



**FIGHT** COLORECTAL CANCER™

# **PATH TO A CURE**

## **2024 PROGRESS REPORT**

*GETTING SH!T DONE*

# 1 BIOLOGY AND ETIOLOGY

**PROGRESS INDICATOR:** Applying what we know from biology and hereditary risk to reduce late-stage colorectal cancer.

**OBJECTIVE 1** Further research the nature, biology, and implications of colorectal cancer, throughout the continuum of age (while also considering younger adults versus older adults). Understanding parameters, including stage, location, histopathology, and underlying genetic and molecular “drivers.”

**PROGRESS:**

- ✓ Fight CRC’s Early Age Onset Work Group completed a review of red flag signs and symptoms and diagnosis delays for early-onset colorectal cancer, with a manuscript submitted for publication in Winter 2023. Identifying these warning signs can be lifesaving, enabling earlier and more effective treatments.
- ✓ In December 2023, Fight Colorectal Cancer, in collaboration with the National Cancer Institute and Vanderbilt University, hosted an Early Age Onset Research meeting. This discussion will be followed by an international Early Age Onset Think Tank in July 2024. Convening scientists from all over the world will accelerate progress.



*The focuses and challenges for us EAOCRC patients are different from those diagnosed at later stages. Long-term survivorship has to be highly focused on both quality and quantity of life in treatment solutions, and bringing together the top minds in the CRC community at the EAO Think Tank is critically important to sharing information and integrating multidisciplinary teams and approaches to find the answers we need.”*

— Phuong Gallagher, Stage IV Survivor, Think Tank Attendee

- ✓ In January 2023, the National Cancer Institute (NCI) launched a Notice of Special Interest (NOSI): Research on the Etiology, Early Detection, Screening and Prevention of Early-Onset Colorectal Cancer, a funding opportunity for research grants focused on early-age onset colorectal cancer. This investment signifies a commitment to improving treatment and early detection.

**OBJECTIVE 2** Research the role and impact of health disparities in those developing colorectal cancer, exploring factors such as biology and socioeconomic status; research to inform evidence-based interventions in areas of biology and healthcare policy.

**! IN PLANNING AND DEVELOPMENT PHASE.**

**OBJECTIVE 3** Improve dissemination and implementation (spreading the information and putting into practice) of evidence-based and population-based strategies for genetic and hereditary colorectal cancer, specifically Lynch syndrome.

**PROGRESS:**

- ✓ The Fight CRC Hereditary and Genetic Workgroup is actively advocating for the inclusion of Lynch Syndrome as an ICD-10 code. This change would simplify tracking, treatment, and funding for related medical expenses, benefiting patients and their families.

# 1 BIOLOGY AND ETIOLOGY

- ! While the Access to Genetic Counseling Services Act did not pass in the 2022 legislative cycle, Fight CRC and partners are committed to reintroducing it in 2023/2024, providing more individuals with essential information about their risk.
- ✓ In 2023, a Merit-based Incentive Payment System (MIPS) measure regarding tumor screening for Lynch syndrome was approved, ensuring that no one at risk is overlooked and that timely screenings are available to all.

## OBJECTIVE 4 Progress research and exploratory science to advance our knowledge of Lynch syndrome.

### PROGRESS:

- ✓ Fight Colorectal Cancer's Genetics and Family History Advisory Council has developed a comprehensive white paper with data and figures, initiating advocacy efforts with the Commission on Cancer to incorporate multigene panel testing for Lynch syndrome. This push for genetic testing can lead to more accurate diagnoses and clearer treatment paths.
- ! The U.S. Preventive Services Task Force (USPSTF) plans to post a draft research plan for public comment, focusing on risk assessment, genetic counseling, and genetic testing for Lynch syndrome-related cancer in adults. Our involvement in providing feedback demonstrates the importance of patient voices in shaping research.

# 2 PREVENTION AND EARLY DETECTION

**PROGRESS INDICATOR:** Advancing colorectal cancer prevention and early detection.

## OBJECTIVE 1 Improve dissemination and implementation (spreading the information and putting into practice) of the evidence-based colorectal cancer screening interventions for the average-risk population.

### PROGRESS:

- ✓ Fight CRC's president, Anjee Davis, served on the President's Cancer Panel committee publishing, Closing Gaps in Cancer Screening: Connecting People, Communities, and Systems to Improve Equity and Access with a companion brief focused on colorectal cancer screening.
- ✓ In March of 2023, Fight Colorectal Cancer worked with the White House and federal agencies in response to the Cancer Moonshot initiative to underscore the national commitment to increasing screening rates, ultimately leading to early detection and reduced CRC-related deaths.



*Standing at the White House, I represented the intersectionality of my experience as a black, queer colorectal cancer survivor. Teaming up with Fight Colorectal Cancer, our collective aim is to break down barriers to screening, ensuring that every individual, irrespective of their background, has an equal opportunity for early detection and improved outcomes.”*

— Paula Chambers Raney, Stage I Survivor

## 2 PREVENTION AND EARLY DETECTION

- ✔ Fight CRC developed and disseminated resources for patients, providers and health insurers to educate them on the recent policy change to remove out-of-pocket costs for patients needing a colonoscopy after an abnormal non-invasive test to help ensure that the policy is effectively implemented and patients see the benefit.
- ✔ Fight CRC successfully secured report language in the FY23 federal funding bill to direct the National Cancer Institute (NCI) to develop a strategic plan addressing the rising number of young CRC patients, persistent health disparities in CRC prevalence, and the need for better treatment options.
- ★ **Fight CRC launched a screening quiz tool and guided more than 3,000,000 users to know their risk level for colorectal cancer and find providers to get screened if necessary.**
- ✔ ARPA-H is currently funding a project aimed at enhancing multi-cancer early detection (MCED) by understanding cancer cell profiles. This project seeks to develop precise and cost-effective MCED tests for colorectal cancer and other cancer types, potentially enabling earlier detection and improved outcomes.
- ✔ An \$8 million grant was awarded to Dr. Fola May and team as a part of Stand Up to Cancer Health Equity Dream Team focused on improving colorectal cancer screening in medically underserved communities.
- ✔ ARPA-H launched the Biomedical Data Fabric Toolbox to facilitate research accessibility and collaboration, accelerating advancements in cancer prevention and early detection.
- ✔ Advocacy efforts resulted in the delay in the implementation of a prior authorization policy by UnitedHealthcare, ensuring that patients can access colonoscopy screenings without unnecessary barriers.

### OBJECTIVE 2 Improve dissemination and implementation of the evidence-based colorectal cancer screening for the increased, high-risk and symptomatic patients.

#### PROGRESS:

- ✔ Fight CRC hosted *United in Blue*, a flag installation on the National Mall in Washington, DC to emphasize the urgency and the need for action to address the rising cases of CRC among young adults.
- ✔ Fight CRC led a letter with the American College of Gastroenterology, the American Gastroenterological Association and the American Society for Gastrointestinal Endoscopy to the Departments of Health and Human Services, Treasury and Labor urging them to cover surveillance colonoscopy without out of pocket costs to the patient.

### OBJECTIVE 3 Further research and examination of colorectal cancer screening uptake for those younger than age 50 to reduce early-age onset colorectal cancer.

#### PROGRESS:

- ✔ Fight CRC is actively collaborating with partners to advance the Access to Genetic Counseling Services Act, increasing congressional support for legislation that improves access to genetic counseling for those at risk of hereditary cancer.
- ✔ By advocating for colorectal cancer screening to begin at age 45, Fight CRC aims to detect and treat the disease at earlier stages.

### OBJECTIVE 4 Research minimally invasive strategies for preventive cancer screening, including analysis of blood, urine, and saliva (i.e., “liquid biopsies”); and examination of the oral and intestinal microbiome.

#### PROGRESS:

- ✔ The National Cancer Institute (NCI) is establishing the Cancer Screening Research Network (CSRN), focusing on trials and studies related to cancer screening. This network aims to develop innovative, less invasive screening methods, such as liquid biopsies, to improve accessibility and patient comfort during screenings.

# 3 TREATMENT

**PROGRESS INDICATOR:** Expanding treatment strategies for colorectal cancer patients.

**OBJECTIVE 1** Increase clinical trial enrollment, particularly for late-stage disease, microsatellite stable, and early-age onset patients.

**PROGRESS:**

- ✔ Fight CRC's expanded Clinical Trials Finder now incorporates MSI-I trials, bolstered by extensive dissemination of trial information through blogs, online dialogues, and webinars. Such efforts are critical in guiding patients towards pertinent research studies.

**OBJECTIVE 2** Increase biomarker and molecular testing (localized versus metastatic).

**PROGRESS:**

- ✔ Fight Colorectal Cancer has partnered with the National Comprehensive Cancer Network (NCCN) and Pfizer in a \$1 million initiative to increase the adoption of biomarker and molecular testing. This alliance is a cornerstone in personalizing therapy regimens and elevating patient care standards.
- ✔ The Biomarkers Campaign led by Fight CRC underscores health equity, advocating for widespread use of biomarker testing to individualize treatment plans.

“ I really enjoyed these resources and I learned so much more about my biomarkers. There's some things I didn't know and I'm really reevaluating some of the tests I'd like to have done now.”

— User Feedback

Thank you, thank you, thank you for what you provided below. Education about your tumor is key to be the best advocate for yourself when talking to your medical team. I have found Fight CRC my “to go to” information resources since 2021, when I was still trying to understand what was happening to me and to my body. This is a great improvement to what was previously provided. God bless our community of champions for this newly structured site.”

— User Feedback

- ✔ The College of American Pathologists, backed by Fight Colorectal Cancer, published guidelines for testing mismatch repair (MMR) and microsatellite instability (MSI), which are essential in identifying patients suitable for immune checkpoint inhibitor therapy. These guidelines have also been officially endorsed by the American Society of Clinical Oncology (ASCO).
- ✔ The publication of College of American Pathologists (CAP) guidelines in August 2022 is helping pathologists optimize testing methods for identifying eligible patients for immunotherapies, potentially leading to life-saving treatments.

**OBJECTIVE 3** Design trials that are individualized-sequence therapies.

**PROGRESS:**

- ✔ Tempus Health's collaboration with Fight CRC strives to build a public compendium of standardized patient tumor data linked to clinical outcomes, focusing on metastatic colorectal cancer. This initiative is poised to spur research leading to more tailored therapeutic sequences.

# 3 TREATMENT

- ✓ The international CIRCULATE study delves into the role of ctDNA in stage III colon cancer, aiming to deepen our understanding of cancer biology and responsiveness to treatment. These efforts are in synergy with the ongoing COMMIT study, which evaluates the integration of diverse treatment mechanisms for mismatch repair-deficient metastatic colorectal cancer.
- ✓ The FDA-approved combinations of immune checkpoint inhibitors and the positive outcomes from trials targeting genetic mutations (such as the NCI trial with vemurafenib and the MOUNTAINEER trial for HER2 positive cases) showcase the potential of these precision medicine approaches.
- ✓ Liquid biopsy research, including the COBRA trial focused on ctDNA, exemplifies the innovative methods under investigation for the early detection, monitoring, and management of colorectal cancer, potentially revolutionizing the standard of care and aligning with the objectives of expanded treatment strategies.

**OBJECTIVE 4** Strengthen infrastructure design and development to advance treatment and clinical care.

❗ **IN PLANNING AND DEVELOPMENT PHASE.**

**OBJECTIVE 5** Increase federal funding for colorectal cancer research to achieve previously listed objectives.

❗ **IN PLANNING AND DEVELOPMENT PHASE.**

# 4 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.

❗ **IN PLANNING AND DEVELOPMENT PHASE.**

**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.

**PROGRESS:**

- ✓ The American Society of Clinical Oncology has updated guidelines for the surveillance and survivorship care of patients after curative treatment of colon and rectal cancer, ensuring that survivors receive evidence-based care.
- ✓ The Comprehensive Cancer Survivorship Act, introduced with the leadership of the National Coalition for Cancer Survivorship, would provide coverage for care planning services; develop survivorship navigation services; create employment assistance grants for survivors and their families; provide coverage for fertility preservation services; and look to develop additional reimbursement models.

# 4 SURVIVORSHIP AND RECURRENCE

**OBJECTIVE 3** Expand research efforts to improve and advance development of emerging and new technologies for early detection, screening, and prevention of recurrence.

**PROGRESS:**

- ✔ The international CIRCULATE study investigating ctDNA in stage III colon cancer is a significant step in improving early detection of recurrence and tailoring treatment. These efforts collectively demonstrate a commitment to advancing colorectal cancer research, treatment, and survivorship, ultimately leading to better outcomes for patients.