



Mount Sinai

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Staying at the Transplant Living Center

THE TRANSPLANT ISSUE

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APRIL 15-28, 2013

## 'Kidney Swap' Program Increases Living Donations

When former New York Jets running back Dennis Bligen was diagnosed with focal segmental glomerulosclerosis (FSGS) in 2011, and told by doctors that he needed a new kidney, the news came as a shock.

For his long-time friend, Jill Christensen—who worked with him in the athletics department at St. John's University in Queens, N.Y.—the news was a call to action. "I just knew I would get tested [to become a donor]," she says. But it turned out that Ms. Christensen's kidneys were not an appropriate match.

Around the same time in Virginia, John Detwiler also was told that his kidneys were not a match for the daughter of his colleague in New York, who desperately needed a transplant. Independently, however, he and Ms. Christensen learned they could

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From left: Sander Florman, MD, Director of the Recanati/Miller Transplantation Institute, and the Charles Miller, MD Professor of Surgery, with patient Dennis Bligen



From left: Kelly Smith and her daughter Matilda, a liver recipient, with doctor Ronen Arnon, MD, MHA, Director of Pediatric Liver Disease and Transplantation at the Recanati/Miller Transplantation Institute

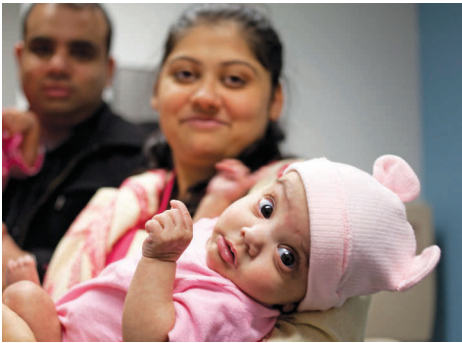
## Neonatal Transplants Save Lives

It was the longest drive of Kelly Smith's life: four hours in an ambulance from Syracuse, N.Y., to The Mount Sinai Hospital beside her 9-day-old daughter, Matilda, who was critically ill. Seemingly healthy on the day she was born in early September, Matilda had become lethargic and sick after nursing only a few days later. Tests in Syracuse revealed acute neonatal liver failure—a rare, life-threatening condition. Matilda's best hope was a liver transplant.

"These are the most challenging cases that we see," says Ronen Arnon, MD, MHA, Director of Pediatric Liver Disease and Transplantation at The Mount Sinai Medical Center's Recanati/Miller Transplantation Institute (RMTI). "They are extremely high-risk conditions that are associated with very high mortality rates, both with and without transplantation. Many infants never even get the opportunity to be considered for transplant because they are not seen at centers that can provide this service to this age group."

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## › Neonatal Transplants Save Lives *(continued from page 1)*



Above: Ali Naqvi and Sumera Adnan with their baby Alina, a liver recipient

At right: Toddler Ariz Gadit received a liver transplant in 2011.



Last fall, Matilda was the RMTI's second high-risk neonatal liver transplantation case, and the third in just more than a year, reflecting the institute's growing reputation as a leader in this emerging field. At the time, lying in a crib just across from Matilda in the Pediatric Intensive Care Unit was baby Alina Naqvi, born prematurely to parents Ali Naqvi and Sumera Adnan.

Following her birth in July, Alina struggled to gain weight. When she became jaundiced, her local doctors on Long Island thought she had a gastrointestinal condition. But by August, after failing to respond to treatment, her endocrinologist referred her to Mount Sinai, where she was evaluated and quickly placed on the pediatric liver waiting list.

Alina weighed just two pounds when a match was found in

October. Within days, Matilda was also matched and transplanted. Today, five months after their transplantations, both infants are home, happy, and doing well.

Matilda and Alina joined Ariz Gadit, who received a transplant in 2011, as the RMTI's tiniest liver patients. Baby Ariz was transplanted three weeks after being born with acute liver failure. Now, one-and-a-half-years later, he is a happy and rambunctious toddler. RMTI physicians will monitor the children throughout their lives.

"It is always important for those of us who work in transplant to try to make something good come out of tragedy and to save lives," says Sander Florman, MD, Director of the Recanati/Miller Transplantation Institute. He points out that each of the donated livers for RMTI's tiny patients came from a deceased infant. "We forget that for the families of the deceased donors, transplant helps them heal as they recognize the others whose lives are saved."

## Finding Comfort in Knitted Blankets

Three years ago, Sharon Jones began knitting as a way to ease the pain she felt after losing her 17-year-old son Andrew in a car crash in 2007. "When you lose a child, it doesn't go away," says Ms. Jones, a Manager of Grants and Contracts in The Mount Sinai Medical Center's Department of Pediatrics. "The knitting keeps me thinking about something else."

The knowledge that Andrew was an organ donor, who helped many recipients, provides solace, as well. So when Ms. Jones recently learned about "Sean's Gift," a national initiative to give handmade blankets to the families of deceased organ donors, she decided to turn the lunchtime knitting club she had started at Mount Sinai a year-and-a-half ago into a similar initiative here.

The club, which meets three or four times a week at 1 pm in Levy Library in Annenberg, is an informal gathering of knitters who come when they can squeeze in a free hour at lunchtime. On any given day, Ms. Jones says, three or four knitters show up.

So far, the group has donated several knitted blankets to the Recanati/Miller Transplantation Institute that were

made by friends outside Mount Sinai. But plans are under way to begin work on the first knitted patchwork blanket that will be given to the family of an organ donor at Mount Sinai. The blankets will provide families with warm memories of their loved ones.

Sean's Gift was started by Long Island mother Marie

LaPersonerie, whose 24-year-old son Sean, an Iraq war veteran, was struck by a car while crossing the street near his home on New Year's Eve in 2011. When Mrs. LaPersonerie's friend gave her a blanket to wrap Sean in before donating his organs, she became inspired to do the same for other families.

Ms. Jones says the Mount Sinai effort helps comfort her, as well. Though initially uncertain about the idea of organ donation, she had agreed to it when asked in 2007. Ms. Jones remembers that when she came home from the hospital she found a blank organ donor card in Andrew's wallet, which suggested to her that donation is what he would have wanted.

"Andrew was born at Mount Sinai so I'm trying to do my part to continue his story here, and to help other people," she says.



Front Row, left to right: Hyacinth Jones, a Laboratory Technician with Mount Sinai Heart; knitting club founder Sharon Jones; and Linnette Bowes, Administrative Assistant with the Recanati/Miller Transplantation Institute/Liver Disease. Back Row, left to right: Carolyn Quinn, Administrative Assistant with The Mindich Child Health and Development Institute; Carla Monaco, Special Projects Coordinator with the Jack and Lucy Clark Department of Pediatrics; and Oksana Yershov, a Research Associate with the Jack and Lucy Clark Department of Pediatrics

# Questions and Answers About Organ Donation

Every 15 hours, someone in New York State dies waiting for an organ transplant. The shortage of available organs is so severe that in 2012, as many as 9,914 people were listed as waiting for transplants in New York State, for which there were only 358 deceased donors and 481 living donors, according to the U.S. Department of Health and Human Services. One donor can save up to eight lives.

The New York Organ Donor Network (NYODN), a federally designated organ procurement organization, and one of the nation's largest, serves a diverse population of 13 million people in the New York metropolitan area. The organization facilitates donation with The Mount Sinai Medical Center's Recanati/Miller Transplantation Institute, nine other transplant centers, and more than 90 hospitals in the region.

Helen Irving, President and CEO of the New York Organ

Donor Network, and a former Vice President of Operations at The Mount Sinai Hospital, discussed the importance of organ donation with *Inside Mount Sinai*.

## Q. Which organs can be donated?

**A.** You can donate your heart, kidney, pancreas, lungs, liver, and intestines. You can also donate eyes, cardiovascular tissue, heart valves, bone, skin, and soft musculoskeletal tissue.

## Q. What is the best way for people to donate their organs?

**A.** Anyone applying for a New York State driver's license, a non-driver's ID, or renewing a license can check off the donor box. People can also sign up when they register to vote. The NYODN website has online enrollment forms that donors can sign and mail into either the NYODN



Helen Irving, President and CEO of the New York Organ Donor Network

or the New York State Department of Health. To obtain the forms, go to [www.donatelifeny.org](http://www.donatelifeny.org). You can also sign up on the NYS Donor Registry via the Department of Motor Vehicles on its online portal at [www.mydmv.ny.gov](http://www.mydmv.ny.gov).

## Q. Do you have to be 18 to join the donor registry?

**A.** Yes, but minors can instruct their parents or legal guardians to make them donors.

## Q. Can the families of deceased organ donors prevent donation from happening?

**A.** No. If the deceased donor is entered into the registry, his or her donation is considered a gift that is irrevocable and protected by law.

## Q. Do any religions discourage organ donation?

**A.** All major religions support organ donation and view it as a noble gift.

## Q. Should people interested in organ donation discuss this with their families or loved ones?

**A.** It is important that loved ones know your wish to be a donor. In the event of a tragedy, they can donate your organs knowing that is what you would have wanted. Without this discussion, they would be left to make a decision at a highly emotional time.

## › 'Kidney Swap' Program Increases Living Donations (continued from page 1)

still help their friends by joining the National Kidney Registry's "kidney swap" program, comprised of willing kidney donors who are not a match for their intended recipients, but could be a match for someone else.

In August 2012, after Ms. Christensen and Mr. Detwiler joined the "kidney swap" program, the chain came together. Mr. Detwiler was a match for Mr. Bligen; Ms. Christensen was a match for a man in Wisconsin; and a third living donor in New England was a match for the girl in New York. Four of the six surgeries took place at The Mount Sinai Hospital.

"Finding the right combination of donors and recipients is a bit of an art form," says Antonios Arvelakis, MD, Assistant Professor of Surgery, who recently joined Mount Sinai to expand the institution's participation in the National Kidney Registry "kidney swap" program. More than 7,700 patients in New York State are currently waiting for a kidney. The wait time in the region can be as long as five years.

"Kidney swaps are an important means to increase living donations," says Dr. Arvelakis. "In part, by conducting more swaps between RMTI [Recanati/Miller Transplantation Institute] patients, Mount

Sinai expects to increase the number of living donor transplants by 20 or 30 a year." Mount Sinai conducted 74 living donor kidney transplants in 2012.

After the surgeries, Mr. Detwiler met Mr. Bligen and Ms. Christensen at Mount Sinai. "We were all just thrilled," says Mr. Bligen. "You'd think that I would have been the most excited. But you know, it seemed like those two were just as happy to give an organ as I was to receive one."

In November 2011, Mr. Bligen's family created the Dennis Bligen Kidney Foundation to raise awareness about renal failure and the importance of kidney donation. Last month, the foundation made a major gift to RMTI to help increase the number of living donations, particularly in minority communities. "Most people are amazed by how prevalent chronic kidney disease is," says Mr. Bligen.

In recognizing the importance of living donors, RMTI founded the Zweig Center for Living Donation in 2010, to provide comprehensive medical, surgical, and psychological care for those who donate a kidney or part of their liver. The Zweig Center is one of the largest living donor programs in the United States.

## Staying at the Transplant Living Center

Out-of-town patients and their families find a supportive and convenient oasis at the Recanati/Miller Transplantation Institute's Transplant Living Center (TLC), a suite of rooms on East 95<sup>th</sup> Street that provides affordable overnight accommodations. The TLC—with 10 bedrooms, 7 bathrooms, living and dining areas, and 2 kitchens—is located in a doorman-operated apartment building that is within walking distance to The Mount Sinai Medical Center. Free WiFi and a free shuttle service to and from the hospital are provided.

Patients who come for evaluations often stay at the TLC, along with families whose loved ones are undergoing transplant surgery.

Mount Sinai employee Allyson Reala, who manages the TLC, calls it a “home away from home.” The center provides a warm environment for people who arrive there during a time of great stress. Ms. Reala, a former kidney transplant patient herself, says, “It’s like a family here,” since guests are surrounded by others who are experiencing the same concerns. She adds, “I’ve been uplifted, inspired, and empowered by many of the people who have stayed here.”

*For additional information, email [TLC@mountsinai.org](mailto:TLC@mountsinai.org).*



Allyson Reala, Manager of the Transplant Living Center, helps visitors feel at home during a stressful time.

## Announcements

### Donate Life Month Events

James Pardes, Vice President of Marketing for the New York Organ Donor Network, will discuss new ways to reach the New York City population and encourage donor registration.

**Friday, April 19**  
**1425 E. 98<sup>th</sup> Street**  
**Icahn Medical Center**  
**Room 4-82**  
**Noon – 1 pm**

*RSVP to Sharyn  
at 212-659-8027, extension 88027*

### **Please join RMTI staff and patient team for The American Life Foundation's Liver Life Walk**

**Saturday, April 20**  
**9:30 am - Noon**  
**Clinton Cove at**  
**Hudson River Park**  
**55<sup>th</sup> Street and the**  
**West Side Highway**

*For additional information, go to:  
[www.go.liverfoundation.org/goto/  
MountSinaiRMTI](http://www.go.liverfoundation.org/goto/MountSinaiRMTI)*



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## Organ Donation Drive

Transplant recipient Kerry Williams volunteered at The Mount Sinai Medical Center's organ donor education and registration drive on April 9 outside the Plaza Café to help raise awareness and increase donations.

