



# BRIDGES

A Newsletter for Donor Families



## What Is Bridges?

The name of this newsletter derives from an acronym that reflects the services FLDRN offers to our donor families: **B**uilding **R**elationships, **I**ntegrating **D**onation, **G**rief, **E**ncouragement and **S**upport.

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## Welcome!

The purpose of a newsletter is to provide you with information and to tell you about events that we have had or events that are coming up.

Welcome to BRIDGES, our premier edition!

This newsletter was developed for you. We are always looking for events that are relevant to donor families. In addition, we will be listing any events that are coming up that you might find of interest.

We are also looking for volunteers who are interested in being a featured writer for the newsletter every now and again. The topics could include: "My Story," "How I Cope with the Holidays," or a touching experience that happened because of organ donation.

We are willing to entertain any ideas you might have. The goal is to make this newsletter *your* newsletter, with subject matters that interest you! Our first guest journalist's article, "Planning for Our Future," is featured below.

### **Judy Hess, LMSW, OPC**

*Finger Lakes Donor Recovery Network  
Referral and Family Services Coordinator*

**CONTACT US:** Email Judy Hess: [Judy\\_Hess@URMC.Rochester.edu](mailto:Judy_Hess@URMC.Rochester.edu); or call her at 585-272-4930.

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### **Some of the Highlights of This Edition of BRIDGES:**

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## Donor Mom Helene Brings Her Personal Story to Legislative Education Day



On April 16, Helene Ehmann made the road trip to Albany, NY in support of New York Alliance for Donation (NYAD) Annual Legislative Day.

Helene brought with her not only her story of being a donor mom, but also a picture of her son, Scott.

She made the most of her day in the Capitol with her group and at every stop through the legislative corridors. Helene's story brought a personal reality to the legislators.

The photo shows Helene meeting with State Senator Mike Ranzenhofer (R-Monroe, Genesee, and Erie Counties). Senator Ranzenhofer actually got to hold and look at the picture of Helen's son and organ donor hero while she shared Scott's story.

Thank you to Helene and all of the Finger Lakes Donor Recovery Network volunteers, who took time out to help educate our lawmakers to make registration on the New York State Donate Life Registry one step easier.

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## Planning for Our Future: Personal Self Determination



**By Patricia Lippincott Knox, MSN, FNP, ACHPN**

**Palliative Care Service, State University of New York (SUNY) Upstate Medical University Center for Bioethics and Humanities**

In our current economic climate, many of us are putting a lot of thought and planning into how and when we will be able to afford to retire, and how we will manage our health care costs, as these are one of the primary causes of personal bankruptcy today.

How many of us plan to have our choices or goals of what we want our medical future to be, in terms of how they are documented or discussed?

What would have happened if Terri Schiavo had a legally documented advance directive executed? Would the family have had less conflict and less public invasion into their lives if her wishes had been documented?

### **Patient Self Determination Act**

In 1990, the Patient Self Determination Act was enacted, allowing people to determine and document what their personal wishes are. We need to have discussions with our loved ones on what our wishes would be for our care when we are not able to make these decisions ourselves.

No one likes to talk about death or dying and that includes many health care professionals.

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What kind of care do we see ourselves wanting when we are facing life limiting or end of life decisions? Do we want decisions based upon our values? Or are we comfortable not providing some direction to those who will make the decisions?

Advance Directives are a tool that can be very comforting for our loved ones when they are making decisions based on our wishes, not what they are struggling to understand about the likely medical outcome.

### **Parents' Conversation with Their Son**

I always think of a case that has stayed with me for over a decade: Parents of a 17-year-old, who was involved in a motor vehicle accident and suffered very serious brain damage, were discussing the choices they had to make. They were in significant emotional pain but told me their story.

They had a conversation with their son a year prior when, as a family, they visited a friend whose life was being maintained with artificial measures. This young man clearly stated that if anything like this injury occurred to him he did not want to be kept alive, as this was not quality of life for him.

So as parents, who were faced with decisions no parent ever wants to deal with, felt comforted by knowing what their son would want them to do. They made their decision to allow nature to take its course and they wanted to donate his organs so others would live.

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## **Exclusively for FLDRN Families: A Facebook Donor Family Support Page**

**By Kelly VanDeMar, OPC, FLDRN Family and Referral Services Coordinator**

The FLDRN Family Services' Donor Family Support Page is our newest way to connect families and offer real time support.

Our families have utilized this Facebook site to share their grief journey, discuss how they cope with loss day to day, share different things they have done to commemorate their loved one, and to get the word out about different memorial events happening around town.



**The group is “closed,” so only those who are cleared through FLDRN have the ability to post or see any information.**

All of our families are invited to join our Facebook Donor Family Support Page. If you are interested and have not yet received your invitation from us, please call or contact us at anyone of our emails (see below) and we will get you started!

You do not have to be a Facebook expert or even know how to get on the Facebook to join. We will help you with that as well.

**CONTACT US: Call Judy Hess, Susan Miller or Kelly VanDeMar at 585-272-4930 or reach one of us via email: Judy Hess: judy\_hess@urmc.rochester.edu; Susan Miller: susan\_miller@urmc.rochester.edu; Kelly VanDeMar: kelly\_vandemar@urmc.rochester.edu**

## Quilts for Display

For years, FLDRN has collected patches that you have made, in honor of your loved ones. Our family donor quilter, Barbara Bennett, has put them together into four beautiful quilts.

We would like very much to make them available to you for any family gathering that you may have.

We have cataloged who is on each quilt, so we can get you the quilt with your loved one's patch on it.

There is a calendar that you can book your date to ensure that you have the quilt for the day you need it.



**CONTACT INFORMATION:** Please call Susan Miller, Family Services Coordinator at 585-272-4930.

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## FROM THE COMMUNITY EDUCATION DEPARTMENT: National Donate Life Month, Other Programs and Upcoming Events



April was National Donate Life Month and the FLDRN celebrated in many ways during this month-long recognition of donation and transplantation. FLDRN staff members got into the spirit of “Wear Blue and Green Day” at a monthly staff meeting.

Activities included ceremonies at several area hospitals, **Donate Life Night with the Amerks**, and **Wear Blue and Green Day**.

Every effort focused on raising awareness about donation, enrolling people on the New York State Donate Life Registry, and honoring donor families.

**Donate Life Night with the Amerks:** Rochester Americans Hall of Famer Gates Orlando, a heart recipient, and his daughter joined FLDRN's Rob Kochik and Amy James (far right) for a never-to-forget moment during the evening.

You and your loved one matter so much to us and we strive to honor the legacy of your decisions.

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**Other initiatives included DMV trainings, Team Finger Lakes, and our volunteer program:**

- **DMV:** The New York Alliance for Donation received a grant to train DMV representatives about donation and transplantation. Approximately 96% of New York Residents have enrolled as an organ, eye, and tissue donor at their DMV office, so we are pleased to help representatives obtain accurate information to pass on to their customers.
- **TEAM FINGER LAKES:** Team Finger Lakes is FLDRN's team of donor families and recipients who are interested in participating in the 2014 Transplant Games of America in Houston, TX. All are welcome!
- **VOLUNTEER PROGRAM:** Finally, our volunteer program officially launched in January and we have several donor family members that have joined our program.

**CONTACT US:** If you are interested in learning more about Team Finger Lakes or about becoming a FLDRN volunteer, please email our Community Education Manager, Amy James at [Amy\\_James@URMC.Rochester.edu](mailto:Amy_James@URMC.Rochester.edu) or call her at 585-683-3174.

**UPCOMING DATES**

**Team Finger Lakes meetings:** The first Tuesday of each month; 6 pm at the FLDRN offices

**June 14, 2013:** The 3rd Annual Ryan Converse Memorial Golf Tournament, Watertown, NY. For information about sponsorship or registration, contact: [ryanconversememorial@gmail.com](mailto:ryanconversememorial@gmail.com).

**Summer Events:** Please look for us at many of our area's summer festivals! Check out our Events Calendar on our website.

Please contact our Community Education Department if there are any community efforts or events in which you would like us to participate. (See Amy James's contact information, above.)

Thank you!

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**Email Addresses Wanted!**



It is our goal to have everyone's email address so that we can send you this newsletter, emails and other materials via the internet.

If you are willing to do so, please provide your name and your email address to Judy Hess. You can email Judy at [judy\\_hess@urmc.rochester.edu](mailto:judy_hess@urmc.rochester.edu).

**Your privacy is extremely important to us. We do not share our email list with anyone. It is for our use only to keep you aware of events and items of interest to you.**

Of course, we realize that some of you don't have an email address. If you don't, or would prefer not to receive the newsletter via email, we will continue to send you the newsletter via U.S. Postal service.

## Join Us to Celebrate Your Loved Ones at a Family Picnic

There is a beautiful park in Elmira, NY that has donated an area to Sharron O'Buckley, one of our Donor Moms. She took this space and created a beautiful memorial to her son, Michael, and has opened it up to all donor families.

Each family has the opportunity to place a stone in the park with their loved ones information on it. We will be celebrating all of your loved ones this summer at an old fashioned family picnic. FLDRN will provide the hamburgers and hot dogs. We are asking families to bring a dish to share.

**If you are interested in having a stone made for your loved one**, please contact Brian Ganello at Earth, Wood and Stone at 607-329-5868, which is located in the Arnot Mall in Elmira. Brian hand makes each stone and can give you all the details on pricing, size, lettering, etc. **He needs to have the order by July1st in order to guarantee completion on time.**

This event is open to all our families and we honestly cannot wait to spend time with all of you!

**Place:** Eldridge Park, Elmira NY

**When:** August 18, 2013

**Time:** Noon – 4pm in the Pavilion

**Bring:** A dish to pass

**RSVP: By August 12, 2013**

**Call Judy Hess, Susan Miller or Kelly VanDeMar at 585-272-4930, or email any one of us:**

[judy\\_hess@urmc.rochester.edu](mailto:judy_hess@urmc.rochester.edu),

[susan\\_miller@urmc.rochester.edu](mailto:susan_miller@urmc.rochester.edu),

[kelly\\_vandemar@urmc.rochester.edu](mailto:kelly_vandemar@urmc.rochester.edu)

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**Thank you for helping to give the Gift of Life. Please encourage relatives and friends to register as a donor by visiting our website:  
[www.DonorRecovery.org](http://www.DonorRecovery.org)**

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