



FLDRN UPDATE

THE GENERAL-INTEREST NEWSLETTER OF THE
FINGER LAKES DONOR RECOVERY NETWORK

GIFT OF LIFE STORY:

How “Third Time Lucky” Saved Herb’s Life

An act of kindness, donating blood, uncovered shocking news for Herbert Bond Jr. and his family: He’d been walking around with Hepatitis C, probably for several years.

When he needed a liver to save his life, it would take two unnerving setbacks before he would be brought back from the brink.



For Herbert Bond Jr., a Hamlin, NY resident popularly known as Herb, life was moving along normally as he reached his mid-50s.

Married, the father of four, and a proud grandfather, Herb was an asbestos removal estimator. In his spare time, he loved to go fishing. He also took special delight riding around on his golf cart with family members on trails through rough, muddy terrain, as though it were a four-wheeler.

All that changed back in 2008, when Herb decided to donate blood.

Instead of saving someone else’s life, his own life was suddenly threatened. A few days after making the donation, Herb was informed that his blood couldn’t be used because he had hepatitis C.

Diagnosed with a potentially fatal disease, Herb’s only focus was to stay alive, not only for his own sake, but for the sake of his large, loving family.

And, not incidentally, he also wanted to be around a lot longer to spend time with another love of his life, Foxy, a Pomeranian, who was constantly at his side.

Events Moved Fast—and Not for the Best

Two months after hearing the grim news, Herb was in end-stage liver failure. His name was added to the liver transplant list at Strong Memorial Hospital/University of Rochester Medical Center.



Herb and his family knew full well that because of the shortage of organ donors, a new liver might not be available in time to save his life.

Tanya Herrold, one of Herb's daughters and who volunteers for Finger Lakes Donor Recovery Network with her husband Bill, admits: "At times we thought a call may never come. Then after four years, on a snowy day in 2012, Dad called to say 'They're transplanting me.'"

Many of Herb's family members, including his wife Roberta (Bobbie), their children (in addition to Tanya, they are Leanna, Herb and Alexis) and their spouses, excitedly descended on Strong Memorial. They spent the day at the hospital while tests were being conducted.

After 15 hours of waiting, they were informed the liver wasn't suitable for transplant.

"This was tough on everyone," Tanya recalls. "We ran the gamut of emotions that day."

None of them could have imagined that history would cruelly repeat itself.

Hopes Raised, and Dashed, Once Again



About two months later, the Bond family gathered again at the hospital because there was a potential donated liver. After waiting for hours, the anesthesiologist said they were 15 minutes away from the transplant. They just needed the last biopsy result.

A half hour later, a resident delivered the bad news: The liver wasn't healthy enough to be transplanted.

Tanya remembers how, for the second time, their hopes had been dashed. "My dad said there would never be a liver for him. But I encouraged him and we all prayed that there would be a liver, at the right time."

By the end of 2012, Herb's health was deteriorating at such an alarming rate that he was constantly being admitted to the hospital.

Desperately ill: Herb Bond lies hospitalized, in late January 2013.

In January 2013, with poor liver function and kidney problems, Herb spent 23 days in a row hospitalized. He had even spent New Year's Eve in the ER.

“I Gave It to God”

During this difficult time, Tanya found strength in her faith. “I gave it to God,” she says. “I told God I could no longer handle the stress and I asked Him to handle it.”



One of Herb’s grandchildren, Ayanna Herrold (shown here with him), told the doctor, “Take care of my papa” — the name she fondly uses for her granddad.

Tanya explains that one biblical verse in particular, enabled her to get through the series of crises. It was from Isaiah 40:31:

But they that wait upon the Lord shall renew their strength; they shall mount up with wings as eagles, they shall run and not be weary, and they shall walk and not faint.

When yet another call from Strong Memorial came, on February 15 this year, the family attempted to keep their emotions intact. Now age 60, Herb had been on the transplant list for five long years.

This time, the third time, indeed proved to be the right time. More than 12 hours after receiving the initial phone call, the doctors said the liver was perfect for transplanting.

It was already the next day, February 16. Herb was on his way to the O.R. Tanya’s daughter, Ayanna, who is 13, hugged one of the surgeons and told him to “take care of my papa,” her grandfather.

Again, Tanya’s faith guided her. “I began to pray,” she remembers. She also prayed for the donor of the liver, a 20-year-old woman, and her family.

“I prayed with the anesthesiologist and most of the staff from the fourth floor,” she says. “It was important for me, as a Christian, to pray for the donor family. While we were experiencing this moment of joy, relief and hope, they were experiencing the loss of a 20 year old.”

What the Transplant Means to Herb

The transplant was a success and these days, Herb is doing really well. “It’s a second chance at life,” he says. “I can continue to enjoy my grandkids and kids. I feel ten years younger.”

In fact, Herb and Bobbie have six grandchildren—and they are extra excited that he got his transplant because, together, they are now looking forward to the arrival of their seventh!

Many people are on Herb’s ‘thank you’ list, including the doctors and staff at Strong Memorial, and his family who never allowed him to give up.



Having fun in their much-loved golf cart: Herb and his wife, Bobbie, with Foxy, the center of attraction!

Most important, Herb will forever be grateful to his donor. “She means a lot to me. I feel so sorry she died at such a young age. I can only imagine the courage it took for her family to bring joy to so many during their time of mourning.”

Though he can’t return to work, Herb is able to go fishing again. He spends a lot of time with his family.

Of course, Herb is thrilled that he can resume driving his golf cart around on trails, through the mud, with his grandchildren coming along for the ride.

When it comes to riding the golf cart, the Bond family is always accompanied by the ever-loyal Foxy.

As Tanya describes it, “Foxy loves riding on the golf cart, and she always has to be up front!”

What a Coincidence, When Tanya Decided to Volunteer for FLDRN!

Here’s a strange twist to the events surrounding Herb Bond’s transplant this past February.

Even before her dad needed a transplant, Tanya Herrold was an organ donor advocate, and had signed up to be a donor.

Now, with her dad on the liver transplant waiting list, she was more determined than ever to encourage other people to become organ donors.

So, Tanya submitted her volunteer form to Finger Lakes Donor Recovery Network (FLDRN).

But as Tanya’s dad had been in the hospital at Strong Memorial for over three weeks, and in critical condition, Amy James, FLDRN’s community education manager, agreed to meet with her at the hospital on February 15, 2013. It would be an opportunity to get to know each other.

It turned out to be a whole lot more than merely a routine first meeting.

Incredibly, just 15 minutes after getting together in the hospital lobby, Tanya and Amy received word that a liver might be available for Herb. Two previous potential livers had turned out to be unsuitable for transplantation.

An Opportunity to View the Transplant Side

Tanya invited Amy to join the family so that she could follow the transplant process with them. Tanya is pleased that although Amy hesitated at first, concerned that the family might want to maintain their privacy, she decided to accept the invitation.

“Amy was very respectful,” Tanya says. “But I felt it was important for her to see the transplant side while also acknowledging that the generosity of a young woman and her family was making the transplant possible. She does public education, and she would have a personal story to share.”

“This experience was so rewarding both professionally and personally.” — FLDRN’s Amy James

For her part, Amy says, “This experience was so rewarding both professionally and personally. The Bond family somehow knew how important it was for me to experience what families go through as they wait for a life-saving transplant for their loved one, and I am forever grateful for their insight.”

A Busy, Busy Volunteer!

Since then, Tanya has proven to be an enthusiastic, very busy volunteer. For instance, she helps to set up and work information tables at events.

She also chairs the Casino Nights committee, securing financial contributions for Team Finger Lakes who will attend the 2014 Donate Life Transplant Games.

Recently, Tanya says, she was given the opportunity to share her experience with the mother of a donor. “We were both crying. It was a big moment in my life, to hear about the experience from the other side.”



Tanya Herrold (right), volunteers at an event for FLDRN, with Amy James, our community education manager.

ROSE BOWL PARADE

FLDRN's 2014 Donor and Recipient Honorees Are Named

As we have done for the past six years, the Finger Lakes Donor Recovery Network has the pleasure of participating as a sponsor of the Donate Life Float.

We will honor a deceased liver donor and a liver transplant recipient from our area at the Rose Bowl Parade on January 1, 2014.

Remarkably, the donor's granddaughter also happens to be a transplant recipient.



Organ Donor

The deceased organ donor whose life will be celebrated at the Rose Bowl Parade is **Christine Springer**. At the age of 71, Christine became a liver donor and saved the life of a 61-year-old man.

By a strange coincidence, Christine's granddaughter, Ali Brown, received a life-saving liver at age 11 from an anonymous 13-year-old.

The theme for the 2014 Donate Life Float will be "Light Up the World."

In the official news release about the float, the organizers said, "Five enormous lamps [representing the lighting up of the world] will be adorned with 72 memorial floragraph portraits of deceased donors whose legacies of life shine brightly."



Ali Brown (left), Christine's granddaughter, with her mom, Molly deRoos. Ali is a liver recipient.

A memorial floragraph to honor liver donor Christine Springer will be displayed on the Donate Life Float.

Christine's daughters — Molly deRoos (Ali's mother), Robin Springer and Kate Springer — who made the decision to donate their mother's organs, will remember and honor her with one of the memorial floragraphs at the parade. Members of the family may also attend the parade and help build the float.

Recalling how she felt when Rob Kochik, FLDRN's executive director, told her that Christine would be honored on the Donate Life Float at the Rose Bowl Parade, Molly said: "I was overcome with emotion. It's not often that I'm speechless, but I never expected something like this. My mother would be humbled to be honored in this way."

Organ Recipient



Liver recipient Richard Perez (second from left) will ride on the Donate Life Float. With him are, from left: Nancy Metzler, the administrator with the Solid Organ Transplant Department at URMC; Amy James, FLDRN's community education manager; Maria Aponte, Richard's wife, and Rob Kochik, the FLDRN executive director.

Liver transplant recipient **Richard Perez** will be one of the 30 people riding on the Donate Life Float.

On July 21 this year (2013), Richard celebrated the 10th anniversary of his transplant.

In 2002, Richard discovered that his liver was failing. It turned out to be cirrhosis of the liver due to hepatitis C. His only hope was a transplant.

After spending ten months on the waiting list, Richard received a new liver from a deceased donor at Strong Memorial Hospital/University of Rochester Medical Center.

Richard says, "I feel wonderful! My life has changed in ways I cannot explain and every day I'm so thankful to my donor and their family. Even though I have to take anti-rejection medication twice a day and need to be careful and prevent getting sick, I live a relatively normal life."

He adds: "Because someone made that decision ten years ago, I was able to see my son graduate from college and help plan his upcoming wedding. I'm looking forward to grandkids!"

FLDRN Delighted to Recognize Honorees

Rob Kochik, executive director of FLDRN, said: "We are delighted to be honoring Christine and Richard. Christine's generous gift at age 71 reinforces the fact that individuals are never too old to be organ donors. Without his transplant Richard wouldn't be alive, let alone taking part in the Rose Bowl Parade, which is viewed worldwide."

Q&A:

How Can I Sign Up to Become an Organ Donor in New York State?

You'd like to become an organ donor in New York State. So, what do you have to do? This Q&A is designed to answer many of your likely questions.

Q: How old do I have to be to become an organ donor in New York State?

You have to be at least 18. After that age, it doesn't matter how old you are because people in their 90s have been healthy enough to donate organs.

Q: Is it enough just to sign the back of my New York driver's license?

It's a good idea to sign the back of your driver's license as you're definitely stating you want to be an organ donor. The problem is, if the situation arises where you can give the gift of life, it may be difficult to locate your driver's license or non-driver ID card. If your card isn't found, nobody will know about your important decision. So your generosity will be in vain, and lives will be lost.

Q: If signing my driver's license isn't enough, what should I do?

Good question! The key is to enroll in the New York State Donate Life Registry. It's the official registry in our state. When you enroll, you are legally consenting to being an organ, eye and tissue donor upon your death. No one else can reverse your decision.



Register to Become an Organ, Eye or Tissue Donor

If you enroll on New York State's MyDMV website, you will be able to do so electronically in one step. Log onto www.dmv.ny.gov/mydmv/organ-pop.htm.

What is it?

- This MyDMV service allows you to register **online through MyDMV** as an organ, eye or tissue donor in the Department of Health (DOH) Donate Life Registry without the need to download, complete and return a printed form.
- There is a tremendous need for organ donations in NYS. The DMV and DOH Web sites have more information [about the program](#).

Q: Does it mean that signing the back of my license doesn't enroll me in the registry?

That's correct.

Q: Okay, then how can I enroll in the New York State Donate Life Registry?

There are numerous ways to do so. One way is to sign up at the DMV office when you go there to apply for, or to renew, your driver's license or non-driver ID. There's a question on the driver's application form that asks you whether you wish to be an organ donor. Once you've registered this way, you'll receive an acknowledgement in the mail. If you are receiving a new driver's license card, the words "organ donor" and a red heart symbol will be printed on the front of it at no extra cost.

Q: What if I don't need to go to the DMV any time soon? I already have a driver's license or non-driver ID, and now I want to become a donor.

Another excellent question! If you have a New York driver's license or non-driver ID card, you can create a MyDMV account on the DMV website at <https://my.dmv.ny.gov/crm/?register=T>. In this secure section, click on the link "Register to become an organ, eye and tissue donor." The sign-up process allows you to enroll electronically in the Donate Life Registry. The secure sign-up also gives you access to other MyDMV services, and services from other New York State agencies.

Q: If I don't have a driver's license or non-driver ID, can I still register online without using MyDMV?

Yes, log onto <https://apps.health.ny.gov/professionals/patients/donation/organ/DonorRegistration.action>. Even though you won't be able to enroll electronically, you can fill out a donor registration application form online but you'll need to download it. In other words, once you've completed the form, please print, sign and return it. Your registration isn't effective until your signed consent form is received.

Q: What if I don't want to enroll online? Is there a way I can get hold of an enrollment form and mail it in?

There sure is. You can contact Finger Lakes Donor Recovery Network, the federally-designated organ procurement organization in your area, and request a Donate Life Registry application form. Email Amy James, FLDRN's community education manager, at Amy_James@URMC.Rochester.edu or call her on 585-272-4930. This way, you can complete, sign and mail the form without going online. Or, next time you register to be a voter in New York, there's a section where you can enroll as an organ donor.

Q: Should I tell my family members that I have enrolled?

You're strongly encouraged to inform them of your legally-binding decision to donate.

Q: What if I change my mind after I enroll?

We hope you won't ever feel the need to do so, but should you wish to remove your name from the registry, you can.

Q: After I enroll in the registry, how would other people know that I'm a donor when I die? How can I fulfill my decision to save lives?

Authorized personnel at hospitals and those affiliated with organ procurement organizations have access to the confidential database. They would confirm your registration. If you haven't told your loved ones about your enrollment, your life-saving decision will provide a great deal of comfort to them. Also, they won't need to make a choice on your behalf at a very difficult moment in their lives.

DID YOU KNOW

Every 13 hours, someone dies waiting for an organ transplant in New York State?

Please enroll right now in the New York State Donate Life Registry:

<http://www.health.ny.gov/professionals/patients/donation/organ/>

For more information, visit the donor registration section on our website:

www.donorrecovery.org/learn/become-a-donor/

3 FACTS YOU REALLY NEED TO KNOW ABOUT...

Organ Donation

As with other issues, it's important that you make an informed decision about organ donation. Here are three key facts that we hope will encourage you to give the Gift of Life.



FACT#1: *Even if emergency room doctors know you enrolled to be an organ donor, their number one priority is to save your life.*

Organ donation can only be considered after brain death has been declared by a physician. The doctors and nurses working to save your life are separate from doctors who perform organ transplants.

FACT#2: *When you're waiting for a transplant, all that matters is your medical condition. Everyone listed is treated objectively and as equals.*

What really counts is the severity of your illness, time spent waiting, blood type, and other important medical information. Your income and social status have no bearing when determining how organs are allocated.

FACT#3: *The recommended way to become an organ donor is to enroll in the New York State Donate Life Registry. The Donor Registry is a confidential database and your decision is legally binding.*

Signing your driver's license is helpful but not sufficient. For example, if there's a possibility you could be a donor your license card may not be easily located. That's why you should add your name to the New York Donate Life Registry. In all cases, it's wise to inform your family or next-of-kin of your decision.

OUT AND ABOUT

It's time to catch up with some recent events and programs FLDRN participated in, to promote the importance of organ, eye and tissue donation.

Donate Life Night with the Syracuse Chiefs: Donation's Blue and Green Colors Light Up NBT Bank Stadium



At the Syracuse Chiefs Donate Life Night: Left to right, Joan Burke from the Musculoskeletal Transplant Foundation (MTF) and Sue Sprague, a kidney and pancreas recipient.

On June 28, 2013, six donation and transplantation agencies in the Syracuse area, including Finger Lakes Donor Recovery Network, collaborated with the Syracuse Chiefs to present "Donate Life Night with the Chiefs."

The other participating agencies were SUNY Upstate Medical Center, Crouse Hospital, Central New York Eye and Tissue Bank, Musculoskeletal Transplant Foundation (MTF) and Transplant Awareness Organization.

It was a wonderful night highlighting the success of transplantation and encouraging those in attendance to enroll in the New York State Donate Life Registry.

The National Anthem and first pitch were each performed by local residents who have been impacted by donation.

Announcements about donation and transplantation were made throughout the game, and, just before the fireworks began, fans waved the blue and green glow sticks they received when entering the park, lighting the stadium in the colors of donation.

They Had a Ball! Kicks4Kidneys Soccer Tournament Supports Transplant Games Athletes

Kicks4Kidneys is an annual co-ed soccer tournament that raises funds so that Team Finger Lakes can attend the Donate Life Transplant Games of America.

The July 2014 Games will be held in Houston, Texas.

In the 6th annual Kicks4 Kidneys tournament, four teams spent July 21, 2013 in support of this event at Honeoye Falls-Lima High School. They played hard and had fun along the way!

The tournament's winning team was Dickey's Tavern, led by their captain, Jeff Brickand.

Special thanks to Tim Parks and Jamie Friello for their dedication to making this event a success.



You have to love their names! The Kicks4Kidneys tournament teams pictured here are "Cool Runnings" in black, and "Dickey's Tavern" in gray (the winning team). The other teams that participated were "Sharknado!" and "The Human Feet Horses."

Fundraising and Fun at Red Wings Home Plate Concession Stand

Eleven Finger Lakes Donor Recovery Network staff and volunteers volunteered at the Rochester Red Wings home plate concession stand on August 3, 2013. The group ran the registers and filled food orders with lots of laughter and fun along the way!

The Red Wings allow not-for-profit organizations to staff home plate in an effort to raise money.

Our group, including two recipients on Team Finger Lakes, raised money to send the team to the 2014 Donate Life Transplant Games of America.

NEWS IN BRIEF & UPCOMING EVENTS



■ **TRANSPLANT GAMES:** Finger Lakes Donor Recovery Network is pleased to support Team Finger Lakes as they attend the Donate Life Transplant Games of America every two years. We are excitedly awaiting the 2014 Games, which will take place from July 10-15, in Houston, Texas.

The Games highlight the success of transplantation as organ recipient athletes demonstrate their strength and determination and their appreciation for the gift of life they have received.

To watch the pride on our athletes' faces as they participate, medal winners or not, also makes this experience rewarding for donor family members and medical professionals who attend.

If you're interested in joining the team, or supporting the team, please contact Amy James, FLDRN Community Education Manager, at 585-683-3174. Or email Amy Jones: Amy_James@URMC.Rochester.edu.

Casino Night: We'll be having a "Casino Night" fundraiser in October to benefit Team Finger Lakes as they raise funds to attend the 2014 Donate Life Transplant Games of America. The Halloween-themed night will be held **Saturday, October 19 from 8-11 pm.**

Your ticket purchase includes "gambling money", DJ entertainment, photo booth, and appetizers. Best Costume will be awarded! Prize raffles and a 50/50 raffle will also benefit the team.

Purchase tickets for Casino Night: For tickets (\$15 before September 15, \$25 after September 15) please contact Tanya Herrold 585-705-2515 or Mike Swete 585-755-2600. We hope you can join us!

■ **SAVE THE DATE! NATIONAL DONOR SABBATH LATER THIS YEAR:** National Donor Sabbath is a nationwide annual observance **November 15-17**, and there is no cost to participate. All major religions encourage life-saving organ donation as one of the noblest human actions.

Clergy participation is particularly important because people look to their faith leaders for guidance regarding serious decisions in their lives.

Faith leaders of all religious denominations, along with other community leaders, can help to spread the facts about organ donation and increase organ donation sign-up by participating in National Donor Sabbath.

Want to participate? Please contact Amy James, FLDRN Community Education Manager, at 585-683-3174. Or email Amy Jones: Amy_James@URMC.Rochester.edu.

AN INVITATION TO VOLUNTEER FOR US!

Finger Lakes Donor Recovery Network is always looking for volunteers to help staff events. Please call Amy James, FLDRN Community Education Manager, at 585-683-3174 if you are interested in joining our volunteer program!

E-NEWS SIGN-UP

Sign up to receive news, including our FLDRN Update quarterly newsletter, via email from Finger Lakes Donor Recovery Network: Visit www.donorrecovery.org/eneews-signup-page/