The mountain setting
Pursuing the passion
Our backyard
Nine months later...
Life suddenly changes

- Knocked off foundation
- Fear of the unknown
- Uncertainty
- Stress
Hurdles
Hurdles

- Finding right hospital
Hurdles

• Finding right hospital
• Finding a donor
Hurdles

- Finding right hospital
- Finding a donor
- The “conditioning” phase
Hurdles

• Finding right hospital
• Finding a donor
• The “conditioning” phase
• Engraftment
Hurdles

- Finding right hospital
- Finding a donor
- The “conditioning” phase
- Engraftment
- Discharge
Hurdles

- Finding right hospital
- Finding a donor
- The “conditioning” phase
- Engraftment
- Discharge
- 100-Day quarantine
Hurdles

- Finding right hospital
- Finding a donor
- The “conditioning” phase
- Engraftment
- Discharge
- 100-Day quarantine
Hurdles

- Nine more months
- Nearing the finish line
Hurdles

- Finding right hospital
- Finding a donor
- The “conditioning” phase
- Engraftment
- Discharge
- 100-Day quarantine
- 1-Year “Survivorship”
A special milestone
Transition from a clear course...
...to wandering in the desert
A Medicine Cabinet Map of GVHD

- Eyes
- Lungs
- Immune suppressant
- Anti-inflammatories
- Skin
- Gastrointestinal
- Mouth
- Teeth
- Antibiotics
Other symptoms

Liver
Cramps
Muscle weakness
Stiffness
Fatigue
cGVHD: “The Private Burden”
So Many Offshoots

Bodily Symptoms

Lifestyle → Relationships
Career → Emotional state
Skin problems

Lesions
Rashes
Blotches
Basal cancer
Squamous cancer
Most visible, but least impactful
Dry mouth
Cramps

Abdominal
Fingers
Toes and calves
Hamstring
Unpredictability = stress
Effect on social life
Effect on work
The Dry Eye Journey

- A seven-year quest
- OTC drops & artificial tears
- Warm compresses
- Tear duct plugs
- Blood serum tears
- Contacts
- Scleral lenses
- Prose lenses
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Lungs

↓Oxygen - ↑CO2
Lifestyle
Everyday chores
Housing decisions
The Perfect Storm: Year-6 Downturn

- Lungs
- Muscle weakness
- Heartburn
- Cramps
- Fatigue
The Perfect Storm: Year-6 Downturn

- Lungs
- Muscle weakness
- Heartburn
- Cramps
- Fatigue
- Emotional effects
- Lifestyle changes
“Medicines” come in many forms

- Sayings
- Words of wisdom
- Metaphors
- Guiding principles
“Juice his vegetables!”

Critical thinking & judgment

• Take initiative & responsibility - be an “educated consumer”
• Practice self-awareness - recognize our vulnerabilities
• Avoid snake oil, quackery, and scams
• Recognize things that simply don’t work for us
“Blanket Kicking”

A method to let off steam

- Outlet for emotion
- A communication device
- Gives partners permission to vent
- De-escalates tension
- Maintains and builds relationships
A guiding wisdom

“The Serenity Prayer”

The serenity to accept the things I cannot change
The courage to change the things I can
The wisdom to know the difference
Take what it gives you
Take what it gives you

- Adjust gears & cadence
- Find comfortable rhythm
- Take rest stops
- Communicate limitations
- Appreciate the ride
Thank you!

Peter Gordon