What happens when a patient rep becomes a trial subject participant?
Becoming a patient rep

- Lurie Cancer Center SRC since 2005
- Personally motivated
- Responsibility to patient
- Despite occupation, basically clueless
Protocol ≠ informed consent

- Needed to read and understand protocol first
- Seldom found consent form parallel
- Always issues with readability and clarity
- >1 hour per trial
2010
First time CLL was treated since diagnosis 10 years before
2 months before wedding, moving, etc., etc., etc.
My role as patient rep offered no help
First informed consent

- Form itself lost in the blur
- Left study after single treatment
Second informed consent

- Entered another trial 1 year later
- Not allowed to see protocol!?!?
- Constantly referred to consent form; never without it
  - Procedures
  - Side effects
- Still on trial and stable over a year later
As a patient rep...

- Editorial distracting
- Sought continuity
- Sensitive to conveying respect
  - “Subject” vs. “participant”
  - Reasons why from protocol
  - Calendars to maintain control
As a participant...

- Dependent and vulnerable at outset
- Becoming connected and confident
- Transition a direct result of my study coordinators
As a patient rep...

- Struggled through protocols alone
- Editorial detachment
As a participant

- Surrounded by supportive, empathetic people
  - Crowding into tiny exam rooms
  - Chit chat even during bone marrow biopsy
  - Making appointments for me
  - Becoming my friends
Getting it

- The consent form became real to me only when I truly needed it
  - Trial becomes central focus of life
  - Every word matters
  - Expectations depend on it
  - Someone out there needs you
My coordinators

- Humanize the research and medical establishment
- Help with frustrating logistical arrangements
- Warm, accessible, engaged
- On my side
A few “don’ts”

- “I understand you have congestive heart failure!!”
- Sending it in
Thank you!