MAY 28, 1992
BEFORE DIAGNOSIS
NAKED
AND
UNABLE TO BREATHE
LYMPHANGIOLEIOMYOMATOSIS

“**I’VE SEEN IT IN A BOOK**”
Going Back To Work

- Wearing Oxygen
- Panic Attacks
- Pulmonary Rehab
God Kisses

- My Company
- My LTD
- My Urologist
Some Days

- LIVING
- WITH
- LAM
- Spoon Theory
Going to NIH 2001
NIH Says It Is Time

- 2001: Time to Start Lung Transplant process, you have Got to Be Kidding Me
- Referral from Pulmonologist to Barnes
- Meeting Barnes Staff & going thru transplant tests, etc
- Required other tests, shots, losing weight
- Assigned a Pre-Transplant Nurse
COUGH, COUGH, COUGH

OH NO, NOT AGAIN!!!
MY CT Scans  2007
WHAT 100 FEET OF TUBING CAN DO
Before I went Active On List

- Had to go thru Many of Tests again
- I already needed 15 liters to walk any length
- Going Officially **Active** on the Lung Transplant List
Attending Pulmonary Rehab
Oxygen Systems

- Tanks
- Helios
- Marathon
- Companion T
Carrying 2 Companion T’s
My Husband’s Surprise
After:
MOVING to MARY’S
I GOT THE CALL!!!!!!

- August 1, 2011
- 7:30 AM
- MONDAY MORNING
- Barnes Hospital
LAM Lungs
New Healthy LUNG S!!
ICU & Hallucinations
Husband Ron
Observation Unit
My Medications
Complications

- Increased infections of all kinds
- Acute and chronic rejection of lungs
- Narrowed airways in lungs
- Decreased wound healing
- Skin thinning, tears, bruises, rashes
- Increased risk for malignancy (cancer)
- Weight gain, fluid retention
- Tremors of hands and arms
- Insomnia
- Increased hair growth on face and body
- Hair loss or thinning

- Headaches
- Nausea, vomiting, diarrhea
- Blood clots
- High blood pressure (hypertension)
- Diabetes, possibly requiring insulin
- High cholesterol and high triglycerides
- Osteopenia or osteoporosis
- Gastric reflux (heartburn)
- Cataracts of the eyes
- Kidney disease and kidney failure
Leaving The Hospital

- Had to deal With Steps from Day 1
- Attended Barnes Pulmonary Rehab the Very Next Day
- 5 Times a Week at Barnes for Rehab, also Bloodwork 2x week, Xray 2x time & all the other tests they wanted & Clinic.
- For 3 months since Day of Transplant
Healing at Home

- Why You Have to have 24/7 Caregiver
- Learning to Re-Breathe
- Letting Go of the Oxygen
- Not Driving
- Celebrating Each Step Forward
Last Day of Rehab
Spirometry
The New Me

In one breath, a moment lost.
In one moment, a miracle shared.
Good-Bye Oxygen
Precautions After Transplant

- Wearing a Mask
- Sanitizer with You Always
- Washing Hands
- Touching Things
- Germs
- Children
- Flu & Cold Season
Follow Up Care

- Clinic
- Labs
- PFT’s
- Bronchoscopies the 1st Year
- Calling Transplant Coordinator for Everything
- Exercising
Transplant mentors plan their monthly meetings and discuss how to guide patients waiting for their transplants.
I want to inspire people. I want someone to look at me and say “Because of you, I never ever gave up”
NEVER GIVE UP