



TRIO NEWSLETTER

Long Island Chapter of Transplant Recipients International Organization

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Winter 2010

Our General Meetings are held on the second Wednesday of each month from September to June. Our holiday party in December substitutes for the December meeting. The meetings begin at 7:30 PM and are held at

145 Community Dr., Manhasset, NY.

General Membership Meeting With Guest Speaker- Dina Grgas - by Helena McDermott



This past Fall, we welcomed as a guest speaker one of our own, Dina Grgas. Dina is a 20 year organ recipient and Long Island TRIO member. She is also a nutritionist at St. Francis Hospital, with a focus on dietary nutrition intervention. She spoke about moving forward after transplant, but recognizing that some factors are out of our control because of the medications that we ingest.

As an example, she noted that prednisone increases the appetite and may lead to osteoporosis. Therefore if we are on this medication we need to take measures to avoid more damage. Simple portion control can assist with an unnerving appetite. In order to reduce the risk of osteoporosis we can take a calcium vitamin or expose ourselves to the sun (even

in the winter months) for 15 minutes a day, and exercise to build bones.

Many of us take prograf and cellcept which can cause high blood pressure, cardiovascular disease, and diabetes. Dina said it is extremely important to read labels and look out for all the usual suspects, like salt, sugar, fat and also the good ingredients, such as fiber. Fiber helps with blood sugar control, for those of us who are diabetic. Diabetes and heart disease can come from hormones through meat raised on hormones. It is wise to eat red meat (the size of your palm) no more than twice a week. Also take note if the milk you're drinking is hormone free. Although thought to be recommended, eating too much fruit can accrue too much sugar in our bodies. Splenda for example, is so sweet it actually makes your body crave more real sugar. As for cholesterol, we should not be consuming more than 200 milligrams a day. Dina mentioned that the best way to lower cholesterol is to eat flax seed, olive oil and canola oil.

Dina suggested that before you accept taking an additional medication; ask your doctor if you can have dietary modifications first. It is our job to be proactive and we can do so by exercising, reading labels, and practicing portion control. Diana explained that considering a diet similar to a diabetic diet is actually the healthiest way to eat. She emphasized that we could and should control our problems, instead of letting them control us.

We thank Dina Grgas for inspiring us to live a healthy lifestyle and giving us the knowledge we need to do so.

February 10, 2010 General Membership Meeting With Special Guest Speaker- Dr. Mailloux

Our February 10th meeting will feature Dr Mailloux's special program presentation: "What is being done in CKD (Chronic Kidney Disease) Education".

There will be guests from NSHS participating as well. This promises to be a very interesting meeting and we hope you will make every effort to attend.

Dr. Mailloux is a good friend of our chapter and it's always exciting when he attends our meetings as a special guest speaker.

Upcoming Events

February 10, 2010

General Membership Meeting with special guest Dr Mailloux-special program presentation:

"What is being done in CKD (Chronic Kidney Disease) Education"

July 30, 2010-August 4, 2010

U.S. Transplant Games-Madison Wisconsin

Brooklyn woman thrives after five transplants

By Erin Durkin

Source: Daily News: December 31st 2009

Just eight months ago, Kristin Molini was a bone-thin 74 pounds, spending 13 hours a day hooked up to an IV for the nutrition she needed to survive.

The young Brooklyn woman's skin was bright yellow with jaundice. She was in constant pain and could barely leave the house.

But in a stunning turnaround, when the ball dropped on New Year's Eve, the 22-year-old Gravesend resident was out celebrating with friends - and with five new organs transplanted in a rare and complex surgery.

It took two years, but Molini received a new liver, stomach, pancreas and large and small intestine in a delicate 13-hour operation at New York-Presbyterian Hospital Columbia.

Her feet firmly planted on the road to recovery, she's not looking back.

"I keep saying 2010's my year," she said. "I'm just ready to live."

Molini was a junior in high school when she was diagnosed with a rare medical condition, intestinal dysmotility, which paralyzed her digestive organs.

It got so bad she had to stop eating, relying on an IV feed that kept her alive but destroyed her liver.

"I was at every ER imaginable," she said. "The pain was just terrible. It was unbearable.

"I couldn't move," she said. "I was going from the bed to the couch....I didn't see outside for a while. I didn't think I was going to make it."

Molini got on a transplant list at Children's Hospital of Pittsburgh, but the search for a donor was hampered by her rare blood type and tiny frame.

Last spring, she was added to the list at Columbia and on the morning of May 4, the phone rang.

"When you first get listed, you're jumping at every phone call...thinking this could be it," said Kristin's mother, Cinzia Molini, 45. "At this point I no longer jumped for the phone.

"I heard, 'We have an offer,'" she said. "It was a perfect match."

Kristin and her family rushed uptown, and she was wheeled into surgery that night.

"It was probably the longest, most emotional day of my life. I was crying, I was bawling," she said. "I didn't know if I was going to wake up.

"As I'm rolling away from my family, I'm just saying goodbye, and I'm crying," she said, "And I see this little cooler come in and I'm like, 'Oh yeah, that's for me.'"

Dr. Tomoaki Kato, director of the liver and intestinal transplant program at Columbia, led a team of three surgeons, two anesthesiologists, and four nurses in the grueling all-night surgery.

Only 300 such surgeries - known as multivisceral transplantations - have been performed worldwide since the 1980s. "It's still a very uncommon surgery," Kato said.

He said, Molini had to take the change, because without the surgery, "she would have died."

While Kato's team worked, Molini's family sat in the waiting room, reading letters she had written for them.

"Yes, it is very scary and yes, it will be a long hard road ahead, but I am ready,"

she wrote. "No matter what happens, I know how much you love and care about me....I have no regrets."

The best moments since the surgery have been the everyday activities most people take for granted.

She ate real food for the first time since 2005.

Molini grew up on big Sunday dinners and refused to give up the tradition. She learned to cook meals she couldn't even taste.

"I watched Food Network - every day, every night. I was up all night because I was in pain," she said. "I fell in love with cooking, but I couldn't taste it, so I went by smell." She's finally getting to taste some of her creations!

"Things that excite me can be very, very small. ... Even just going to the store, it just makes me happy."

She plans to enroll at Kingsborough Community College next fall and study to become a physician's assistant - and maybe a surgeon.

"I get to plan my life now. I don't know what the future holds, and that's the fun part. ... Before, I didn't even know if I had a future."

You can read the whole story on our organization's website- www.litrio.org.

New Members

Pat Kasiba

Ernesto P Molmenti

John Lourenco

Thomas D Schiano MD

Irene Torino

John and Nancy Sullivan

Mary Lieberman

Russell G and Joyce Tisman

Happy Re-Birthday to you!

December, January and February Re-Birthdays

December Re-Birthdays

Alfred Boccafolo-December 20, 1992 Liver
Tom Boyle- December 13, 2007 Kidney
Melissa Brennan December 21, 1997 Kidney
Steve Buonomo- December 29, 2008 Liver
Jim Conte- December 20, 1994 Kidney
Jerry Fechter- December 28, 2004 Kidney
Healey- December 3, 2002 Kidney
Nicola Iacobellis December 26, 2000 Liver
Vincent Marcianta December 28, 2007 Heart
Lou Reardon December 10, 2007 Heart
Walter Ruzek December 5, 1989 Kidney
Richard Walk December 27, 1996 Kidney

January Re-Birthdays

Joseph F Amsterdam January 6, 2005 Liver
Tom Bush January 14, 2007 Kidney
Hugh Collins January 23, 2008 Kidney
Joe DiFilippis January 14, 2009 Liver
George Dillon January 15, 1997 Liver
Howard Fields January 3, 1995 Kidney
Neil Gilmartin January 6, 2000 Liver
Dina Grgras January 15, 1990 Liver
Sunilkumar Krishnan January 6, 2006 Liver
Franklin T Lloyd January 1995 Kidney
Kristen Merz January 19, 2007 Kidney
Scott Nathanson January 14, 2007 Kidney
Brian Strauss January 9, 2007 Kidney
Catherine M Tenaglia Jan 13, 2007 Kidney

February Re-Birthdays

Robert Carroll February 1, 2006 Liver
Carl Caruso February 18, 1998 Kidney
Keith Dobish February 21, 2001 Kidney
Mary Graffeo February 23, 2009 Kidney
Grace LaBarbera February 26, 1991 Liver
Krista Lesinski February 27, 2007 Liver
Bill Moore February 29, 2008 Liver
Angelo Stekardis February 8, 2008 Lung
Larry Swasey February 6, 1988 Heart

The Passing Of Jules Feuer

I regret to report that our chapter has lost a great friend, a wonderful person, a dedicated volunteer and someone who will be missed by all of us at Long Island TRIO.

Jules Feuer passed away on December 26, 2009 at approximately ten in the morning. We attended a very special memorial service at Noon on January 10, at the Glen Cove Mansion.

We attended this memorial service and helped honor and remember Jules as we supported Rochelle as best as we could.

I have always found that when our chapter needs volunteers to help work at tables at events, Jules and Rochelle always made themselves available and were not only dedicated but were so very effective and sensitive with great success with regard to enrolling new registrants to the Donate Life Registry in order to help save lives.

It is our sincere hope that Rochelle will continue to volunteer with our chapter and I believe that she will continue her great work.

The Passing of Don Treffeisen

by Mike Sosna and Walter Ruzek

As we reported in this publication, we are deeply saddened at the passing of Don Treffeisen, our friend and a Co-founder of our Long Island chapter of TRIO. Don will be sorely missed by so many of his friends and colleagues and his legacy will live on. Don was an efficient and dedicated volunteer for Long Island TRIO.

Don used to enjoy chatting with me about how much our chapter has grown and how pleased he was as he observed so

many wonderful volunteers picking up the ball and effectively carrying it to an even more productive platform. Don and Anne used to modestly show enjoyment and were proud at LI TRIO events as they watched volunteers make so much of their vision a reality.

We have so many wonderful memories of our chapter's founders, Anne and Donal Treffeisen and we will share some of them with you.

Walter continues:

I met Don Treffeisen at my first LI TRIO meeting held at Macys Roosevelt Field in March 1990. He and Anne founded the group 2 years earlier following Anne's successful liver transplant performed by Dr. Lewis Teperman, who also assisted in founding LI TRIO.

At that time, LI TRIO needed someone to maintain the membership database and so I was fortunate enough to join the board of directors and spent time with Don and Anne as well as other wonderful people, some of whom still come to the Holiday Party. There was Marie & Ron Healey, Eulene & Bob Smith, Vicki & Ed Itts, Betty & Vito Suglia and Bobby Carroll who had a liver, kidney and pancreas transplant.

Don was the guy who often carried the ball but Anne was the quarterback and directed the action. Don did all of the work to get LI TRIO established as a "Not for Profit" organization. Our board still uses copies of his notations of the various government ID numbers. He attended to details like that for many of TRIO's endeavors in the early years and he stayed involved as LI TRIO grew to its current high level of activity. He was always available to share his thoughts.

What I remember most about Don is that he so appreciated what Anne went through and her new found life after transplant that he would do anything possible to help Anne achieve TRIO's goals. Don left us a wonderful example of love!

The Newsletter of The Long Island Chapter of Transplant Recipients International Organization is mailed free to all members. Please send any letters and any other correspondence to:
 LI TRIO
 P.O. Box 81, Garden City, NY 11530

Please send all articles, member profiles, stories, anecdotes and other newsletter submissions to:

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 Little Neck NY 11362
 Tel: 516.902.8111 / Fax: 516.482.2599

LI TRIO MISSION STATEMENT

Long Island TRIO is a non-profit all volunteer organization committed to improving the quality of lives touched by the miracle of transplantation through support, advocacy, education, and awareness.

NEWSLETTER STAFF

Mike Sosna—Editor

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Holiday Party Chairpersons	Florence and Jerry Sosna	516-482-2908

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LI TRIO Tribute Cards

Florence Sosna has LI TRIO Donation Tribute Cards "In Memory Of" or "In Honor Of" a loved one.

You can contact her at 516-482-2908. At your request, Florence will customize, address and mail the card to your party in honor of a loved one and/or special occasion or in memory of a loved one.

Transplant List Stats:

- 105,239 Americans are on the organ transplant waiting list.
- Reported January 8, 2010: There were 23,846 transplants between January 2009 and October 2009.
- Reported January 8, 2010: There were 12,180 donors between January 2009 and October 2009.
- Every 12 minutes, another name is added to the national transplant waiting list.