

LI TRIO UPDATE

THE LONG ISLAND CHAPTER OF TRANSPLANT RECIPIENTS INTERNATIONAL ORGANIZATION

▲ April 2009

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 Upcoming April Meeting



The guest speaker for our Long Island TRIO Meeting being held on April 15, 2009 at 7:30 PM is Ruthee Lu Bayer, MD-Assistant Professor of Clinical Medicine New York University School of Medicine and Director of Hematopoietic Stem Cell Transplantation North Shore University Hospital. Dr. Bayer is from North Shore LIJ-Monter Cancer Center. Please join us on April 15 for a very worthwhile meeting and discussion as we meet, greet, support, and participate in a question and answer session with our guest speaker.

▲

Our March 2009 Meeting with Tina Mein

Our March 2009 guest speaker was Tina Mein and we want to thank her for speaking with our group and for creating a therapeutic environment where everyone in the room participated and shared personal experiences and concerns. Here is one member's perspective with respect to this very worthwhile support session. Tina Mein is currently a Senior Clinical Intern in the Marriage & Family Therapy Clinic located in the Saltzman Center at Hofstra University. In May of 2009, she will be receiving her Masters Degree in Marriage and Family Therapy. She is a member of the American Association for Marriage and Family Therapy. In addition, she possesses a background in Crisis Intervention Counseling and has volunteered her services to the Long Island community for over three years.

Tina's extensive background consists of counseling individuals, families, and couples. She has developed and implemented workshops focusing on the empowerment of women and children of divorce. In addition, she has implemented an effective workshop aimed exclusively toward caregiver needs and those of their families.

and bone complications.

On March 11, 2009, I had the pleasure of attending LI TRIO's general meeting with guest speaker Tina Mein. Mein is currently a Senior Clinical Intern in the Marriage & Family Therapy Clinic at Hofstra University Mein helped create a dynamic where the group was able to share their feelings about chronic illness; pre-transplant and post-transplant. Mein highlighted the people that share the process of transplantation, that are always there and often unrecognized; the caregivers. This approach was particularly interesting to me, a kidney transplant recipient, because as thankful as I am for all the support my husband/caregiver give; I am also guilty of being a pain in the ___! When my husband asks, "Did you take your meds?" I'll respond in an exasperated "Yes." Of course when I do actually forget, I am thrilled he is there to remind me. One of the groups at Mein's Clinic caters to caregivers and is called Caring for Caregivers. Some of the caregivers in attendance shared their perspective of the role and as well as the stress that comes along with the title.

UPCOMING EVENTS AT LI TRIO

- ▲ April is Organ Donation Awareness Month Please refer to events published in this LI TRIO Update newsletter.
- ▲ The guest speaker for our Long Island TRIO Meeting being held on April 15, 2009 at 7:30 PM is Ruthee Lu Bayer, Director of Hematopoietic Stem Cell Transplantation at North Shore University Hospital.
- ▲ Our April meeting will be held on April 15, 2009 instead of on April 8.
- ▲ Our May meeting will be held on May 20, 2009 instead of on May 13.
- ▲ Long Island TRIO presents: Organ Donation Awareness Night at CitiField confirmed for August 19, 2009! Ticket information and other details will be forthcoming. The LI TRIO Singers are performing the National Anthem at this Atlanta Braves Vs. New York Mets game at 7 PM.
- ▲ The LI TRIO Singers are performing the National Anthem at the Ducks Game on August 31, 2009.

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:

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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 7:30 PM 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!!

***** Our April meeting will be held on April 15, 2009 instead of on April 8. *****
***** Our May meeting will be held on May 20, 2009 instead of on May 13. *****

(Continued from Page 1)

Aside from the open forum of personal experiences, Mein also engaged the group in a Life Change Test that consisted of 43 Life Events with a specific numeric value attached to each event. If we had experienced the event in the past year we were instructed to write the point value on the line in the Score column. This test was to determine how much stress is in our lives. Mein stated the reason for the determination is because stress causes illness, which we all need to prevent. My score, although not a surprise, was a wakeup call for more stress reducing activities. Being a part of the meeting itself and hearing the experiences of others is one of the ways I have begun to deal with stress. Mein also mentioned exercising and keeping a positive outlook.

After I returned home from the meeting that night, I was eager to share the enlightening experience that I had with Tina Mein and my fellow members of LI TRIO. I gave my husband the "Stress Test" which was a springboard for the conversation that followed. For the first time since my transplant it was about his experience and not mine. ▲
- Helena McDermott



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The Remember And Rejoice Event At St. Patrick's Cathedral

Our friends at our sister chapter-TRIO Manhattan held the annual "Remember and Rejoice" event at St. Patrick's Cathedral on April 4, 2009 at 2 PM-3:30 PM. Mike Sosna and his father, Jerry Sosna were among the special guest speakers at St. Patrick's Cathedral as they honored and thanked Donors and Donor Families as part of the Ecumenical Service in the Cathedral.

St. Patrick's Cathedral is located at 5th Avenue and 50th Street, Manhattan. The service included prayer, speeches by recipients, donor families and living donors, and candle lighting. This is an annual event and if you were not able to be present this year, you will want to attend next year's event. ▲



Legislative Initiatives

The United States Of America

Extend Immunosuppressive Drug Coverage

LI TRIO supports H.R.1458. This legislation will end 36-month limit on vital anti-rejection meds for kidney transplant patients. Legislation has been introduced in the House and Senate to end the 36-month limit on Medicare coverage of immunosuppressive drug coverage for kidney transplant patients.

Title: To amend title XVIII of the Social Security Act to provide continued entitlement to coverage for immunosuppressive drugs furnished to beneficiaries under the Medicare Program that have received a kidney transplant and whose entitlement to coverage would otherwise expire, and for other purposes.

Sponsor: Rep Camp, Dave [MI-4] (introduced 3/12/2009) Cosponsors (7)
Related Bills: S.565

Latest Major Action: 3/12/2009 Referred to House committee. Status: Referred to the Committee on Ways and Means, and in addition to the Committees on Energy and Commerce, and Education and Labor, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned. ▲

New York State- Legislative Initiatives Day: April 21, 2009



On Tuesday, April 21, we will be joining transplant recipients, donor family members, hospital staff, and organization professionals on a trip to Albany to meet with State legislators to discuss ways to help increase organ, eye and tissue donation.

We are joining our region's OPO, NYODN in this important effort. Each year close to 100 volunteers from the Greater New York Area have traveled to Albany to give our cause visibility. This has helped accomplish many goals including the New York State Gift of Life Medal law, a Donate Life license plate design, and a new Registry of Consent.

Please check our organization's website at www.litrio.org for more information.▲

April Is Organ Donor Awareness Month

Long Island TRIO will be represented at Mount Sinai.

We will be promoting the importance of Organ Donation Awareness month this month at Mount Sinai Hospital in Manhattan.

The events are being held April 20th- 24th. This will be a seven day event. We are seeking volunteers to help provide educational information and promote organ donation awareness. Time slots are flexible. Please contact LI TRIO board member volunteer Dave Rodgers 516 449-1421 or dokholiday44@hotmail.com.

Please check out
www.litrio.org
for additional news
and event details.

Join us at the National Kidney Foundation's Long Island Walk

NKF- Kidney Walk at Hofstra University- Long Island- May 31, 2009.

ALF Liver Walk Long Island – May 17, 2009- 212.943.1059.

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

You are invited to a Recognition Ceremony- LIONS EYE BANK- April 26 at 1 PM in Rust Auditorium at North Shore LIJ, Manhasset NY.

Kidney and Urology Foundation -Kidney Walk at Eisenhower Park- May 17, 2009. Parking lot 5. More info at www.litrio.org.

Fugitive accused of arranging bogus transplant

By William Kates, AP Writer Mar 20, 2009:

SYRACUSE, N.Y. – A fugitive American who claimed he was a psychiatrist will be returned to upstate New York to face federal charges he took \$70,000 for a bogus promise of a liver transplant in the Philippines, a federal prosecutor said Thursday.

Jerome Howard Feldman, 67, was indicted last month on federal wire fraud charges and arrested Feb. 2 in Manila, acting U.S. Attorney Andrew Baxter said. Feldman had been a fugitive since 2001 on state and federal fraud, racketeering, money laundering, and stolen property charges in Florida.

The federal indictment said he used aliases to trick a Canadian couple into wiring him a total of \$70,000 to arrange a liver transplant at a Philippine hospital. It alleged that he posed as a doctor online and promised that the money would cover medical bills for the procedure, which was to be performed on the husband by another doctor.

But hospital staff in the Philippines told the man that the promised transplant doctor did not perform such procedures, and that they had never heard of the doctor Feldman claimed to be. The husband died on July 11, 2008, at the Philippine hospital without receiving a transplant, Baxter said. Investigators also found at least six other victims of the scheme. Approximately \$400,000 had been wired to Feldman's alias by victims, Baxter said. Feldman, who was currently being held in Guam on immigration charges, will return to New York in the next several weeks, Baxter said. Feldman did not have a lawyer.

If convicted on the wire fraud charge, he faces a maximum penalty of up to 20 years in prison.▲

ARTIFICIAL LIVER EXTENDS LIVES

Source: NewYork-Presbyterian Hospital Research Office (212) 305-3839

BACKGROUND:

Each year, more than 6,000 people undergo a liver transplant in the United States, says the Organ Procurement and Transplantation Network. Patients receive donor livers either from someone with a healthy liver who has recently died or a family member who donates part of his or her liver. The Mayo Clinic says patients who qualify for liver transplants have failed to respond to other medical or surgical treatment for serious problems caused by a liver disorder; need a transplant to replace cancerous tumors of the liver or bile ducts like hepatocellular carcinoma and cholangiocarcinoma; or need a transplant to cure abnormalities in metabolism that threaten long-term health. Some diseases that damage the liver to the extent that a patient might need a transplant include Hepatitis B and C, alcoholic liver disease, genetic high cholesterol and liver tumors if they are confined to the liver.

For patients who might otherwise die, a liver transplant is a life-saving operation. About 75 percent of patients survive three years or longer after a transplant, according to the National Institutes of Health. Risks involved with liver transplants are most serious after surgery. These include a life-long need for immunosuppressive drugs -- which weaken the body's ability to fight off infections -- and transplant rejection. Transplant rejection happens when the body of a patient who has received an organ attacks that transplanted organ. Doctors try to prevent this by "typing" the organ to identify antigens it contains and make the new organ match the patient as closely as possible. However, since no two people are identical, no two people have identical organs.

A DANGEROUS GAP:

While 6,000 liver transplants are performed every year, 27,000 die from liver disease. This is in part because it's hard to replace the functions of the liver without a transplant. Dialysis can provide good support for failed kidneys, various assistive devices can sustain a failed heart, but options like that aren't available for failed livers. "The attempt to provide liver support has been far more challenging because most of those efforts were largely focused on trying to replace the filtering capabilities of the liver without replacing the synthetic functions, or the things that the liver cell makes that are also missing in the failing liver," Robert S. Brown, Jr., M.D., a liver disease and liver transplant specialist at NewYork-Presbyterian Hospital/Columbia in New York, N.Y., told Ivanhoe.

A NEW SOLUTION:

A new out-of-body artificial liver is addressing the problem by essentially doing what dialysis does for kidneys. A patient's plasma passes through the dialysis membrane in the machine. The plasma then filters through human liver cells. "That plasma then bathes these liver cells, and the liver cells perform their function and return purified and detoxified plasma to the patient," Dr. Brown said.▲



To Remember Me

Give my sight to the man who has never seen a sunrise, a baby's face or love in the eyes of a woman.

Give my heart to a person whose own heart has caused nothing but endless days of pain.

Give my blood to the teenager who was pulled from the wreckage of his car, so that he might live to see his grandchildren play.

Give my kidneys to one who depends on a machine to exist week to week.

Take my bones, every muscle, every fiber and nerve in my body and find a way to make a physically challenged child walk.

If you must bury something, let it be my faults, my weaknesses, and all prejudices against my fellow man.

*Give my sins to the devil.
Give my soul to God.*

If, by chance you wish to remember me, do it with a kind deed or word to someone who needs you.

*If you do all I have asked,
I will live forever.*

-Robert N. Test



Policy Proposals Issued for Public Comment

Policy and By-Law Proposals- Please note the April 24, 2009 deadline for comments

The Organ Procurement and Transplant Network (OPTN) policy development process includes solicitation of public feedback on policy and bylaw proposals. This process is called public comment and it allows the public an opportunity to submit their feedback before the same policies and bylaws are reviewed and considered by the OPTN/UNOS Board of Directors.

The field of organ transplantation depends on the cooperation of many people and organizations, and it is vital to ensure the opinions of all interested parties are heard and addressed. Input from transplant candidates -the people most affected by new or revised policy -- is an important part of the public comment process. The OPTN strongly encourages all interested individuals -- especially transplant candidates - to express their views on policy proposals by getting involve in the public comment process.

Public Comment Notice

To: OPTN/UNOS members and other interested persons
From: Karl J. McCleary, Ph.D, MPH, Director of Policy, Membership and Regional Administration
Re: OPTN/UNOS policy proposals for public comment

Eight policy proposals are now being offered for public comment. These proposals were developed by a number of OPTN/UNOS committees.

UNOS is requesting your input on these proposals by April 24, 2009.

When the public comment period ends on April 24, 2009, each sponsoring committee will review all feedback provided and make necessary modifications. The OPTN/UNOS Board of Directors may then review and vote on these proposals at its meeting on June 22-23, 2009.

For questions about a particular proposal, please contact your regional administrator at (804) 782-4800. Thank you in advance for your careful review and feedback on these policy proposals. Your consideration and feedback on these important issues is appreciated. ▲

Organ Transplantation and Donation Facts at a Glance

People of all ages and medical histories should consider themselves potential donors. Your medical condition at the time of death will determine what organs and tissue can be donated.

Organs and tissues that can be donated include: heart, kidneys, lungs, pancreas, liver, intestines, corneas, skin, tendons, bone, and heart valves.

All major religions approve of organ and tissue donation and consider donation the greatest gift.

An open-casket funeral is possible for organ and tissue donors.

Medicare information courtesy of MRC

**** Would you like to check out a recording brought to you by the Medicare Rights Center?

Medicare is making some changes to costs and coverage that may affect you in the New Year. To help you understand and prepare for these changes, the Medicare Rights Center is offering an online presentation, "Changes to Medicare in 2009." You will learn about the following:

Increased Premiums, Deductibles and Copayments
Extra Help Changes
Expanded Part D Off-Label Coverage for Anti-Cancer Drugs
Ongoing and Recent Changes
New Advance Beneficiary Notices (ABNs)
New Claims Processing Offices (Medicare Administrative Contractors)
Extension of Therapy Cap Exceptions
New Marketing Protections for Consumers
What You Should Be Doing Now

Click the link on our website at www.litrio.org or copy this link:

<http://tinyurl.com/d2deov>

Here is a very helpful Medicare Publication:
Choosing a Medigap Policy -2009
<http://tinyurl.com/39r8aq>



Please read the following press release issued by our national organization:

Transplant Recipients International Organization, Inc. (TRIO)

Issues Position Statement on Incentives for Organ Donation

Washington, DC—Transplant Recipients International Organization, Inc. (TRIO), has formally adopted a position statement that TRIO supports the concept that reward for organ donation must be studied in America.

With the number of patients awaiting solid organ transplantation in America having exceeded 100,000, TRIO has come to the conclusion "that rewards and incentives for organ donation should be studied to assure that such efforts would, indeed, increase donation."

In part, TRIO's position states: "The concept that incentives, benefits, or gratuities should recognize an important life saving contribution such as organ donation

to fellow Americans is one which seems just and proper, especially if the concept is

studied in real-time trials . . ."

Further, TRIO's position suggests that "a compassionately offered but highly regulated set of benefits might be studied from state to state or among selected organ procurement organizations."

After publishing its proposed position statement on benefits, rewards and incentives for organ donation, and inviting public comment, TRIO solicited input from its Chapters and members. With no significant opposition, the TRIO

Board of Directors formally adopted the position statement on November 18, 2008.

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Michael Sosna, Chairman Public Policy
Transplant Recipients International Organization, Inc. (TRIO)

Artificial Pump Effectively Backs Up Failing Hearts

ScienceDaily Apr. 2, 2009

Patients with severe heart failure can be bridged to eventual transplant by a new, smaller and lighter implantable heart pump, according to a just-completed study of the device. Results of this third-generation heart assist device were reported at the 58th annual meeting of the American College of Cardiology on March 30.

The device, called a left ventricular assist device (LVAD), is the latest generation of heart assist devices. The LVAD was tested at five main sites: Washington University School of Medicine in St. Louis, the University of Minnesota, Mt. Sinai School of Medicine, Inova Fairfax Hospital and the University of Pittsburgh.

"LVADs have allowed us to support patients until they can receive a heart transplant, so they are called a bridge to transplant," says Gregory Ewald, M.D., a Washington University cardiologist at Barnes-Jewish Hospital and medical director of the Heart Failure, Cardiac Transplantation and Total Artificial Heart Program.

An LVAD is implanted inside the chest cavity near the heart and is connected to the heart's left ventricle (pumping chamber). It assists the patient's weakened or damaged ventricle in pumping blood through the body. By restoring a normal blood flow, the device improves patients' health. Because it is powered by portable battery packs, patients usually go home while they wait for a heart transplant.

Patients who received the LVAD in the study were approved and listed for cardiac transplantation.

Answering standardized questionnaires for patients with heart failure, they reported a significantly improved quality of life after receiving the device, indicating that their heart failure was less apt to interfere with everyday activities such as housework, hobbies or sleeping or to affect their mood, ability to concentrate or energy level.

The positive results from this clinical study mean the VentrAssist will be submitted to the U.S. Food and Drug Administration for approval for use as a bridge to heart transplant. In the interim, Washington University School of Medicine will continue to provide the device to patients as part of a clinical trial. ▲

Fighting For His Life

A brave Brazilian man is fighting for his life — with two beating hearts inside his body.

Source: .thesun.co.uk

The unnamed 53-year-old is in a stable condition after a 12-hour operation.

But doctors at Sao Paulo's Heart state that his condition is critical.

The patient has suffered severe lung hypertension that stopped his heart pumping blood around his body.

So he was given the new donor organ to prop up his own heart.

The "new" heart was placed on the right side of his chest and is linked to his original heart by a vein, arteries of the lung and the aorta.

"This is not a routine transplant, the situation is exceptional," Surgeon Alfredo Fiorelli, who carried out the transplant, said. "The next 72 hours will be fundamental to evaluate his state."

"One heart would not be capable of pumping enough blood to the whole body since the patient's lungs were damaged.

"The traditional transplant would not be recommended and the only alternative was placing a second heart besides the original one as an aide."

He added: "The patient will be kept alive in an artificial state for two months. Without this operation, the patient's chances of survival were unlikely.

Eventually the healthy heart is expected to take over the principal functions of its weaker counterpart, which will beat slower and slower with time.▲



Testing shows which kidneys last after transplant

Apr 2, 2009 By Gene Emery

(Reuters) - Using a scoring system to evaluate kidneys from older donors increases the chance they will remain healthy if transplanted, according to a team of Italian doctors.

The findings could expand the pool of transplantable kidneys by 25 to 30 percent, said Dr. Giuseppe Remuzzi of the Mario Negri Institute for Pharmacological Research in Bergamo.

In the United States alone, 80,000 people are on the waiting list for a transplant and are instead receiving dialysis, which is much more expensive.

The Remuzzi team, reporting in the New England Journal of Medicine, found that better-scoring kidneys lasted at least two years in 91 percent of the recipients, even if the donors were aged 60 and older.

That's the survival rate for kidneys from younger donors, he said.

The recipients received one kidney if tissue samples from each donated organ scored a 0 to 3 on a 12-point health scale. Pathologists examined blood vessels, connective tissue and other structures in the kidneys.

Zero was the healthiest score. When the kidneys each scored a 6 or less, both were transplanted into the same recipient. Less-healthy kidneys were discarded.

The idea was, you have to look at what you are transplanting," Remuzzi said in a telephone interview.

The tissue sample took about 15 minutes to evaluate and was taken as the kidney was removed from the cadaver.

Without such an evaluation, an age difference of 10 years can make a big difference in the success rate of a transplant.

The United Network for Organ Sharing says the failure rate for a kidney from someone who is age 70 or older is 24 percent higher than it is for a kidney from someone age 60 to 69.

With the scoring system, the rates were the same whether the donor was in his 60s, or much older.

With this approach, selection criteria might be extended to increase the number of available transplants without increasing the risk of premature graft failure among recipients of kidneys from older donors," the Remuzzi team wrote in a letter to the Journal.

Remuzzi said that at his institution older donors now account for nearly 45 percent of transplants.

In a second study in the journal, Dr. David Talbot and colleagues at Freeman Hospital in Newcastle upon Tyne in Britain found that using a machine to preserve kidneys from dead donors greatly helped them last and stay suitable for transplant.▲

Member News:

From Alfred Boccafola:

'Just to let you know that I am undergoing Chemotherapy at the Mayo Clinic in Rochester, Minnesota.

In November I had surgery to remove a tumor from my small intestine. The doctors have given me a very good prognosis.

My wife April and I are staying in Rochester at the Gift of Life Transplant House.

I will get in touch with you when we get back to Long Island. Thanks.

- Alfred Boccafola ▲

Long Island TRIO mourns the loss of Mr. Pasquale (Rocco) Andriola who was a dedicated member of LI TRIO in particular and the volunteer transplant community in general. Mr. Andriola was instrumental in the formal introduction of our LI TRIO Speakers Bureau to Chamaine High School. We once again send our condolences to the Andriola family.

USA Waiting list candidates:
101,483 as of this writing

Transplants January-December 2008
27,958

HAPPY APRIL RE-BIRTHDAYS!

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

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Rose Garden Ceremony and Minutes— Jo Michaels	516-798-8411
Rose Garden Logistics—Dave Rodgers	516-449-1421
Data Base Manager—Howard Pohl	631-884-0482
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

WELCOME NEW LI TRIO MEMBERS

Vincent Marcianta	Janine Rempe
Deserie Matos	Frank Winter
Sharon L. Ross	Deena Diamond
Karen Farkas	

VISIT LI TRIO ONLINE: www.litrio.org

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LI TRIO

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