
Living...

**Post Transplant
And
With cGVHD**

A Patient's Point of View

Ellen Ryan Frank, PhD

Lessons Learned 1:

First and foremost:

YOU ARE NOT
A
Hypochondriac
Really!

Lessons Learned 2-3:

- Call BMT Doctor or Nurse Practitioner First
 - Do not get into trouble, no self-diagnosis
 - Let them triage for you
 - May take negotiation
 - Email, txt, call
- The rare PCP understands cGVHD diagnosis and treatments, let alone the drug regimen you are on
- Advocate for Yourself

Your Post Transplant Care Team



- Dentist
- PCP
- Oncologist
- GI
- Skin
- ObGyn
- Cardio
- Annual Checkup
- Psych

Lessons Learned 4-7:

- Each person's experience is unique
- Hesitate to generalize to all cGVHD patients
- Search for an expert:
 - If you do not get an answer that makes sense
 - Just doesn't feel right
 - You still do not feel well
 - Go further, get a 2nd opinion
 - Trust your instincts
- So far, seems to be an answer for almost everything

Lessons Learned 8-9:

- Your support system can change significantly over time
 - It's been years, you are cured!
 - You LOOK great
 - You should be grateful to be alive
- What's GVHD?
 - Cannot expect friends and families to know
 - Quality of Life
 - Support Groups

And Finally 10: YOU!

- Be kind to yourself, it is a new road we travel
- Cut yourself some slack
- Reach out, we are out here
- This is an endurance run, not a sprint
- You're OK, I'm OK!

Thank you! Be well.

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