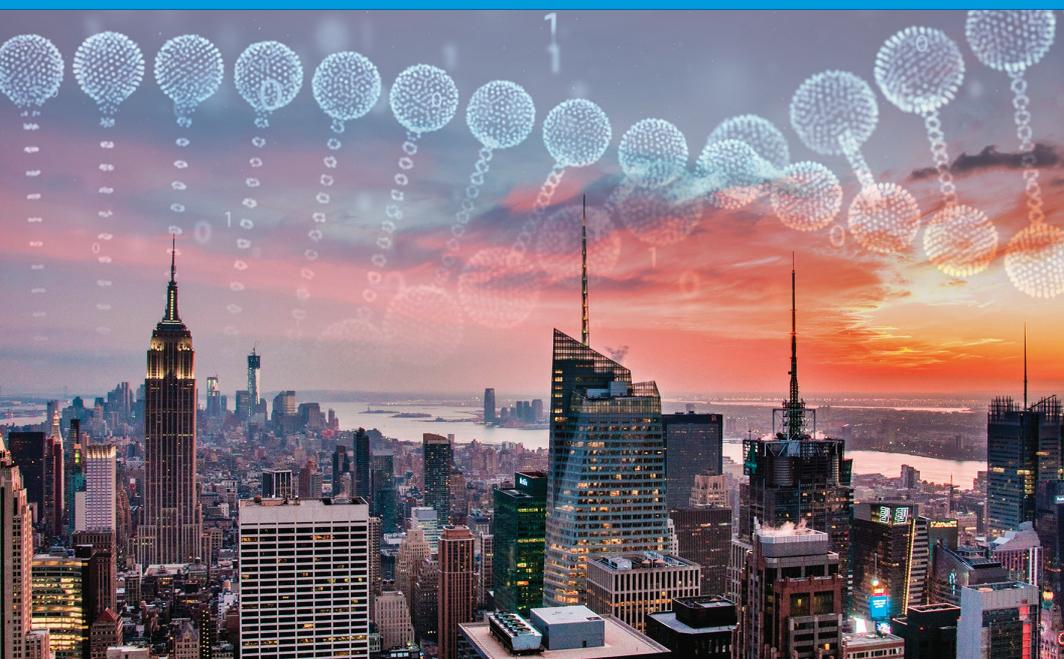


# EAO-CRC

EARLY AGE ONSET COLORECTAL CANCER  
SUMMIT 2019



**Northwell Health**  
Cancer Institute



**DONALD AND BARBARA  
ZUCKER SCHOOL of MEDICINE  
AT HOFSTRA/NORTHWELL**

## Performing a Knowledge GAP Analysis and Building a Strategic "Action Plan" to Reduce EAO-CRC Incidence and Mortality

*Credit Designation: Northwell Health designates this live activity for a maximum of 11 AMA PRA Category 1 Credits™.*

Thursday, May 2, 2019 • 7:00 am – 6:45 pm

Friday, May 3, 2019 • 8:00 am – 12:30 pm

The Times Center • 242 West 41st Street • New York, NY 10018

[coloncancerfoundation.org](http://coloncancerfoundation.org)



#EAOCRC19

**THIS EVENT WILL BE VIDEO RECORDED**

**POSTER ABSTRACTS**

## **ABSTRACT AWARDS**

### **FIRST PLACE**

#### **DOES THE IMPACT OF TUMOR SIDEDNESS DIFFER FOR YOUNG-ONSET VS. LATER-ONSET COLORECTAL CANCER?**

Lucas D. Lee, MD

The University of Texas MD Anderson Cancer Center,  
Houston, Texas

### **SECOND PLACE**

#### **THE PSYCHOSOCIAL AND FINANCIAL BURDEN ON CAREGIVERS OF YOUNG-ONSET COLORECTAL CANCER PATIENTS**

Kimberley Newcomer, BS, CPPN

Colorectal Cancer Alliance, Washington, DC

### **THIRD PLACE**

#### **CLINICOPATHOLOGICAL, FAMILIAL, AND MOLECULAR CHARACTERIZATION OF RECTAL CANCER WITHIN EARLY-ONSET COLORECTAL CANCER**

José Perea, MD, PhD

Fundación Jiménez Díaz University Hospital and Health  
Research Institute, Early-Onset Colorectal Cancer-UAM  
Observatory, Madrid, Spain

## **P1. The HEROIC Registry: Opportunities for collaboration**

Allison M. Burton-Chase PhD<sup>1</sup>, Robin Dubin<sup>2</sup>,  
Dave Dubin<sup>2</sup>

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Corresponding Author: Robin Dubin; robin@aliveandkickn.org

**Program Description:** AliveAndKickn, whose mission is to improve the lives of individuals and families affected by Lynch Syndrome through research, education, and screening, maintains the HEROIC Registry. It is the first of its kind patient-centric genetic database that will enable patients to take an active role in furthering research into Lynch Syndrome genetic mutations.

**Program Objectives:** The HEROIC Registry allows patients to contribute medical information and their experiences living with Lynch Syndrome and its associated cancers to help researchers develop new treatments, understand the various Lynch genetic mutations, write research articles, and conduct further studies and clinical trials. Ultimately, the goal of the Registry is to have aggregate data from thousands of individuals with Lynch syndrome.

The HEROIC Registry was launched in February of 2016. Potential participants were notified about the availability of the Registry via the AliveAndKickn website, email announcements, social media promotions, conferences and awareness events, and AliveAndKickn's clinical and institutional partners offered the opportunity to contribute their health information. As of March 2019, 232 individuals have added their data to the Registry. Of those, 181 have a known Lynch syndrome mutation and were on average 42 years old at the time of diagnosis. 28.5% report having had a diagnosis of colorectal cancer with an average age of 42 at diagnosis; 23.2% of female respondents report having had endometrial cancer with an average age of 47 at diagnosis. 9.5% of female respondents report having had breast cancer with an average age of 50 at diagnosis. 8.9% of female respondents report having had ovarian cancer with an average age of 44 at diagnosis. 30.4% are cancer-unaffected. Additional data in the Registry include screening and surveillance behaviors, family history, and interest in participating in future research studies.

**Audience:** The HEROIC Registry provides a unique opportunity for health care providers and researchers to partner directly with a patient-advocacy organization for the purposes of improving patient care in this population. It also has the benefit of including a diverse set of patients who are being seen in a variety of health care settings, which can aid in exploring research questions outside of a single institution.

**Future Directions:** As the registry grows, it allows AliveAndKickn to provide support, advisory services, and patient engagement on grant applications to researchers around the country. We anticipate that this registry will become a major future resource to help engage Lynch syndrome patients in research.

Previous versions of this abstract have been presented as posters at NSGC, CGA and ASPO. Data has been updated to reflect current participation in the registry.

## **P2. Information needs of patients and survivors with early age onset colorectal cancer (EAORC): Findings from an international cross-sectional online survey**

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<sup>1</sup>University of British Columbia Faculty of Pharmaceutical Sciences, Vancouver, Canada; <sup>2</sup>BC Cancer, Vancouver, Canada; <sup>3</sup>Simon Fraser University Faculty of Health Sciences; <sup>4</sup>University of British Columbia Faculty of Medicine

**Background:** Early age onset colorectal cancer (EAOCRC) patients and survivors have unique needs but to our knowledge, their information needs has not been well described. Our objective is to describe the information needs of individuals who have been diagnosed with CRC before the age of 50 (EAOCRC) as compared to those diagnosed at later age, at or after 50 years (LAOCRC).

**Methods:** We launched an online survey and applied a mixed-mode approach involving 'online' (e.g., social media promotion) and 'offline' (e.g., recruitment at oncology clinics) strategies. Survey items were adapted from prior surveys on needs of cancer patients and survivors, with respondents indicating that specific information needs queried have: 1) been met; 2) not met; or 3) not applicable/not a need. We used descriptive statistics to characterize whether information is needed and whether information has been met, applying a cut-off of 50% of responses to indicate underserved areas. We compared information needs between EAOCRC and LAOCRC using Chi-square tests.

**Results:** As of March 11<sup>th</sup>, 2019, 1321 individuals accessed the online survey. After excluding non-responses and partial responses, our sample included 883 respondents overall with 380 EAOCRC and 503 LAOCRC. Among respondents, 541 (61.3%) were females and 341 (38.6%) males. In terms of represented countries, 401 (45.4%) of respondents were from Canada, 344 (38.9%) from the United States, and 120 (13.6%) from the United Kingdom. With respect to cancer site, 513 (58.1%) of respondents reported having colon cancer, 254 (28.8%) rectal cancer, and 111 (12.6%) both sites, and the majority were diagnosed at Stage III (365, 41.3%) or Stage IV (199, 22.6%). As shown in Table 1, there is substantial unmet information need for both EAOCRC and LAOCRC during diagnosis, treatment, and survivorship. Furthermore, we observed differences in information needs between EAOCRC and LAOCRC across specific items at diagnosis (e.g., reason for cancer), treatment (e.g., others' experiences with treatment), and survivorship (e.g.,

long-term side effects of treatment).

**Conclusion:** Findings from our online survey shows many areas of unmet information needs for patients and survivors of CRC. Further differences between EAOCRC and LAOCRC suggest areas where targeted/specific resources are needed.

**Table 1. Information needs of CRC patients and survivors at diagnosis, treatment, and after treatment**

\*Information need items indicated in bold font indicate underserved areas for both EAOCRC and LAOCRC with >50% of respondents reporting unmet needs; Information need items indicated with

•• indicate areas where EAOCRC and LAOCRC differ, based on Chi-square test

**Table 1. Information needs of CRC patients and survivors at diagnosis, treatment, and after treatment**

	Information needed	Information not needed	Information need has been met	Information need has not been met*
<b>Information need among all respondents on CRC at time of diagnosis</b>				
Cancer location	839 (98.01)	17 (1.99)	635 (75.69)	204 (24.31) ••
Cancer stage	805 (98.05)	16 (1.95)	555 (68.94)	250 (31.06)
Surviving cancer	784 (97.15)	23 (2.85)	407 (51.91)	377 (48.09) ••
Reason for cancer	763 (96.58)	27 (3.42)	135 (19.69)	<b>628 (82.31)</b>
Risk for family	784 (97.27)	22 (2.73)	375 (47.77)	<b>409 (52.17) ••</b>
Research/trials	704 (89.91)	79 (10.09)	161 (22.87)	<b>543 (77.13)</b>
Specialized tests	747 (94.56)	43 (5.44)	221 (29.59)	<b>526 (70.41) ••</b>
<b>Information need among respondents currently undergoing treatment</b>				
Complementary treatments	192 (93.66)	13 (6.34)	30 (15.63)	<b>162 (84.38) ••</b>
Clinical trials	189 (94.50)	11 (5.50)	30 (15.87)	<b>159 (84.13)</b>
Chances of cancer coming back	180 (90.45)	19 (9.55)	58 (32.22)	<b>122 (67.78) ••</b>
Exercise and physical activity	194 (96.52)	7 (3.48)	77 (39.69)	<b>117 (60.31)</b>
Nutrition and diet	201 (97.57)	5 (2.43)	71 (35.32)	<b>130 (64.68) ••</b>
Bowel activity	206 (100.00)	0 (0.00)	95 (47.98)	<b>103 (52.02)</b>
Others' experiences with treatment	191 (94.55)	11 (5.45)	59 (30.89)	<b>132 (69.11) ••</b>
<b>Information need among respondents who have completed treatment for CRC</b>				
Dealing with a stoma	213 (58.84)	149 (41.16)	128 (60.09)	85 (39.91) ••
Exercise and physical activity	379 (97.93)	8 (2.07)	193 (50.92)	186 (49.08)
Nutrition and diet	382 (99.22)	3 (0.78)	158 (41.36)	<b>224 (58.64) ••</b>
Bowel activity	381 (97.94)	8 (2.06)	154 (40.42)	<b>227 (59.58)</b>
Others' experiences after treatment	337 (93.61)	23 (6.39)	93 (27.60)	<b>244 (72.40) ••</b>
<b>Information need among all respondents on impacts of CRC on life</b>				
Sexual activity	669 (87.45)	96 (12.55)	235 (35.13)	<b>434 (64.87) ••</b>
Fertility	353 (47.19)	395 (52.81)	167 (47.31)	<b>342 (57.38)</b>
Work	596 (77.5)	173 (22.5)	254 (42.62)	<b>250 (63.29) ••</b>
Parenting	395 (53.38)	345 (46.62)	145 (36.71)	<b>250 (63.29)</b>
Mental health	714 (92.49)	58 (7.51)	227 (31.79)	<b>487 (68.21) ••</b>
Bowel activity	767 (100.00)	0 (0.00)	262 (35.69)	<b>472 (62.31)</b>
Long-term side effects of treatment	715 (96.46)	50 (6.54)	164 (22.94)	<b>551 (77.06) ••</b>

\*Information need items indicated in bold font indicate underserved areas for both EAOCRC and LAOCRC with >50% of respondents reporting unmet needs; Information need items indicated with

•• indicate areas where EAOCRC and LAOCRC differ, based on Chi-square test

**P3. Does the impact of tumor sidedness differ for young-onset vs. later-onset colorectal cancer?**

Lucas D. Lee, MD<sup>1</sup>; Scott Kopetz, MD, PhD<sup>2</sup>; Cathy Eng, MD<sup>2</sup>; Miguel Rodriguez-Bigas, MD<sup>1</sup>; Brian K. Bednarski, MD<sup>1</sup>; Eduardo Vilar, MD, PhD<sup>3</sup>; Michael Roth, MD<sup>4</sup>; George J. Chang, MD MS<sup>1,5</sup>; Y. Nancy You, MD, MHS<sup>1,3</sup>

Departments of Surgical Oncology<sup>1</sup>, Gastrointestinal Medical Oncology<sup>2</sup>, Clinical Cancer Prevention<sup>3</sup>, Pediatrics<sup>4</sup>; Health Services Research<sup>5</sup> at The University of Texas MD Anderson Cancer Center

**Background:** Colorectal cancers (CRCs) are heterogenous. Right- vs. left-sided CRCs are being regarded and treated differently. Meanwhile, distinct attention is being paid to young-onset (YO, <50 years) CRCs, particularly those not associated with hereditary syndromes. We aimed to compare the impact of tumor-sidedness on the somatic mutation profiles and on survival of YO- vs. later-onset (LO) CRC.

**Methods:** CRC patients who had been prospectively enrolled for somatic genomic testing at our institution were identified. A panel of 46 or 50 cancer-related genes with 740 mutational hotspots had been analyzed using the Ampliseq Ion Torrent Assay in a CLIA-certified molecular pathology laboratory. Patients were excluded for microsatellite unstable CRC, tumor cell viability <30%, or hereditary CRC syndrome. Clinical data were retrospectively retrieved.

**Results:** Among 1006 CRC patients, 339 (33.7%) had YO-CRC. There was male and white race predominance (54.5% and 71.7% respectively). YO-CRCs were mostly left-sided (colon distal to the splenic flexure and rectum, N=278, 82.3%) and metastatic (N=287, 84.7%). Metastatic right- (N=126) vs. left-sided (N=412) LO-CRCs differed in more prevalent mutations in extended *RAS* (49.4 vs. 61.9%;  $p=0.013$ ) and *BRAF* mutations (7.5 vs. 13.5%;  $p=0.04$ ). In contrast, metastatic right- (N=52) vs. left-sided (N=235) YO-CRCs did not differ in these genes, but left-sided YO-CRCs were more frequently mutated in *TP53* (68.5 vs. 51.9%;  $p=0.023$ ) and *APC* (43 vs. 23.1%;  $p=0.008$ ), and less frequently mutated in *SMAD 4* (10.2 vs. 25%;  $p=0.004$ ) than right-sided YO-CRCs. For metastatic YO-CRCs, overall survival (OS) was significantly inferior for right vs. left sided tumors (median OS: 35 vs. 50 months;  $p = 0.011$ ). This impact of tumor side was similar among metastatic LO-CRCs: (median OS: 37.00 vs. 44.00 months;  $p = 0.009$ ).

**Conclusion:** Tumor-sidedness impacts survival outcomes of metastatic CRC similarly in YO- and LO-CRCs. The current recommended frontline treatment for metastatic CRC differ by tumor-sidedness, but reflects the mutational prevalence of extended *RAS* and *BRAF*, observed largely in LO-CRCs but not in YO-CRC. Thus, optimal treatment regimen of metastatic YO-CRC warrants additional consideration based on personalized tumor profile rather than on tumor-sidedness alone.

#### **P4. Patient advocacy: One size does not fit all**

Anita Mitchell Isler, anita@colonstars.org

Washington Colon Cancer Stars 501C3

**Program Description:** Major program components include a peer-to-peer support group, a school program, and community outreach.

**Program Objectives:** Major program objectives include saving of lives through education; education to facilitate change in behavior, and support to empower better outcomes.

**Audience:** Peer-to-peer support groups meet once a month in person. Support groups led by peer mentors provide an authentic perspective and help not only patient, but also researchers, as we are taking part in focus group for researchers to help shape future studies. Patients that are empowered to advocate tend to be more comfortable asking questions and taking part in trials.

The school program is based on the understanding that children are great motivators for family members to take care of our health. Our school program educates children in the classroom, assembly or even science fair in a fun interactive way while meeting national science guidelines. Children bring the family to the science night or encourage the conversation at home about colorectal cancer prevention. We also provide speakers at workplace health events and medical students on request.

**Future Directions:** Our vision is a future with more lives **saved** with **On Time Screening**. Knowledge on **Prevention, Symptoms** and **Family History** are critical with the **Early Onset Rise** in Colorectal Cancer. Education is key and can be shared no matter the age.

#### **P5. The psychosocial and financial burden on caregivers of young-onset colorectal cancer patients**

Kimberley Newcomer, BS, CPPN;<sup>1</sup> Ronit Yarden, PhD, MHSA<sup>2</sup>

<sup>1</sup>Manager of Never Too Young Program, <sup>2</sup>Director of Medical Affairs at the Colorectal Cancer Alliance  
**Background:** Colorectal cancer (CRC) incidence is on the rise among adults younger than 50 years old. Patients and survivors often rely on the assistance of a caregiver, an unpaid or paid member of a patient's social network who helps them with the activities of daily living. Little is known about the unique challenges that caregivers of young-onset patients face and how it affects their quality of lives. This study aims to identify the unmet needs of young-onset (YO) caregivers.

**Methods:** The national nonprofit Colorectal Cancer Alliance launched an online survey for caregivers of YO-CRC patients and survivors via multiple social media channels for 30 days. The survey intended to capture self-reported data and consisted of 18 questions related to the quality of life experiences with no exclusions except for caregiving.

**Results:** Caregivers (n = 427) were diverse in age, gender, race, and ethnicity; however, the majority of respondents were between the ages of 30 and 39.

Caregivers' key challenges included insufficient psychosocial (66%) and financial support (43%). Sixty-seven percent of caregivers were spouses of the patient, parenting children under 18. The majority of them (59%) reported their loved one experienced changes in their ability to perform expected social tasks, including those of a spouse, child rearer, friend, or worker. Many caregivers experienced depression, pain, stress, despair, and loss of sleep, sexuality, and faith/hope, which may cause additional strain on their relationship with their patient. Caregivers indicated a lack of sufficient resources for transportation to treatment, doctors visits, child care, and for household maintenance. One in three caregivers reported missing three days or more of work each month to care for their loved one.

**Conclusions:** Our survey indicates that caregivers need additional resources to manage everyday tasks. Additional tools and support may enable caregivers to devote more time to self-care, which may alleviate some of the psychosocial burdens of caregiving, especially while simultaneously managing childcare and career. Finally, caregivers noted a dearth of information on prevention and surveillance available to family members.

## **P6. Clinicopathological, familial, and molecular characterization of rectal cancer within early-onset colorectal cancer**

José Perea<sup>1,3</sup>, Sandra Tapial<sup>4</sup>, Juan Luis García<sup>5</sup>, Sergio Hernández-Villafranca<sup>1</sup>, Jessica Pérez-García<sup>5</sup>, Giuliana Martina Cavestro<sup>6</sup>, Damián García-Olmo<sup>1,3</sup>, Miguel Urioste<sup>7,8</sup>, Rogelio González-Sarmiento<sup>5</sup>.

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**Background:** Early-onset colorectal cancer (EOCRC) is the only one that is increasing talking about colorectal cancer (CRC) incidence, and the perspectives are remarkably increasing, especially for rectal cancer (RC). The aim of our study is to analyze the differential features of RC within EOCRC.

**Methods:** Retrospective study of 82 consecutive EOCRCs. We defined three correlative locations: right colon, left colon and rectum. We carried out a comparison between colon cancer (right and left locations) and RC, and afterwards, between the three groups, for clinicopathological, familial and molecular features.

**Results:** Differences within the comparative analysis between colon cancer and RC were more remarkable when comparing the three different locations. RC was diagnosed in more advanced stages (67% III y IV), with a worse Overall survival (OS) and Disease-free Survival (DFS), compared with left-sided, and even more with right-sided (OS: 45, 55, 82 months; DFS: 37, 49, 72 months, respectively). Talking about familial cancer history, right-sided colon cancers showed a high aggregation (80%), compared with the 52% and 63% of left-sided and RC, being within this the majority cases linked with Lynch syndrome (LS) associated neoplasms (56%). Nevertheless, from a molecular point of view, RC did not show Microsatellite instability, while 30% of right-sided colon cancers were LS cases. The Methylator phenotype was also predominant within right-sided colon cancer, and the Chromosomal instability for RC showed paradoxical results: for punctual alterations were the tumors that presented fewer per case and, on the contrary, in relation to complete chromosomes, those that showed a greater number of losses.

**Conclusion:** Our results show the importance of considering early-onset RC as a different disease, compared with the other colon locations.

## **P7. Survey of Young Onset Patients, Survivors and Caregivers: Self-Reported Clinical, Psychosocial, Financial and Quality of Life Experience**

Ronit Yarden, PhD, MHSA<sup>1</sup>; Kimberley Newcomer, BS, CPPN<sup>2</sup>

<sup>1</sup>Director of Medical Affairs, <sup>2</sup>Manager of Never Too Young Program, at the Colorectal Cancer Alliance, Washington, DC

**Background:** Colorectal cancer (CRC) is the second leading cause of cancer-related death among males and females in the US. Despite a decrease in overall incidence and mortality, there has been an alarming increase of CRC diagnosis among young adults (20-49 years old). The Colorectal Cancer Alliance launched a comprehensive survey for young-onset CRC patients and survivors via social media to track the self-reported clinical, psychosocial, financial and quality of life experiences of this often overlooked, group.

**Methods:** The survey was completed by 1195 living patients and survivors. The majority of participants (57%) were diagnosed between the ages of 40 and 49, 33% of patients/survivors were diagnosed between the ages 30-39 and about 10% were diagnosed before the age of 30. Only 8% of the respondents were diagnosed with Lynch syndrome although about 28% reported some family history.

**Results:** Our survey revealed a higher proportion of the young-onset patients and survivors (71%), diagnosed with advanced stage tumors, compared with ACS report for overall CRC patients (60%). The late stage diagnosis subjected young patients to aggressive therapies and a substantial decrease in quality of life including neuropathy, anxiety, clinical depression, and

sexual dysfunctions. Most respondents (63%) waited 3-12 months before visiting a doctor, with higher proportion of females waited more than 12 months compared with males (22% vs. 15%  $p = 0.02$ ). Moreover, even when visited their doctors, most patients indicated that they were initially misdiagnosed. The majority of the respondents (67%) saw at least 2 physicians, and some more than 4 physicians, prior to their diagnosis. Patients that saw 3 or more physicians prior to diagnosis were more likely to be diagnosed with advanced disease. Interestingly, half of the patients that were seen by one physician also claimed they were initially misdiagnosed.

**Conclusion:** Our survey indicates that medical professionals and young adults need to be aware of the increasing incidence of young-onset CRC, and the importance of timely screening when signs and symptoms are present, regardless of age. Yet, 50% of physicians did not explain to the patients' family members about their elevated risk of the disease and their need for screening.