



# Transplant Times

Newsletter of the Transplant Awareness Organization of Greater Rochester

Providing support, understanding, education and resources for transplant recipients candidates and their families.

January / February 2012

www.tao-rochester.org

1.888.664.1463

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### Membership Meeting Guest Speakers / Topics

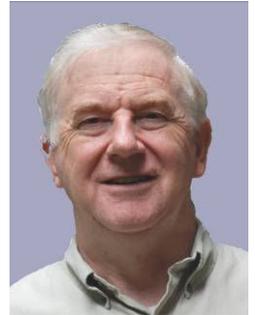
**January 14, 2012**  
Holiday Party

**February 20, 2012**  
Dr. Aizhong Li  
Acupuncture, its theory, practice and benefits

### TAO Meets

**3rd Monday of the Month**  
**Christ Episcopal Church**  
**Fellowship Room**  
**36 South Main Street**  
**Pittsford, NY**

## A Message from the President



As I sit here writing this note in late December, the Rochester landscape remains green, and the hoped for white Christmas is beginning to look very doubtful. If you are not into skiing, which I am not, the one great compensation for living in Rochester is the expectation that Santa Claus will arrive amidst gently falling snowflakes. However, with or without snow, I hope this holiday season brought you joy and time with family and friends, and that the New Year will bring with it the blessings of good health. If you are on the waiting list for a transplant, may you be blessed with the Gift of New Life in this New Year.

Some months ago, the TAO board conducted a self assessment looking at the things that the organization does well and those things that it could improve upon. In December we held a workshop to discuss this further, and to identify some explicit actions that would improve the organization in areas where we felt it was falling short. **We continue to seek suggestions from all of our membership on making the organization more effective.** If you have some ideas please send them to me in an email at GeoffF21@yahoo.com and I will bring them to the attention of the board at our next meeting. We welcome any and all input.

Let me close by wishing you all a Happy and Healthy New Year. I look forward to seeing many of you at our monthly membership meetings which resume again in February.

*Geoff Foley*

## Board of Directors & Officers

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## 'Heart In A Box' Organ Preservation Helps Save Portsmouth Mom Of Two

First Posted: 01/4/12 02:25 PM ET Updated: 01/4/12 04:06 PM ET

Amy DeStefano started off the New Year with a new lease on life when she got the heart for which she had waited three years.

After a virus damaged her heart in 2009, the 40-year-old mom of two anxiously waited for her name to climb to the top of the donor list, Seacoastonline.com reports. When DeStefano finally got her match on Dec. 30, she was the first person in New England to get a transplant in such unconventional packaging.

The organ was preserved with the relatively new "heart in a box" technology, which relies on a machine to keep the heart beating long after a standard cooler can.

"Amy is a pioneer," DeStefano's sister, Lisa, told Seacoastonline.com.

Such pioneering may give way to saving many more lives.

Because the standard cooling method only preserves a heart for about six hours, viable organs are often damaged, or can't make their way in time to the recipients in need, according to UCLA Health.

"If we're able to safely transport donor hearts across longer distances, from the East Coast to West Coast for example, we may be able to increase the pool of donor hearts available to patients," Abbas Ardehali, M.D., surgical director of the UCLA Heart and Lung Transplant Program, told the news outlet.

Donate Life America, a nonprofit that facilitates donor registries and promotes donor education programs, currently has 112,178 people waiting for transplants. The organization helped foster 28,665 organ transplants in 2010, a statistic that could very well increase with the help of this groundbreaking preserving technology.

Though the idea of a preserved beating heart may cause some to shudder, families waiting for a transplant interpret the procedure in a different way, writes Arthur Caplan, Ph.D., director of the Center for Bioethics at the University of Pennsylvania, in an MSNBC editorial.

"There is no denying that, as Poe understood, the image of the beating heart outside the body is macabre," Caplan writes. "That is until you imagine a family grieving over the loss of a loved one because there was no heart to transplant. That truly nightmarish image is the one this new machine may help prevent."

## United Network for Organ Sharing

Candidates listed as of 1/6/2012

**90,470** Kidney  
**16,097** Liver  
**3,115** Heart  
**2,102** Kidney/Pancreas  
**1,668** Lung  
**1,325** Pancreas  
**275** Intestine  
**62** Heart/Lung

112,427 **TOTAL**

Total may be less than sums due to patients in multiple categories

[www.unos.org](http://www.unos.org)

## Transplant Anniversaries

ELIZABETH BRIAN	LIVER	January 2005
JANE CLEWELL	LIVER	January 2005
HELEN COX	KIDNEY/PANCREAS	January 1996
DANIELE DIIULIO	LIVER	January 2003
DAWN MESCHI	KIDNEY	January 2001
ANN MARIE SCROGER	LIVER	January 2007
PAT STEWART	KIDNEY	January 1994
GUY VALONE	KIDNEY	January 2009
JERRY BLUFF	LUNG	February 2004
WAYNE DICKINSON	LIVER	February 1997
MATTHEW FELO	LUNG	February 2007
PATRICIA LEGGE	KIDNEY	February 1996
SHIRLEY NEWMAN	KIDNEY	February 2008
JOSEPH NOLAN	KIDNEY	February 2006
AISHA O'MALLY	HEART	February 2004
SALLY PALOZZI	LIVER	February 2007
GREG POST	KIDNEY	February 2008
LANA WAY	KIDNEY	February 2008
JOHN WOOD	LIVER	February 2009

# TRANSPLANT GAMES OF AMERICA

## *Bowling Fundraiser*

### **Sunday**

February 12, 2012

**50/50 Raffle**

#### Squad Times:

12:30 p.m. – 2:00 p.m.

2:30 p.m. – 4:30 p.m.

5:00 p.m. – 7:00 p.m.



*\$10/Bowler, Pizza Included*  
*Cash Bar*

For information please contact Tim Parks @ [tparks@paychex.com](mailto:tparks@paychex.com) or  
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Parkview Lanes × 4306 Culver Rd × Irondequoit, NY

## Where Germs Lurk on Planes

*What to Do When Stuck at 30,000 Feet Next to Sneezers and Coughers*

By SCOTT McCARTNEY

It's a common complaint: Fly on a crowded plane and come home with a cold. What's in the air up there?

Air travelers suffer higher rates of disease infection, research has shown. One study pegged the increased risk for catching a cold as high as 20%. And the holidays are a particularly infectious time of year, with planes packed full of families with all their presents and all those germs.

Air that is recirculated throughout the cabin is most often blamed. But studies have shown that high-efficiency particulate air (HEPA) filters on most jets today can capture 99.97% of bacterial and virus-carrying particles. That said, when air circulation is shut down, which sometimes happens during long waits on the ground or for short periods when passengers are boarding or exiting, infections can spread like wildfire.

One well-known study in 1979 found that when a plane sat three hours with its engines off and no air circulating, 72% of the 54 people on board got sick within two days. The flu strain they had was traced to one passenger. For that reason, the Federal Aviation Administration issued an advisory in 2003 to airlines saying that passengers should be removed from planes within 30 minutes if there's no air circulation, but compliance isn't mandatory.

Much of the danger comes from the mouths, noses and hands of passengers sitting nearby. The hot zone for exposure is generally two seats beside, in front of and behind you, according to a study in July in the journal *Emerging Infectious Diseases*, published by the U.S. Centers for Disease Control and Prevention.

A number of factors increase the odds of bringing home a souvenir cough and runny nose. For one, the environment at 30,000 feet enables easier spread of disease. Air in airplanes is extremely dry, and viruses tend to thrive in low-humidity conditions. When mucous membranes dry out, they are far less effective at blocking infection. High altitudes can tire the body, and fatigue plays a role in making people more susceptible to catching colds, too.

Also, viruses and bacteria can live for hours on some surfaces—some viral particles have been found to be active up to a day in certain places. Tray tables can be contaminated, and seat-back pockets, which get stuffed with used tissues, soiled napkins and trash, can be particularly skuzzy. It's also difficult to know what germs are lurking in an airline's pillows and blankets.

Research has shown how easily disease can spread. Tracing influenza transmission on long-haul flights in 2009 with passengers infected with the H1N1 flu strain,

Australian researchers found that 2% passengers had the disease during the flight and 5% came down within a week after landing. Coach-cabin passengers were at a 3.6% increased risk of contracting H1N1 if they sat within two rows of someone who had symptoms in-flight. That increased risk for post-flight disease doubled to 7.7% for passengers seated in a two-seat hot zone.

The epidemic of severe acute respiratory syndrome (SARS) in 2002-03 suggested a wider exposure zone, however. On one flight studied, one passenger spread a particular strain to someone seated seven rows away, while people seated next to the ill passenger didn't contract the disease.

That said, most people sitting near someone who is ill probably won't get sick. "When you get aboard an aircraft, most of us don't have a say on who we sit next to. But that doesn't doom you to catching the flu," said Mark Gendreau of Boston's Lahey Clinic Medical Center.

In 2005, he was part of a team that published a paper in the *Lancet* that concluded the perceived risk for travelers was higher than the actual risk, and that's still the case today, he said.

Even so, there are some basic precautions passengers can take to keep coughs away.

- **Hydrate.** Drinking water and keeping nasal passages moist with a saline spray can reduce your risk of infection.
- **Clean your hands** frequently with an alcohol-based hand sanitizer. We often infect ourselves, touching mouth, nose or eyes with our own hands that have picked up something.
- Use a **disinfecting wipe** to clean off tray tables before using.
- Avoid **seat-back pockets**.
- **Open your air vent**, and aim it so it passes just in front of your face. Filtered airplane air can help direct airborne contagions away from you.
- **Change seats** if you end up near a cougher, sneezer or someone who looks feverish. That may not be possible on very full flights, but worth a try. One sneeze can produce up to 30,000 droplets that can be propelled as far as six feet.
- Raise concerns with the crew if **air circulation** is shut off for an extended period.
- Avoid airline **pillows and blankets** (if you find them).

"If you take the proper precautions, you should do quite well," said Dr. Gendreau. "In most of us, our immune system does what it was designed to do - protect us from infectious insults."

### Hidden Dangers in Security

You think the plane is bad? Security checkpoints harbor a host of hazards as well, researchers say.

People get bunched up in lines, where there is plenty of coughing and sneezing. Shoes are removed and placed with other belongings into plastic security bins, which typically don't get cleaned after they go through the scanner.

A National Academy of Sciences panel is six months into a two-year study that is taking samples at airport areas to try to pinpoint opportunities for infection.

With limited resources, airports and airlines have asked researchers to help figure out where best to target prevention, said Dr. Mark Gendreau of Boston's Lahey Clinic Medical Center who is on the panel.

Check-in kiosks and baggage areas are other prime suspects in addition to security lines, he said.

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## Tops Never Stops . . .

Tops cards help TAO raise money. The Tops Gift Card Program allows our nonprofit organization to earn a 5 % return by selling Tops Cards. The more we sell, the more we earn. The cards are available in \$25s and \$50s increments. Contact Bonnie Haefner at 391-3555.

## United Way Reminder:

TAO is recognized as a "donor designation eligible agency for the United Way campaign" Our agency number is 2493.



United Way  
of Greater Rochester

## Are you interested in becoming more active in your organization?

Have you ever thought about becoming a member of the Board and being active in shaping your organization? Now's the time to get involved. Elections are rapidly approaching and we are looking for new Board members. The Board meets once a month prior to the general membership meeting. There are some activities and responsibilities outside of the board meeting that entail some time. TAO is looking for committed people that are willing to get involved and work to keep the organization viable. Please contact your president, Geoff Foley if you are willing to be nominated for a board position.

### Join a Committee

Sunshine , Newsletter,  
Membership, Awareness  
Interested? Call **1.888.664.1463**

## Shopping at Amazon?

TAO can benefit from your purchases. Simply go to [www.tao-rochester.org](http://www.tao-rochester.org) and click on the Amazon widget and do your shopping!

## Transplant Times

### Submission Deadline

For March/April 2012 issue:  
Monday, February 6, 2012

Articles /ideas email to:

[auggieday@aol.com](mailto:auggieday@aol.com) or send by mail to:

TAO, PO Box 23552, Rochester, NY 14692-3552

## New therapy found for rare lung disorder

University of Cincinnati Academic Health Center CINCINNATI—Researchers at the University of Cincinnati (UC) and Cincinnati Children's Hospital Medical Center have found that the FDA-approved drug sirolimus, used primarily to prevent rejection in organ transplant patients, stabilized lung function in women with lymphangiomyomatosis (LAM).

The Multicenter International LAM Efficacy of Sirolimus (MILES) trial was the first randomized, controlled study designed to develop a therapy for this life-threatening illness, which currently has no cure or treatment. These results are being reported in the March 16, 2011, online edition of the *New England Journal of Medicine*. LAM is a progressive, cystic lung disease that occurs almost exclusively in women. In LAM, an unusual type of smooth muscle cell grows uncontrollably and spreads from an unknown source to restricted areas in the body, including the lungs, lymph nodes and vessels and kidneys, limiting the flow of air, blood and lymph. Shortness of breath and recurrent lung collapse are common in patients with LAM, and until now, lung transplantation has been the only hope for patients who progress to respiratory failure.

"LAM affects about five people per million and occurs in 30 to 40 percent of women with tuberous sclerosis complex (TSC), a genetic disorder which also causes tumors to form in the kidneys, brain, heart and other organs," says Frank McCormack, MD, director of the pulmonary, critical care and sleep medicine division at UC and lead investigator on the study.

"Sirolimus, otherwise known as rapamycin, showed promise for patients with LAM in a pilot study conducted in Cincinnati and reported in the *New England Journal of Medicine* in 2008, but the relative risks and benefits of sirolimus for treatment of patients with this condition have remained unclear. In this international, multicenter study, we evaluated the safety and efficacy of one year of sirolimus in stabilizing and/or improving lung function in women with LAM."

McCormack says LAM cells isolated from lung lesions have TSC mutations and exhibit activation of a key sirolimus-sensitive growth pathway. When exposed to the drug in culture, the growth of LAM cells is stopped. Experiments in TSC animal models have also demonstrated that sirolimus shrinks tumors in the liver and kidneys.

The MILES study was conducted within the National Institutes of Health (NIH)-supported Rare Lung Diseases Consortium, led by UC and Cincinnati Children's physician and pulmonary biologist Bruce Trapnell, MD, and co-directed by McCormack, and involved 13 institutions from around the world. Data was reported using Internet

-based systems connected to a centralized, Internet-based data coordinating center headed by Jeffrey Krischer, MD, at the University of South Florida, Tampa.

"The trial included a screening visit and a year-long double blind, placebo-controlled treatment period, followed by a year of observation," says McCormack.

All eligible participants were female, aged 18 years or older and had a confirmed diagnosis of LAM with abnormal lung function.

Patients meeting the criteria were randomly assigned to either receive an initial dose of oral sirolimus at 2 milligrams per day or a matched placebo, and sirolimus levels were measured at each follow-up visit. Results were revealed only to an independent medical monitor who made dosing recommendations to maintain serum levels within a pre-specified target range.

A total of 89 patients with LAM were enrolled in the United States, Canada and Japan. Patients underwent baseline lung function testing, and lung function and exercise outcomes were measured over the course of six visits in the first year. Participants were also given questionnaires to determine how their symptoms changed throughout the course of the study. Researchers found that sirolimus stabilized lung function and was associated with improvement in measures of functional performance and quality of life.

Sirolimus also reduced levels of serum vascular endothelial growth factor-D, or VEGF-D, a protein that is known to be elevated in LAM. VEGF-D promotes the growth of lymphatic vessels and can be involved in the spread of cancers.

"After discontinuation of sirolimus, lung function decline resumed and paralleled the placebo group," McCormack says. "Adverse events were more common with sirolimus, but the frequency of serious adverse events between the groups was not different."

McCormack says that these results suggest that sirolimus may be useful as therapy for moderately severe LAM-related lung disease.

"LAM is typically slowly progressive, and sirolimus therapy has risks, so treatment decisions should be individualized. Care must be taken in generalizing the results to those with milder or more severe lung disease due to LAM," he says. "Also, additional trials are needed to determine the optimal dose and duration of treatment with sirolimus. Given the toxicity profile of the drug during a one-year period, the long-term safety of this approach over an extended course must be carefully evaluated."

The trial involved efforts by the LAM Foundation that lobbied for the NIH's attention, organized and recruited patients and supported pivotal basic and clinical research that formed the scientific basis for the study.

This study was funded by the NIH Office of Rare Disease Research, the Food and Drug Administration, the LAM Foundation, the Japanese Ministry of Health,

## Save The Date . . .

**Euchre Tournament, March 19**  
*(Details to follow)*

## Wishes of Wellness To...

Our healing thoughts and prayers go out to Jack Wesline and Dan Newhouse



## Gift IDEAS . . . .

**A contribution to TAO in honor of or in memory of a loved one, special person or relative is always a thoughtful gift. It is a gift of caring that you can give on any occasion - a birthday, an anniversary or a special holiday.**

Please make your check payable to:  
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Mail to: TAO, PO Box 23552  
Rochester, NY, 14692-3552

## Contributions

*We wish to acknowledge and thank the following individuals and / or organizations who made contributions to TAO.*

*If we omitted you, please let us know so that we may post in the next issue. **THANK YOU.***

Shirley Tuites in memory of Dick Tuites  
Pricilla Imburgia in memory of Frank Imburgia  
Patricia Bianchi to the Blanket Project  
Bernie Pierce  
Joanne Rourke  
Ernst Baier  
Tom & Chris Arcara  
Norman and Phyllis Breen  
Peter Davis  
Rob Kochik  
In Memory of Linda Jordan:  
Duane P. Jordan  
Niacet Men's Club  
United Steelworkers' Union, Local 4-0058

Labour and Welfare, the Canadian Institutes of Health Research, Cincinnati Children's, UC, the Tuberos Sclerosis Alliance and Vi and John Adler and the Adler Foundation.

Pfizer, maker of sirolimus, provided the drug and financial support but had no role in study design, conduct, analysis or reporting. McCormack cites no conflict of interest.

Regulatory oversight was provided by the National Center for Research Resources of the NIH. Participating centers included UC; Cincinnati Children's; the University of Toronto, Canada; the University of Texas Health Science Center at Tyler; the University of California at Los Angeles; Oregon Health and Science University, Portland; Niigata University Medical & Dental Hospital, Japan; National Hospital Organization Kinki-Chou Chest Medical Center, Osaka, Japan; the National Jewish Medical and Research Center, Denver; the National Heart, Lung, and Blood Institute, Bethesda; Medical University of South Carolina, Charleston; the Cleveland Clinic Foundation; and Brigham and Women's Hospital, Boston.

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katie.pence@uc.edu  
513-558-4561

## TAO Organ Specific Support Groups

### **"OPEN AIRWAYS" - Lung Gathering Group**

Tuesday, January 17th Noon Mike's Diner  
Monday, February 13th Noon Mike's Diner  
Monday, March 6th Noon Mike's Diner  
Contact Joanne Schum at 585-671-7635 or  
twoluckylungs@juno.com if interested in attending.  
MIKE'S NEW YORK DINER is at 3423 Winton Place  
(S. Winton Road Area, and Brighton Henrietta Town  
Line Road area)



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TAO / Rochester Membership Application

No one is denied membership because of financial considerations

- DUES: \$20 Family \$100 Institution New Member Renewal Date unable to make dues payment at this time

Extra contributions to help our organization are always welcome, and are tax-deductible. Make checks payable to: TAO of Greater Rochester, PO Box 23552, Rochester, NY, 14692-3552.

Name (please print) Spouse/companion

Address City State Zip

Phone ( ) E-mail

- Candidate Recipient Family Member Donor Family Friend Professional

Candidate/Recipient information: # of Transplants Hospital

Date(s) Organ(s)/Tissue(s)