

# LI TRIO UPDATE

THE LONG ISLAND CHAPTER OF TRANSPLANT RECIPIENTS INTERNATIONAL ORGANIZATION ▲ APRIL 2008

THE LONG ISLAND TRIO GENERAL MEETINGS ARE HELD ON THE SECOND WEDNESDAY OF EACH MONTH FROM SEPTEMBER TO JUNE  
OUR DECEMBER HOLIDAY PARTY SUBSTITUTES FOR THE DECEMBER MEETING. THE MONTHLY MEETINGS BEGIN AT 7:30 PM AND ARE HELD AT:  
145 COMMUNITY DRIVE, MANHASSET, NY

## Our Next Meeting With Special Guest Dr. Distant

Dale A. Distant, M.D., Chief, Transplantation Division and Associate Professor at SUNY Downstate Medical Center has initiated the use of the dual kidney transplant technique which allows the transplantation of kidneys from older donors which otherwise might not be used. Dr. Distant is a wonderful speaker and an expert on both extended criteria organ donation and on allocation details regarding UNOS's new protocols. Since we are currently in a comment period with respect to UNOS and kidney allocation protocols, this is a great opportunity for our membership to ask questions and obtain a great deal of information.

Dr. Distant is the Director of Kidney Transplantation and his innovative leadership has allowed Downstate's transplant program to move forward and flourish in the ever expanding field of transplantation. You are invited to join us for an informational and enjoyable evening on April 9, 2008.

## Our March 2008 Monthly Meeting With Dr. Lionel Mailloux

**W**e were very pleased to have Dr. Lionel Mailloux as our speaker for our March General Meeting. Dr. Mailloux is a dear friend of our chapter and refers many new members to LI TRIO.

Dr. Mailloux provided a Power-Point presentation about renal vascular disease also known as renal artery stenosis (RAS), a leading cause of kidney disease and failure. Renal artery stenosis is the narrowing of the renal artery, most often caused by atherosclerosis or fibromuscular dysplasia. This narrowing of the renal artery can impede blood flow to the target kidney. Hypertension and atrophy of the affected kidney may result from renal artery stenosis, ultimately leading to renal failure if not treated.

Many patients with RAS have no symptoms but can still have hypertension or chronic kidney disease. In fact, most cases of renal artery stenosis are asymptomatic, and the main problem is the high blood pressure that cannot be controlled

with medication. The disorder may be discovered when the physician notes a bruit (loud whooshing sound) over the kidney during examination with a stethoscope (auscultation).

RAS occurs about 20% of the time for those with atherosclerosis. As with coronary arteries, RAS can be treated with a stent. However, with an arteriogram of the kidney comes a danger of cholesterol plaque breaking off and damaging the kidney or traveling elsewhere. This risk must be weighed against the benefit of restoring increased blood flow to the kidney. Although it provides the best image, a CT arteriogram is to be avoided if possible as it requires dye that can be damaging to the kidneys. For that reason, among others, it is said that the nephrologist must be the "Beacon of reason".

A recent study shows that early intervention to control hypertension is a very important part of preventing RAS. Another RAS study has begun and will track statistics

## UPCOMING EVENTS AT LI TRIO

**\*\* Check out the dates and times of our Donate Life Month events on Pages 4 and 5 of this publication \*\***

### Gift Of Life Events for Donate Life Month

- ▲ **3/31:** Southside Hospital
- ▲ **4/4:** Huntington Hospital
- ▲ **4/4:** Harborfield High School
- ▲ **4/8:** Staten Island University Hospital
- ▲ **4/9:** LIJ Medical Center

- ▲ **4/10:** North Shore University Hospital
- ▲ **4/14:** Franklin Hospital
- ▲ **4/17:** Forest Hills Hospital
- **4/5:** TRIO Manhattan's Remember and Rejoice Ceremony at St. Patrick's Cathedral
- **4/12:** ALF Re-Birthday Party at Winthrop Hospital

- **7/11-7/16:** The 2008 U.S. Transplant Games will be held in Pittsburgh, PA
- **8/11:** LI TRIO Singers are performing at LI Ducks baseball game
- **9/25-9/27:** TRIO convention at the Millennium Hotel in Saint Louis, MO

## LONG ISLAND TRIO UPDATE

The Newsletter of **The Long Island Chapter of Transplant Recipients International Organization** is published monthly and 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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## LI TRIO GENERAL MEETINGS

The Long Island TRIO General Meetings are held on the second Wednesday of each month beginning at 7:30PM from September to June. Our December Holiday Party substitutes for the December Meeting. The monthly meetings are held at:

**145 Community Dr., Manhasset, NY**

## 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.

**JOIN US!**



for the next three years.

Many of Dr. Mailloux's patients attended the meeting and openly expressed gratitude for his excellent care. We are grateful to Dr. Mailloux for his enlightening talk and visual presentation and for his willingness to entertain our questions. We look forward to him visiting LI TRIO again soon.

- Walter Ruzek

Please check out  
[www.litrio.org](http://www.litrio.org)  
for our list of  
"Donate Life  
Month Events"!

## "LI TRIO TRIBUTE CARDS AVAILABLE"

Florence and Jerry Sosna will send lovely LI TRIO "In Memory of" and "In Honor of" Tribute cards in your name. Please call 516-482-2908 or e-mail [jerrysosna@aol.com](mailto:jerrysosna@aol.com)



## A Special Thank You To The LI TRIO Board Of Directors

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## Some Imperfect Hearts OK for Transplant

*Ventricular thickening didn't affect outcomes, could expand donor pool, experts say*

Source: ScoutNews, LLC

A heart needn't be perfect to be used in a transplant, a new study shows.

Five-year results for people given hearts with mild-to-moderate left ventricular hypertrophy (LVH) -- a thickening of the heart's main pumping chamber -- were as good as for those who got hearts with no problems, cardiologists at Cedars-Sinai Medical Center in Los Angeles report in the March 25 issue of the *Journal of the American College of Cardiology*.

The findings might help expand the donor pool for heart transplants, one expert said.

"Up to this time, any patient who had more than minor LVH would not be accepted into our donor pool because we thought we would have worse results over time. This paper suggests that is not the case," said Dr. Allan Stewart, director of aortic surgery at NewYork-Presbyterian Hospital/Columbia University Medical Center, in New York City.

In the Cedars-Sinai study, the largest of its kind to date, researchers reviewed outcomes for 427 patients who underwent heart transplant at the center between 1989 and 2004.

The survival rate of the 62 recipients of transplanted hearts with LVH was comparable with that of 365 people who got hearts without LVH, said study senior author Dr. Alfredo Trento, director of cardiothoracic surgery at Cedars-Sinai.

In the first 30 days, 98 percent of those getting heart with LVH survived, compared to 97 percent of those getting normal hearts. The five-year survival numbers were even better for people getting LVH hearts -- 84 percent, compared to 70 percent for those getting normal hearts. But those better results were a statistical quirk, he added quickly: "I don't think you can make any inference from that."

Cedars-Sinai surgeons began accepting LVH hearts "because the donor

pool was not providing enough donors, so you have to go to less optimal -- but what we think are still good -- hearts," Trento said.

Reluctance to accept LVH for transplant was due to "worry because these hearts are not as compliant," he said. "If a heart is thick it cannot relax enough to receive blood, so you have what we call diastolic dysfunction."

However, based on the results thus far, "we will continue to use them," Trento said. "Some people say that if you follow up patients with these hearts, they don't behave as they should. But they do. We have noticed that when we do an echocardiogram on follow-up, the heart sort of tends to regress toward normal."

The Cedars-Sinai results could well affect medical practice, Trento said. "In this environment where the donor pool is not optimal, I think this paper will move people to take hearts with moderate LVH," he said.

NewYork-Presbyterian's Stewart agreed. His hospital has the largest heart transplant program in the country, averaging over 100 operations per year.

While he was encouraged by the Cedar-Sinai study, he added that, "of course before we completely change our practice we would want to see more data."

Any change in the program would be driven by the same shortage of donor hearts that motivated the Cedars-Sinai cardiologists, Stewart said. "Right now we're limited by the available list of donors," he said. For someone who has been on the list for a transplant for long enough to arouse concern, "I would be more apt to take a heart with LVH based on this article," he said.

"Normally we would say we don't accept donors with LVH," Stewart said. "Now we can try it and see what our own experience is."



## Sister's Kidneys Save Her Brother's Life

*Sister's death saves Bayside man's life*

By Noah C. Zuss

In death, Sunyun Lee was able to give her brother Seung Hoon a new lease on life.

Three days after she died on Jan. 18, a team of doctors from North Shore University Hospital transplanted both her kidneys into Seung Hoon, saving his life.



*Sunyun Lee with her husband and son Chris.*

Mr. Lee was in terrible pain going through the ordeal of kidney disease, but he did not suffer alone. When diagnosed, he refused to begin dialysis.

But his sister insisted that he begin treatment to keep him alive while a kidney could be found. Ms. Lee was his strongest supporter--she forced him to hope and diligently cared for him until her sudden death from a brain aneurysm.

She always accompanied him to appointments for dialysis treatment and even oversaw his care. Now she is gone, but remains part of her brother spiritually and physically.

Walking slowly and looking exhausted, a tearful Mr. Lee spoke of his sister through a Korean interpreter. He said that he could feel her spirit living on through him, and that he "would be careful to protect it."

Sunyun Lee, a mother of two from Bayside died unexpectedly, but her death was not in vain, her kidneys provided Mr. Lee with the gift of extended life.

Packed board rooms with large conference tables tend to be bland

*See Sister's Kidneys Save Brother's Life Page 6*

## April is National Donate Life Month

30 Days to Help Save a Life: What to Do in April



National Donate Life Month was established in 2003. Every day in April, people across the U.S. make a special effort to celebrate the tremendous generosity of those who have saved lives by becoming organ, tissue, marrow, and blood donors and to encourage more Americans to follow their fine example.

Please point your browser to our organization's website at [www.litrio.org](http://www.litrio.org) to view A Proclamation by the President of the United States of America.

On 28 March, George W. Bush wrote:



*"NOW, THEREFORE, I, GEORGE W. BUSH, President of the United States of America, by virtue of the authority vested in me by the Constitution and laws of the United States, do hereby proclaim April as National Donate Life Month. I call upon health care professionals, volunteers, educators, government agencies, faith-based and community groups, and private organizations to help raise awareness of the urgent need for organ and tissue donors throughout our Nation.*

*IN WITNESS WHEREOF, I have hereunto set my hand this twenty-eighth day of March, in the year of our Lord, and of the Independence of the United States of America the two hundred and thirty-first.*

GEORGE W. BUSH

Donating organs, marrow, and tissue is a kind and compassionate act that can protect and enhance the precious gift of life. During National Donate Life Month, we recognize the generosity of donors and raise awareness of the importance of donating.

- *Make it known: I want to be a donor*
- *Register with The New York State Donate Life Donor Registry*
- *Say YES to donation on your driver's license.*
- *Tell your family, friends, physician, and faith leader that you want to be a donor.*
- *Fill out and sign a donor card, have it witnessed, carry it with you.*

Our LI TRIO meetings begin at 7:30 PM and are held at 145 Community Dr., Manhasset, NY. Next Meeting-April 9, 2008 with Dr. Distant



## Gift Of Life Celebrations at the North Shore-LIJ Health System



These inspiring events serve as a reminder of the critical need for more organ, tissue, bone marrow and blood donors, and educate us about the ways we can help make that happen.

- Southside Hospital - Bayshore - March 31, 2008 10:30 AM to 2 PM - Boardroom
- Huntington Hospital - Reception - April 4, 2008 12:30 PM to 2:00 PM- Main Lobby
- Harborfield High School LI TRIO Educational Program and Flag Raising April 4, 2008 7:45 AM to 11:45 AM
- Staten Island University Hospital - Main Lobby - April 8, 2008 10 AM to 11 AM
- LIJ Medical Center - Teaching Center April 9, 2008 12 PM to 1 PM
- North Shore University Hospital - Rust Auditorium - April 10, 2008 11 AM to 12 PM
- Franklin Hospital, Valley Stream - Shankman Auditorium - April 14, 2008 10:30 AM to 2 PM
- Forest Hills Hospital - 8th Floor Conference Room April 17, 2008 10:30 AM to 2:30 PM

For more information on the above events at NS-LIJ, please call Joy at 646.219.4400 Extension 2514



ALF Greater New York Chapter Re-Birthday Party will be held at 10 AM on April 12, 2008 at Winthrop Hospital.

Contact: Tracy Merlau at 212-943-1059 ext 12.  
Winthrop University Hospital - Community Outreach Center - 101 Mineola Boulevard, Mineola, NY

## Donate Life Walk at Stony Brook University

Date: Wednesday, April 23, 2008  
Time: 12:50PM to 2:50 PM  
Location: Student Activities Center (SAC) Plaza



## Long Island Walk The Walk

May 18, 2008 9:30 AM  
Long Island, NY  
Eisenhower Park  
Kidney Urology Foundation  
of America  
1.800.63.DONATE

### Did you know:

- ☛ Each year, 10 to 14 thousand people who die meet the criteria for organ donation, but less than half are actually donors
- ☛ 84,000 Americans die from kidney disease or conditions associated with kidney disease each year. 98,362 people in the United States need an organ or tissue transplant to save or drastically improve the quality of their lives
- ☛ 13 minutes from now a new name will be added to the organ waiting list

## ALF - Long Island Liver Walk Eisenhower Park

May 18th, 2008 8:30 AM  
Contact: Gina Parziale at  
212-943-1059.

### July 11-16, 2008:

The 2008 U.S. Transplant Games will held in Pittsburgh, PA. For more information please call 1.800.622.9010.

### August 11, 2008:

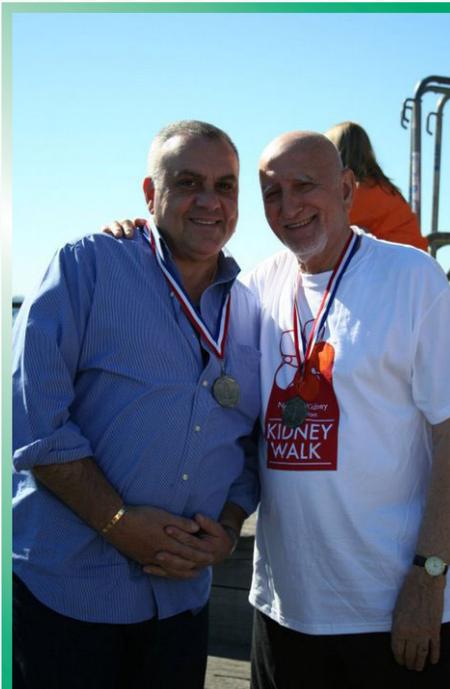
The TRIO Singers are performing The National Anthem at the Long Island Ducks baseball game. Save the Date! All TRIO members and interested parties are welcome to join us at the game.

## Remember And Rejoice

TRIO Manhattan is having their annual inter-religious celebration for donor families, recipients, living donors, and transplant professionals on Saturday, April 5, 2008, at St. Patrick's Cathedral, 5th Ave & 50th Street, Manhattan, New York, from 2:00 until 3:30 p.m.

The celebration will include brief speeches by donor families, recipients, living donors and medical professionals. No tickets or reservations are required. LI TRIO highly endorses and recommends this event that is so excellently planned and implemented by our sister TRIO chapter, TRIO Manhattan.

*Check your email box and future issues of this publication for information about the LI TRIO Singers, Shea Stadium and The New York Mets this summer!*



## NKF Serving Greater New York Long Island Kidney Walk

Date: Sunday, June 8, 2008  
Location: Hofstra University, Hempstead  
Contact: Lindsay Gilman at 212.889.2210 x203



26 Million people have chronic kidney disease and another 20 million are at risk. The NKF's Kidney Walk presents an occasion for dialysis patients, organ transplant recipients, donor families, living donors, the medical communities, and the general public to celebrate LIFE and support the Foundation's mission.

The NKF's Kidney Walks are designed to help people understand the need for early detection of kidney disease. In addition to raising funds for research and help for patients and their families, the Kidney Walk is a great way to bring the community together.

The National Kidney Foundation's Kidney Walk is a non-competitive walk focusing on education and prevention of kidney and urinary tract diseases, and awareness of the need for organ donation. The Kidney Walk presents an occasion for dialysis patients, organ transplant recipients, donor families, living donors, the medical and business communities, and the general public to celebrate life and create lasting community advocacy.

## TRIO National Conference

LI TRIO is pleased to publicize the scheduling of a joint convention to be held by Transplant Recipients International Organization (TRIO) and the International Transplant Nurses Society (ITNS). This convention will be held from September 25, 2008 to September 27, 2008 at the Millennium Hotel in Saint Louis, Missouri.

Some of the sessions being considered as viable subjects that affect transplant recipients include: advances in immunosuppressive medications; changes in Medicare coverage; aftercare of the transplanted patient; changes being discussed by OPTN/UNOS regarding the allocation of organs to different aged patients on the waiting list; effective ways to communicate with your local, state and national elected officials to promote issues important to transplant recipients and candidates; current and new trends in transplantation such as therapy to reduce antibody levels, DCD (Donation After Cardiac Death), The studying of presumed consent, and financial assistance to donor families to pay for burial expenses of the donor.

TRIO is attempting to make the cost of attending our convention as reasonable as possible for 2008. In the coming months, we will be informing you of the fees to attend this conference. The conference fee will include continental breakfasts, speaker lunches, all of the conference seminars and hopefully, the joint banquet, which will be held on September 27, 2008. TRIO has reserved a block of hotel rooms at the Millennium Hotel at a low convention rate (for TRIO members and their families) of \$139.00 a night; the same room rate that the ITNS members are receiving.

St. Louis, Missouri is an excellent choice for a meeting place due to the mild weather conditions during the later part of September. St. Louis (besides being a center of commerce) has many excellent entertainment attractions for the entire family. St. Louis is an airport hub center thereby providing many reasonably priced airlines flights from any location within the United States.

Check your email box and future issues of this publication for more information.

*Sister's Kidneys Save Brother's Life (continued)*

places, but this press conference was filled with emotion. Doctors praised the surgery and congratulated Mr. Lee on his newly extended life, but he was lost in isolated sadness as his mother wept to his side. Through an interpreter he said, "I miss my sister very much. She was always with me, and I cannot believe this happened."

Without the kidney transplant from his sister, Mr. Lee would have continued to suffer. Finding an available donor is not easy; there are currently more than 5,000 people in the New York area on the waiting list and 6,000 die each year waiting for a transplant nationally.

Because of the severity of Mr. Lee's illness he was placed on the United

Network for Organ Sharing waiting list immediately but after his sister died, the Lee family decided to donate her organs to her brother.

Following Ms. Lee's death, doctors from North Shore University Hospital determined her kidney was a match for her brother. Trying to find a kidney for Mr. Lee otherwise would have been a lengthy, arduous process. The average wait time for a matching donor is seven years.

The Lee's decision to provide a donation to Seung Hoon from his sister turned a tragedy into a gift of love. This gift however came with consequences and was a bittersweet episode for the Lee family.

Ms. Lee leaves behind her two children and a loving extended family. Her son Chris, 14, said her death brought the family closer together and that she will always be remembered.

"She was always caring for others, but maybe she was too busy to care for herself. It was the only way to save my uncle. I think of her as a hero."



LI TRIO thanks our friends at Eisenhower Park for their dedication and commitment in developing and supporting our Donor Rose Garden efforts. LI TRIO's Dave Rodgers is pictured with Eisenhower Park's Jane Durland, Katy Kocienda, and Mitch Brumberg.

## LI TRIO MEMBER PROFILE:

### CLAUDIA GRAMMATICO

*We are pleased to present this profile of Donor Mom and LI TRIO member Claudia Grammatico.*

*Reprinted with permission from the New York Daily News*

### **Mother advocates for organ donations**

"He looked like he was sleeping."

Claudia Grammatico's eyes still cloud up as she recalls that more than eight-year-old vision of her son Paul, lying in a hospital emergency room.

Though his body was virtually unscarred, the 26-year-old successful stockbroker and athlete was brain-dead, killed with his best friend, Michael Penny, in a May 19, 1999, traffic accident in Atlantic Beach, L.I. Both were thrown from the car they were in, which was being driven by a drunken driver.

"I was devastated," Grammatico said. "That was my son. When you lose a child, you lose part of your future."

In the emotional blur that was her son's final hours, the Valley Stream mom did something that would change her life, the lives of dozens, if not hundreds, of other people, and in the process created a lasting legacy for Paul, her only son.

When doctors approached her about donating Paul's organs, Grammatico said yes.

"They took Mike directly to the morgue," Grammatico said. "I was given something his mother was not given, and that was a chance to say yes."

"You don't say that yes loudly, you whisper it," she said. "That has to be one of the holiest words I have ever said."

That yes meant a new life for then-48-year-old Joe Senatore of Bay Shore, L.I., who got Paul's heart, and for the 63-year-old retired science teacher in Kansas and 54-year-old Nevada father who each got a kidney, the 56-year-old upstate New York

woman who got his liver and the 59-year-old Massachusetts woman who got one of his lungs.

Paul's tissue and bone marrow also were procured and utilized.

Grammatico would meet Senatore during an annual ceremony for organ-donor families and transplant recipients at St. Patrick's Cathedral. Her life also has been transformed.

Grammatico, 59, has become a tireless campaigner for organ donation, traveling across the metro area, state and country. She remains active with the New York Organ Donor Network.

She established a foundation in Paul's name, donations from which prompted mercyFirst, a Syosset, L.I., home for teen boys that Paul had supported, to name one of its dormitories Grammatico Hall in his honor.



"Sixteen boys live in Paul's building," Grammatico said. "It was dedicated a year to the day from when his heart was transplanted. Many of these boys were abandoned. Paul always supported them. He liked the Sisters of Mercy [who founded the facility that became mercyFirst]."

Eyewear giant Davis Vision embraced the boys at mercyFirst, giving them free annual vision care and sponsoring junkets to Jets and Yankees games.

Valley Stream High School renamed its annual wrestling tournament in Paul's honor, and city officials planted a tree in his name in a local park.

Grammatico also wrote a song about organ donations, "The Gifts of Life and Love," which has been sung at Knicks and Rangers games and has become so popular that it has been recorded by 23 different artists, and has several Spanish language ver-

sions.

Grammatico has been featured in a documentary about organ donations, "The Space Between Breaths." The former schoolteacher now does bereavement workshops for those trying to cope with a loved one's loss.

"There are people who can't see light in the darkness," she said.

She has evolved into a member of a larger family - the world of organ donors and transplant recipients and their families, bonded by lives saved by lost lives.

"Every donor family is my family, because we know what it means to lose a loved one," she said.

Standing in Nassau Medical Center, where Paul had been airlifted, and seeing him lying there, Grammatico said even in her grief organ donation seemed the right thing to do.

"When you lose a loved one that way, it doesn't matter if you are rich or poor, it is still incredibly painful to deal with," she said. "You don't want to think about what they have to do to get the organs. I always ask donor families how they came to do what they did."

EVERY second Saturday in May, the song she wrote in 2001 is sung at the "Remember and Rejoice" celebration at St. Patrick's Cathedral.

Grammatico, whose license plate reads DONORMOM, has found her calling.

"Horrible things do happen to regular people," she said. "When something like this happens, people have the chance in death to save someone else's life."

Grammatico can be reached at [ClaudPaul@aol.com](mailto:ClaudPaul@aol.com).

**USA waiting list candidates:  
98,362 as of this writing**

**Transplants January - December 2007  
28,352 as of 03/14/2008**

**Donors January - December 2007  
14,395 as of 03/14/2008**

## HAPPY APRIL RE-BIRTHDAYS!

Happy belated Re-Birthday to Robert Carroll who received his liver transplant on 2/1/06.

Herbert W. Riemer	April 9, 2006	Kidney
Pasquale Andriola	April 18, 1988	Liver
Michael Murphy	April 10, 2004	Kidney
Alvin J. Futterman	April 8, 2005	Kidney
Evelyn Alvir	April 15, 2004	Kidney
Gillian Cohen	April 17, 2005	Liver
George Donohue	April 12, 1996	Kidney
Margaret Gonzalez	April 18, 2002	Kidney
Fran Addazio	April 11, 2002	Kidney

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Donor Families & Social Secretary— Barbara Musto	516-671-5793
Singers and School Speakers— Sue Tietjen and George Tietjen	516-746-0693
The Ways and Means Committee/ Holiday Party Chairpersons— Florence & Jerry Sosna	516-482-2908

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