

## SUMMARY OF THE RESEARCH BRIEF

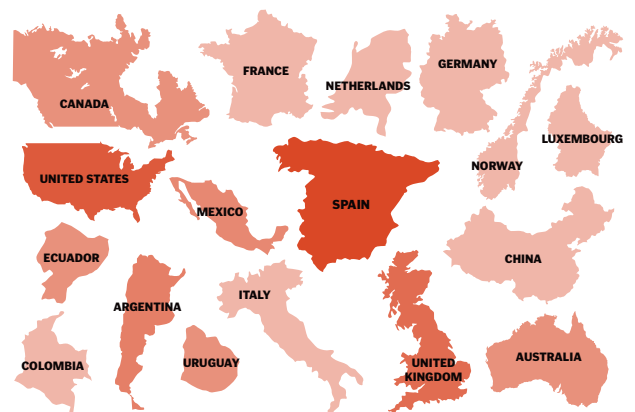
# EARLY-AGE ONSET INTERNATIONAL SYMPOSIUM

A virtual multidisciplinary event hosted by Fight Colorectal Cancer in June 2020 to discuss early-age onset colorectal cancer from a global perspective.

## BACKGROUND

In February 2019, Fight CRC convened a global, multidisciplinary working group to explore sporadic early-age onset colorectal cancer. This was in direct response to the increase in incidence rates of colon and rectal cancer in those under the age of 50. From this initial meeting, a formal work group of nearly 80 global experts was formed. Experts came from a wide range of disciplines, including researchers, oncologists, public health professionals, and patient advocates. Over the course of the past year, the work group has reconvened at in-person and virtual meetings, and have begun working on projects focused on etiology, clinical public health, and practice based research.

To continue the momentum, Fight CRC virtually co-hosted the 2nd annual Early-Age Onset Colorectal Cancer (EAO CRC) International Symposium in June 2020 in partnership with the medical community from the Jiménez Díaz Foundation Hospital in Madrid, Spain. During this symposium, thought leaders, researchers, clinicians, and patient advocates from around the globe spent time discussing the current burden of EAO CRC and explored a collaborative path forward.



Countries represented at EAO CRC International Symposium

## OVERARCHING THEMES AND NEXT STEPS

Discussions focused on the three priority areas for EAO CRC research: etiology, clinical public health, and practice-based research.

## ETIOLOGY

Increasing rates of EAO CRC are a common issue in North America, Europe, and Oceania, as well as South Korea. Studies to date demonstrate that increased screening and colonoscopy use does not explain trends.

Risk factors can be divided into genetic and environmental/lifestyle (obesity, type 2 diabetes, sedentary lifestyle, alcohol, and tobacco, etc...) categories.

Research by Dr. Richard Hayes, Professor of Epidemiology at New York University School of Medicine, highlighted that more than 50% of EAO CRC cases are attributable to known EAO CRC risk factors. Approximately 80% of EAO CRC cases account for those that do not have a genetic predisposition. Dr. Jose Perea, of the Jiménez Díaz Foundation Hospital, focused on this subgroup and discussed that EAO CRC have certain characteristics compared to late-onset colorectal

cancer such as the alteration of specific genes. Dr. Perea highlighted that next steps should include integrating an omics approach, along with the analysis of environmental influences (microbiome and exposomes). Given the importance of understanding geographical differences, international multicenter studies are required to adequately identify environmental factors.

In regards to the environmental and lifestyle factors that have been identified as risk factors for EAO CRC, symposium participants highlighted a need for more life-course investigations and studies of epigenetic/in utero risk modifying factors, the exposome, and the microbiome.

## **CLINICAL PUBLIC HEALTH**

### **Family History**

Heather Hampel, MS, LGC of the Ohio State University Comprehensive Cancer Center presented data from an analysis of EAO CRC patients under age 50 from the Ohio Colorectal Cancer Prevention Initiative, illustrating that nearly half (44%) of EAO CRC patients could have had their diagnosis prevented by collecting family history data and implementation of earlier and more frequent surveillance using colonoscopy. Approximately 12-16% of EAO CRC patients have a genetic mutation and another 9-14% have a first degree relative with CRC. The percentage of EAO CRC patients with a first degree relative with advanced adenomas is unknown, but is thought to be at least 14%. Results demonstrate that surveillance guidelines for hereditary CRC are more effective than the guidelines for those with a family history of CRC or advanced adenomas.

One of the prevalent themes that arose during Hampel's presentation discussed mainstreaming germline genetic testing. According to Hampel, "one thing I'd like people to consider is why the guidelines recommend that all pancreatic cancer patients undergo germline testing with a mutation prevalence of 8.4% but they do not recommend that all CRC patient undergo germline genetic testing even though the prevalence of hereditary cancer syndromes is higher, 10% in CRC."

### **COVID-19**

The symposium also included discussion of the impacts of COVID-19 on cancer patients, including those with EAO CRC, and clinical care. Overall, preliminary research in China, the US, and Italy demonstrated that cancer patients are experiencing higher rates of adverse health outcomes including severe health events and mortality when diagnosed with COVID-19. Other impacts of COVID-19 included:

- Reduced timeliness of treatment and diagnosis
- Increased social isolation
- negative psychological impacts

Even though cancer patients are at higher risk of contracting severe COVID-19, high-quality care should be maintained for cancer patients including those with EAO CRC.

## **PRACTICE-BASED RESEARCH**

EAO CRC patients face many challenges throughout the continuum of their care, from pre-diagnosis to post-treatment. In the quest for an explanation of their symptoms, over half of patients self-reported a misdiagnosis, three-quarters saw at least two doctors prior to their diagnosis, and almost 20% were not diagnosed for at least a year. Many EAO CRC patients have experienced long-term side effects, some of which are common among cancer patients (physical, mental and emotional, and financial), and others that are unique to younger adults (fertility and career challenges).

Two major themes emerged throughout conversations between patient advocates and the provider community including:

1. Importance of provider education and awareness
2. Exploring non-invasive screening opportunities

There are opportunities to address these challenges from multiple levels, including patient advocates, provider education, and shared decision making, and policy and systems.

## NEXT STEPS

Cross-cutting themes among each of these focus areas emphasized a need for research efforts that are collaborative, global, and integrated. The symposium attendees also called for increased diversity among study populations, including racial/ethnic, geographic diversity, and a diversity of disciplines and roles involved.

The Fight CRC Working Group plans to continue as a convening for EAO CRC research and practice opportunities through a dedicated approach and activities to: create a worldwide network, engage clinicians, researchers, patients, and families, update knowledge through learning opportunities, and create collaborations. The International Symposium will continue on an annual basis in summer 2021.

To learn more, visit [FightCRC.org/research](https://FightCRC.org/research).