



# Alicia Staley

**VP, Patient  
Engagement**

**Why do you care so much  
about the patient experience?**

# My Cancer by the Numbers

**3** cancer diagnoses (Hodgkin's and BC)

**34** years of total survivorship

**19** years old at first diagnosis

# Hodgkin's Overview

**6** months until definitive diagnosis

**1** bone marrow biopsy

**1** chunk of left hip removed

**15** weeks of radiation

**33** radiation tattoos

**2** major surgeries to prep before chemo

**3** weeks longest hospital stay

**1** ELF experience on the pediatric floor

**8** cycles of ABVD chemotherapy

**6** additional weeks of radiation

**3.5** years for treatment journey

# Breast Cancer Overview

**2** different breast cancer diagnoses

**3** major surgeries

**3.5** years for treatment journey

# Additional Overview

- 12** surgeries in total
- 5** organs removed
- 5** major medical imaging types
- 4** clinical trial opportunities
- 3** clinical trial opportunities declined
- 1** med device trial participation
- 1** functioning lung



I'm quitting







**I'm not stopping**

# My Patient 'Experience'

**1,000+** pages of medical records, records from 1990-93 were not retained

**300+** hours in travel time for Hodgkin's treatment

**16** different patient portals at **4** different medical centers with different record retention policies

**3** portal instances are now archived, not searchable, and currently not accessible or offline – this is my current fight with my healthcare team

Did not participate in **3** clinical trials due to lack of information and understanding of trial

No support group that covered my scenarios - created my own **#BCSM (40,000+)**



**This is My Moonshot**



**This is Your Moonshot**