My Background
But it started with a bell…
Overview of the NCI Office of Cancer Survivorship (OCS)
NIH: Conducting and Supporting Research
NIH includes 27 Institutes and Centers
In recognition of the large number of individuals surviving cancer for long periods of time and their unique and poorly understood needs
Mission of OCS

To support research that both examines and addresses the long- and short-term physical, psychological, social, and economic effects of cancer and its treatment among pediatric and adult survivors of cancer and their families.
Who is a Survivor?
Cancer Survivor: An individual is considered a cancer survivor from the time of diagnosis, through the balance of life.

Exponential Growth in the Number of Cancer Survivors

18.1 MILLION CANCER SURVIVORS

16.3 MILLION CANCER SURVIVORS LIVING 5+ YEARS
People with Metastatic Cancer in the US*

**TODAY**
623,405

**EXPECTED BY 2025**
693,452

*This includes the number of people in the US living with the most prevalent metastatic cancers: breast, prostate, lung, colorectal, or bladder cancer or metastatic melanoma*
I strongly identify as a breast cancer survivor. It’s this seminal part of my young adulthood. But I feel differently about “survivor” in the context of having a glioblastoma, which is an incurable, grade four brain tumor. So, I identify as a breast cancer survivor, but a brain cancer patient.

Age 33, multiple cancers

Survivorship at Different Stages

GOAL OF CARE: TREATED WITH CURATIVE INTENT

DIAGNOSED WITH EARLY-STAGE CANCER

DIAGNOSED WITH ADVANCED OR METASTATIC CANCER

PROGRESSES TO METASTATIC CANCER

GOAL OF CARE: TREATED WITH INTENT TO PROLONG LIFE

GOAL OF CARE: END-OF-LIFE CARE

DIAGNOSED WITH OR PROGRESSES TO END-STAGE CANCER

NCI Survivorship Research and Funding
What is Survivorship Care?
Comprehensive Survivorship Care

- Prevention/surveillance of recurrence and new cancers
- Surveillance/management of effects of cancer and its treatment
- Health promotion/preventive care

Care Coordination

Institute of Medicine. *From cancer patient to cancer survivor: Lost in transition.*
Quality Care for Cancer Survivors

- National Academy of Medicine recommendations:
  - Prevention and surveillance for recurrence
  - Surveillance/management of physical and psychosocial effects
  - Promoting healthy lifestyle behaviors
- Identifying and managing comorbidities
- Screening for subsequent cancers
- Monitoring and improving mental well-being
- Managing late- and long-term conditions
- Coordinating care
Survivorship Grant Portfolio
2017-2021
Cancer Types

- Breast: 34.5%
- Pediatric: 12.1%
- Lung: 9.0%
- Prostate: 9.7%
- Colorectal: 8.9%
Population Focus

- Cancer caregivers: 10.0%
- Advanced or metastatic cancer survivors: 8.0%
- Pediatric survivors: 7.9%
- Adolescent and young adult survivors: 7.2%
- Older adults: 7.0%
- Adult survivors of pediatric cancers: 7.9%
- Sexual and gender minority survivors: 0.26%
Study Type

**Intervention studies**
- 0%: 22.0%
- 20%: 32.0%
- 40%: 40.8%
- 60%: 25.1%

**Observational studies**
- 0%: 19.0%
- 20%: 32.0%
- 40%: 25.1%
- 60%: 19.0%

**Psychosocial or supportive care**
- 0%: 32.0%
- 20%: 25.1%
- 40%: 19.0%

**Lifestyle or health behaviors**
- 0%: 32.0%
- 20%: 25.1%
- 40%: 19.0%

**Care delivery**
- 0%: 32.0%
- 20%: 25.1%
- 40%: 19.0%
Gaps in Survivorship Research

Populations that need more attention:

- Advanced and metastatic cancer survivors
- Older adult survivors
- Rare cancer survivors

Topics and methods:

- Health disparities experienced by specific groups of survivors:
  - Socioeconomically disadvantaged survivors
  - Sexual and gender minorities
  - Groups living in geographically rural areas
- Financial impacts of cancer (hardship, employment, health economics)
- Implementation science approaches
Example OCS Areas of Interest

- Primary care for cancer survivors
- Understudied symptoms and toxicities
- Survivorship care delivery
- Specific populations
  - People living with advanced and metastatic cancer
  - Survivors of childhood, adolescent, and young adult (AYA) cancers
  - Medically unsupported/underserved survivors: rural, low income, sexual and gender minority survivors
OCS Engagement with Survivors
How Does OCS Engage with Survivor Advocates?

- Identify emerging unmet needs based on survivor perspectives
- Seek perspectives that inform NCI scientific initiatives
- Share survivor experiences as part of OCS webinars and NCI-led meetings
- Publish survivor stories on OCS website
- Work with NCI Office of Advocacy Relations
NCI Office of Advocacy Relations (OAR)

- As part of NCI’s Office of the Director, OAR engages cancer research advocates and organizations, serving as a link for advocate stakeholders to collaborate with NCI.

- OAR works with individual research advocates, local and national advocacy groups, and professional societies to ensure the collective patient perspective is included in NCI efforts to advance cancer research and improve patient outcomes.

On the web: [advocacy.cancer.gov](advocacy.cancer.gov)

Via email: [NCIadvocacy@nih.gov](mailto:NCIadvocacy@nih.gov)

On Twitter: [@NCIadvocacy](https://twitter.com/NCIadvocacy)
Example Initiative: Survivorship Needs for People Living with Advanced and Metastatic Cancers
Virtual Meeting on Survivorship Needs for Individuals Living with Advanced and Metastatic Cancers

Meeting Agenda

• Keynote presentation: Dr. Ryan Nipp
• Patient/survivor panel
• Scientific Sessions:
  - Symptom management
  - Epidemiology & surveillance
  - Psychosocial research
  - Healthcare delivery research
  - Health behaviors research
Promote grant applications
Promote efforts to identify population
Assess and enhance available data resources
Understand unmet needs
Enhance awareness of need for research
Research to Understand and Address the Survivorship Needs of Individuals Living with Advanced Cancer (R01 Clinical Trial Optional)

Next application date: September 2023

*NCI has committed $32.5M for this initiative
*Requires engagement with survivors in all aspects of the research

Go to Survivorship.cancer.gov for more information
Blending Survivorship and Palliative Care for People with Advanced Cancer in the Precision Oncology Era

Laura A. Petrillo, MD
Palliative Care Physician, Massachusetts General Hospital
Assistant Professor, Harvard Medical School

Anne H. Charity Hudley, PhD
Cancer Survivor
Associate Dean of Educational Affairs and Professor of Education, Stanford University

December 13, 2022, at 2 p.m. ET
OCS DIRECTOR’S SERIES

Opportunities to Advance the Science of Survivorship in Neuro-Oncology

May 2, 2023, at 2 p.m. ET

Emily S. Tonorezos, MD, MPH
Director, Office of Cancer Survivorship
National Cancer Institute

Terri S. Armstrong, PhD
Senior Investigator and Deputy Chief, Neuro-Oncology Branch
National Cancer Institute

Kimberly Wallgren
Caregiver and Executive Director
Collaborative Ependymoma Research Network (CERN) Foundation, a program of the National Brain Tumor Society

Scan for more info ➤

NATIONAL CANCER INSTITUTE
Division of Cancer Control & Population Sciences
Sexual Concerns of Cancer Survivors: Are We Closer to Addressing this Unmet Need?

Jennifer B. Reese, PhD
Associate Professor, Cancer Prevention and Control Program
Fox Chase Cancer Center

June 13, 2023, at 2 p.m. ET
Optimizing Care Delivery for Cancer Survivors: Engaged, Pragmatic, Multi-team & Multi-level

Simon Craddock Lee, PhD, MPH (he/him/his)

Chair and Sosland Family Professor in Preventive Medicine
Department of Population Health, School of Medicine
University of Kansas Medical Center

September 19, 2023, at 2 p.m. ET
YOU’RE NOT ALONE.

Tamika Felder, Cancer Survivor
There is not one right way through cancer, and you have to be aware of what makes sense for you.

Bob
Cancer Survivor
“Cancer’s in my life, on my terms.”

Bethany Ross
Cancer Survivor
In August 2018, at the age of 30, after being sick for nine months, I was diagnosed with Stage IV neuroendocrine cancer in my appendix, pancreas, lymph nodes and spread to my liver.

I had two surgeries, including a liver resection and 4 months of hormone treatments to help my symptoms.

Currently having a recurrence in my stomach and on monthly treatments again.

I joined CPAT in 2020 after hearing a session at CancerCon (young adult cancer conference) and knowing that I needed to make what happened to me mean something.
Bethany Ross
Advocating for Quality Cancer Care Through Storytelling

Bethany Joy @BethanyJoy28 - Jul 21
Oh hey you know just featured by the National Cancer Institute today... 😊

Dear Cancer... 

Bethany Ross
Cancer Survivor

Dear Cancer,

I hate you. You took more from me than you ever will from anyone. There I was, newly married, thirty years old, and running half marathons, when you decided to invade my body and life. I had been sick for nine weeks, vomiting every day and seeing doctors after doctor, and no one could figure out what was wrong with me. I had doctors tell me it was a stomach bug, that I was just sleeping too much, that I just needed to eat healthier. They wouldn’t even consider the possibility of cancer. You gelded me at my peak, showing me that I had completed my “growing” and that I was never going to be able to “grow up.” You stupid, selfish, cruel disease. You’ve stolen my future, my family, my peace. I can’t even look at a baby anymore. They make me sick to my stomach. You’ve taken away my joy, my purpose, my reason for existing. You’ve taken away my life, and I hate you for it. 

NCI Office of Cancer Survivorship @NCICancerSurv - Jul 21
Bethany was going to do whatever it took to survive NeuroendocrineCancer. She was determined to beat the odds and share her journey. For her, cancer was the catalyst for living a fuller life. cancercontrol.cancer.gov/nci/resources/... #CancerSurvivorStories @BethanyJoy28

CANCER’S IN MY LIFE ON MY TERMS.

Bethany Ross
Cancer Survivor

The way fast tried to appear once after another and told me so. That’s not your job anymore. That’s now cancer’s.” Bethany, don’t lie, killed that. You get to decide what you are now. No matter what, we’re still fighting. At the end, I didn’t know how to deal with you, but I knew I had to survive. Surviving was the goal. Right? I was going to be the best, the most informed. I was going to be the strongest. That was a lie. The cancer just took over. The scientific part of my brain said I was after all a chemistry major in college. I had my studies and meet oncology appointments with a notebook full of questions. I was ready to take on a scientifically correct. The thing I had prepared for was how to take on you spiraling. No one prepared me for what you would do to my entire life—my future, my earnings, and my life outside of cancer. For a while I was happy I was in survival mode, living from one Celeste...
Thank You!

Michelle Mollica, PhD, MPH, RN, OCN
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