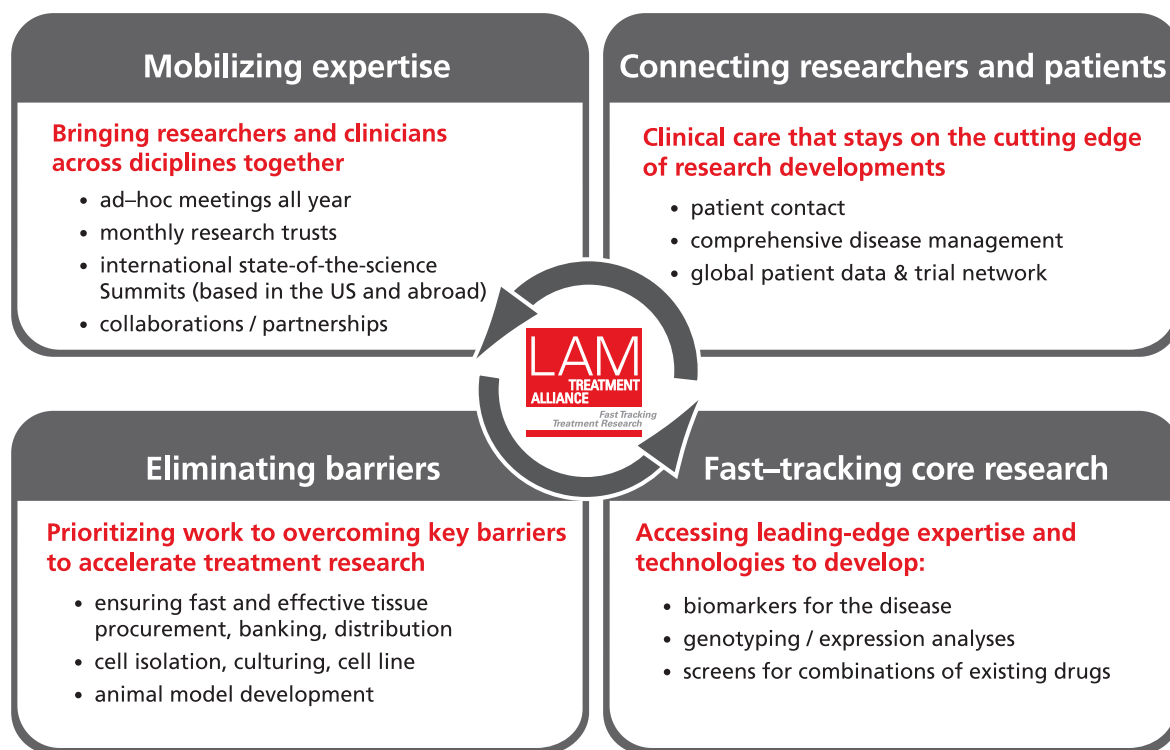


Welcome and *Thank You!*

Welcome to the LAM Treatment Alliance's (LTA) first issue of *Fast Track News!* We hope you will enjoy learning about the enormous impact your support has had on our efforts to fast track treatment research. We thank you for your generosity and your patience as we work hard to advance our mission. The time we have dedicated to advancing research and connecting patients with their needed care teams has been consuming, yet immensely satisfying.

Thanks to your support we have raised more than \$1.8 million in our brief existence. Your donations have gone to work in a real way, right away. We are making remarkable strides with more than 11 research projects currently underway. Through the efforts of our exemplary Scientific Advisory Board we have grown to become a critical convener in the field, forging strong and strategic collaborations with academia, the pharmaceutical

There is no cure for LAM and currently no effective treatment. However, there are great grounds for promise that a treatment can be found.



industry and government agencies. As shown above, our proactive approach to LAM research gives structure to our fast-tracking efforts and ultimately ensures maximum impact of your support. An added benefit is that these efforts help to enhance science beyond LAM, leading to improved treatments and cures for other more common, life-threatening diseases.

The LAM Treatment Alliance is lean: no bureaucracy, no bloated chain of command, no waste. Our efficient organizational structure helps us move LAM science forward.

On the research front, we are idea rich. As developments emerge from the scientific work underway, we respond immediately. We have additional researchers eager to work. Research projects cost on average, \$150,000 each. We fund those projects with the potential to lead to our overall mission – a treatment, and ultimately a cure for lymphangioleiomyomatosis (LAM) in the fastest time possible. We are truly grateful to our donors and the scientists who make our mission achievable.

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Our Mission and *Core Values*

Our mission is to find a treatment for LAM in the fastest time possible by supporting an aggressively funded high-impact research strategy. Our goal is to stay lean without sacrificing the quality of research or the integrity of the scientific process. Excellence, impact and collaboration are our core values.

Help us save resources! Please e-mail us at Newsletter@LAMTreatmentAlliance.org if you would prefer to receive future issues of *Fast Track News* via e-mail.

A Letter from the Executive Director

Dear Friends –



Amy Farber, PhD

As many of you know, in April 2005, at 35 and newly married, my husband Michael and I were about to start a family when I received the startling diagnosis of LAM. Along with my diagnosis came the warning that carrying a child might accelerate the disease. LAM – (Lymphangiomyomatosis)... the disease no one had heard of; no one except the quarter of a million young women who will face premature death from the disease.

With the support of so many of you, in 2006 I founded the LAM Treatment Alliance (LTA). My goal, and the organization's mission, is to take a fast-track approach that cuts through the medical bureaucracy to find an effective treatment, and a cure for LAM. This is a race against time. You have understood that point and your solidarity has been my inspiration more often than you may realize. The LTA is well on its way, working strategically towards an achievable mission.

And – more exciting news. Michael and I joyfully announce the birth of our daughter, Charlotte Anouk Nurok, born through gestational surrogacy in March 2007. Charlotte is yet another reason why this mission matters.



Charlotte Nurok at five months old.

It's been an incredible 18 months. There has been something very magical and, to use a popular word, organic, about the adventure thus far. The generosity of spirit I have encountered from friends, to their extended circles, to scientists, to donors and patients, has made this work possible. To Michael – my partner and guide every step of the way, and to those of you who have spearheaded and sustained our fundraising efforts – you have inspired my faith that we really can foster, fund and fast-track LAM research. To patients and your communities throughout the world, your solidarity is sustaining.

The fact that, to date, the press, including the *Wall Street Journal*, the *New York Times*, *Glamour* and *The Charlie Rose Show*, has reached out to us to endorse our goals, our approach, and our achievements reflects the richness and strength of our work and the global community we have created. Indeed, together, we are moving mountains.

With my most heartfelt gratitude for all that you have done. Onward!

Amy Farber, PhD

The LAM Treatment Alliance **Salutes Family and Friends in Los Angeles!**

The Fundraising Committee:

Melvyn Farber	Cari Levin	Ande Rosenblum	Jerry Weissman
Tamar Gertler Kane	Suzy Marks	Trisha Sarkisian	Judith Farber Weissman
Barbara Koffman	Berta Pitt	Sara Smirin	

And, our grateful appreciation to the following people who hosted events to make science, fundraising and LAM awareness possible. Thank you for believing in this mission. To you and to other key angels who have made progress in research possible, you bring inspiration each day. Onward!!!

- | | | |
|----------------------------------|----------------------------|--|
| ❖ Justine Stamen Arrillaga | ❖ Judy and Michael Israel | ❖ Ande and Bruce Rosenblum |
| ❖ Roxana Badin | ❖ Tamar and Matt Kane | ❖ Whitney Rosenson |
| ❖ Catherine Bridge | ❖ Rob Kaplan | ❖ Trisha and Keith Sarkisian |
| ❖ Mary and Dan Cohrs | ❖ Tina and James Kenefick | ❖ Wendy Schwartz |
| ❖ Sarah and Chuck Cox | ❖ Tami and Kurt Kroner | ❖ Katherine and Joe Silver |
| ❖ Melvyn Farber | ❖ Suzy and Wally Marks | ❖ Sara and Greg Smirin |
| ❖ JJ Ramberg Glass | ❖ Judith and Herman Palarz | ❖ Amy Waldman |
| ❖ Cari Levin and Guy Goldschmidt | ❖ Berta and Lou Pitt | ❖ Judith Farber Weissman and
Jerry Weissman |
| ❖ Libby and Dan Harrison | ❖ Tracy and Brad Raphael | |
| ❖ Corey and Layne Hirsch | ❖ Julie and Fred Reisz | |

If you would like to host a fundraising event, please e-mail us at Events@LAMTreatmentAlliance.org

Promising Progress

Our progress is the concrete promise of a brighter future for individuals with LAM and other life-threatening diseases. We are working steadfastly to ensure that a diagnosis of LAM has new and brighter implications.

We're proud of our progress and the people who have helped make our achievements possible. Our accomplishments include:

- ✓ Recruiting an active Nobel-caliber Scientific Advisory Board.
- ✓ Developing a LAM/TSC Seminar Series at Harvard Medical School dedicated to accelerating scientific work on LAM as well as the closely related disease, tuberous sclerosis.
- ✓ Convening state-of-the-art Summits in Boston and Stockholm, bringing the world's top researchers together with leaders in fields relevant to potential LAM treatments. These sessions led to collaborative research projects that focus on finding new approaches to solving key barriers to effective treatment.
- ✓ Hosting the first Global LAM Patient Summit in Oxford, England in January 2008. Our goal is to coordinate LAM patients and organizations to maximally enable the discovery of an effective treatment for LAM.
- ✓ Collaborating with Novartis to support drug trials for LAM. Following our Stockholm Summit, Novartis convened a meeting for LAM clinical investigators from around the world. The next Novartis investigator meeting will be held at our Global LAM Patient Summit in Oxford in January 2008.
- ✓ Partnering with the National Institutes of Health (NIH) and the National Disease Research Interchange (NDRI) to reduce turnaround time on LAM tissue requests from researchers. The turnaround time has gone from one year on average, to under a week in some cases.
- ✓ Fostering relationships resulting in early LAM biomarker development research so that disease progression and potential treatment efficacy in patients can be monitored far in advance of conventional measures.
- ✓ Developing a plan to implement a new model of LAM patient clinical care with a direct link into the research pipeline.

Who's Who

on our *Scientific Advisory Board*

We have gathered the best and the brightest. Our highly active Nobel-caliber Scientific Advisory Board guides the agenda and the strategy for inviting, reviewing and funding high impact LAM research collaborations on a rolling basis. We are most grateful to them for the inspiration they provide and their dedication in support of our critical mission.

Robert Langer, ScD
LTA Scientific Advisory Board Chair
Massachusetts Institute of Technology
Biomedical Engineering;
Targeted Drug Delivery

Lewis Cantley, PhD
Beth Israel Deaconess Medical Center,
Harvard Medical School
Systems Biology; Cell Signaling

George Demetri, MD, FACP
Dana Farber Cancer Institute,
Harvard Medical School
Oncology; Sarcoma

Judah Folkman, MD
Children's Hospital,
Harvard Medical School
Vascular Biology; Angiogenesis

Jan-Åke Gustafsson, MD, PhD
Karolinska Institutet, Sweden
Nuclear Receptor Biology;
Estrogen Signaling

Sten Lindahl, MD, PhD, FRCA
Karolinska University Hospital,
Karolinska Institutet, Sweden
Nobel Assembly, Nobel Committee,
Nobel Foundation
Anesthesiologist / Intensivist;
Oxygen Research

Steven Shapiro, MD
University of Pittsburgh
*Pulmonology; Matrix Degrading
Proteinases*

In-depth profiles of our Scientific Advisory Board can be found at www.LAMTreatmentAlliance.org and will be featured in future issues of *Fast Track News*.

LAM / TSC Seminar Series

Begins Third Year

At our monthly LAM / Tuberous Sclerosis Complex (LAM / TSC) Seminar Series meetings at Harvard Medical School, leading researchers and clinicians come together across disciplines to pool knowledge, identify gaps in research and brainstorm novel therapeutic approaches to treating LAM and Tuberous Sclerosis, a related disease. Given that the majority of the attendees are principal investigators who head their own laboratories, we also aim to recruit new scientists to pursue LAM research.



LTA's Amy Farber, PhD and University of Pennsylvania's Peter Crino, MD, PhD, a presenter at a recent LAM / TSC Seminar Series meeting.

Meetings are open to all. They are well attended by scientists and clinicians representing many of the major medical institutions and universities in Massachusetts, throughout the country and, increasingly throughout the world. Additionally, these seminars have attracted attendees from Ariad Pharmaceuticals, the LAM Foundation, the Lymphatic Research Foundation, the National Institutes of Health, the Tuberous Sclerosis Alliance and the Veterans Administration.

We are grateful for the strong support the LAM / TSC Seminar Series has achieved from the research community, volunteers, Harvard Medical School and our foundation partners including the LAM Foundation (providing initial major support) and the Tuberous Sclerosis Alliance, (providing major support through a three-year grant).

Are there topics you would like to see included in the *Fast Track News*? Please send your ideas to Newsletter@LAMTreatmentAlliance.org.

LAM Treatment Alliance **Timeline of Achievements**

2005

O – April

Amy Farber is diagnosed with Lymphangi-oleiomyomatosis (LAM).

F – May

Fundraising kicks off with the first of many house parties in California – \$19,000 is raised for LAM research.

A – May

Amy Farber works with CA Senator Barbara Boxer to have LAM included in US House of Representatives and US Senate Report Language.

F – May

Farber family kicks-off letter writing campaign sending out over 1000 letters within a few months.

F – June - December

Harvard-Westlake launches a letter writing campaign spearheaded by 10 graduating classes to raise funds and awareness for LAM.

F – June

The first of two fundraisers at the Chin Chin Restaurant in Los Angeles raises funds for LAM research.

F – June

Maggie Sharaf launches first LAMonade stand to raise funds for LAM research.

PA – July

Amy Farber is interviewed on WNYC public radio's *Leonard Lopate Show* to discuss rare diseases and LAM.

R – October

Launch of the LAM / Tuberous Sclerosis Complex (LAM / TSC) seminar series at Harvard Medical School.

PA – November

Amy Farber is featured in *New York Times* article, "Hard to Pronounce, Infinitely Harder to Cure," by Jane E. Brody.

F – November

Kay and Dave's Restaurant in Los Angeles event raises funds for LAM research.

R – December

Inaugural LAM Summit at Harvard Medical School establishes priority research streams for accelerated treatment research.

PA – December

Julia Wick features Amy Farber in Harvard-Westlake's *The Chronicle*.

2006

PA – Winter

Trisha Farber Sarkisian publishes a letter in *Harvard-Westlake Life* about her sister Amy Farber's fight against LAM.

F – January

LTA supporter Suzy Marks celebrates her birthday by asking family and friends to donate to the LTA in lieu of gifts.

F – January

The second of two fundraisers at the Chin Chin Restaurant in Los Angeles raises funds for LAM research.

PA – January

Amy Farber speaks at the Leo Baeck Temple in Los Angeles, "When Calamity Strikes Someone You Love."

PA – January

Amy Farber speaks at the Archer School for Girls in Los Angeles about mobilizing researchers to find a treatment for LAM.

PA – February

Story by Libby Motika published in *Palisadian-Post*, "Patient, Crusader, Courageous Advocate: Amy Farber is in a Race For Her Life."

PE – March

Article entitled "Amy Farber Advances the Cause of Social Medicine as an Academic and a Patient" appears in Harvard Medical School newsletter.

F – April

Kat Cohen and Herve Larrechette's wedding raises funds for LAM research.

PA – April

Amy Farber speaks at the Brentwood School in California about finding a treatment for LAM.

PA – April

Amy Farber speaks to science classes at Harvard-Westlake about LAM science.

O – May

The LAM Treatment Alliance (LTA) officially receives tax-exempt status as a 501 (c) (3) non-profit.

F – May

Brentwood School Bake Sale raises funds in support of LAM research.

F – May

Polkadot and Moonbeams "Shop for a Cure" event raises funds for LAM research.

F – June

The Sy Devore Store "Shop for a Cure" event raises funds to support LAM research.

PE – June

Amy Farber sits on Harvard School of Public Health panel discussing "Biomedicine and Integration on Public Health, Innovative Research, International Health Care, and Ethics."

PA – June

LTA is featured in a front page story in *Wall Street Journal* by Pulitzer Prize winning journalist Amy Dockser Marcus.

R – June

The LTA begins conversations with academic research centers about the creation of multi-disciplinary clinical centers for LAM patients.

R – June

LTA sponsored LAM Cell Summit at Harvard Medical School with goal of establishing validation criteria for LAM cells, and strategizing next steps for greater tissue access by more scientists.

O – July

The LTA moves into new, donated office space in the heart of Harvard Square in Cambridge, MA.

PA – August

Amy Farber is interviewed about LAM and the LTA on PBS's *The Charlie Rose Show*.

F – August

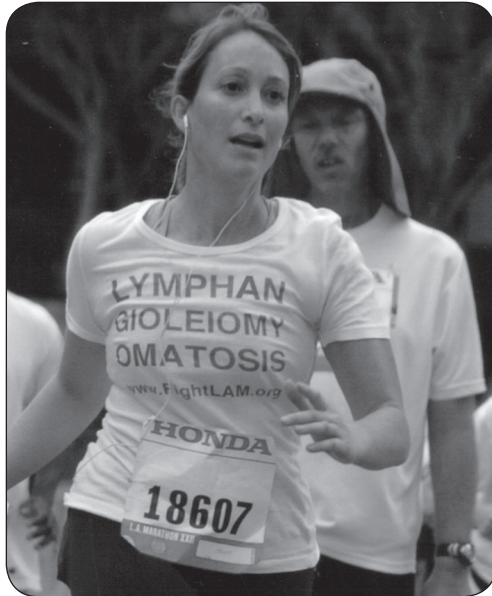
LTA supporter Adriane Bishko asks friends and family to donate to the LTA in celebration of her birthday.



A moment in front of the Nobel Forum while at LTA's Global LAM Summit are (l to r) Eleanora Miano, Italy; Havi Carel, UK / Israel; Michelle Gonsalves, France; Anke Müller, Germany; Amy Farber, USA; Viera Reptova, Austria and Heather Telford, Australia

Attention Marathoners! You too can help our cause by raising funds for LAM research during any upcoming marathon. A generous LTA donor has offered to match dollars runners raise up to \$10,000.

For more information e-mail us at Athletes@LAMTreatmentAlliance.org



Cari Levin, who has confronted her own serious health challenges, ran the LA Marathon for LAM research. High school runners in LA are training to run the LA Marathon for LTA this year. Thank you, Cari!

PA – September

Amy Farber speaks at MIT about “Rethinking Medicine: New Ways to Solve Old Problems.”

F – September

Letter writing campaign in honor of Anne Levine raises funds for LAM research.

F – September

Berkeley Goldschmidt launches first LAMonade stand to raise funds for LAM research.

R – October

The second year of the LAM/TSC seminar series begins.

F – October

Sophie Soloman Bat Mitzvah raises funds and awareness for LAM and LTA's efforts.

PA – November

Amy Farber appears on the *Montel Williams Show* to discuss LAM and the importance of accelerating the pace of LAM research.

F – November - December

Sari Carel's letter writing campaign raises funds for LAM research.

F – Fall

Emily and Larry Levine kick-off Florida / Massachusetts based campaigns.

O – January

LTA reaches its first \$1 million milestone.

F – February

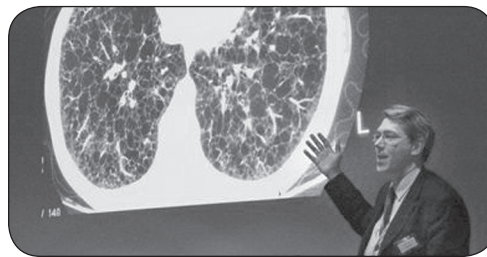
LAM patient Monique Coles' brother and sister-in-law (Dave and Kris Mason) climb Mt. Kilimanjaro, raising funds in support of the LTA.

PA – February

LTA / Novartis-sponsored Global LAM Summit is covered by the Swedish *Gothenberg Post*.

R – February

LTA / Novartis-sponsored Global LAM Summit is held at Stockholm's Karolinska Institute in the Nobel Forum with the following goals – global tissue access, best practice guidelines, global research collaboration and new drug targets.



William D. Travis, MD, a thoracic pathologist at Memorial Sloan-Kettering Cancer Center addresses lung destruction in LAM at the LTA's Global LAM Summit in Stockholm.

F – March

LTA supporter Cari Levin runs the LA Marathon and raises funds for LAM research.

PA – March

Swedish publication *Svenska Bagblad* covers LTA Global LAM Summit with article entitled “I Am Not Ready To Die Now.”

PA – May

Amy Farber is named *Glamour Magazine's* “Hero of the Month” in its May issue.

F – May

Marlborough School fundraiser in Los Angeles for LTA is spearheaded by Olivia Kaplan.

PA – Summer

Amy Farber is featured in *Northeastern Law Magazine*, “True Gift,” by Michelle Bates Deakin.

F – June - July

Letter writing campaign spearheaded by the LTA Indiana Chapter raises critical funds for LAM research.

F – June - August

The LTA Indiana Chapter hosts a three-part Poker Run fundraiser in support of LAM research.

F – July

LAM patient Havi Carel asks her wedding guests to make donations to the LTA in lieu of gifts.

PA – August

Actress Debra Messing of *Will and Grace* fame records a radio public service announcement in New York City for LTA.

PA – August

Debra Messing announces LTA as her favorite charity in *Daily Variety*.

F – August

The LTA Indiana Chapter holds its first annual LAMJAM featuring silent and live auctions.

F – August

Hasten Hebrew Academy Tea raises funds and awareness for LAM research.

F – August

Donations are made to the LTA in honor of Beth Farry and Chris Lee's marriage.

R – September

The LAM / TSC Seminar Series kicks off its third year.

F – September - October

The Sam Goldenberg Memorial is set up to advance LAM treatment research and to commemorate his life.

KEY

A – Advocacy

F – Fundraising

PA – Public Awareness

PE – Professional Education

R – Research

O – Organizational



LAM Treatment Alliance's Scientific Chair, Dr. Robert Langer, Awarded National Medal of Science

The receipt of the **National Medal of Science**, considered America's highest honor for scientific achievement, punctuates an exceptionally distinguished career for Robert Langer, ScD. His revolutionary discoveries have led to new medical treatments that have profoundly affected the well being of mankind. His research has led to an abundance of published articles, patents, and nearly 150 other noteworthy honors including the Charles Stark Draper award, deemed to be the equivalent of the Nobel Prize for engineers and the world's most prestigious engineering prize from the National Academy of Engineering.

Please join us in celebrating Dr. Langer's momentous scientific achievements!

By Lara Harisay, LTA Volunteer

Ask the Doctor: An Introduction to Gestational Surrogacy for LAM Patients

What medications are used to retrieve eggs?

The surrogate and the LAM patient may use pills containing estrogen and progesterone, to synchronize their menstrual cycles. The LAM patient may be able to avoid this exposure. After about 14 days, both the surrogate and the LAM patient start taking Lupron, an injection that turns off some of the body's normal reproductive hormones. This helps the physician to control the cycle and ensure that the surrogate's uterus is ready to receive the embryos.

The egg donor starts taking hormones, gonadotropins (usually FSH analogues), via injection on her third day of the cycle to stimulate the ovaries to produce many eggs instead of one. The fertility hormones are taken from 7 to 12 days depending on the LAM patient's response to the medication.

Once the egg follicles grow to become the right size, the LAM patient is given an HCG shot which helps the eggs to mature. The physician team can then retrieve the eggs after 36 hours.

How long does the egg retrieval process take?

The stimulation involves exposure to about three weeks of medication. The removal itself is a surgical procedure that lasts approximately 20 minutes and is done with ultrasound guidance.

Is the egg retrieval process painful?

In order to avoid the discomfort from the process, women usually undergo anesthesia.

Is there a way to tell if any of the eggs are "good" eggs?

It is not readily apparent if there are good or bad eggs. However, after the eggs are fertilized with sperm and incubated for two to five days, the physician team can assess the quality of the embryos.

What are the odds of success after implantation into the surrogate?

The pregnancy rate depends on the genetic material from the couple and many additional factors related to timing, the surrogate etc.

How many eggs are implanted? How is this decided?

Physicians use an algorithm taking into consideration the age of the couple, the number of cycles, the quality of the embryos and the wishes of the intended parents. Usually, one to two eggs are implanted.

How much estrogen would a LAM patient need to be exposed to in order to retrieve / transfer her eggs?

Each egg donor responds differently to the drugs, so this is dependent on the individual. LAM patients may be able to work with their reproductive endocrinologist and the treating team to minimize exposure to estrogen while maximizing the chances of successful retrieval.

Is there a way to get rid of the estrogen once the eggs are removed?

Physicians can use Lupron to try to bring estrogen levels down to normal but it is not clear how much of a difference this makes in terms of the woman's overall exposure to estrogen.

What are potential implications for LAM patients of doing several rounds of eggs retrieval?

One or several rounds of high estrogen may provide less exposure to estrogen than sustained exposure over the course of a nine month pregnancy. Estrogen is thought to accelerate the progression of LAM. Therefore, gestational surrogacy may put LAM patients at less of a risk than traditional pregnancy.

For more information about surrogacy and the process of finding a surrogate who is willing and able to carry a child using ones own biological material, visit www.surrogacy.com.

By Nelly Pitteloud, MD

Reproductive Endocrinology Unit
Massachusetts General Hospital – Boston, MA

We are grateful to Mark Hornstein, MD, for his input. Dr. Hornstein is a reproductive endocrinologist at Brigham and Women's Hospital in Boston and is Associate Professor of Obstetrics, Gynecology and Reproductive Biology at Harvard Medical School.

LAM Patients throughout the World to Attend LTA Global Patient Summit

On January 11 – 13, 2008, patients, researchers, clinicians, and pharmaceutical and LAM organization representatives, will come together in Oxford, England for the LAM Treatment Alliance Global Patient Summit.

The Summit will focus on taking concrete steps to ensure that global patient coordination helps to maximally support progress in LAM research – in the fastest time possible. Our aim is to identify ways that patients can advance treatment research. We invited representatives from LAM organizations in every country where LAM

patients are known to us so that we can ensure the involvement of as many people as possible in the search for treatment.

Sessions will address ways in which patients can support treatment research through tissue procurement efforts and other areas where patient participation is crucial. We will give updates on clinical trials underway or in the pipeline, and discuss coordination among patients, researchers and pharmaceutical companies interested in LAM.

The LAM Treatment Alliance works hard to build networks that support research

globally. The intent of the Summit is for patients to return to their countries with information about improving and globalizing collaborations to maximize our efforts in fast-tracking treatment for LAM.

By Havi Carel, PhD, LTA Volunteer

DISCLAIMER:

The articles contained in this newsletter are provided for information only. The information is to be used as an aid in understanding current medical knowledge. The articles are not intended as a substitute for medical / professional advice and should not be relied upon as such. The LAM Treatment Alliance (LTA) does not engage in the practice of medicine. A physician should always be consulted for any health problem or medical condition.

A Closer Look Inside *The Indiana Chapter*



Monique Coles, age 36 - Indianapolis, Indiana

The Indiana Chapter of the LAM Treatment Alliance has been fundamental in developing a grassroots awareness of LAM and in raising funds to bring women with the disease one step closer to a cure. Through their tremendous dedication, creative spirit and strong ties to the Indianapolis community, they have raised local awareness and contributed thousands of dollars towards a cure for LAM. As is the case with many of the LAM Treatment Alliance chapters, it began with one woman's unfortunate struggle with LAM.

Monique Coles' Story

Chad and I had built the perfect life when LAM came along and changed everything.

When I met the man I'd spend the rest of my life with, I was nearly 30. So when we married, I was eager to stop working and start

a family. Our son Mason was born after an easy pregnancy, then our daughter Indy came quickly after a much tougher one.

After the babies were born, I had an MRI. Something showed up that concerned my doctor. He sent me to a surgeon, who found a mysterious abdominal cyst. He suggested that we monitor it with regular scans.

One morning I awoke with severe stomach pain. A trip to the ER and a CT scan resulted in the doctor giving me morphine and sending me home. My abdominal cyst had bled and I had to follow up with my surgeon. But the radiologist had a hunch that I might have LAM.

My surgeon, with limited knowledge of LAM, sent me to a pulmonologist. After seeing my CT scan and results from breathing tests he said, "Yep, you've got it. By the way, you shouldn't get pregnant again. There's nothing you can do, just go home and we'll schedule another CT scan to watch the progression."

When I got home, I looked up LAM online. Seeing the life expectancy made me woozy, then angry. This is no way to learn you have a disease that will take your life! I cried for days. I would never see my children grow up. Worse, I would leave them without a mother. But of course there was something we could do.

Taking Control – The Coles' Fight Against LAM

Soon after Monique's diagnosis, the Coles began to cope through mobilization. Their focus became clear: to find a cure in the shortest amount of time possible. Internet searches led them to the LAM Treatment Alliance (LTA) where they connected with Amy, its founder and fellow LAM patient. They realized that the LTA's mission and organizational strengths complimented their own. "Here is a community whose goal is to fast-track research and who has solid ties to the medical and the scientific communities. My family's strengths were in marketing and media. We pooled our efforts knowing that our fundraising would go to this aggressive and focused research agenda. Establishing this collaboration was our first real glimmer of hope."

Immediately after connecting with the LTA, the Coles set out to build awareness and raise dollars to fund LAM research. Since then, they have hosted several events, raised tens of thousands of dollars and greatly heightened the awareness of LAM in the Indiana region. We salute the Coles family and the Nurok, Nitsun and Hasten families as well as all of our Indiana supporters. Onward!

For information about the Indiana Chapter please visit www.IndyLAMEvents.com.

Interviewed by Lara Harisay, LTA Volunteer

Research Update

Thanks to the generosity of our donors and the great dedication of our scientists, the projects to the right represent some of the research that is now underway, with numerous other projects in varying stages of review. Watch for additional updates on the progress of LAM research in future issues of *Fast Track News!*

INSTITUTION	LAB	FOCUS
Brigham and Women's Hospital / Harvard Medical School	Kwiatkowski Lab	LOH and mutational analyses of LAM specimens and cell lines
Children's Hospital Boston / Harvard Medical School / National Institutes of Health - Heart, Lung and Blood Institute	Moses Lab / Moss Lab	Developing urinary MMPs as potential biomarkers for LAM
Children's Hospital Boston / Harvard Medical School	Folkman Lab	LAM cell culturing / growth
Dana-Farber Cancer Institute / Harvard Medical School	Brown Lab	Hormonal dependence of LAM / Disease model
Fox Chase Cancer Center	Henske Lab	Role of estrogen in LAM progression / Disease model
Johns Hopkins Medical Center	Watkins Lab	Xenograft model of LAM
Karolinska Institute	Gustafsson Lab	Role of ER beta in the proliferation and migration of LAM cells
University of Helsinki	Alitalo Lab	LAM cell culture / growth / Disease model
University of Milan / National Institutes of Health – National Heart, Lung and Blood Institute	Gorio Lab / Moss Lab	LAM cell isolation techniques / knowledge transfer and training

LAM Treatment Alliance

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Cambridge, MA 02138
USA

www.LAMTreatmentAlliance.org

FIRST CLASS MAIL

LAM Patient Spotlight: *Phoebe Bustamante*



Phoebe is a young woman with LAM and an active volunteer with the LAM Treatment Alliance. She gratefully shared some of her personal experiences in an effort to increase awareness about LAM.

Q. How did you first discover that something seemed wrong with your body?

In 1996, when I was 23 years old, I experienced intense pain that lasted for several nights. It was determined that I had a kidney tumor (angiomyolipoma) and a hemorrhage. I had surgery on my kidney and no recurrence of symptoms. No one told me that this kidney problem could be part of something else – something even more complicated.

Q. How long did it take for you to get diagnosed with LAM after your symptoms began?

Ten years later, when I wanted to get pregnant I went back to the doctor. With my history of kidney problems, I wanted to confirm that my body could handle the pregnancy. That's when I had a CT scan and they discovered the cysts in my lungs.

Q. How did the diagnosis affect your friends and family?

Besides being upset about the disease curtailing my lifespan, they were also disappointed about the fact that carrying out a pregnancy in the conventional way might accelerate the disease and put me at additional risk.

Q. Have you been able to connect with other LAM patients?

Yes. My doctor told me to contact Amy. It's been great to be able to connect to another patient, especially one who has used her diagnosis

as a means to create change. Volunteering at the LTA has been a comforting experience. I know that something is being done about this fatal disease that to date has no treatment.

Q. Who has inspired you since your diagnosis with LAM?

Amy. She completely changed her life when she was diagnosed. At first I was intimidated. Was I supposed to change my life like she did to fight for this cause? I then realized that the fact that she dedicates her life to this cause puts me at ease. I will contribute where I can, but I can still live how I always lived.

Q. If you had the opportunity to say something to the general public about LAM, what would it be?

I simply want to create more awareness. Awareness so that more doctors will be informed, that LAM patients can feel confident in their medical care, that there is more money dedicated to finding a treatment, and that more researchers will be inspired to study LAM. It's hard enough to deal with a fatal illness; it adds another layer when no one knows about the disease.

Q. What does the work of the LTA mean to you given what you are facing?

I feel great comfort knowing that the LTA exists. I've attended the seminars and while the advanced science is often hard to understand, it's comforting to know that some of the best and brightest scientists are sharing their insights about LAM. My pulmonologist also attends, and by him staying well informed, I know I will get the best medical care.

Interviewed by Sarah Elgart, LTA Staff