

# TOWARD HEALTH RESEARCH DATA THAT SERVE CLINICIANS AND PATIENTS

The Cancer Research Data Commons Fall Symposium

**Amanda J. Borens, MS**  
**Data Scientist and Cancer Patient**

**October 17, 2024**

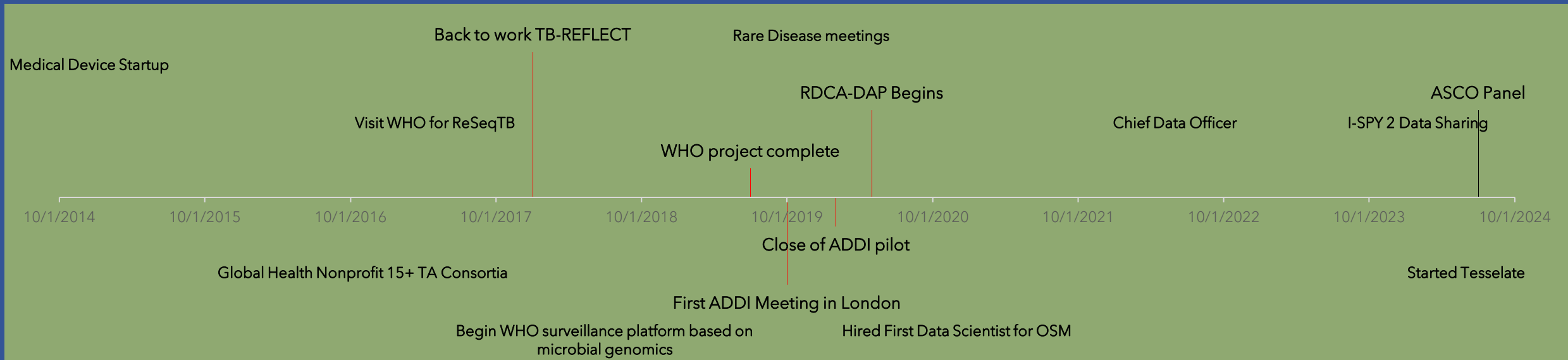


# Professional Background

Data Consultant  
Former Chief Data Officer  
Nearly 30 Years in Data Science



# A Decade of CRDC and Me



**AMANDA BORENS, M.S.**

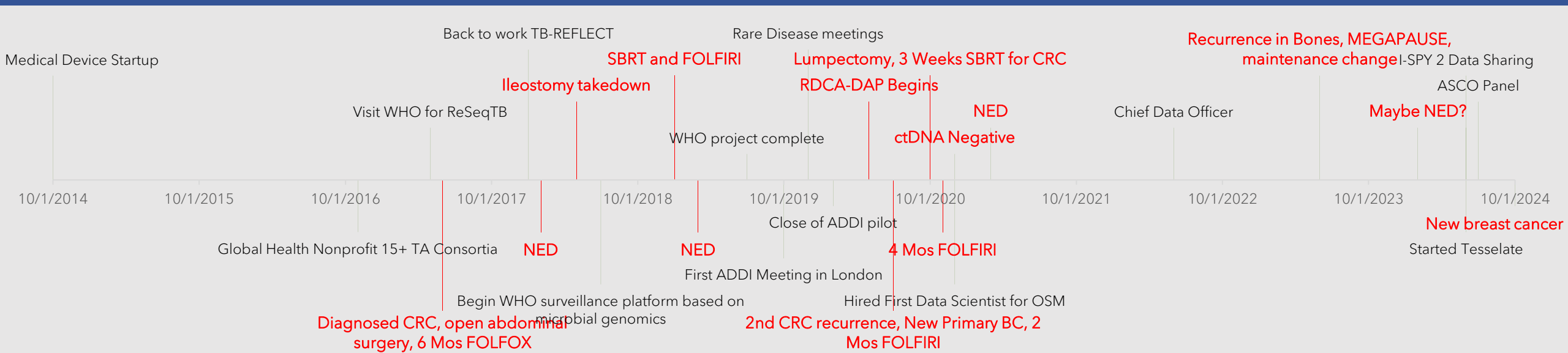
Chief Data Officer

Amanda has a unique breadth of life science data curation and analysis experience, having led technical teams in all phases of the FDA-regulated medical software development lifecycle for

**Congratulations  
Metadata Automation  
DREAM Challenge  
Winners**



# A Decade of CRDC and Me, *continued*



# We are getting better at *treating* cancer

*The rate of cancer death has been decreasing, and people are living longer with cancer than ever before. Approximately 64% of US patients diagnosed with cancer in 2005 have lived 10 years or more beyond diagnosis, up from 35% for those diagnosed in 1975. — American Society of Clinical Oncology Cancer Advances Report, 2018.*

- 5-year survival 13%
- 91% of patients with recurrence by 3 years died before 5 years

\*Secondary use →

## Disease-Free Survival Versus Overall Survival As a Primary End Point for Adjuvant Colon Cancer Studies: Individual Patient Data From 20,898 Patients on 18 Randomized Trials

Authors: [Daniel J. Sargent](#), [Harry S. Wieand](#), [Daniel G. Haller](#), [Richard Gray](#), [Jacqueline K. Benedetti](#), [Marc Buyse](#), [Roberto Labianca](#), ... [SHOW ALL](#) ..., and [Aimery De Gramont](#) | [AUTHORS INFO & AFFILIATIONS](#)

Publication: Journal of Clinical Oncology • [Volume 23, Number 34](#) • <https://doi.org/10.1200/JCO.2005.01.6071>

↗ 11,968 / 543



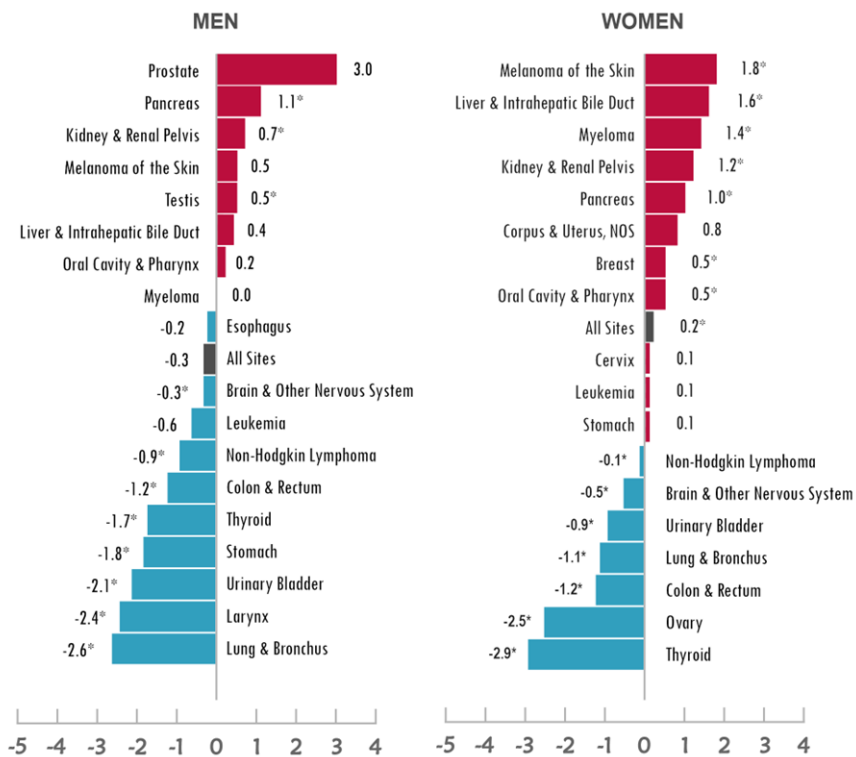
### Abstract

#### Purpose

A traditional end point for colon adjuvant clinical trials is overall survival (OS), with 5 years demonstrating adequate follow-up. A shorter-term end point providing convincing evidence to allow treatment comparisons could significantly speed the translation of advances into practice.

# We are getting better at *treating* cancer

## NATIONAL TRENDS IN RATES OF NEW CANCER CASES



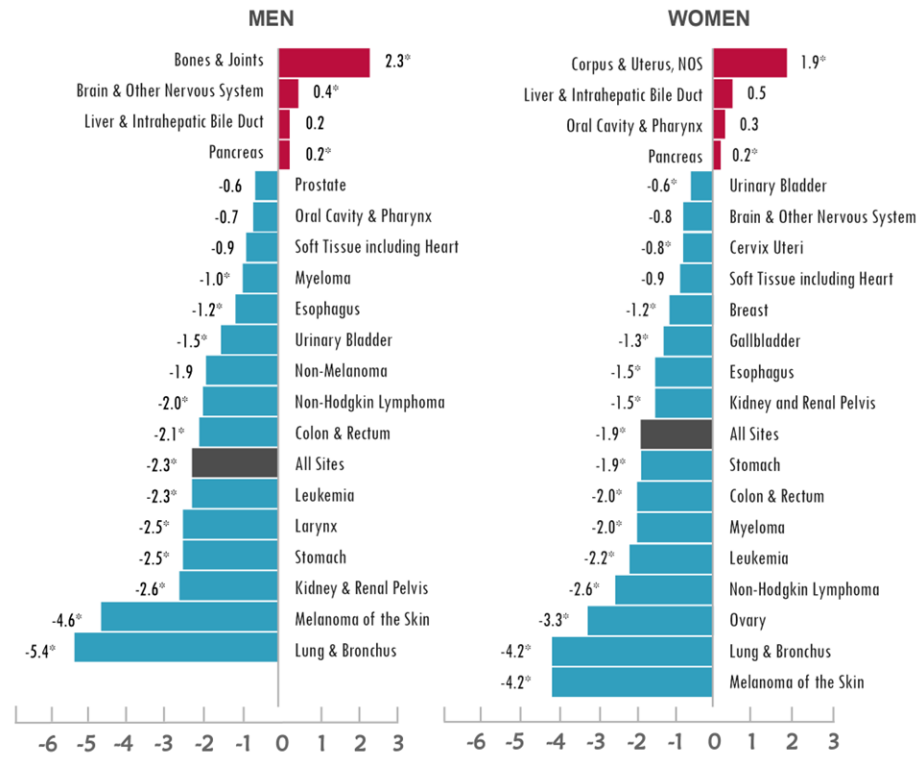
AVERAGE ANNUAL PERCENT CHANGE (AAPC) 2014-2018

AAPC = average annual percent change

\*AAPC is significantly different from zero ( $p < .05$ ).

seer.cancer.gov  
Source: Annual Report to the Nation

## NATIONAL TRENDS IN CANCER DEATH RATES



AVERAGE ANNUAL PERCENT CHANGE (AAPC) 2015-2019

AAPC = average annual percent change

\*AAPC is significantly different from zero ( $p < .05$ ).

seer.cancer.gov  
Source: Annual Report to the Nation

# Not Just New Drugs and Trials

How clinical research has helped me  
in the last 8 years

*(some breakthrough medical devices,  
some approvals, not always profit-driven)*


- 1962 - 5-FU, but optimized dosing more recent
- 2004 (2 decades ago) Oxaliplatin, but combination studies and length of nasty treatment optimized
- 1996 Irinotecan, but when to use in metastatic setting and how to offset side effects
- 2017 Ribociclib, but more recently for maintenance
- 2019 - *not a drug*, but ctDNA Signatera has saved me endless amounts of open-ended worrying
- 2019 Caris has guided both colon and breast treatments
- 2022 Capecitabine label and safety updates, but I started using it early 2021 for maintenance therapy, plus DOSING and effectiveness of dose reduction
- 2024 Guardant 360, but I started using it in 2020 and has helped with managing 2 cancers at once
- 2019 SBRT in place of surgery in CRC



Chapter 12 - Generation and interpretation of big data in pediatric drug development

Jeffrey S. Barrett <sup>1, a</sup>, Amanda Borens <sup>1</sup>, Solange Corriol-Rohou <sup>2</sup>

**Congratulations  
Metadata Automation  
DREAM Challenge  
Winners**



AMANDA BORENS, M.S.

Chief Data Officer

Amanda has a unique breadth of life science data curation and analysis experience, having led technical teams in all phases of the FDA-regulated medical software development lifecycle for



# Happy Milestones

- Meaningful contributions to medical science
- Celebrating 19 years of marriage in January
- Celebrated my 50<sup>th</sup> birthday a year ago
- 34% of our lives together as partners and parents





- 34% of our lives together as partners and parents
- 42% of my son's life





# Looking Forward

What do we want from the next 10  
years?

# What We **MUST** Do

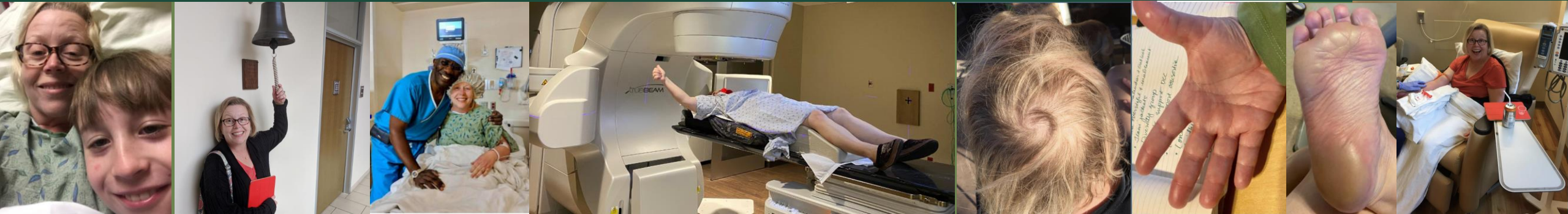
- SHARE IT
- USE IT



# What "Better" Looks Like

In my eighth year of treatment

- Currently treated at 2 NCI-designated cancer centers, consultations at 3 other cancer centers across California, Arizona, and Texas
- 6 months FOLFOX, 12 months FOLFIRI, 3.3 years capecitabine
- 11 months hormone blockers, denosumab, ribociclib
- 4 weeks SBRT
- 3 major surgeries at 3 unaffiliated hospitals, 2 inpatient stays ~3 weeks
- Biopsies! Colon, transesophageal nodes, bone/spine, axillary
- 28 CT scans, 12 PET, 10 MRI, 3 X-Ray, 7 ultrasound, 3 EKG, 1 ECG, 4 mammograms
- Miscellaneous specialists at various offices - endocrinology, Gyn, Cardiology, PCP
- Participant in three clinical studies - including WGS





# SHARE YOUR DATA

Honor those patients' sacrifices

# A Tale of Two Cancer Patients

My late father  
and me





# USE CRDC DATA

It isn't a used car

## **contact info**

Amanda J. Borens

[amandajborens@gmail.com](mailto:amandajborens@gmail.com)

Tesselate Data Consulting, LLC

Patient Advocacy

