



BRIDGES

A Newsletter for Donor Families

Spring 2016



What Is BRIDGES?

This newsletter's name derives from an acronym reflecting the services Finger Lakes Donor Recovery Network offers to our donor families: **B**uilding **R**elationships, **I**ntegrating **D**onation, **G**rief, **E**ncouragement and **S**upport.

Donate Life Transplant Games

The Donate Life Transplant Games of America will take place June 10-15, 2016 in Cleveland, Ohio.

Before you know it, Team Finger Lakes will be heading to Cleveland to participate in the Games! Thus far, 24 recipients, five donor families, and four living donors have worked very hard to make this adventure a reality. Along with dozens of other teams from across the county, our team members will participate in various sports, activities, and ceremonies in celebration of the Gift of Life.

While some choose to compete in athletic competitions (golf, basketball, volleyball, swimming, badminton, table tennis, bowling, etc.), others will attend workshops or participate in several non-athletic competitions (trivia, Texas Hold-em, etc.) There is something for everyone, and team members are there to support each other through the celebratory moments as well as the moments of reflection and gratitude.

Those attending say they are looking forward to the experience. We look forward to sharing their stories and pictures with you in upcoming newsletters.

Also, stay tuned to learn the location of the 2018 Games!

MORE INFORMATION: Please contact Amy James, our Community Education Manager, at 585-272-4930, if you would like to receive information about Team Finger Lakes and future Transplant Games.

What's Going on in Albany?

On March 2, Finger Lakes Donor Recovery Network (FLDRN), along with representatives from other organ, eye and tissue agencies, and volunteers from around the state, convened in Albany for State Budget Advocacy Day. The day was organized by the New York Alliance for Donation to highlight funding needs and proposed legislation to help increase the number of lives saved or improved by organ, eye and tissue donation.

Groups visited with over 35 legislators, and asked them to support funding in the 2016-17 budget that would address a state-wide strategy to increase awareness and availability of life-saving and life-improving organs and tissues for transplantation.

Members of the Assembly were also asked to approve a 4-year or permanent extension of Lauren's Law. Lauren's Law mandates applicants at the New York State Department of Motor Vehicles to choose whether they wish to register, or postpone their decision to make an anatomical gift.

In the first month after being fully implemented in November of 2015, the percentage of individuals enrolling in the New York State Donate Life Registry nearly doubled—from an average of approximately 10 percent to 17 percent. The New York State Senate had already voted to extend Lauren's Law and the Assembly will be voting on it next.



New York State Senator David Carlucci (front row) meets with members of the donation community, including FLDRN's executive director, Rob Kochik (back, right). Senator Carlucci, along with Senator Felix Ortiz, proposed the extension of Lauren's Law.

Finally, representatives were encouraged to consider passing legislation to allow 16 and 17 year olds to register their "intent" in the Donate Life Registry.

New York's current minimum age to register is 18, while 46 other states have a minimum of age 16 or lower, or no age minimum at all. The bill proposes parents would still provide final permission for donation until the individual reaches age 18.

Donor Family Network Fundraiser - Casino Night

Finger Lakes Donor Family Network (FLDRN) is having a fundraiser Casino Night on April 15, 2016, from 6-10 p.m. It is at the Maplewood Inn at 400 7th North St in Liverpool, NY. Tickets are \$25 per person, which gives you your playing chips, food, soda coffee and desserts with a cash bar. Rooms for the night are \$79 for anyone who wants to come and join us and may live far away.

We would love to see you all there to meet some of our other donor family members. If you can't make it and would like to help in some way we could use major sponsors, ticket sellers, donations and raffle baskets. If you think you can help or need tickets, you can reach Michelle Lester at 315-673-9126/315-430-2677 or at mle350@aol.com. Please mark your calendars and come spend the evening with other donor families, recipients and friends and family. We hope to hear from you soon.

The proceeds from this fundraiser go to providing pins, brochures, newsletters, grave markers and also bereavement materials. We have sent 15 to 20 local families to the Donate Life Transplant Games of America in the past 14 years; 10 or more families to Washington DC for the Donor Recognition Ceremonies, as well as helping with the local Donation Recognition Ceremonies and other events honoring our loved ones.

FLDRN has also helped to sponsor four families to attend the New Year's Rose Bowl parade in Pasadena, California, because their loved ones' floragraph was on the Donate Life Float.

We help with recruiting donor family members who want to help spread the facts about organ donation, because only someone who has been in that situation can tell you the story of how donation helped them through one of the roughest times you can go through. We speak at Health Fairs, the New York State Fair booth, schools, churches, a local Tomato Fest and many other educational venues.

Money that is raised is also used to pay fees for some of these events, such as the cost of postage and paper supplies, as well as reimbursement for the donor family volunteers for travel expenses.

FLDRN Donor Family Support Page on Facebook!

We have created a Donor Family Support Page on Facebook. It is called the "FLDRN Donor Family Support Page." This page has all of the same features but provides increased privacy and security for all our families.

We currently have 48 members on our page, and it has been so rewarding and heartwarming to see the support that you have been giving each other. It is why this page was created!

Even though each of your experiences are different, there is a common bond among you: you are all donor families... and who best to support donor families, than donor families?

If you a donor family member who has not been invited to join the FLDRN Donor Family Support Page on Facebook, just send us a quick note with your email address, and we will send you an invitation once all of the privacy paperwork has been completed. You can reach either Judy or Jeff at: Judy_Hess@urmc.rochester.edu or Jeffrey_Mancini@urmc.rochester.edu, or by calling the office at 585-272-4930.

A Gift of Life Unites Two Families In Heart and Song at the Golisano Children's Hospital, Rochester, NY

WHEN: Friday, April 29, 2016 from 10:30 a.m. – 11:30 a.m.

WHERE: Golisano Children's Hospital

WHAT: Join us for a moving tribute and musical performance.

All are welcome to attend this special gathering when Holly Campbell of New York and Kim Scadlock of Iowa reunite to sing "For Good" in honor of their sons, Jake and Beckham. Plus, hear how this song and the gift of life have united these two moms and their families.

Most of you have heard the Campbell's donation story, but for those of you who haven't: When Jake, their 11-week-old son died, Holly and Andy donated his heart. Holly and Andy have met the recipient of Jake's heart. His name is Beckham. Holly found out that as she was singing goodbye to Jake, Beckham's mother was singing the same song to Beckham.

On April 29, both mothers will join their voices and will be singing this song together at the Golisano Children's Hospital.

Upcoming Events

April – The whole month is National Donate Life Month!!

1-30 Cuts for a Cause at "The Shop" in Syracuse

8 Paint Westvale Purple 5K Run/Walk

15 Donor Family Network Fundraiser – Casino Night

15 Blue and Green Day – Wear your Donate Life Colors!!

17 Rochester River Run – Genesee Valley Park, Round House Shelter

29 Galisano Children's Hospital – Donor Mom and Recipient Mom sing "For Good" together

June

10–15 Donate Life Transplant Games of America

July

22 Katie Starr Memorial Golf Tournament

October

6 Donor Enrollment Day

For further information regarding any of these events please call the office (585) 272-4930.

DONOR FAMILY EMAIL ADDRESSES NEEDED!

We like emailing *BRIDGES* to you, our donor families. If you are reading this on the website and would like the newsletter emailed to you, kindly provide us with your first and last name, your email address, and tell us that you wish to be added to our distribution list. Please send your request to Judy Hess at: Judy_Hess@urmc.rochester.edu or call her at 585-272-4930.

Of course, we also invite you to keep up-to-date by visiting our website at www.donorrecovery.org/families-of-donors/news/ for "News and Events for Donor Families" found in the "Families of Donors" section.