

BRIDGES

A Newsletter for Donor Families

Fall 2016



What Is BRIDGES?

The name of this newsletter derives from an acronym that reflects 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.

“S.5313-A/A.4990-B:” Update on New York Legislation

Written by Jeffrey Mancini, Family Services Coordinator

The title “S.5313-A/A.4990-B” may look like some type of an eye test. In reality, the letters and numbers correspond to a new bill recently signed into law by Governor Cuomo that will allow 16 and 17 year-olds to register as organ donors in New York State. For decades, the minimum age to enroll in the New York State Donate Life Registry has been 18.

The Young Adult Enrollment Act passed in the State Assembly by a vote of 133 to 4, and the State Senate by a 59 to 1 margin before landing on Governor Cuomo’s desk. Once the bill takes effect in February 2017, New York State will join forty-six other organ donor registries across the country that provides young adults under age 18 the opportunity to document their intent to donate.

The legislation was proposed to help increase organ and tissue registration rates in New York, that continue to lag behind the rest of the country in terms of the percentage of the population who are registered organ donors. Currently, the national average is 52%; New York State’s average is 27%; and FLDRN’s service area registration rate averages 34%.

Another hurdle the Young Adult Enrollment Act will help to overcome is the missed opportunity to enroll new drivers in the donor registry. It is estimated that approximately 88% of organ donor registrants sign up in the New York State Donate Life Registry through the Department of

Motor Vehicles. Given the fact that New York State license renewals occur once every eight years and that the minimum age to register as a donor has been 18, visitors to the DMV wouldn't have the opportunity to enroll in the donor registry until their late 20's. All that will change with the new bill, allowing 16 and 17 year olds who go to the DMV for a drivers permit, license or non-driver's ID to also enroll as an organ donor.

Since the law provides young adults the chance to register their "intent" to donate, an important safeguard in the legislation provides parents the final say - or "consent" - about donation, should something happen to their child. At age 18, the registration is automatically updated from "intent" to "consent."

In the words of Governor Cuomo: "With thousands of New Yorkers still waiting for the gift of life, we continue to focus on making organ and tissue donations available to all those in need... We take another step to grow the state's Donate Life registry and create opportunities to save lives."



Volunteers Enroll Organ Donors at "The Great New York State Fair"

Written by Judy Hess, Family Services Coordinator

Several FLDRN staff and volunteers offered their time to sign up organ donors at New York State Fair. This year, the Fair reported a record 1,117,630 attendees, which reflects a 23% increase in attendance over last year. This increase could be related to the new renovations that have occurred since last year, but I personally feel that the wonderful weather we had this summer helped to contribute to at least some of the increase.

While you were there, if you were seeking out some shade from all that hot sun, you could find FLDRN staff and volunteers in the Science and Industry Building manning the Donate Life booth, and our Community Education Manager, Amy James, was volunteering at the League of Women Voters booth in the Arts and Home Center Building. Amy has been helping to run voter drives since New York's voter registration form also includes a section to register as an organ and tissue donor.

This year's goal was to enroll 1,000 fair-goers in the New York State Donate Life Registry. Despite the record attendance, we fell a little short - obtaining 876 new registrants. It's still pretty amazing to think that nearly 900 people who weren't registered are now signed up to donate!

A special thank you goes out to our donor family volunteers: Donna Dunn, Carol Johnson, Michelle Lester and her daughter, Mia. We always appreciate the help of our family volunteers, as they can best tell those who are contemplating registering as an organ donor how donation makes a difference in so many lives. Thank you all!



Judy Hess, Bill Sainsbury and Kate Haswell show their FLDRN muscle and help enroll organ donors at the Fair.



Amy James (left) registering organ donors alongside the League of Women Voters.

Don't Look Now, but the Holidays are coming. Some Insightful Ideas on How to Cope.

Written by Jenna Heery, Family Services Coordinator

"I was beginning to do better. I thought I was doing better. But a few days ago, the holidays just hit me." - Quote from the devotional *Healing After Loss* by Martha Whitmore Hickman

It was her first Christmas without her husband. Yet another milestone in a year of firsts after his death – that first anniversary, first birthday, first Thanksgiving, and now the first Christmas without him there. And like a wave, the grief hit her.

This woman's story reflects a familiar pain felt by so many during the holidays. Thanksgiving, Chanukah, Christmas, New Year's, birthdays, anniversaries – holidays are meant to be filled with happy memories and joyous celebrations with family and friends. There is an inescapable expectation that during the holidays everyone is supposed to be happy and to enjoy themselves. And yet, after the loss of a loved one, these expectations can feel impossible and overwhelming. Once happy memories may now be dulled by grief as you struggle with your loved one's absence. Joy can seem out of reach when you may instead feel unbearably sad. It is not uncommon when surrounded by so much celebration to feel especially sad, lonely, or depressed. As an anonymous author once wrote, "Grief and the holidays go together like fire and ice. When everyone around you wants to be happy and joyful, the pain of loss can be harder to bear."

However, if we let go of some of these unrealistic expectations and leave room for grief, this upcoming holiday season does not necessarily have to be entirely unhappy. There are many ways to help cope with grief during this difficult time of the year. Here are a few tips to make it through:

- **Accept your limitations**

With so many expectations and social pressures, the holiday season can feel overwhelming. Even people who are not working through grief can feel overwhelmed by the pressures and fatigue that comes with the holidays. Be gentle with yourself. Remember, grief is both emotionally and physically stressful. Though you may wish to push yourself to attend some events, you also may not want to accept every invitation you receive or participate in all of your usual activities. Gauge your limits, and be sure to care for yourself and your needs first. Remember the old adage, “You are not required to set yourself on fire in order to keep others warm!”

- **Adjust your expectations**

Likely, no matter how hard you try, the holidays just will not feel the same as they did before. As newspaper columnist Sarah Briggs wrote about the first Christmas after the death of her father, “Without Dad, we couldn’t muster any enthusiasm for our annual Christmas traditions. Dad was goofy at Christmastime and his excitement was contagious. No one could take his place; no one wanted to.” Be prepared for similar feelings of loss and grief to arise so that you are not surprised with disappointment if the holidays feel different from before. It will take time to adjust, and that is okay.

- **Embrace your emotions**

Remember that there is no right or wrong way to experience your grief. It is okay to feel sad, even in the midst of the joys of the holidays. Give yourself permission to cry whenever you need to. Crying is not a sign of weakness; it is healing. At the same time, though, it is also okay to feel happy. Also give yourself permission to laugh, to celebrate, and to have fun. It is not a betrayal of your loved one or disrespectful to their memory to experience joy.

- **Facing holiday traditions**

Part of the reason the holiday season can be so difficult during grief is that the holidays are so centered on traditions. Yet, you may find that this year these traditions may feel too painful or may lose some of their joy without your loved one’s presence. Remember that it is perfectly acceptable for old traditions to be put on hold or even to end, if needed. If you always hosted the same meal with the same food, feel free to try something new. Order in or eat out if the thought of preparing a feast is too overwhelming. Open presents at a different time or place. Think of taking a trip over the holidays if you need an escape. Gauge your needs and dare to try something new. With time, new traditions may emerge.

- **Making new memories**

Finally, there are many ways to honor the memory of your loved one during the holiday season. Offering a meaningful tribute to them can be especially helpful and therapeutic. Some ideas include:

- Light a special memorial candle or leave an empty chair in honor of your loved one at each family gathering or event to represent their presence.
- Have a special time for family members to share holiday memories about your loved one.
- Purchase a gift for your loved one and then donate it to someone in need. Or give money in the amount you would have otherwise spent on gifts to a charity dedicated in your loved one's name.
- Offer a prayer or a toast to your loved one during your holiday meal.
- Attend a "Blue Christmas" service, a "Longest Night of the Year" service, or another religious service that specifically focuses on healing during the holidays.

These are just some examples of the many ways you can remember your loved one this holiday season. Choosing an activity that the entire family can participate in can help strengthen the bonds of togetherness and solidarity for your family. These kinds of tributes can be especially helpful for children dealing with loss. Choose a tribute that feels most meaningful to you and would have best represented your loved one.

If the holidays this season hit you like a wave, we hope these tools can help you hang on. However, if you find that you need more support, know that you are not alone. Talking with a counselor or clergy and confiding in family or friends can be very helpful in offering you support through the difficult moments. Also, know that Finger Lakes Donor Recovery Network is here for you. We offer the support of our Family Services Coordinators whenever you may need it. These trained professionals offer comfort and continued support to our donor families and can direct you to other helpful resources as needed. Our FLDRN Donor Family Support Facebook Page, a private and closed Group just for donor families, may also provide a safe space of support for you during this difficult time. There you can reach out to other donor families who may understand your journey better than most due to their shared experience and loss.

Even if these may not be the happiest holidays, all of us at Finger Lakes Donor Recovery Network wish you a holiday season filled with comfort and peace.

Donor Sabbath

National Donor Sabbath occurs annually, two weekends before Thanksgiving. This year's observance takes place November 11, 12 & 13. It is a time for faith leaders of all denominations across the country to help bring awareness to their communities about the pressing need for organ, eye and tissue donations to save lives.



National Donor Sabbath is supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration, together with national, state, and local donation organizations, faith communities, health providers, community organizations, and concerned individuals.

For more information and to download National Donor Sabbath materials

for your place of worship, please visit our website, <http://www.donorrecovery.org>. If you're interested in our Speakers Bureau program, please email Amy James at: Amy_james@urmc.rochester.edu or call her 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 for "[News and Events for Donor Families](#)."

FLDRN Donor Family Support Page on Facebook

Our Family Services team is pleased to offer donor family members the opportunity to join the "FLDRN Donor Family Support Page," on Facebook. This is a Closed Group, meaning only members can post and see stories on the Page, providing increased privacy and security for all our families. We currently have 58 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 is 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 are 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. Email [Judy Hess](#), [Jeff Mancini](#) or [Jenna Heery](#) or contact them by calling the Rochester office at (585) 272-4930.

Upcoming Events

Log on to www.donorrecovery.org for information on these and other upcoming events.

2016

November 11-13 – National Donor Sabbath

2017

February 10 – Donate Life Night with the Rochester Americans

April 7 – Donate Life Night with the Elmira Jackals

May 7 – Donor Family Celebration, Holiday Inn Liverpool, NY

June 4 – Donor Family Celebration, Double Tree, Rochester, NY