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## ONE MAN'S JOURNEY THRU TRANSPLANTATION

### The Beginning – Abject Fear!

- ◉ May 2007 First Visit to Pulmonologist-Philadelphia.-Major Surprise!
- ◉ July 2007 Moved to Charlotte ( kismet )
- ◉ September 2007 first Visit to Duke

### The Diagnosis

- ◉ Thanksgiving 2007 – drilled a core sample
- ◉ Slept in a chair for 6 weeks
- ◉ Confirmed IPF
- ◉ Transplant becoming real– but distant

### Progression

- ◉ December 07—looking to join studies
- ◉ January 07 eliminated from studies
- ◉ February 07—started occasional oxygen

### Progression

- ◉ May 08 started re-hab in Charlotte
- ◉ In beginning only needed O<sub>2</sub> with heavy exercise – 2 liters
- ◉ August trip to Vegas –needed portable oxygen
- ◉ By September 08=Fulltime O<sub>2</sub> at 2-3 liters
- ◉ Exercise at 6 liters

### Progression Ends

- ◉ October 08—attended 1 week transplant testing at duke to qualify for entry
- ◉ Dec 5, 2008 moved to Durham Full time
- ◉ Started 5 day/week rehab (entered Duke transplant program)—10 liters O<sub>2</sub> at Exercise
- ◉ Needed to achieve 125% of ideal BMI (225 lbs)
- ◉ Making great Friendships and attending lectures (as are my "CareGivers")—learning a lot/working hard
- ◉ Late Feb 2009 was at 230 lbs and using 30 liters of O<sub>2</sub> at exercise—6 at rest

## Transplantation

- ◉ March 1, 2009– Respiratory Therapist saves my life
- ◉ Same week I am placed on the list
- ◉ First of 3 “dry runs”
- ◉ Several friends have gone in and returned to re-hab with transplants
- ◉ The Power of the “Terrible Towel” becomes evident
- ◉ March 17, 2009 (ST Pat’s day) at 4:00– Got “the call”
- ◉ 2:30 am March 18—surgery began and ends 3:00 that afternoon

## Post Transplant

- ◉ Hospital for 12 days
- ◉ Bronchoscopy everyday (4 days) no Anesthesia
- ◉ Arterial Blood gas every morning at 4
- ◉ Walking immediately (tubes/catheter/IV and all)
- ◉ Must complete 1 mile before released

## Post Transplant Rehab

- ◉ 23 sessions before you can leave Durham
- ◉ Clinic once per week
- ◉ Weak day 1 but gain strength quickly
- ◉ Stomach wrap and Feeding tubes
- ◉ Swallow tests are Key
- ◉ May 6, 2009 – Free at Last, Free at last, Good God Almighty, Free at Last

## Critical Success Factors

- ◉ Pulmonary Nurses and Respiratory Therapists in Charlotte and at Duke
- ◉ Your CareGivers
- ◉ Support system you develop in “the program”
- ◉ Friends at rehab pulling for you
- ◉ Taking on the “fight” like you are training for a Championship heavyweight boxing match
- ◉ Caring Bridge ( [www.caringbridge.com](http://www.caringbridge.com) )