



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