

# LI TRIO UPDATE

THE LONG ISLAND CHAPTER OF TRANSPLANT RECIPIENTS INTERNATIONAL ORGANIZATION

▲ Nov 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

## Steroid Therapies Following Transplant Can Be Eliminated, Study Suggests

Using modern immunosuppressive drugs eliminates the need for steroid therapy as early as seven days following a transplant surgery while still maintaining kidney function, according to new research.

ScienceDaily (Nov. 5, 2008) — A new study by researchers at UC shows that using modern immunosuppressive drugs eliminates the need for steroid therapy as early as seven days following a transplant surgery while still maintaining kidney function.

Steve Woodle, MD, chief of UC's transplant surgery division, principal investigator and designer of the study, says the elimination of a daily dose of steroids following transplantation minimizes chronic health conditions common to kidney transplant recipients.

The data—from what is believed to be the longest-running, double-blinded study of its kind in the transplant field—is published in the October issue of the *Annals of Surgery*.

"Steroids have long been the primary source of morbidity and complications following (Continued on page 2)

## Our October 2008 Monthly Meeting With Stephen Knapik

**O**ur October Meeting speaker was Steve Knapik, former director of the Lions Eye Bank for Long Island now in charge of the Living Donor program at Stony Brook Medical Center. Steve, well known to LI TRIO for his many years of work in the transplant community, was stepping in for Stony Brook transplant surgeon Dr. Wayne Waltzer who was unable to attend.

Steve recalled that his interest in transplantation began in 1982 while working as an RN helping to treat a trauma victim. He assisted in a kidney transplant that resulted from the death of the trauma victim and was thoroughly amazed when the kidney began to work immediately. Steve recalled that in 1987 there were about 15,000 people on the waiting list as opposed to 100,000 today.

Steve proceeded to update the attendees on the Stony Brook kidney program. Candidates undergo one stop testing and agree to a contract that they will complete it within 12 weeks. Living donors are screened to be sure they are under no pressure to donate. Steve makes sure donors understand they can call him and

reconsider at any time.

After 20 years of transplant experience Steve is still amazed to see people return to a normal life and go home a week after transplant with new color and life in their face and able to eat food like bananas that have been off their menu. He recalled TRIO member Jan Schichtel who has had her kidney for over 26 years and past LI TRIO president Artie Michaels who ran marathons.

Steve pointed out that only about 1% of deceased donors are suitable donors and many of them do not become donors because relatives do not allow it. That is why it is so important to register to become a donor. A question came from the audience: "Can an entire eye be transplanted?" The answer is "no" because the optic nerve can't be connected. Another question: Is there an age limit to being a donor. The answer is "no" because the liver keeps regenerating.

There were many more questions that Steve answered for individuals after the meeting. We wish Steve every success and are grateful that he was able to be with us. - Walter Ruzek

## UPCOMING EVENTS AT LI TRIO

- ▲The month of November: Donor Sabbath is observed each weekend.
- ▲November 12: Long Island TRIO Meeting 7:30 PM at 145 Community Drive Manhasset, NY
- ▲ November 14: UNOS Benefit Concert - Hank's Saloon in Brooklyn 7 PM-- Midnight
- ▲ December 6: LI TRIO's Annual Holiday Party 7 PM -11 PM Call 516.482.2908.

## 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 7:30 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!

## Total artificial heart to be ready by 2011: Research Team

Mon Oct 27 Agence France Presse

A fully implantable artificial heart designed to overcome the worldwide shortage of transplant donors will be ready for clinical trial by 2011, the French professor behind the prototype said Monday.

Leading heart transplant specialist Alain Carpentier, head of the European research team behind the project, said the prosthetic heart was ready to be manufactured and should be ready for human use "within two and half years".

Biomedical firm Carmat, a start-up funded by the European space and defence group EADS, France's state innovation agency, venture capital firm Truffle and Carpentier himself, are to produce the heart at a site near Paris.

Several teams around the world are racing to develop a total artificial organ able to permanently replace the human heart, in answer to a worldwide shortage of heartdonors. ▲

(Continued from Page 1) successful kidney transplantation," Woodle says. "This study demonstrates that elimination of even small, daily prednisone (pred-ne-zone) doses does not compromise results while minimizing weight gain, diabetes and bone complications."

Corticosteroids were the first anti-rejection drug used in transplant patients, dating back to the first transplant surgeries over 50 years ago.

Traditionally patients who have undergone organ transplantation have required life-long steroid treatments given in combination with other drugs that help suppress the body's immune system and allow the transplanted organ to function properly.

However, the steroid treatment—given as the oral drug, prednisone—can cause serious side effects including cardiovascular disease, high cholesterol and blood pressure, weight gain, diabetes, bone weakness and cataracts.

To test the effectiveness of early steroid elimination, researchers studied 397 patients from 25 U.S. kidney transplant centers for a five-year period following transplant. They administered low doses of prednisone to one group of transplant patients while the other group of patients received a placebo.

The results showed that early steroid elimination caused reduction in many steroid-related complications, even when prednisone was given in very low doses.

Kidney function was similar in both patient groups. "By demonstrating identical kidney transplant survival and function for five years, we now have a scientific basis for offering steroid-free therapies in kidney recipients," Woodle says.

However, he notes that risk of rejection episodes in patients was slightly increased with early (Continued on page 3)

## LI TRIO Board Of Directors

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LI TRIO

*The Long Island Chapter of  
Transplant Recipients International Organization  
Requests the Pleasure of Your Company at Our  
Annual Holiday Party Dinner Dance  
On Saturday, The Sixth of December,  
Two-thousand and Eight  
At Seven O'clock in the Evening  
The Elks Club, Grand Ballroom  
901 Lakeville Road  
New Hyde Park, New York*

*We look forward to celebrating with you.  
The favor of a reply is requested by November 15, 2008  
\$30.00 per person, \$15.00 per child under 10*

*M* \_\_\_\_\_

*Number attending \_\_\_\_\_ Amount enclosed \_\_\_\_\_*

*I am unable to attend but would like to make a  
Contribution / donation of \$ \_\_\_\_\_*

*Please make checks payable to: LI TRIO  
Mail to: LI TRIO, Mr. and Mrs. Jerry Sosna, 14 Webb Hill Road  
Great Neck, New York 11020*

(Continued from page 2) steroid discontinuation. "These episodes were mild and easily treated," he says.

He adds that although the five-year kidney transplant survival and function were identical between those who received prednisone and those who received other immunosuppressive drugs in this study, it doesn't mean that it will be the same in 10 or 20 years.

"Our hope is that with our modern anti-rejection drugs and new drugs being developed, even this small risk of increased rejection combined with longer-term results will not be changed," he says.

The results of this study are now being used in different transplant populations, resulting in much lower prednisone doses or complete elimination with fewer complications.

This study also involved researchers from the University of Wisconsin; the University of Utah; the Methodist Hospital, Houston; and Weill Cornell Medical College.

Please check out  
[www.litrio.org](http://www.litrio.org)  
for additional news.

This study was funded by Astellas Pharma U.S., Inc." Study authors cite receipt of payment for participating in pharmaceutical-sponsored speaking engagements about immunosuppressants. This article's source is from materials provided by University of Cincinnati.▲

### 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)

## Transplantation: 'Molecular Miscegenation' Blurs The Boundary Between Self And Non-self

Source: Federation of American Societies for Experimental Biology

A new discovery by London biologists may yield new ways of handling the problem of transplant rejection. In a research article published in the November 2008 print issue of The FASEB Journal the scientists confirm the two-way transfer of a molecule (called "MHC") that instructs the immune system to tell "self" from "non-self."

By disrupting the transfer of this molecule, newly transplanted organs should become "invisible" to the host's immune system. Such an advance would be considered a major medical breakthrough because current methods of preventing organ rejection involve weakening the host's immune system, which can lead to life-threatening infections.

"The medical potential of this finding is enormous," says Gerald Weissmann, M.D., Editor-in-Chief of The FASEB Journal, "Understanding molecular miscegenation should not only make transplantation more widespread and effective, but also shed light on how microbes disrupt our body's immune apparatus for distinguishing self from non-self."

The researchers made this discovery when they transplanted kidneys or hearts from one set of mice into another, with each set of mice having a different version of the molecule being studied. The researchers then conducted tests to see if the molecules were transferred. In the recipient mice, the donated kidneys or hearts and the host tissue expressed both types of molecules. This is the first time that this transfer has been shown to happen in a living system.

Wilson Wong, senior researcher on the study from King's College London, states that although the findings are tantalizing, they represent only a very primitive understanding of this phenomenon. Nevertheless, he hopes "that this study will lead to a better understanding of the immune system to benefit the development of new therapies in areas related to transplantation."▲

## President George W. Bush signed into law the Stephanie Tubbs-Jones Congressional Gift of Life Medal Act

WASHINGTON, D.C. – U.S. Senator Sherrod Brown (D-OH) today announced that President George W. Bush signed into law the "Stephanie Tubbs Jones Gift of Life Medal Act." This bill, authored by Brown in the Senate, is based on legislation introduced by Tubbs Jones that would award a Congressional medal to organ donors.

"Stephanie led by example," said Brown. "Along with millions of Americans, Stephanie made the decision to donate her organs. These contributions should be encouraged and recognized."

The Stephanie Tubbs Jones Gift of Life Medal Act of 2008 makes any organ donor in the nation – and the family of any organ donor – eligible for a Stephanie Tubbs Jones Gift of Life Medal. The organ donor's family would receive the medal through the Organ Procurement and Transplantation Network under the Secretary of Health and Human Services. Congresswoman

Tubbs Jones, who represented Ohio's 11th Congressional District since 1998, passed away on August 20 after suffering a brain aneurism. Tubbs Jones entered public life in 1982 when she was elected to serve on the Court of Common Pleas. In 1991, she went on to become the first woman and the first African-American to serve as Cuyahoga County Prosecutor, a position she held for eight years. In the House of Representatives, Tubbs Jones championed improved access to health care, organ donation awareness, improved voting rights, and quality education for all.

### 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

Four policy proposals are now being offered for public comment. These proposals were developed by a number of OPTN/UNOS committees. We are requesting your input on these proposals by January 2, 2009.

Go to <http://unos.org/policiesAndBylaws/publicComment/proposals.asp>

### LI TRIO'S ANNUAL HOLIDAY PARTY

Come join us on Saturday evening December 6, 2008 from 7 PM to 11 PM for a lovely hot buffet, DJ entertainment as well as some special surprises. The party will be held in the beautiful Catering Hall of The Elks Club at 901 Lakeville Road, New Hyde Park.

Invitations were sent under separate cover via U.S. Mail. Call 516.482.2908.▲

Anti-rejection Drug May Increase Risk Of Diabetes After Kidney Transplant. visit [www.litrio.org](http://www.litrio.org) for the story.

Double Heart Transplant for infant twins- Please visit [www.litrio.org](http://www.litrio.org) for the full story.



*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.*

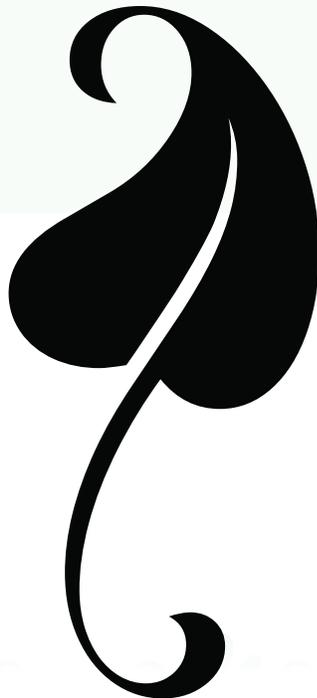
*Give my sins to the devil.*

*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.*



The SUNY Oneonta Women's Lacrosse team of which Brianne Ruzek is co-captain participated in a Kidney Walk. One of the teammates had this to say about it:

"Today we took part in a charity fundraising kidney walk. As we anxiously waited to register at 11 am, we drank a lot of free coffee. Then at 1 pm we started to make our way around the Alumni Field House.

There was a live band jamming as we walked and conversed lap by lap. Everyone was in a happy-go-lucky spirit. Also, coach took some phenomenal pictures. It was a great experience had by all!" ▲



## New York State Donate Life Registry

Registry of Consent as of July 23, 2008!

BY JORDAN LITE DAILY NEWS STAFF WRITER

Thought you'd made it clear on your driver's license that you were an organ donor? Turns out, you hadn't actually consented; your family could still override your wishes. Beginning Wednesday, a new system to register donors will eliminate that layer of red tape. If you sign up, instead of asking your loved ones for consent when you die, transplant coordinators will notify them that you are a donor.

"Family permission wouldn't be required to proceed with an organ donation," said Claire Pospisil, a spokeswoman for the state Department of Health. "The individual's consent would suffice." The change, approved by the Legislature in 2006, makes New York the 44th state to establish such a "registry of consent," rather than rely on its eight-year-old "registry of intent." Right now, just 8% of New York residents are donors, and 9,000 are waiting for organs.

"It's a very substantial change, legally," said Elaine Berg, director of the New York Organ Donor Network. "So many times people have said to us, 'What? My family, my parents, my husband can say no after I signed on?' and until now the answer to that was yes, unfortunately," she said.

"We hope the new concept will make people secure that if they donate, that their wishes will be respected." Transplant coordinators will still ask for family permission of

New Yorkers in the old registry, said Julia Rivera, a spokeswoman for the donor network.

The Health Department will send people in that registry a letter explaining how to join the new one. In the interim, residents can download and mail in a form to join the Donate Life Registry.

Soon, they will be able to register online through the Health Department. Official organ-procurement organizations and the Department of Motor Vehicles also will help register donors.

You can find the form by visiting our organizations's website at [www.litrio.org](http://www.litrio.org). ▲

### Make Your Voice Heard About Allocation for Kidney Transplant

Should the oldest person be lowered to the bottom of the kidney transplant waiting list? Should the sickest candidates be bumped to the top of the waiting list? The youngest? When there aren't enough organs to go around, it's a formidable challenge for physicians and policymakers to balance the need to be fair and efficient when deciding how to allocate donated kidneys.

To improve the national policy for allocation of deceased donor kidneys, the Organ Procurement and Transplant Network/United Network for Organ Sharing (OPTN/UNOS) is examining and modeling various methods

If you have something to say on the subject, the time to speak up is now. As part of this ongoing process, the OPTN/UNOS Committee is soliciting public input for ideas and commentary that could inform a future policy proposal.

Responses will be incorporated into additional public discussion, including a public forum tentatively scheduled for January 26, 2009.

You can let the policymakers know what you think by responding to a series of questions.

Please visit [www.litrio.org](http://www.litrio.org) for more information on the Kidney Allocation Policy Development and to submit your feedback. ▲

## Office of Senator

### Kemp Hannon

#### FOR IMMEDIATE RELEASE

### Hannon legislation makes it easier to become organ donor

Senator Kemp Hannon (R-Garden City), Chair of the Senate Health Committee, announced legislation he sponsored to make it easier to become an organ donor was signed into law by Governor David A. Paterson.

The new law provides an option to register and enroll in the "New York State Donate Life Registry" on statewide voter registration applications. Senator Hannon said, "thousands of people die every year waiting for donated organs. In New York alone, as demand for organs outpaces supply, nearly 9,000 people are on a waiting list for donated organs."

One organ donor can save or enhance the lives of up to 50 people through an organ or tissue donation that may restore eyesight, help fight infections in burn patients, or delay the onset of organ failure.

In February, Senator Hannon joined with members of the Long Island Transplant Recipients Organization to promote organ donation throughout New York State. At the time, Senator Hannon also urged donors to let their families know of their intentions and to put their wishes in writing so they cannot be disputed.

Senator Hannon said, "This law reduces barriers for individuals to become organ donors by allowing for convenient registration and enrollment in the Donate Life Registry for the many New Yorkers who fill out voter registration applications every year."

More information at [www.litrio.org](http://www.litrio.org) ▲



## LI TRIO MEMBER PROFILE:

### From Apprehension To Appreciation

By Karen Paulick

Life has new meaning for me since my liver transplant in September 1996. I had hoped when I was first diagnosed with Primary Biliary Cirrhosis in 1986 that medical technology would come up with a cure for the condition, so I wouldn't need a transplant. I wanted to learn everything there was to know about this disease, so I joined the American Liver Foundation. This group was extremely supportive and helped me to deal with this new life-threatening problem. At first, I must say I thought I would beat this "thing." I did everything I could to improve my set of circumstances, including eating well, getting lots of exercise, and maintaining a positive attitude. I even tried some of the techniques taught by Dr. Bernie Siegal, such as relaxation and imaging. These all worked to help me deal with my situation as best as I could, but nevertheless the condition of my liver continued a slow downward spiral.

I had been an elementary school teacher for 15 years, when my son was born in 1989. At that time I decided to leave teaching. Some of the symptoms of the disease, including fatigue and itching, were becoming unbearable. I decided that what energy I did have should be devoted to raising this little "miracle" of mine. I continued to see my doctor in New York, and we tried new medicines. Still, I was hopeful that I could put off getting a transplant for as long as possible. My problems escalated in the spring of 1995. I was spending a lot of time going to the doctor for stomach problems and was diagnosed with ulcerative colitis. This was causing me to lose weight and to have even less energy. Finally, in February of 1996, I was advised by doctors to get to a hospital to be evaluated for a liver transplant. I chose the University of Pittsburgh Medical Center, and went there immediately.

Going through all the tests and evaluations was time consuming. I spent several days in Pittsburgh having my body examined and going

through lots of blood work! (I hate blood work!)having my body examined and going through lots of blood work! (I hate blood work!)

When I left there I knew that the time was getting close. I prepared my family and hoped for the best.

I got the call that a donor liver was available, and the operation was performed on Sept. 8, 1996. I was a success, things went smoothly, and I was released from the hospital within two weeks. Now that I've experienced a transplant and its benefits, I really believe that receiving an organ transplant is truly a miracle. I think about it often and marvel that doctors are able to give new life to someone.

I feel that I have energy I never knew was possible. I am active and am exercising regularly and enjoying life to its fullest. If anyone asked me if I would I go through the surgery again, I'd say, "Absolutely!"

I wish I had done it sooner. Before my transplant I truly thought the experience would be much worse. I really haven't had any side effects from the medicines except for some weight gain from prednisone. Everyone tells me I look wonderful. This is a pleasant remark to hear since I looked and felt quite sick before the operation.

Now I try to spread the word about organ donation to everyone I meet. I believe I have an obligation to my donor and donor family to make other people aware of organ donation. I'm so pleased to be a member of Long Island Trio but unfortunately never get to the meetings due to the distance from my home.

Since I can't do much on the meeting level, I do all that I can to spread the word about organ donation to friends, family and anyone who will listen. I had a magnetic sign made for the back of my van that says, "Make a Miracle - Be an Organ Donor" and has the TRIO tree of life logo. I hope people will be affected when they see it. Sitting in traffic on the LIE should be good publicity.

It's my hope is everyone knows that donating organs saves lives. It sure saved mine!

Karen Paulick lives with her husband Walter and son Jeffrey in Riverhead, New York. She volunteers at her son's elementary school, teaches Sunday school and loves to sew. ▲

## Extend Immunosuppressive Drug Coverage

LI TRIO supports Medicare's coverage of immunosuppressive medications for all transplant recipients.

LI TRIO is building support for current bills that will extend Medicare coverage for life-saving immunosuppressive drugs for the life of kidney transplant. If passed, kidney recipients could continue to receive these drugs under Medicare Part B with and will continue to pay the usual premium.

Organ transplant recipients must take immunosuppressive drugs for the life of the transplant to prevent the body from rejecting the organ. Currently, Medicare pays for most kidney transplants but covers drugs for only 36 months after the transplant as part of the Medicare ESRD benefit.

After that, kidney recipients must pay for immunosuppressive drugs through private insurance, public or pharmaceutical programs or pay out-of-pocket (Medicare covers drugs without a time limit if the patient qualifies because of age or disability status).

Immunosuppressive drugs are expensive, but the alternative is even more costly. If the kidney transplant fails, the person returns to dialysis at a cost of over \$68,600 per year to Medicare. And because dialysis is physically draining, quality of life often suffers too.

As reported on [www.litrio.org](http://www.litrio.org), similar legislation has been introduced in the House of Representatives, and LI TRIO sent over 600 letters of support in August and September. Now we need your help to build Senate support for this important legislation.

Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients S 2320-Senate  
HR 3282- House of Representatives ▲

USA waiting list candidates:  
100,447 as of this writing

Transplants January 2008  
16,386

## HAPPY NOVEMBER RE-BIRTHDAYS!

Anna Abbate	November 11, 2000	Liver
Susan Beck	November 16, 2002	Kidney
Melissa Brennan	November 17, 1992	Kidney
Hyman Easton	November 21, 2004	Kidney
Tonia Finkelstein	November 26, 1997	Kidney
Debbie Greenberg	November 21, 2004	Heart
Joe Mocniak	November 1, 1993	Kidney
Fran Oreckinto	November 25, 2000	Kidney
Ralph Zegel	November 26, 1997	Heart
Bella Rose Zuccato	November 30, 2006	Liver

## SUBCOMMITTEE CHAIRPERSON CONTACT

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E-Mail Tree—Joe LaBarbera	litrio@gmail.com
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Website Design/Legislative Initiatives & Guest Speakers—Mike Sosna	mike@sosproductions.com
Special Projects—Ed Burki	516-620-3700
Rose Garden Ceremony—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

Angela Barbosa  
Laura Overton LCSW  
Tara Starna  
Angelo Stekardis

VISIT LI TRIO ONLINE: [www.litrio.org](http://www.litrio.org)

E-MAIL LI TRIO: [mike@sosproductions.com](mailto:mike@sosproductions.com)



**LI TRIO**

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