IBC Storytelling Talking Points

1. Before Diagnosis

- What symptoms did you first notice?
- Did you know about IBC before this?
- How long did it take for you to be diagnosed?
- Were you misdiagnosed at first? What was that like?

2. Diagnosis

- What were the exact words your doctor used?
- How did you feel emotionally and physically at that time?
- Did you have to advocate for yourself to get answers?

3. Treatment Journey

- What treatments did you go through? (chemo, surgery, radiation, clinical trials, etc.)
- How did your body respond?
- What was the hardest part of treatment?
- Were there any unexpected moments—good or bad?

4. Emotional & Mental Impact

- What helped you cope on the hardest days?

- Did you have support from family, friends, or other patients?
- How did you deal with fear, anger, or uncertainty?

5. The Invisible and the Unexpected

- What's something people *don't* see or understand about IBC?
- How did it impact your relationships, career, body image, or finances?
- Did you face judgment or misunderstanding because IBC doesn't form a lump?

6. What You've Learned

- What has IBC taught you about yourself?
- Is there a moment or experience that changed your perspective?
- What do you wish more people (and doctors) knew about IBC?

7. Message to Others

- What would you say to someone newly diagnosed?
- What do you want the world to understand about IBC?
- Why is it important to you to share your story?

💡 Optional Tips:

- You don't have to answer every question—just the ones that resonate with you.
- You can write your story, record a voice memo, or even speak it into your phone.
- There's no "right way" to tell your story—raw and real is better than polished and perfect.