

***FIGHT*** ***COLORECTAL CANCER***<sup>®</sup>

**PATH  
TO A  
CURE  
REPORT**



# SURVIVORSHIP AND RECURRENCE



**FIGHT COLORECTAL CANCER™**  
PATH TO A CURE OBJECTIVES AND STRATEGIES

## CHALLENGES & OPPORTUNITIES

# 4

PROGRESS INDICATOR:  
**ENHANCE QUALITY  
OF LIFE AND  
PREVENT RECURRENCE**



**FIGHT COLORECTAL CANCER™**  
PATH TO A CURE OBJECTIVES AND STRATEGIES

**CHALLENGES &  
OPPORTUNITIES**



**ERIN & CURT  
CHAMPION HIGHLIGHT**

Fight CRC research advocates are helping to guide research led by Dr. Erin Van Blarigan at the University of California, San Francisco (UCSF). Dr. Van Blarigan’s research, funded by the National Cancer Institute, is investigating different interventions to help colorectal cancer survivors increase exercise, and improve diet and BMI after diagnosis, following the American Cancer Society guideline score.

Four advocates with various backgrounds are informing the study design and recruitment materials to ensure that the focus of the study remains patient-centric and can positively impact the quality of life of cancer survivors post-treatment.

According to Curt Pesmen, a stage III colorectal cancer survivor and research advocate contributing to the study, *“Dr. Van Blarigan’s research quickly incorporates each advocate’s suggestions to add ‘real-world’ exercise and diet advice without creating additional survivorship burdens on the patient.”*

This type of survivorship research is crucial to understanding how to best support the patient community and ensure that the tools and recommendations are actionable.

**KEY  
MESSAGES**



FIGHT COLORECTAL CANCER™  
PATH TO A CURE OBJECTIVES AND STRATEGIES

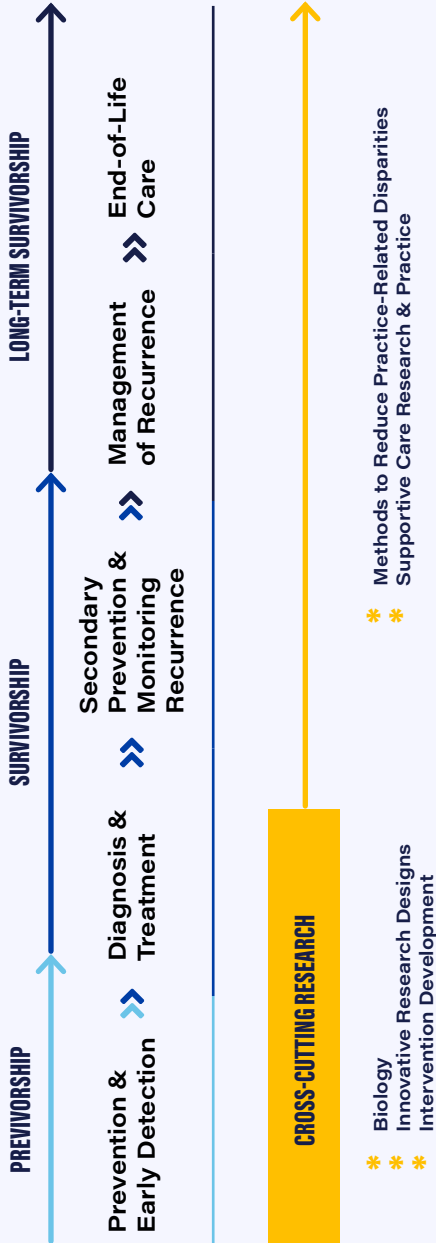
CHALLENGES & OPPORTUNITIES

PATH TO A CURE  
KEY MESSAGES  
SURVIVORSHIP AND RECURRENCE

- \* There are over 1.5 million colorectal cancer survivors in the United States. The five-year survival rate for people with colorectal cancer is 65%.<sup>(44)</sup>
- \* Considering caregivers is also part of survivorship. There is growing research and focus on the role and needs of caregivers.
- \* There is an opportunity to provide guidance and consensus on colorectal cancer survivorship standards. Part of the equation is delivery of care for virtual, telehealth, or in-person visits. Let's have focused discussions on how to support the unique issues faced by young patients, late-stage patients, and those with specific tumor types and/or receiving specific types of targeted therapies.
- \* Our goal is for patients to live longer and enjoy their quality of life. To do this successfully, survivorship research efforts must elaborate and inform patients and their loved ones on the many issues relevant to long-term survival and risk of recurrence.
- \* Late-stage survivors struggle with fear of cancer recurrence/ progression and feelings of powerlessness, sadness, or frustration from the life-changing effects of treatment and surgery.

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Continuum of  
Colorectal Cancer Research



Adapted from: Warren, J. (2017, December). Achievements and Next Steps to Tackle Cancer Grand Challenges. McGill Integrated Cancer Program Institute for Applied Cancer Science. <https://slideplayer.com/slide/13852896/>; <https://slideplayer.com/slide/13852896/>



**FIGHT COLORECTAL CANCER™**  
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**CHALLENGES &  
OPPORTUNITIES**

**Funding  
Beyond NCI**

The Department of Defense Peer Reviewed Cancer Research Program (PRCRP) supports innovative, high-impact cancer research.

The FY21 PRCRP has a focal area examining gaps in quality of life and/or survivorship that may affect the general population but have a particularly profound impact on the health and well-being of military service members, veterans, and their beneficiaries. As the military is seeing an increase in colorectal cancer in young service members, ensuring the opportunity to test models of survivorship care is an area of research focus and priority.<sup>(45)</sup>

The Centers for Disease Control and Prevention (CDC) supports, designs, implements, disseminates, and evaluates public health research to assess the needs of cancer survivors and caregivers, specifically, through work in surveillance and the National Comprehensive Cancer Control Program and dedicated research opportunities.<sup>(46)</sup>

Patient-Centered Outcomes Research Institute (PCORI) funds patient-centered outcomes research studies that also often include patient populations traditionally excluded from cancer clinical trials, such as older adults and those with comorbid health conditions.

One area emphasized by stakeholders that has been missing to date in research is the assessment of caregiver outcomes, which could be of particular benefit in colorectal cancer.<sup>(47)</sup>



# CHALLENGES

## SURVIVORSHIP

Currently, there are over 1.5 million colorectal cancer survivors in the United States. The five-year survival rate for people with colorectal cancer is 65%.<sup>(44)</sup>

The term “survivorship” covers physical, psychological, social, and financial issues affecting patients during and after treatment. Our community of colorectal cancer survivors includes people with no disease, people who continue to receive treatment to reduce their risk, and those who manage a chronic but well-controlled disease with quality of life. It is incredibly important to recognize that colorectal cancer impacts families and entire communities of people.

While there are wellness and medical guidelines for colorectal cancer patients after treatment is complete, gaps remain in *who* and *how* survivorship care is delivered. There is also variability from institution to institution about how survivorship care is delivered.

**The bottom line: Colorectal cancer survivors are often lost in the transition.**

*“An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.”*

— National Cancer Institute Office of Cancer Survivorship  
(adapted from the National Coalition for Cancer Survivorship)<sup>(48)</sup>

We are devoted to understanding the etiologies of cancer and improving treatments. Yet to truly succeed in our effort to find a cure, we must seek opportunities to expand cancer research efforts to include data on survivorship through clinical trials, large cohort studies, cancer registries, and national surveys. We need to understand the unique needs of colorectal cancer survivors in order to build programs that will meet their needs and improve overall quality of life for our community.

You are alive, but are you suffering?

## FIGHT COLORECTAL CANCER™ PATH TO A CURE OBJECTIVES AND STRATEGIES

### CHALLENGES



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**Ben White**  
Diagnosed at 26 | Stage III CRC

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# SUPPORT



# CHALLENGES

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PATH TO A CURE OBJECTIVES AND STRATEGIES

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SURVIVORSHIP

STRAIGHT TALK  
FROM COLORECTAL CANCER SURVIVORS

**Bowel dysfunction  
causes physical  
and lifestyle  
limitations,  
leading to a lesser  
quality of life.**

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CHALLENGES



FIGHTING IN HONOR OF  
**Melvin Fernandez**  
Diagnosed at 42 | Stage III CRC

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# CHALLENGES



## CHALLENGES

### SURVIVORSHIP

#### STRAIGHT TALK FROM COLORECTAL CANCER SURVIVORS

Physical symptoms hinder return to work; survivors experience meaningful impairment in completing everyday tasks, which can in turn cause financial burdens.

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FIGHTING IN MEMORY OF  
Robyn Schmid Tiffie  
Diagnosed at 31 | Stage IV CRC

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# CHALLENGES

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SURVIVORSHIP

STRAIGHT TALK  
FROM COLORECTAL CANCER SURVIVORS

Side effects and recovery can be daunting and negatively impact quality of life.

Survivors need real-world education on side effects, the surgery process, and long-term adjustments.

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CHALLENGES



Dr. Ryan Fields  
CRC Surgeon

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SURVIVORSHIP

STRAIGHT TALK  
FROM COLORECTAL CANCER SURVIVORS

Late-stage survivors struggle with fear of cancer recurrence/ progression and feelings of powerlessness, sadness, or frustration from the life-changing effects of treatment and surgery.

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CHALLENGES



FIGHTING IN MEMORY OF  
**Chris Ganser**  
Diagnosed at 34 | Stage III CRC

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# CHALLENGES

## SURVIVORSHIP

### STRAIGHT TALK FROM COLORECTAL CANCER SURVIVORS

There are unique colorectal cancer functional limitations. Patients young and old alike face issues around sexuality.

For many, stomas can cause body image issues and reduce confidence.

## FIGHT COLORECTAL CANCER™ PATH TO A CURE OBJECTIVES AND STRATEGIES



### CHALLENGES

- \* In late 2019, the American College of Surgeons Commission on Cancer (CoC) released *Optimal Resources for Cancer Care: 2020 Standards for Cancer Program Accreditation*. This was a big win for all survivors. <sup>(49)</sup>

This policy set a standard to require the cancer program's cancer committee to oversee the development and implementation of a survivorship program directed at meeting the needs of cancer patients treated with curative intent. <sup>(49)</sup>

Today, there is a stronger focus on cancer survivorship and the needs of cancer patients; however, these interventions are often not reimbursed. Survivorship is an under-resourced area.



- \* To have a successful survivorship program, we must address the patient as a whole person. Easier said than done!

### OPPORTUNITIES

- \* Based on the literature across all cancer types, we know treatment summaries (TS) and survivorship care plans (SCPs) are being implemented, but the data is mixed about their impact on improving patient outcomes. We know patients are riddled with challenges beyond treatment of their cancer. From mental health to nutrition, cancer patients face an avalanche of challenges, and there is a lot of thought and consideration on how to support patients in their survivorship journey.

How can we develop research efforts that include a holistic approach to survivorship?

- \* There is an opportunity to provide guidance and consensus on colorectal cancer survivorship standards. Part of the equation is delivery of care for virtual, telehealth, or in-person visits.

Let's have focused discussions on how to support the unique issues faced by young patients, late-stage patients, and those with specific tumor types, and/or receiving specific types of targeted therapies.

Colorectal cancer survivors are a diverse group facing long-term treatment side effects. Our research efforts should encourage and empower a proactive approach to support their overall health. From implementing survivorship care plans to unpacking the real-life experiences and quality of life of survivors, we can and should use this knowledge to inform future funding opportunities.

# UNITIES



# CHALLENGES

## RECURRENCE



From surviving to thriving, you can't help but think about recurrence. Approximately 30%–40% of patients develop recurrence following surgery, and 40%–50% of recurrences are apparent within the first few years after initial surgical resection.<sup>(51)</sup>

Recurrent disease usually presents as distant metastasis in the liver or lungs or as locoregional recurrence in the pelvis or peritoneum.<sup>(51)</sup>

The following are general statistics about the chance of recurrence:

- \* Stage I < 10%
- \* Stage II 10%-15%
- \* Stage III 25%-40%
- \* Stage IV 50%-70% (after liver resection)

Adapted from: NCCN Treatment/Recurrence Staging Protocols



## CHALLENGES

- \* Numerous studies have shown the clinical utility of ctDNA, a noninvasive biomarker which can predict minimal residual disease (MRD), and how it can help us stratify colorectal cancer patients who are more likely to relapse.<sup>(52)</sup>

However, what this means for guiding a patients' treatment is still an active and important research question. The biggest questions are: Will patients treated with pre-surgical therapy, surgery, and post-surgical chemotherapy have additional treatments if there are signs of MRD? And how do we provide mental health support for those who do receive a positive ctDNA test?

Research advances in this area are especially important for our metastatic and early-age onset patients. Individuals ages 25 years old and younger with colon cancer appeared to be at higher risk for relapse and death than older adults, according to data published in Journal of the American College of Surgeons.



## OPPORTUNITIES

- \* ctDNA research is advancing rapidly, but are the study designs strong enough to change clinical practice? That's what we are striving for.  
  
There is strong momentum to find clinical utility for these tests to help patients with a lower risk of recurrence avoid the side effects of additional treatment and those with a higher risk receive proactive care.  
  
There is great promise to use ctDNA tests with current standard monitoring guidelines in the early detection of recurrence, but it will only make a difference if patients have access to these advances.
- \* Our goal is for patients to live longer and enjoy their quality of life. To do this successfully, survivorship research efforts must elaborate and inform patients and their loved ones on the many issues relevant to long-term survival and risk of recurrence.

## POLICY SHOUT OUT

Coverage policy will play an important role when it comes to adoption of new tests. The potential clinical adoption of ctDNA assays for MRD assessment depends in part on coverage in both the commercial market and among public payers such as Medicare.

Various Medicare contractors have issued local coverage determinations (LCDs) for validated tests able to detect molecular recurrence or progression before it is evident through clinical or radiographic evaluation, but more needs to be done to ensure full coverage for all patients and clinical adoption.<sup>(53)</sup>



# OPPORTUNITIES



# TIME TO GET SHi★T DONE



## FIGHT COLORECTAL CANCER™ PATH TO A CURE OBJECTIVES AND STRATEGIES

# SURVIVORSHIP AND RECURRENCE

## PROGRESS INDICATOR: ENHANCING QUALITY OF LIFE AND PREVENTING RECURRENCE

### OBJECTIVE 1



Development and research of survivorship care delivery intervention and approaches, which take into account the whole person—all of one's health conditions and social conditions, not just one's colorectal cancer.

#### Strategies:

1. Build consensus guidelines for Commission on Cancer survivorship recommendations for colorectal cancer survivorship taking into account the following key aspects:
  - a. Integration of professional and evidence-based colorectal cancer survivorship guidelines in survivorship interventions;
  - b. Improve ways to reduce suffering and mortality among survivors, and promoting return to life, work, and school;
  - c. Focus on the needs of caregivers;
  - d. Integrate evidence-based psychosocial services into standard of care;
  - e. Enhance the education of survivors and all clinicians;
  - f. Define quality measures for colorectal cancer survivorship care;
  - g. Provide viable strategies that bridge care delivery with primary care and oncology care;
  - h. Provide survivorship care that is sustainable, accessible, affordable, and equitable.
2. Build models of care and integrate what is published, established, and known about the specific needs of the differing "types" of colorectal cancer patients.
3. Include research advocates in designing and testing models of care delivery and approaches to risk stratification for colorectal cancer survivors that consider the whole person.
4. Implement and develop quality measures for survivorship care.
5. Increase the number of grants, dollar amounts, and grant mechanisms of PCORI, NCI, DOD, and CDC to fund colorectal cancer survivorship opportunities.



## OBJECTIVE 2

**Increase the capacity of healthcare delivery systems, primary care, public health, and the health workforce to bridge care needs of colorectal cancer patients post-treatment.**

Strategies:

1. Focus specific strategies to educate primary care providers and help bridge care from oncologists to primary care providers for longer-term management of colorectal cancer survivors' needs and prevent recurrence.
2. Advocate with the CDC for supportive care and community-based services that must be purposefully developed for colorectal cancer survivors so they may continue their social, recreational, and vocational roles and functions in daily life.
3. Explore methods of care delivery for virtual, telehealth, in-person, or other delivery of care mechanisms to specifically support the needs of colorectal cancer patients.
4. Provide policy expertise to create sustainable patient navigation throughout the oncology care continuum, including into cancer survivorship.

## OBJECTIVE 3

**Expand research efforts to improve and advance development of emerging and new technologies for early detection, screening, and prevention of recurrence.**

Numerous studies have shown the clinical utility of ctDNA, a noninvasive biomarker which can predict minimal residual disease (MRD), and how it can help us stratify colorectal cancer patients who are more likely to relapse. However, what this means for guiding a patient's treatment is still an active and important research question.

The biggest questions are: Will patients treated with pre-surgical therapy, surgery, and post-surgical chemotherapy have additional treatments if there are signs of MRD? And how do we provide mental health support for those who do receive a positive ctDNA test?

Research advances in this area are especially important for our metastatic and early-age onset patients. Individuals ages 25 years old and younger with colon cancer appeared to be at higher risk for relapse and death than older adults, according to data published in Journal of the American College of Surgeons.

Strategies:

1. Assess the ability and extent for ctDNA tests to guide treatment decisions and monitor for MRD and recurrence in colorectal cancer.
2. Gather stronger data from patients to monitor recurrence, ctDNA, and the correlation with clinical outcomes.
3. Identify high-risk patients with remaining microscopic disease, so that treatment and follow-ups can be tailored accordingly.





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A vertical sequence of 14 blue characters showing the progression of the letter 'A' from a tall, narrow shape to a short, wide shape. The sequence starts with a tall, narrow 'A' at the top and gradually transforms through intermediate shapes to a short, wide 'A' at the bottom.

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