



# Patient Perspective on Clinical Trials

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# SKIPPER

Defined as the one man badass  
enough to make a nuclear submarine  
as his personal fishing boat

My plan for 2011

# The Reality



# Mission Success



# Chronic Graft Vs Host Disease and Clinical Trials



# Reasons to Participate

- Chance to give back
- Improving treatment options
- Generally little to no cost to patients
- Small population
- Could improve your outcome
- Pride in knowing you helped find a new treatment
- Out of options



# Pitfalls of clinical trials

- Potential complications
- Some are “Randomized”
- It might not work
- Extra doctor visits
- Extra labs or testing
- Log/data keeping
- What happens when the trial ends?
- Is there a plan B or C?



# Things to do

- Do your research, know what is out there and what is on the horizon (This is how I found out about Rockstar)
- Talk to your doctor about options
- Read through everything
- Have your caregiver read through everything
- Ask your doctor questions



# My Clinical Trials

- cGVHD –
  - Imbruvica
  - Jackifi (ongoing approval)
  - Rockstar (Rezurock – FDA Approved) and Imbruvica
- Neutropenic diet
- Effects of exercise on recovery post transplant
- Use of HGH for immune system recovery

