy drive, raffle, food, song and dance, food, silent auction and a loving tribute Tree of Life ceremony in memory of organ donors. Registration is FREE for FOTA members, or \$30 per person. For more information, please visit www.floridaorgantransplant.org.

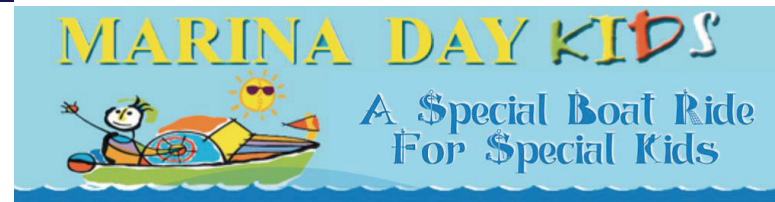
2019 EVENTS RECAP



The 2nd Annual Transplant Wild Adventure Fun Run/Walk Presented by Global Reach Rx was held at Zoo Miami last April. In honor of National Donate Life Month, over 100 walkers and runners made their way through the Zoo and celebrated organ/tissue donation at the Safari Festival with carnival games, music, photo booth, lite bites, raffle and more!

We celebrated Lissette Linares as the Top Fundraiser who raised over \$1,100 in loving memory of her father, Luis Linares, a longtime kidney recipient and transplant advocate. Thanks to Lissette and her team, The Kidney Beans, presenting sponsor Global Reach Rx, South Florida Small Business Accounting, Wetzel & Associates, and all participants, we reached our goal of \$15,000 raised! A big THANK YOU to all involved, and looking forward to the 2020 event.

Save the date for the **3RD ANNUAL FUN RUN/WALK** Saturday, April 25, 2020 at Zoo Miami. Stay tuned for more details!



FOTA's Annual Marina Day is a special Boat Ride for transplant kiddos by the U.S. Coast Guard and the U.S. Coast Guard Auxiliary held each June. 100 Children and families joined together at the Dr. Von D. Mizell-Eula Johnson State Park (formerly known as John U. Lloyd Beach State Park) for a demonstration on boat safety by the US Coast Guard, ride on the water and a picnic celebration. It was a hot and sunny day and a lovely memory for all!



Thanks to a partnership with the Miami Marlins, 100 transplant families were in attendance to cheer on the Marlins for the final game of the season against the Washington Nationals. We brought lady luck as the Marlins WON and we enjoyed time together for a day at the ballpark.





FLORIDA ORGAN TRANSPLANT ASSOCIATION
Helping Organ Donor and Transplant Families

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Join over 10 Million Floridians to give the Gift of Life

A single organ/tissue donor can save the lives of more than 50 people. For more information and to sign up, please visit www.donatelifeflorida.org.

While a signed donor card and a driver's license with an "organ donor" designation are legal documents, your family will ultimately give consent when the time has come. It is important to share your decision to donate life with your family. Once you've made the decision to become an organ/tissue donor, please share this card with your family and start the conversation today!



Name _____ Date _____
 Dear _____ (next of kin)
 I have made the important decision to sign up to become an organ/tissue donor. Although I have _____ signed an organ donor card and/or _____ signed up through my state's registry, and it's legally binding, the medical team may ask your for permission at the time of my passing to proceed with this gift. Please honor my wishes and allow me the chance to make a difference in up to 50 lives by becoming an organ tissue/ donor.
 _____ I signed up to donate everything I can
 _____ I signed up with donation limitations that include _____
 Let's talk! With love, _____
 (donor signature)



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