Journey to lung transplant

Cathy Conry-Cantilena, MD
Born 3 times

DOB  Union Hospital, Bronx, NY
3.8.2006  Duke University Medical Center
4.30.15  Johns Hopkins Hospital

June 2017:
Each morning, I am so filled with happiness that I breathe easy. I have another day of life. Another day to enjoy my wonderful family, be impressed by whatever weather comes along, no day goes unappreciated, thankful for my donor’s lungs for over 11 years and my daughter’s kidney for 2 years.
Social & symptoms history

- 1989: Move to Maryland from NH, husband, daughter age 3, son age 1
- Healthy working NIH physician/wife & mother
- 1992 pregnancy: difficulty getting back to running
- 1998 pregnancy: short of breath with stairs, housework
- June 2000: upper respiratory infection, wheezing
- CXR local ER: abnormal
Social & symptoms history

• Saw private MD - uncertain diagnosis FEV1= 65% of predicted
• NIH: showed CXR to pulmonologist colleague
• Right place & right time: LAM?
• Visit with Dr. Moss for evaluation = CT scan LAM July 2000 numerous bilateral lung cysts c/w LAM
• 2000-2005: no meds, no cough, no pneumothoraces, gradual decline with weight loss, shortness of breath
• Sought help in Sept 2005. Learned then that the regional highly respected major academic center was not the place for a lung transplant
Committed to living

- September 2005: weight 87lbs, O2 sats room air resting 86%, desat’s with walking to low 70%, FEV 1 = 0.3 L

- September 2005 - January 2006: Life with oxygen with increasing oxygen requirement: husband, children, working

- Depression/Anxiety: Prozac

- Consideration of lung transplant- discussion with husband and support of family

- Research- find the best transplant center
  - What are my chances of getting lungs: Lung allocation score (LAS, April 2005)
  - Best survival
  - What did I need? Double lung transplant
  - Money
  - Moving & my family
Family and Community Support

• Worked until 2.1.2006
• Friends and neighbors: meals and fundraisers
• Daughter age 19 took a medical leave from college to stay with me and she along with husband & 6 year old moved to Durham NC with me
• Friends and neighbors hosted middle- and high school children
• Work colleagues donated leave, hotel points, covered my duties.
Transplant Course-1

• Presented to Duke University Hospital January 15, 2006 after approval from insurance company
  – Evaluation: ABGs, PFTs, V/Q scan, esophageal manometry, cardiac catheterization, 6-minute walk, psycho-social evaluation
• Moved to Durham 2/3/06 for 3 weeks pulm and physical rehab
• Activated on transplant list 2/23/06, 2 dry runs
• Transplanted 3.8.06
Transplant Course-2

• Lived in short term sterile environment with outpatient post transplant rehab X 21 sessions
• Back to work 6.10.06
• First snow skiing vacation post-transplant Christmas 2006!!

– Post transplant course marked by CMV infection from donor lungs and gradual decline in renal function from Tacrolimus
What I learned along the way...
Research: How many patients undergo transplant

2016: Lungs = 6.9% of 33,610 solid organ transplants

Unos.org accession 6.6.17
Number of worldwide lung transplants

Number of lung transplant procedures reported by year and procedure type

Up To Date 2017
Organizations involved in solid organ transplantation: Who’s who

• **HHS/HRSA** - federal agency administers the UNOS contract
• **UNOS** is the *United Network for Organ Sharing* which is a non-profit organization that receives the federal contract to operate the OPTN. UNOS collects and manages data about every transplant event occurring in the United States, and facilitates the organ matching and placement process.
• **OPTN** is the *Organ Procurement and Transplant Network* which is a private, not-for-profit organization with an expertise in organ procurement and transplantation administered by UNOS.
• **OPOs**: All 58 *Organ Procurement Organizations* in the United States are members, by law, of the OPTN
Looking for a transplant center

• “Scientific Registry of Transplant Recipients” = a searchable database

• On line research http://beta.srtr.org

• SRTR's primary source of data is OPTN. This system has undergone numerous changes; it is currently an Internet-based system called **UNet** (SM), which enables organ transplant programs to:
  
  – Register candidates for transplant
  – Match donated organs to waiting candidates
  – Submit data on donors, candidates, and recipients before and after transplant

https://www.unos.org/transplantation/matching-organs

https://optn.transplant.hrsa.gov/data/view-data-reports/
Where to go?

11 Regions

Short wait list time

LU 1.6 Percentage of adult waitlisted candidates who underwent deceased donor lung transplant within 1 year, by DSA, 2012

Candidates listed concurrently in a single DSA are counted once in that DSA; candidates listed in multiple DSAs are counted separately per DSA.
**Example of starting to search...SRTR**

**Transplant Center Search Results**

For more help on choosing a transplant center, read [How do I compare transplant centers?](#)

<table>
<thead>
<tr>
<th>Center Name</th>
<th>Location</th>
<th>Distance</th>
<th>Transplant Volume</th>
<th>Transplant Rate</th>
<th>Outcome Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of Maryland Medical System</td>
<td>Baltimore, MD</td>
<td>37.1 miles</td>
<td>46 ADULTS</td>
<td>740.5 PER 100 PEOPLE PER YEAR</td>
<td>AS EXPECTED</td>
</tr>
<tr>
<td>Inova Fairfax Hospital</td>
<td>Falls Church, VA</td>
<td>12 miles</td>
<td>23 ADULTS</td>
<td>138.5 PER 100 PEOPLE PER YEAR</td>
<td>AS EXPECTED</td>
</tr>
<tr>
<td>Johns Hopkins Hospital</td>
<td>Baltimore, MD</td>
<td>38.4 miles</td>
<td>14 ADULTS</td>
<td>94.2 PER 100 PEOPLE PER YEAR</td>
<td>AS EXPECTED</td>
</tr>
</tbody>
</table>

Showing 3 results for lung transplant centers, adult patients, within 50 miles of 20854

Click column headers below to sort the results by distance, transplant rate, transplant volume, or by outcome assessment:

OUTCOME ASSESSMENT
The outcome assessment is a risk-adjusted assessment evaluating how often patients are alive with a functioning transplanted organ 1 year after transplant. The assessment is assigned after case-mix adjustment for the types of recipients who undergo transplant at the program and the donors used by the program. Programs are placed in the better or worse than expected category if we have 97.5% or greater probability that their outcomes are better or worse than expected based on national norms, respectively; otherwise they are placed in the "As Expected" category. Search results are sorted by adult outcome assessment first by Transplant Volume by default, so programs with the best assessments appear at the top of the list. You can choose to view assessments for pediatric recipients from the recipient drop-down list above; however, SRTR may not evaluate outcomes for pediatric recipients if too few transplants are performed. Click here for more information. You may also evaluate this data using the 5-tier system.
Lung allocation score calculator (LAS) calculator is a tool that is used to estimate each lung candidate's medical urgency and expected post-transplant survival rate relative to other patients on the waiting list for a lung transplant.

The advent of the LAS has shortened time to undergoing lung transplantation and decreased risk of death while on the waitlist for the majority of patients.

LAS scores for LAM pts going to transplant = 45 (Am J Respir Crit Care Med 191;2015:A1436)

https://optn.transplant.hrsa.gov/resources/allocation-calculators/las-calculator/
Facts about lung transplant

- Taller adults have higher lung transplant rates > 160 cm (72 inches )
- Transplanted LAMmies have good survival rates
- The allied health professional team is very important (nurses and rehab professionals)
- Lungs are in short supply: only 15% cadaveric lungs suitable for harvest with short shelf life ( vs. >80% of kidneys)
- Consideration: increased risk donor?
- Go to Midas to get your Muffler: the more lungs transplants the center does, the better. High-volume centers (>or=20 lung transplantations/year) had the lowest 30-day mortality (4.1%) Weiss E et al. Ann Thorac Surg. 2009 Oct;88(4):1062-70
Peri-transplant

• Get early consideration
• Expect to be in hospital about 3 weeks
• “Dry runs” = not all calls to hospitals result in the transplant occurring
• Meticulous compliance post-transplant meds, labs, exercise, home spirometry
Drugs expected post transplant: lifelong immune suppression

VALPOUR M. AMER J TRANSPLANT 2015
Take home messages

• Stay as healthy as possible
• Start early
• Be aggressive
• Be educated, educate doctors in emergencies, have an educated partner to speak for you
• Challenge health professionals with questions
• Be the squeaky wheel
A few of my wonderful friends

Others:
The Tarone family
The Rujinski family
The Dunsmore family
The Keane family
The Antoniou family
The Dunckel family
The Pappas family
My Amazing Family