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

#EAOCRC19

THIS EVENT WILL BE VIDEO RECORDED
COURSE OVERVIEW

This event will bring together leading clinicians, scientists as well as early age onset (EAO) colorectal cancer (CRC) survivors and caregivers from across the country and internationally. The program will provide extensive opportunities for participants to advance their understanding of the rapidly increasing incidence of rectal and colon cancer among young adults under 50 years of age in the U.S. and abroad.

This groundbreaking program will, for a fifth consecutive year, provide all participants the opportunity to hear from and question leading clinicians and researchers on the life saving potential of timely clinical risk assessment/family cancer health history; earliest possible diagnosis, optimal, fertility preserving clinical care, as well as the latest information regarding national and international EAO CRC incidence trends, pathogenesis, and genetics. In addition, this year’s program will present a “Research in Progress” segment featuring currently NCI funded and planned EAO CRC research projects from across America and Europe. Again this year, important Breakout Sessions based on needs-assessments from our survivor community will address challenging issues surrounding Palliative Care, support networks for “Caregivers” and a “Primer” on the “Epigenetics” of EAO CRC specifically requested by our Young Adult CRC Survivor Program Advisory Group.

The course will include lectures, workshops and panel discussions designed to advance the “state-of-the-science” addressing EAO-CRC. Our faculty will once again be world class speakers representing leading academic medical centers with major additional inspiring programmatic contributions from the Early Age Onset Colorectal Cancer Survivor Community of the United States and beyond.

EDUCATIONAL OBJECTIVES

Provide an expert review of the latest published information on the increasing incidence and mortality associated with Early Age Onset Colorectal Cancer in the United States and globally.

Review the State-of-the-Science regarding the known and possible causes of the increasing incidence of EAO-CRC including alterations in our food and water supply, the contribution of novel germline genetic factors and etiologic clues based on the molecular biology of EAO-CRC cancers.

Provide an evidence-based framework for reducing risk, increasing early stage diagnosis and improving treatment and outcomes for young adult colorectal cancer patients.

Define the “Gaps” in our current understanding of Early Age Onset Colorectal Cancer in order to set our clinical and research priorities and develop a strategic plan to reduce EAO-CRC incidence and mortality.

THANK YOU TO OUR SPONSORS AND EXHIBITORS
COURSE DIRECTORS

Thomas K. Weber, MD, FACS
COURSE MODERATOR/CHAIR
Director of Surgical Oncology
Northwest Region at Northwell Health
Professor of Surgery Donald and Barbara Zucker School of Medicine at Hofstra/Northwell
Founder and President
Colon Cancer Foundation

Susan K. Peterson, PhD, MPH
COURSE CO-DIRECTOR AND POSTER SESSION CHAIR
Professor of Behavioral Science
The University of Texas MD Anderson Cancer Center

Wasif M. Saif, MD
COURSE CO-DIRECTOR
Deputy Physician-in-Chief and Director of Medical Oncology
Northwell Health Cancer Institute
Professor of Medicine
Donald and Barbara Zucker School of Medicine at Hofstra/Northwell

PLANNING COMMITTEE

Richard Barakat, MD
Physician-in-Chief and Director
Northwell Health Cancer Institute
Professor, Obstetrics and Gynecology, Donald and Barbara Zucker School of Medicine at Hofstra/Northwell

Cindy R. Borassi
Executive Director
Colon Cancer Foundation

Heather Hampel, MS, LGC
Associate Director, Division of Human Genetics
Associate Director, Biospecimen Research
Professor, Internal Medicine
Licensed Genetic Counselor
The Ohio State University Comprehensive Cancer Center

Krista Nelson, LCSW OSW-C BCD
FAOSW
Oncology Social Worker
Program Manager, Quality & Research, Cancer Support Services & Compassion
Providence Cancer Institute & Providence St Joseph Health

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Assistant Vice President, Continuing Medical Education
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Thomas K. Weber, MD, FACS
Director of Surgical Oncology
Northwest Region at Northwell Health
Professor of Surgery Zucker School of Medicine at Hofstra/Northwell
Founder and President
Colon Cancer Foundation
THURSDAY, MAY 2, 2019

7:00 am–8:00 am  Registration and Breakfast

8:00 am–8:30 am  Framing the Conversation: Strategic Challenges in Current Medical Care that Contribute to Young Adult Colorectal Cancer (CRC) Incidence and Mortality. Survivor Testimonials Underscore Opportunities for Improvement in the Prevention and Care of Young Adult Colorectal Cancer
Opening Remarks: Richard R. Barakat, MD, Physician-in-Chief and Director, Northwell Health Cancer Institute
How the Survivor Testimonials Framed Today’s Program: Thomas K. Weber, MD, FACS, Northwell Health, Colon Cancer Foundation
Housekeeping: Cindy R. Borassi, Colon Cancer Foundation

8:30 am–9:35 am  Session I: The Dimensions of the EAO-CRC Problem: Target Item: Accurate, Regular, Up to Date Measurement of Key Metrics Describing the Early Age Onset Colorectal Cancer Public Health Crisis

8:30 am–8:40 am  Overview of Global EAO-CRC Incidence Patterns and Trends
Thomas K. Weber, MD, FACS, Northwell Health, Colon Cancer Foundation

8:40 am–8:50 am  Overview of United States EAO-CRC Incidence Patterns and Trends
Rebecca L. Siegel, MPH, American Cancer Society

8:50 am–9:00 am  Utilization of CDC Comparative Effectiveness Research Data to Assess Lynch Syndrome Screening and Surgical Management in Early-Onset Colorectal Cancer
Jordan Karlitz, MD, FACG Tulane University School of Medicine (VIA VIDEO CONFERENCING)

9:00 am–9:10 am  Overview of European Cancer Registries Data Resources on EAO-CRC
Irit Ben-Aharon, MD, PhD, Rambam Health Care Campus, Haifa, Israel, European Organisation for Research and Treatment of Cancer (EORTC)

9:10 am–9:20 am  Survey of Young Onset Patients, Survivors, and Caregivers: Self-Reported Clinical, Psychosocial, Financial and Quality of Life Experiences
Ronit Yarden, Ph.D. MHSA, Colorectal Cancer Alliance

9:20 am–9:35 am  Q&A Panel Discussion–Strategic Plan Development

9:35 am–9:50 am  Networking, Coffee, Poster Viewing Break

9:50 am–11:35 am  SESSION II: Family History Ascertainment in the U.S. (Addressing Gap 1) What Steps are Needed to Improve the Well Documented Less Than Optimal Status of this Situation? What is Our Best Information on the Documentation of Cancer Family History in Primary Care? What are the Key Elements Required for Success?
Moderator: Gregory Feero, MD, PhD, Maine Dartmouth Family Medicine Residency, Augusta, ME; Geisel School of Medicine at Dartmouth, Hanover, NH

9:50 am–10:10 am  Electronic Health Records (EHR) and Family Cancer History Ascertainment. The Path Forward?
Gregory Feero, MD, PhD, Maine Dartmouth Family Medicine Residency, Augusta, ME; Geisel School of Medicine at Dartmouth, Hanover, NH

9:50 am–10:10 am  Review of National Colorectal Cancer Roundtable (NCCRT) Family Health History Early Age Onset Colorectal Cancer (EAO-CRC) Task Group Progress and Overview of the NCCRT Risk Assessment and Screening Toolkit to Detect Familial, Hereditary and Early Onset Colorectal Cancer and Next Steps for Dissemination and Implementation
Dennis Ahnen, MD, AGAF, FACG, University of Colorado School of Medicine, Gastroenterology of the Rockies
10:25 am–10:40 am Implementation Plan for 2018 American Cancer Society Recommendations (and Rationale) for Screening for the Early Detection of Colorectal Cancer. Robert A. Smith, PhD, American Cancer Society

10:40 am–10:50 am Strategies for Addressing Early Onset CRC: An NCCRT Report Jan Lowery, Colorado Center for Personalized Medicine

10:50 am–11:00 am Detecting Unaffected Individuals with Lynch Syndrome (DUAL) Sayoni Lahiri, MS, CGC, UT Southwestern Medical Center

11:00 am–11:10 am Prevalence of Advanced Colorectal Polyps Among First Degree Relatives of EOCRC Patients Christine L. Sardo Molmenti, PhD, MPH Feinstein Institute for Medical Research, Northwell Health, Donald and Barbara Zucker School of Medicine at Hofstra/Northwell

11:10 am–11:15 am Integrating Education on the Importance of Family Health History Ascertainment and Earliest Possible Diagnosis into the Entire Continuum of Medical and Specialty Education from Medical School Through Board Certification, CME and Recertification Thomas K. Weber, MD, FACS, Northwell Health, Colon Cancer Foundation

11:15 am–11:30 am Q&A Panel Discussion–Strategic Plan Development

11:30 am–12:15 pm LUNCH

12:15 pm–12:25 pm A Review of the Published Data Documenting Delays in Diagnosis and the Consequences in Terms of Later Stage Diagnosis and Poorer Outcomes Whitney F. Jones, MD, Gastro & Endo Associates

12:25 pm–12:35 pm Overview of the Continuum of Providers Who Interact with Patients Prior to and Up to A Diagnosis Chelsea Boet, MD, Spectrum Health Medical Group

12:35 pm–12:45 pm Lessons Learned: What Have We Learned from Past Public Health Success Stories? Jennifer Brown, PhD, NYC Department of Health & Mental Hygiene

12:45 pm–12:55 pm Lessons Learned: What Have We Learned from Past Public Health Success Stories? Tony Foleno, Senior Vice President, Strategy & Evaluation, Ad Council; President, Society for Health Communication

12:55 pm–1:05 pm Introduction of the EAO-CRC National Clinical Alert and Symptoms and Signs Index Andrew Albert, MD, MPH, Chicago Gastro LLC. Erin Peterson, Colon Cancer Coalition
  • Provider Education Outreach Initiatives
  • Patient Awareness and Advocacy Initiatives

1:05 pm–1:20 pm Q&A Panel Discussion–Strategic Plan Development

1:20 pm–1:30 pm Updates on Current Medical Oncology Approaches to Young-Onset CRC Andrea Cercek, MD, Memorial Sloan Kettering Cancer Center

1:30 pm–1:40 pm Optimal Preservation of Fertility Nicole Noyes MD, Reproductive Endocrinologist, Northwell Health

1:40 pm–1:50 pm Novel Approaches to Metastatic Mismatch Repair (MMR) Deficient and Microsatellite Stable (MSS) Metastatic Colorectal Cancer Cathy Eng, MD, FACP, FASCO, the University of Texas MD Anderson Cancer Center
1:50 pm–2:00 pm  From “Bench to Bedside” CRC Experimental Therapeutics and Phase I & II Trials. What’s New & What’s Next?  Wasif M. Saif, MD, Northwell Health Cancer Institute

2:00 pm–2:10 pm  GAPS in Providing Palliative Care and the Cost Benefit Ratio for Hospital Systems  James T. D’Olimpio, MD, FACP, FAAHPM, Northwell Health Cancer Institute

2:10 pm -2:20 pm  Q&A Panel Discussion

SESSION IVb: Timely, Effective, Quality of Life & Fertility Preserving State of the Art Treatment (Addressing Gap 3)

2:20 pm–2:35 pm  Identifying the Key Elements of a Center for Early Age Onset Colorectal Cancer – Panel Discussion  Eric Reddy, Stage IV Colorectal Cancer Survivor  Andrea Cercek, MD, Memorial Sloan Kettering Cancer Center  Zana Correa, NP, Memorial Sloan Kettering Cancer Center  Kimmie Ng, MD, MPH, Dana-Farber Cancer Institute  Karen Fasciano, PsyD, Dana-Farber Cancer Institute  Christine L. Sardo Molmenti, MPH, PhD Feinstein Institute for Medical Research/ Donald and Barbara Zucker School of Medicine at Hofstra/ Northwell  Thomas K. Weber, MD, FACS, Northwell Health, Colon Cancer Foundation  Krista Nelson, LCSW OSW-C BCD FAOSW, Providence Cancer Institute, Providence St Joseph Health

2:35 pm–2:45 pm  Q&A Panel Discussion–Strategic Plan Development

2:45 pm–3:00 pm  Networking, Coffee, Poster Viewing Break

3:00 pm–5:35 pm  SESSION V: How Did this Happen? Investigating the Causes of Early Onset Colorectal Cancers (EAO-CRC) (Addressing Gap 4)

The Genetics of Heritable CRC: What’s New and Important to Know Regarding the Genetics of EAO-CRC?  Noah D. Kauff, MD, Duke Cancer Institute, Duke University Health System  Thomas K. Weber, MD, FACS, Northwell Health, Colon Cancer Foundation

How Did this Happen? An Overview of Environmental and Epigenetic Factors  Susan Wysocki, APR, CRC Advocate

3:10 pm–3:20 pm  Prevalence and Spectrum of Germline Cancer Susceptibility Gene Mutations Among Patients with Early-Onset Colorectal Cancer  Heather Hampel, MS, LGC, the Ohio State University Comprehensive Cancer Center

3:20 pm–3:30 pm  Molecular Subtype of Colorectal Cancer Associated with Early Age of Onset  Xavier Llor, MD, PhD, Yale University School of Medicine Smilow Cancer Center

3:30 pm–3:40 pm  Germline Genetic Variants Associated with Young-Onset Colorectal Cancer: the MSKCC Experience  Zsofia K. Stadler, MD Clinical Director, Clinical Genetics Service, Memorial Sloan Kettering Cancer Center

3:40 pm–3:50 pm  Germline Genetic Features of Young Individuals with Colorectal Cancer  Elena M. Stoffel MD MPH, Director Cancer Genetics Clinic, University of Michigan

3:50 pm–4:00 pm  Cancer Susceptibility Gene Mutations in Individuals with Colorectal Cancer  Matthew B. Yurgelun MD, Dana-Farber Cancer Institute, Harvard Medical School
What is Driving the Increases in EAO-CRC, 80+% of Which is Not Related to the Named Hereditary CRC Syndromes?

4:00 pm–4:10 pm  Obesity, Sedentary Behaviors, and Early-Onset CRC  
Yin Cao, MPH, ScD, MPH, Washington University School of Medicine

4:10 pm–4:20 pm  New Suspects: Diet, Microbiome, Immunology and Cancer Risk  
Semir Beyaz, PhD, Cold Spring Harbor Laboratories

4:20 pm–4:30 pm  New Research Information: Current Efforts to Investigate the Causes of Increases in MSS CRC Among Young Adults  
• The United States  
  • Current NCI Funded Investigations into the Causes of Early Age Onset Colorectal Cancer:  
  • Colorectal Cancer Risks in People < 50 Years of Age NIH (RO3): Epidemiology, Richard Hayes, DDS, PhD, MPH, the Cancer Institute at NYU Langone

4:30 pm–4:40 pm  • Presentation Early Life Risk Factors and Risk of Colorectal Neoplasia: Kana Wu, MD, PhD, Harvard T.H. Chan School of Public Health, Dana-Farber, Harvard Cancer Center

4:40 pm–4:50 pm  • The European Union: Funded Investigations  
  • European Organization for Research and Treatment of Cancer (EORTC): Young Onset CRC: Causation, Treatment and Outcomes, Irit Ben-Aharon, MD, PhD, Rambam Health Care Campus, Haifa, Israel European Organisation for Research and Treatment of Cancer

4:50 pm–5:00 pm  • European study of Early-onset Colorectal Cancer (EUREOC): A Collaborative Study of the Biology of Young Onset CRC, Jose Perea, MD, PhD, Fundacion Jimenez Diaz University Hospital, Madrid, Spain

5:00 pm–5:10 pm  In Development:  
• CRAYON: ColoRectal Cancer in Adults at Young ONset: New York City Based Prospective Accrual Study of Young Onset Colorectal Cancer  
  Steven H. Itzkowitz MD, Icahn School of Medicine at Mount Sinai

5:10 pm–5:20 pm  • The Beyond CRC Project  
  Kimmie Ng, MD, MPH, Dana-Farber Cancer Institute

5:20 pm–5:30 pm  • The Search for Novel Drivers of Young Onset MSS CRC: An Overview of Current NIH, CDC and ACS Efforts  
  Thomas K. Weber, MD, FACS, Northwell Health

5:30 pm–5:40 pm  • Report Back from Denver EAO CRC Research Meeting  
  Heather Hampel, the Ohio State University Comprehensive Cancer Center

5:40 pm–5:50 pm  Discussion and “Next Steps”

5:55 pm–7:00 pm  Poster Session and Reception
FRIDAY, MAY 3, 2019

8:00 am–9:00 am  REGISTRATION AND BREAKFAST WITH THE EXPERTS (PATIENTS AND THEIR FAMILIES)
Krista Nelson, LCSW OSW-C BCD FAOSW, Providence Cancer Institute, Providence St Joseph Health
Karen Fasciano, PsyD, Dana-Farber Cancer Institute

9:00 am–9:05 am  WELCOME BACK!
Course Co-Director Wasif M. Saif, MD, Northwell Health Cancer Institute

9:00 am–9:05 am  HOUSEKEEPING
Course Co-Director Susan Peterson, PhD, MPH, The University of Texas MD Anderson Cancer Center

9:05 am–10:05 am  SESSION VI: Palliative Care: Why Early is Best. (Including Guidance, Support and Resources to Patients and Caregivers During Their Treatment Journey/Continuum of Care (Addressing Gap 5)
Moderator: James T. D’Olimpio, MD, FACP, FAAHPM, Northwell Health Cancer Institute
Sarah Debord, Colon Cancer Coalition
Andy Esch, MD, MBA, Center to Advance Palliative Care
Karen Fasciano, PsyD, Dana-Farber Cancer Institute
Susan Pfau, MA, Family Innovations and Wilder Foundation
Krista Nelson, LCSW OSW-C BCD FAOSW, Providence Cancer Institute, Providence St Joseph Health

10:05 am–10:25 am  SESSION VI: Epigenetics and its Future Role in the Diagnosis and Treatment of Individuals More Specifically and Accurately
C. Richard Boland, MD, AGAF, UC San Diego

10:25 am–10:45 am  Networking, Coffee, Poster Viewing Break

10:45 am–11:20 pm  STRATEGIC PLANNING SESSION
(Breakout Groups According to Gap)
1. Data, Accurate, Regular to Measurement of Key Metrics
2. Family History Ascertainment
3. Earliest Possible Stage Diagnosis
4. Development of Centers of Excellence Dedicated to the Treatment of EAO CRC Patients and Caregivers
5. Research into the Causes of Early Onset Colorectal Cancers

11:20 am–11:45 pm  REPORT BACK FROM STRATEGIC ACTION PLAN BREAKOUT GROUPS
 THE EAO-CRC PLEDGE

11:45 pm–12:15 pm  ABSTRACT POSTER SESSION AWARDS

CLOSING REMARKS
DENNIS J. AHNEN, MD
For the last 30 years, Dr. Dennis Ahnen has been an active clinician, educator and investigator in the Gastroenterology Division of the University of Colorado School Of Medicine. His research interests have focused on the biologic understanding and prevention of colorectal cancer. His basic science laboratory has focused on colorectal cancer biology and mechanisms of chemoprevention by non-steroidal anti-inflammatory drugs, his clinical laboratory group has conducted numerous colorectal cancer screening and chemoprevention trials, and his behavioral group has focused on interventions to improve colonoscopic screening in high-risk colorectal cancer families. Clinically, Dr. Ahnen is a Co-Founder of the Hereditary Cancer Clinic at the University of Colorado Hospital and Director of the Genetics Clinic at Gastroenterology of the Rockies. He retired from his Veterans Administration faculty position in October, 2014, and is now Professor Emeritus in the Gastroenterology Division at the University of Colorado School of Medicine. Dr. Ahnen is a member of the Colorado Comprehensive Cancer Center where he continues to work with junior faculty and fellows. He is also working with Gastroenterology of the Rockies to implement a CRC prevention program seamlessly into their practice.

ANDREW ALBERT, MD, MPH
Dr. Andrew Albert is the Medical Director of Digestive Health at Advocate Illinois Masonic Medical Center, Chicago. Dr. Albert received the Grand Prize for the 2017 80% by 2018 National Achievement Awards from the National Colorectal Cancer Roundtable (NCCRT) for his leadership in increasing colorectal cancer screening rates at his institution. Dr. Albert’s mission is to end preventable deaths related to colorectal cancer and, through his efforts, Advocate Health System has achieved a greater than 80% screening rate. Realizing that traditional messaging around colon cancer prevention was not enough, Dr. Albert launched the social media campaign, #backoffcoloncancer, in 2017. Within a few weeks, this grass-roots approach became a worldwide movement with thousands of people joining the campaign. He was recently honored for this work as one of 20 Most Inspiring Chicagoans by StreetWise Magazine. Dr. Albert is a leader on the NCCRT Hospital and Health System Advisory Board and leads best practices in colorectal cancer screening across the country. He has published extensively and has presented at numerous conferences, and has collaborated with many colorectal cancer screening advocates across the country. He has also held numerous community and corporate events to bring the messaging to those who need it most. Dr. Albert attended Brandeis University and received his Medical and Masters in Public Health Degrees at the George Washington University Medical Center. He became Chief Resident during his residency at Boston University Medical Center and completed his fellowship in Gastroenterology & Hepatology at Loyola University Medical Center. Dr. Albert has also completed advanced training at the University of Chicago.

RICHARD BARAKAT, MD
Dr. Richard Barakat is an internationally recognized surgeon and clinical investigator who was Chief of the Gynecology Service at Memorial Sloan Kettering from 2001 to 2013 and held the Ronald O. Perelman Chair in Gynecologic Surgery. Dr. Barakat was the lead investigator on several influential research projects at MSK, including a study to compare the benefits of laparoscopic versus standard surgery for patients with endometrial cancer, a study evaluating symptomatic lower-extremity lymphedema in women treated for uterine corpus cancer, and a study testing the efficacy of the Gynecologic Cancer Lymphedema Questionnaire in detecting lower-extremity lymphedema symptoms. Dr. Barakat is author or co-author of more than 340 peer-reviewed articles and numerous textbook chapters and is also an editor of a surgical atlas on gynecologic cancer and of the latest edition of Principles and Practice of Gynecologic Oncology, one of the leading texts in the field.

IRIT BEN-AHARON, MD, PHD
Dr. Irit Ben-Aharon is the Director of the Oncology Division at Rambam Health Care Campus, the largest cancer center in northern Israel, located in Haifa. She is an Associate Professor in the Department of Oncology, Faculty of Medicine, Tel-Aviv University. Dr. Ben-Aharon completed the MD-PhD joint program of Tel-Aviv University and the National Institute of Health’s (NIH) and was awarded her PhD in developmental biology in 2004 and her MD at 2005. Dr. Ben-Aharon completed oncology residency at Davidoff Center, Rabin Medical Center in 2011, followed by a fellowship in oncology at the Dana-Farber Cancer Center in Boston (2010-2011), and a fellowship at Memorial Sloan Kettering Cancer Center, New York as a Fulbright scholar in 2014-2015 focused on gastrointestinal malignancies and young-onset cancer. Dr. Ben-Aharon returned to Israel in 2015, and led the gastrointestinal oncology at Rabin Medical Center. In 2018, she was appointed as the director of the division of oncology at Rambam Health Care Center.

SEMIR BEYAZ, PHD
Dr. Semir Beyaz’ long-term research interests involve the development of a comprehensive understanding of how cancer immune recognition and response pathways are perturbed in response to diet. During his graduate training, Dr. Beyaz developed significant expertise in the assessment of epigenetic, transcriptional and metabolic mechanisms that control cellular fate during cellular differentiation or in response to diet. As a Principal Investigator at Cold
Spring Harbor Laboratory, he focused on dissecting the mechanisms of how pro-obesity diets alter immunity in the intestine and impact intestinal tumor initiation, progression, response to therapy, and whether such changes are reversible.

CINDY BORASSI

Cindy has spent nearly 25 years developing and leading new programs and business initiatives in the non-profit space both in the US and abroad. Her focus is always on building long-term, win-win relationships that strengthen and/or build upon the success of already existing programs and services.

As Executive Director of the Colon Cancer Foundation (CCCF) Cindy leads the Foundation’s national communications and outreach efforts focused on building awareness of colorectal cancer and the importance of early screening and detection of the nation’s second leading cancer killer of women and men. She has been actively involved in the organization and growth of the Foundation’s annual Early Age Onset Colorectal Cancer Summit (EAO-CRC) since its inception in 2015.

Prior to joining CCCF, Cindy served as Development Director for International Executive Service Corps (IESC). As Development Director, Cindy was responsible for IESC’s Corporate, Private and Governmental development efforts. Her primary focus was on building Private-Public Partnerships to leverage existing and new programs around the globe.

Cindy serves on the The (NYC) Citywide Colorectal Cancer Control Coalition (C5), the Westchester Cancer Coalition, the New York State Cancer Consortium, and the National Colorectal Cancer Roundtable (NCCRT) Family Health History Early Age Onset Colorectal Cancer (EAO-CRC) Task Group and is a founding member of the Hudson Valley Cancer Consortium. In her spare time she enjoys spending time with her husband, two children, two dogs, cat and Fred the fish exploring the region’s botanical gardens, hiking and working in her own garden.

CHELSEA BOET, MD

Dr. Chelsea Boet is an alumnus of Kalamazoo College and Wayne State University School of Medicine. Dr. Boet did her internal medicine and pediatrics residency in Grand Rapids, MI at Spectrum Health and Helen DeVos Children’s hospital. Dr. Boet now practices primary care medicine and pediatrics in Grandville, MI. She was diagnosed with stage IV colorectal cancer in 2018. She has an incredibly supportive husband, Pete, and 2 beautiful children, Lillian (age 4) and Oliver (age 15 months).

C. RICHARD BOLAND, MD, AGAF

C. Richard (Rick) Boland, MD, AGAF, is a gastroenterologist and Professor of Medicine at the University of California San Diego School of Medicine. He was born and raised in upstate New York, received a B.A. from The University of Notre Dame and an MD from Yale Medical School. He has a career-long research interest in colon cancer, specifically focusing on the genetic causes of colon cancer and familial cancer syndromes.

Dr. Boland started studying familial colorectal cancer as a medical student, and wrote an MD thesis proposing a novel familial aspect of the disease. After clinical training (and two years as a general medical officer in the Indian Health Service), he resumed research with Young S. Kim, MD, at UCSF, studying glycoprotein biochemistry in colorectal cancer. At the University of Michigan, he continued work on cancer-associated glycoprotein alterations, but in 1990, he redirected his focus to the molecular genetics of colorectal cancer following a sabbatical in the Howard Hughes Medical Institute, at which time he resumed work on the hereditary colorectal cancer disease, which he named “Lynch Syndrome.” He was among the first gastroenterologists to explore “microsatellite instability” in cancer, and his laboratory developed the first in vitro models to study the basic biology of Lynch Syndrome, using stable chromosome transfer to correct DNA mismatch repair (MMR) deficiencies in cultured cells. In recent years, he has contributed to our understanding of the genetic and epigenetic basis of colorectal cancer.

Dr. Boland has been an active clinician and teacher. He has been funded continuously by NIH since 1979, has served on multiple NIH (and other) Study Sections and was the chair of the Clinical Integrative Molecular Gastroenterology Study Section from 2014 to 2016, and was on the Multisociety Task for on Colorectal Cancer from 2012-18. He has published about 400 papers, has an H-Index of 89, and has written authoritative chapters for several textbooks of Internal Medicine, Gastroenterology and Genetics. He was elected into the Association of American Physicians in 2001. Dr. Boland was president of the American Gastroenterological Association (AGA) from 2011-2012, was given the AGA Oncology Section Distinguished Mentor Award, the AGA Beaumont Prize for his research in 2015, and the AGA Friedenwald Medal in 2016.

JENNIFER J. BROWN, PHD

As Assistant Director of the Cancer Prevention and Control Program at the New York City Department of Health, Dr. Brown’s experience includes public health research, cancer prevention, and publications. As a digital editor and writer, her skills also include communications, health and science journalism, outcomes research, medical education, grant writing, and publication.

A senior editor at EverydayHealth.com, a health site, she sets editorial strategy and managed a team of freelance writers, creating preventive health content to empower readers.
YIN CAO, SCD, MPH
Ms. Yin Cao is a cancer epidemiologist focusing on risk prediction, screening and early detection, and chemoprevention of gastrointestinal malignancies. Her research in colorectal, prostate, and breast cancers have produced over 60 original research papers, including 25 first-/senior-author papers and 2 book chapters.

Her major contributions to cancer risk prediction include the development of the first absolute risk assessment tool for high-risk adenoma that could provide guidance for colorectal cancer (CRC) screening (International Journal of Cancer, 2015). I also developed a user-friendly prediction model of breast cancer for younger women who are not recommended for routine mammography (submitted).

Cancer chemoprevention is Ms. Cao’s other focus. Utilizing two large prospective studies, she reported the full constellation of potential benefits of long-term aspirin use in overall cancer prevention (JAMA Oncology, 2016). Her work also provided the first population-based evidence for the role of host immunity in mediating the benefits of aspirin in CRC chemoprevention (Gastroenterology, 2016).

TABITHA CAVANAGH
My new beginning all started in January 2017 when I was unexpectedly diagnosed with stage III colon cancer at the young age of 31 - years before I was due to even think about a colonoscopy. Out of nowhere, cancer chose me. I was a new mom & newly married. Cancer didn’t care. Luckily, I quickly discovered the Colorectal Cancer Alliance. Through their online community, Blue Hope Nation, I was able to connect with patients, survivors and caregivers who were going through a similar experience. For the first time since my diagnosis, I truly felt like I had an ally.

From the day my surgeon shared the heart-breaking news to the moment I rang (and broke!) the bell after my final chemotherapy treatment, I have never felt alone. Had it not been for the unending love and genuine support from my family, friends and the Colorectal Cancer Alliance Nation Of Allies, I am not sure I would be standing here today.

While I most certainly didn’t choose cancer, what I did choose was positivity! Joyful participation was how I decided to beat colon cancer. I realized, sometimes, beautiful things can blossom in the most unlikely places.

My cancer journey has proven to be the best & worst that has ever happened to me. Changing how I saw this disease - and doing something about it- granted me so many blessings, including the opportunity to continue to be a mom and wife. I learned that by creating a stronger mindset, I could get through anything.

Since aligning myself with the Colorectal Cancer Alliance, I have found purpose. I am committed to raising awareness and helping others advocate for their health. We must find out why younger people, like me, are being diagnosed with this disease at increasingly alarming rates.

Days like today matter. You matter. Together, we CAN end colorectal cancer in our lifetime. Tomorrow truly can’t wait.

“Arise, for it is your task, and we are with you; be strong and do it.” Ezra 10:4

ANDREA CERCEK, MD
Dr. Andrea Cercek is a board-certified medical oncologist who specializes in the treatment of patients with gastrointestinal cancers, particularly colorectal and appendix cancer, and those with peritoneal mesothelioma. She specializes in both systemic chemotherapy and regional chemotherapy given directly into the liver or the peritoneal cavity. Her research focus is on the development of new therapies for patients, including molecular-based therapies to improve the outcomes for patients with metastatic disease.

ZANA CORREA, NP, BC
Ms. Zana Correa is an American Nurses Credentialing Center board certified nurse practitioner with 17 years of experience in outpatient gastrointestinal oncology in the departments of surgery, medicine, and survivorship at Memorial Sloan-Kettering Cancer Center. As a nurse practitioner with the Colorectal Survivorship Program, Ms. Correa manages an independent practice caring for colon, rectal and anal cancer survivors. She has presented nationally at conferences including the Oncology Nursing Society and American Society of Colorectal Surgeons annual conference. She co-facilities a support group for colorectal cancer survivors and is on the survivors’ newsletter committee at Memorial Sloan-Kettering. Ms. Correa serves as an adjunct clinical instructor in the Department of Graduate Nursing at New York University.

SARAH DEBORD
Ms. Sarah DeBord was diagnosed with metastatic colon cancer at age 34. In the 7-plus years since, she has turned her diagnosis into a calling, and become an advocate for other young adults diagnosed with colorectal cancer and parents with young families facing cancer. Ms. DeBord works as a communications and program manager for the Minneapolis-based Colon Cancer Coalition, is a contributing writer for CURE Magazine, volunteers her time with the online patient-led support community COLONTOWN, and blogs about her often adventurous experiences of living with chronic cancer at ColonCancerChick.com.
CATHY ENG, MD, FACP

Dr. Cathy Eng, Professor, and Sophie Caroline Steves Distinguished Professor for Cancer Research has served as faculty at MD Anderson for the past 15 years. She has assumed leadership positions devoted to clinical research. She has focused on the development of phase I-III clinical trials using novel therapeutics for biomarker discovery and enhanced drug utilization in colorectal, appendiceal and anal cancer patients.

Within MDACC, she is the Chair of the Multidisciplinary Colorectal Cancer Clinical Research Conference. She chairs the Clinical Research Committee. She is the contact PI for the multidisciplinary NCI National Clinical Trials Network Lead Academic Participating Sites U10 Grant (NCTN LAPS U10 Grant), an umbrella grant to conduct cancer research within all 4 clinical cooperative groups. She serves on SWOG’s and ECOG’s Gastrointestinal Committee and Colorectal Steering Committee and is a co-chair of the SWOG Rectal/Anal Cancer Subcommittee.

Nationally, Dr. Eng has also been highly active serving as the former Chairman of the Scientific Program Committee of the ASCO Gastrointestinal Cancer Symposium from 2012-13; a member of its Steering Committee 2012-2015; ASCO’s Career Development Committee; Education Committee for Colorectal Cancer; co-chaired the ASCO Annual Meeting Gastrointestinal-Colorectal Oral Presentations Session; ASCO Scientific Program Committee Track Leader for the Gastrointestinal Cancer-Colorectal/Liver Track. She is the former Chairman, Steering Committee, GI Cancers Symposium 2016 (ASCO representative). She is currently serving on the ASCO Annual Planning Committee (Colorectal Cancer Track, 2016-2019). She was chosen for the ASCO Leadership Development Program and served on the ASCO Government Relations Committee. She has recently worked with the ASCO Cancer Prevention Committee on HPV vaccination. She has recently served on the ASCO Nausea and Vomiting Guidelines Committee, ASCO Taxonomy Task Force, and is now on the ASCO Social Media Committee. She is the Chairman of the NCI Rectal/Anal Task Force (2nd term).

She has published in many peer reviewed journals including JCO, Lancet Oncology, Nature, Review, Annals of Oncology, Cancer, and Annals of Surgical Oncology. She has recently received a NICI grant

“Administrative Supplements to the institutional CCSG grant to Support Biomarker Studies Associated with NCI-supported Clinical Trials of Immunotherapy”. She is a co-PI for the MDACC Moonshot for HPV-Associated Malignancies (she is the Section Lead for the Rare Cancers subsection). She serves as a consultant to the FDA and AHRQ, Cancer Research UK: Training & Career Development Board - Clinician Scientist Fellowship, the Italian Association for Cancer Research, the Dutch Digestive Foundation, and the Stand Up to Cancer (SU2C) - Farrah Fawcett Foundation Joint Scientific Advisory Committee (USAC).

ANDREW E. ESCH, MD, MBA

Dr. Andrew Esch is a palliative care specialist and consultant focusing on improving the quality of life for patients and their families as they face serious or life-threatening illness through pain and symptom management, coordination of care, and education. Dr. Esch earned his medical degree from the University of Buffalo, where he also earned a combined bachelor of science and master of business administration degree. Currently he is a consultant and faculty member for the Center to Advance Palliative Care (CAPC), and serves as medical director at the Hospice of Orleans in Albion, New York. Prior to joining CAPC, Dr. Esch worked at the Lee Memorial Health System in Fort Myers, Florida, as medical director of palliative care. He has worked in both New York and Florida as a staff physician, a hospice physician, an assistant clinical professor of internal medicine and palliative care.

KAREN M. FASCIANO, PSYD

Dr. Karen Fasciano is a clinical psychologist and Director of the Young Adult Program at the Dana-Farber /Brigham and Women’s Cancer Center. Dr. Fasciano has created a body of innovative clinical interventions to improve emotional care for young adults coping with cancer including an interactive educational website, a series of videos, conversation aids and integration of platforms such as Twitter into clinical care. Most recently she has been working on a smart phone application to help with coping with cancer. Dr. Fasciano consults with other national and international cancer centers around the development of new clinical programs for young adults. In addition, Dr. Fasciano has participated in research publications on young adults coping with cancer. She has co-chaired an international conference on psychosocial oncology and been a member of the board of the American Psychosocial Oncology Society.

GREGORY FEERO, MD, PHD

Dr. Gregory Feero attended the University of Pittsburgh School Of Medicine and graduated with an M.D., Ph.D. (Human Genetics) in 1998. He then completed his medical training at the Maine-Dartmouth Family Medicine Residency in Augusta, Maine. After five years on the faculty of the Maine-Dartmouth Family Medicine Residency, he accepted a position at the National Human Genome Research Institute, National Institutes of Health, where he was a senior advisor to the director, and branch chief of the Genomic Healthcare Branch in the Office of Policy, Communication and Education, Office of the Director. In 2009 he returned to Maine. Dr. Feero currently serves as a consultant to the Jackson Laboratory on education issues, is an associate editor for the Journal of the American Medical Association and serves on the National Academies
of Science, Engineering, and Medicine Roundtable on Genomics and Precision Health. He has authored several book chapters and over 50 peer-reviewed publications and is board certified in family medicine. He is an assistant professor in the Department of Community and Family Medicine at the Geisel School of Medicine at Dartmouth; a clinical associate professor at the University of New England College of Osteopathic Medicine, and a faculty research scientist at Colby College. He currently sees patients at Four Seasons Family Practice in Fairfield, ME.

TONY FOLENO
Mr. Tony Foleno serves as Senior Vice President, Strategy and Evaluation at the Ad Council. In this role, Mr. Foleno advises the strategic planning of more than 35 public service communications campaigns. He also oversees campaign evaluation, establishing key performance indicators and the tools through which they are measured. Mr. Foleno leads cross-campaign analyses designed to optimize Ad Council initiatives, and helps lead Ad Council Edge, a strategic consultancy advising nonprofit and corporate clients. His primary role is to leverage research-based insights into action, helping to ensure that the Ad Council remains a results-driven organization with a single-minded focus on making an impact in people’s lives. Prior to joining the Ad Council in 2002, Mr. Foleno managed projects at Public Agenda, a nonpartisan public opinion research organization. He presently serves as 2018-2020 President of the Society for Health Communication, and is an active member of the Advertising Research Foundation, the American Evaluation Association, the 4As, and AAPOR, and serves on the steering committees for Agents of Change, the Market Research Council, and the Fishlinger Center for Public Policy and Research. He is a graduate of Swarthmore College and holds a MA in Sociology from Columbia University.

HEATHER HAMPEL, MS, CGC
Heather Hampel completed her Bachelor of Science degree in Molecular Genetics at the Ohio State University in 1993. She attained her Master’s degree in Human Genetics from Sarah Lawrence College in 1995. She received certification from the American Board of Genetic Counseling in 1996. She worked as a cancer genetic counselor at Memorial Sloan-Kettering Cancer Center before moving to The Ohio State University Comprehensive Cancer Center (OSUCCC) in 1997. Currently, Heather is a Professor in the Department of Internal Medicine and Associate Director of the Division of Human Genetics. She is also the Associate Director of Biospecimen Research for the OSUCCC. She was the study coordinator for the Columbus-area Lynch syndrome study which determined the frequency of Lynch syndrome among newly diagnosed patients with these cancers. This study culminated in first author publications in the New England Journal of Medicine in May of 2005, Cancer Research in August of 2006, and the Journal of Clinical Oncology in December of 2008. She is now the PI of the Ohio Colorectal Cancer Prevention Initiative which is screening colorectal cancer patients from 50 hospitals throughout the state for hereditary cancer syndromes. The first major publication from that study showing that 16% of early-onset colorectal cancers are hereditary was published in 2017 in JAMA Oncology. Heather Hampel was the Region IV Representative on the Board of Directors of the National Society of Genetic Counselors in 2003-4. She was on the Board of Directors for the American Board of Genetic Counseling from 2006-2011, serving as President in 2009 and 2010. She was elected to the Steering Committee member of the National Colorectal Cancer Roundtable in 2016. She has been on the Council of the Collaborative Group of the Americas on Inherited Colorectal Cancer since 2016 and served as President in 2018.

KEVIN HAYES
Kevin Hays began his colorectal cancer journey when he was diagnosed in April 2014 (age 28) with Stage IIIC colon cancer. Two years after being declared NED he was diagnosed in July 2016 with a recurrence of colon cancer. With findings of peritoneal metastases, Kevin was elevated to Stage IV and underwent HIPEC (Hyperthermic intraperitoneal chemotherapy). A CT scan showed a second recurrence in July 2018. He is currently undergoing FOLFIRI and Erbitux treatment in advance of surgery for a peritoneal metastasis and kicking butt. Kevin Hays focused his attention on advocacy and has participated with the Colorectal Cancer Alliance on the Undy Run Engagement Committee and the Never Too Young Advisory Board. Kevin also sits on the Advisory Board for American Cancer Society in Western New York. Kevin wins on creative strategies to educate and advocate for colorectal health as Founder and Executive Director of Buffalo Colon Corps and the Blue Hope Hard Hat Initiative. In his professional life, Kevin is the Director of Development for Savarino Companies, a Real Estate Developer and Construction Management Company in Buffalo, New York. Mr. Hays has been recognized for his work in real estate development and community service and was named one of Business First’s ‘30 Under 30’. In 2014, he was named one of Buffalo Niagara Partnership’s ‘Spotlight Professionals.’ Kevin Hays resides in the Village of East Aurora near Buffalo, New York with his wife Hilary and has three children, Abigail, Benjamin, and Charlotte.
RICHARD B. HAYES, DDS, PHD
Dr. Richard Hayes is a Professor in the Departments of Population Health and Environmental Medicine at New York University School of Medicine. Dr. Hayes has more than 30 years of experience in designing and carrying out epidemiologic investigations on cancer, including the successful execution of case-control and cohort studies in national and international settings. His past research on the etiology of colorectal cancer has involved investigations of diet, anthropometric factors, and genetics, and, most recently, the human microbiome. His current research involves risk prediction modeling for colorectal cancer, with the purpose of determining the appropriate age for beginning colorectal cancer screening, based on genetic and environmental risks. This research also involves identification of differentials for genetic and environmental risk for those younger than age 50 years and older individuals.

WES HENSEL
Mr. Wes Hensel was diagnosed with stage 3 rectal cancer at age 34 during a colonoscopy, after 4 years of being misdiagnosed with hemorrhoids due to rectal bleeding and being “too young” for anything else. After diagnosis, tumor tissue testing on mismatch repair protein expression and subsequent germline genetic testing found that Mr. Hensel had a MLH1 gene mutation for Lynch Syndrome, despite no family history of colorectal cancer. After extensive treatment with radiation and chemotherapy, Mr. Hensel underwent abdominoperitoneal resection with permanent colostomy at MD Anderson Cancer Center, performed by Dr. Nancy You, followed by additional chemotherapy completed in November, 2018. Now age 36, Mr. Hensel was declared “no evidence of disease” in December, 2018. He has a passion for educating others about early-onset colorectal cancer, and for promoting earlier screening, including colonoscopies as a first line of defense when symptoms arise in younger patients. He also is passionate about promoting healthy eating and fitness for cancer prevention and overall health. Mr. Hensel works as a systems engineer in the aerospace industry, and lives with his beautiful wife and 2 lovely children in Tucson, Arizona.

STEVEN H. ITZKOWITZ, MD, FACP, FACG, AGAF
Dr. Steven Itzkowitz is Professor of Medicine and Oncological Sciences, and Director of the GI Fellowship Program at Icahn School of Medicine at Mount Sinai. His research has focused on reducing disparities in colon cancer screening in the general population, developing new non-invasive stool DNA tests to screen for colon cancer, and detecting and preventing colon cancer in inflammatory bowel disease. At the national level, Dr. Itzkowitz is a current member of the Steering Committee of the National Colorectal Cancer Roundtable and a former Chair of the Gastrointestinal Oncology Section of the American Gastroenterological Association. In New York City, he is a former President of the New York Gastroenterological Association and a founder of the New York Crohn’s and Colitis Organization (NYCCO). He is immediate past Co-Chair of the New York Citywide Colon Cancer Control Coalition (CS Coalition) and current Co-Chair of the CS Coalition Screening Guidelines Committee. At Mount Sinai, since 2000 he has been instrumental in developing and running the institution’s colon cancer screening program among minority populations in East Harlem. His team at Mount Sinai was among the first in the nation to demonstrate the effectiveness of patient navigation to enhance screening colonoscopy adherence, proving also that patient navigation is cost effective. He is the founder and Medical Director of the Mount Sinai CO-CARE Registry for patients and their relatives who are at high risk for colon cancer. He is currently organizing a multi-center prospective study of risk factors for Early Onset CRC among several NYC-area academic medical centers.

WHITNEY JONES, MD
Dr. Whitney Jones is a practicing Gastroenterologist, former therapeutic endoscopist and Clinical Professor at the University of Louisville from 1994 until 2017. In 2003 he founded the Colon Cancer Prevention Project, a state based, nation leading information and advocacy organization. Through the leadership of Colon Cancer Prevention Project and its many partners, Kentucky has more than doubled its screening rates, cut colon cancer mortality by third, and passed into law the lowest barriers for CRC screening of any state. Since 2016, Dr. Jones has implemented systematic hereditary cancer risk assessment and point of service genetic panels testing in both the office and endoscopy platforms to both prevent and better manage the cancer risks of affected and unaffected patients.

JORDAN KARLITZ, MD
Dr. Jordan Karlitz graduated from the University of California at Berkeley with a degree in molecular biology and genetics. He subsequently attended the McGill University Faculty of Medicine in Montreal where he received his medical degree. He received his internal medicine training at the Columbia University College of Physicians and Surgeons/New York Presbyterian Hospital and completed his fellowship in gastroenterology and hepatology at the Albert Einstein College of Medicine/Montefiore Medical Center.
NOAH D. KAUFF, MD
Dr. Noah Kauff is Director, Clinical Cancer Genetics at Duke Cancer Institute in Durham, North Carolina. Dr. Kauff is a gynecologist and geneticist who specializes in the care of patients who may have an inherited predisposition to cancer. His research interests include: a) analyzing the effect of genetic risk markers on the assessment and treatment of individuals with an inherited predisposition to cancer; b) evaluating methods for incorporating genetic risk assessment into the routine care of oncology patients; c) characterizing the efficacy of risk-reducing strategies performed for the prevention of inherited cancers; and d) elucidating differences between inherited and sporadic cancers to assist in the development of targeted therapies for hereditary malignancies.

SAYONI LAHIRI, MS, CGC
Ms. Sayoni Lahiri is a board-certified genetic counselor at the University of Texas Southwestern Medical Center in Dallas. Prior to joining UT Southwestern in 2015, Ms. Lahiri completed her Master of Science degree in genetic counseling at Northwestern University and practiced in Orange, California. In addition to providing genetic counseling for patients at risk for hereditary cancer at multiple UT Southwestern clinics, she is also grant coordinator and oversees two of the department’s population grants that focus on expanding access to genetic counseling and testing services to the underserved population of north Texas. Ms. Lahiri oversees the implementation of a Cancer Prevention and Research Institute of Texas (CPRIT)-funded population screening program for Lynch syndrome at UT Southwestern and Parkland Hospital, and helped create a CPRIT grant-funded genetic patient navigator role to follow patients with Hereditary Breast and Ovarian Cancer syndrome (HBOC) and Lynch syndrome.

XAVIER LLOR, MD, PHD
Dr. Xavier Lior is Professor of Medicine, Medical Director, Cancer Screening and Prevention Program and Colorectal Cancer Prevention Program, and Co-director, Cancer Genetics and Prevention Program at Yale University School of Medicine. After obtaining his MD degree from the Autonomous University Barcelona, Dr. Lior trained in basic research and Internal Medicine at the University of Chicago and completed his GI fellowship at the University of Illinois at Chicago. He complemented his training with a PhD degree in molecular biology from the University of Barcelona. A clinically active gastroenterologist, Dr. Lior’s research and clinical interests relate to colorectal cancer. He has a very active basic and translational research program mainly focusing on two different aspects of colorectal cancer: hereditary and familial forms, and disparities in colorectal cancer. This work has resulted in over 70 scientific publications in this field. He has made seminal contributions to the field of Lynch syndrome diagnosis as well as in the definition of other non-polyposis syndromic colorectal cancer cases. Some of his most recent work is providing important clues to the understanding of the biological differences that contribute to disparities in colorectal cancer. He is a member of the leadership council and Chair of the Education and Training Committee of the American Gastroenterological Association.

JAN LOWERY, PHD, MPH
Dr. Jan Lowery is the Associate Director of Clinical Operations at the Colorado Center for Personalized Medicine. She earned her PhD in Analytical Health Sciences and Epidemiology from the University of Colorado. She is an Adjunct Associate Professor in the Department of Epidemiology at the Colorado School of Public Health.

CHRISTINE MOLMENTI, PHD, MPH
Dr. Christine Molmenti is an Assistant Professor and Cancer Epidemiologist in the Department of Occupational Medicine, Epidemiology and Prevention at the Northwell Health. Her research is focused on the primary and secondary prevention of colorectal cancer through screening/early detection and lifestyle.

KRISTA NELSON, LCSW OSW-C BCD FAOSW
Krista Nelson is trained as an oncology social worker and works in clinical, research and program management roles within Providence Health and Services. Krista Most recently joined the Compassion team as a Program Manager, and has appreciated bringing her clinical expertise to work on creating supportive infusions of compassion to caregivers. She provides individual support as well as group support for those affected with cancer and facilitates an online support group for women with metastatic cancer and runs a program for children with a parent with cancer. Krista defines her role as providing support for people and their families throughout the cancer continuum, and sharing the expertise that she has learned from other patients with cancer. What she loves about working with those affected with cancer, “is being able to witness the grace, courage and life lessons of individuals dealing with cancer and the opportunity to be a part of their journey.” Krista is a past President of the board of directors of the Association of Oncology Social Work and past invited Director of the American Psychosocial Oncology Society. She loves being a part of the national discussion involving the psychosocial care of people with cancer. She has been a speaker at local and national conferences on issues of survivorship, palliative care, distress screening and children who have a parent with cancer. Krista also serves as an Invited Director on the board of directors of the National Accreditation Program for Breast Centers, In
JAMES T. D’OLIMPIO, MD, FACP, FAAHPM

James T. D’Olimpio, M.D., FACP, FAAHPM is the Director of Supportive/Palliative Oncology and leads the Cancer Pain and Symptom Control Service at North Shore University Hospital. He is also an Assistant Professor of Medicine at Hofstra/Northwell SOM. Dr. D’Olimpio has extensive experience in oncology research and treatment, focusing primarily on symptom management including cancer pain, chemotherapy induced peripheral neuropathy, sickle cell disease/painful crisis, and cancer anorexia/cachexia syndrome --the persistent fatigue, anorexia and weight loss associated with cancer. He is an author of multiple professional and technical papers. He is on the Editorial Staff of The Journal of Pain and Symptom Management, The Journal for Supportive Care in Cancer (MASCC) and serves on the Symptom Assessment Management for the American Academy of Hospice and Palliative Medicine/PC-FACS. He was one of the first physicians in the country to become Board Certified in the fields of Internal Medicine, Medical Oncology and Hospice/Palliative Medicine. In addition, Dr. D’Olimpio is a member of the American College of Physicians, American Society of Clinical Oncology; American Academy of Hospice and Palliative Medicine; Multi-National Association of Supportive Care in Cancer (MASCC). Dr. D’Olimpio was the Medical Director for the Hospice Care Network in Westbury from 1992-1999 and helped develop the Hospice and Palliative care programs for that agency through a significant period of growth and change in the field. He has lectured about pain, symptom management and Supportive/Palliative care throughout the country, Mexico, Canada and in Europe and has appeared on CNN as a national expert in pain control, as well as the Today show on NBC as an expert in Pancreatic Cancer.

Dr. D’Olimpio received his Medical Degree from the Autonomous University of Guadalajara and The University of the State of New York and completed his studies in the Fifth Pathway Program at the Mount Sinai School of Medicine in New York, and his Internal Medicine Internship and Residency at Mt. Sinai Hospital & City Hospital Center, Elmhurst. He completed his Fellowship in Oncology/Hematology at Montefiore Medical Center and the Chanin Cancer Institute of the Albert Einstein College of Medicine. Since 2004, Dr. D’Olimpio’s biography has appeared in “Who’s Who in America”.

In 2008, Dr. D’Olimpio was inducted as a Fellow of the American College of Physicians and in November 2011 was awarded Fellowship in the American Academy of Hospice and Palliative Medicine. He was given a QSCAN (Queens Sickle Cell Action Network) service award in 2009 and Keynote Speaker status in 2017. He has also been awarded Castle Connolly Top Doctor for Supportive Care in Cancer (MASCC).
Dr. José Perea is a Consultant Colorectal Surgeon and Associate Professor in the Surgery Department at Fundación Jiménez Díaz University Hospital, Madrid, Spain. Dr. Perea’s clinical and research interests focus on surgery, gastroenterology and oncology, and in particular, understanding the basis of colorectal cancers with differential phenotypes. He coordinates a multicenter multidisciplinary group within Spain, as well as international collaborations, focused on early-onset colorectal cancer and multiple primary colorectal cancers. Dr. Perea received his medical and surgery degree from the Complutense University of Madrid, his specialist degree in general and gastroenterological surgery from the General University Hospital Gregorio Maraño, Madrid, and his PhD (cum laude) from the University of Salamanca. He completed a specialization in clinical research Methodology at the National School of Health, Carlos III Institute, Madrid, and a master of molecular oncology degree from the Spanish National Oncological Research Center (CNIO). Dr. Perea is a member of the scientific committee for the Spanish Society of Coloproctology.

Ms. Erin Peterson is the Communications Director for the Colon Cancer Coalition where she works to reach the unscreened and underserved with the lifesaving messages of on time colorectal cancer screening. Prior to joining the Colon Cancer Coalition in 2011, Ms. Peterson spent ten years working for a marketing and public relations agency with national brands focusing on building partnerships and reaching consumers through unique marketing approaches.

Ms. Susan Pfau is a mental health practitioner with Family Innovations and Wilder Foundation. She also serves as a Kid’s Support Group facilitator at Gilda’s Clubhouse Twin Cities. She earned her MA in Marriage and Family Therapy from Saint Mary’s University in Minnesota and her BA in Family Studies from Metropolitan State of Minnesota. Ms. Pfau serves on the advisory board of the Colon Cancer Alliance.

Eric Reddy is an executive at Frontstream, a global leader and innovator in online fundraising software, where he oversees sales and retention efforts for more than 7,000 nonprofit organizations in North America. Prior to his move to the technology space, Eric worked for over a decade in professionals sports with stints at ESPN, the New Orleans Hornets (NBA), America East (NCAA) and the Providence Bruins (AHL). He was the Co-Founder of Boston’s 2024 Olympic bid, later serving on its Board of Directors and has been a longtime Director at Helping Hands, a nonprofit based in Boston that provides Capuchin monkeys to individuals throughout the country with mobility challenges. He is a graduate of Thomas College in Waterville, ME. Eric was diagnosed with Stage 4 metastatic colon cancer in July of 2017. Following three surgeries and 12 rounds of chemo, he was informed in May of 2018 that there was no evidence of the disease present in his system. He and his wife Maren live just north of Boston with their dog and two cats.
REBECCA SIEGEL, MPH
Ms. Siegel conducts cancer surveillance research across the cancer continuum, from prevention to survivorship, to help inform evidence-based cancer prevention and control in the United States and worldwide. Her primary research interests are emerging trends in cancer occurrence, particularly early-onset colorectal cancer, and cancer disparities based on race, socioeconomic status, and geography.

DIANA SLOAN
Diana Sloan is originally from Chesapeake, Virginia, and is a graduate of James Madison University. She currently lives in Lakeway, Texas, with her husband of nineteen years and their three daughters. Diana was an English teacher until 2012 when she was diagnosed with stage IV colorectal cancer at the age of 38. She is currently incurable and in treatment. Diana now spends her free time making memories with her family and friends and enjoying what her husband aptly named, “The We Don’t Wait” tour. She has also found a new passion in advocating for colorectal cancer patients, especially those diagnosed under 50.

ROBERT A. SMITH, PHD
Dr. Robert A. Smith is a cancer epidemiologist and Vice President, Cancer Screening at the National Office of the American Cancer Society (ACS) in Atlanta, Georgia. He also is Adjunct Professor of Epidemiology at the Rollins School of Public Health, Emory University School of Medicine, and an Honorary Professor, Centre for Cancer Prevention, Wolfson Institute of Preventative Medicine at Queen Mary University of London. His primary research interests are cancer epidemiology, evaluation of cancer prevention and early detection programs, quality assurance in the delivery of health services, and cancer rehabilitation and survivorship. He received his PhD from the State University of New York at Stony Brook in 1983. Prior to joining the staff at the ACS, he held positions with the Boston University School of Public Health, and the Centers for Disease Control. At the ACS he leads the development of cancer screening guidelines, and special research and policy projects focused on cancer prevention and control. He is the author of over 300 peer-reviewed scientific articles, reports, and book chapters, and a frequent lecturer on cancer screening issues. He serves on many international and national government and professional advisory committees and working groups, and in 2017 was a member of the International Agency for Research on Cancer (IARC) Handbooks Working Group for volume 17 on Colorectal Cancer Screening. Dr. Smith was one of the founding members of the National Colorectal Cancer Roundtable, and has served as its Co-Director for 22 years. He also is a founding member of the National Lung Cancer Roundtable and the Principle Investigator of the first 3-year supporting grant. Among his honors, Dr. Smith is an Honorary Fellow of the Society of Breast Imaging; in 2004 he received the Cancer Prevention Laurel for Outstanding National Leadership from the Prevent Cancer Foundation; and in 2011 he received the Medal of Honor from the International Agency for Research on Cancer.

ZSOFIA STADLER, MD
Dr. Zsofia Stadler is a clinical and laboratory investigator with an interest in human cancer genetics with a focus on hereditary and early-onset gastrointestinal cancers. Her research focuses on the use of genomic approaches to improve the identification and characterization of known and novel cancer susceptibility genes for colorectal and pancreas cancers as well as a variety of other inherited cancers. In early-onset, but genetically unexplained cancer patients, her research focuses on the use of whole-genome and exome sequencing to identify novel de novo or inherited mutations that may account for such early-onset malignancies. With tumor-normal DNA sequencing, her team recently demonstrated that high-frequency microsatellite instability predicts for the presence of germline mutations in the DNA mismatch repair genes, diagnostic of Lynch syndrome, across a broad spectrum of cancers. This suggests that Lynch syndrome is a much more heterogeneous disease than previously thought and any cancer patient harboring a tumor with microsatellite instability should undergo genetic testing for Lynch syndrome.

ELENA M. STOFFEL, MD, MPH
Dr. Elena Stoffel is an Assistant Professor of Internal Medicine (academic tenure track) and an associate member of the Cancer Epidemiology and Prevention Group of the University of Michigan Comprehensive Cancer Center. Her clinical and research interests are pathogenesis, early detection and prevention of gastrointestinal cancers, with special focus on genetic factors. Her previous work, funded by a K07 Cancer Prevention, Control and Population Sciences Career Development Award from the National Cancer Institute, examined the impact of genetic risk assessment on health behaviors and clinical outcomes of individuals with inherited predisposition to colorectal cancer. In her current position at the University of Michigan, Dr. Stoffel serves as Director of the Cancer Genetics Clinic, and is principal investigator of
the University of Michigan Cancer Genetics Registry and the Gastrointestinal Colorectal Biorepository. She has experience as principal investigator in research studies assessing utility of novel endoscopic and non-invasive technologies for early detection of colorectal neoplasia. Dr. Stoffel leads a multidisciplinary team dedicated to diagnosis and management of patients with hereditary cancer syndromes. She is a co-investigator on international collaborative research studies encompassing genetic epidemiology of GI cancers and clinical chemoprevention trials for individuals with genetic predisposition for colorectal cancer. Dr. Stoffel is a past President of the Collaborative Group of the Americas on Inherited Colorectal Cancer, a member of the American Gastroenterological Association Nominating Committee for Gastrointestinal Oncology, and the American Society of Clinical Oncology (ASCO) Cancer Genetics Committee. She serves on the National Comprehensive Cancer Network Colon and Rectum Guidelines Committee, and the ASCO Gastrointestinal Cancer Advisory Panel (Cancer.net). Dr. Stoffel has led expert review panels on clinical guidelines for management of individuals with hereditary GI cancer syndromes.

MARY B. STRONG, MA,
Ms. Mary Strong is the Assistant Vice President of Continuing Medical Education at Northwell Health. She holds a Bachelor of Science Degree in Community and School Health Education from the Health Sciences Center, State University of New York at Stony Brook. Her Master of Arts Degree in Health Administration was earned from Hofstra University, Hempstead, NY. Mary is currently responsible for the oversight of Northwell Health CME program consisting of medical conferencing, regularly scheduled series, and enduring materials that are designed to accomplish the CME mission of Northwell Health. She has worked in the field of Continuing Medical Education since 1999 when she became Assistant Director of CME for North Shore-LIJ’s Department of Professional and Public Health Education. Mary began her professional career as a health educator with the Long Island Diabetes Association where she was involved in community education initiatives. As a health educator for North Shore University Hospital, she planned and developed in-service and health education programs for school administrators, health personnel, faculty, parents and students. Additionally, she was responsible for the organization and implementation of a variety of large scale events, such as health fairs and community wellness programs. Her years of experience in adult learning, education and program implementation have carried over to her work in continuing medical education. During her tenure as Director, the CME program of the North Shore LIJ Health System (now Northwell Health) achieved, and has maintained, the level of Accreditation with Commendation (2007-2013; 2013-2019), the highest level awarded to CME providers by the Accreditation Council for Continuing Medical Education (ACCMCE).

DENNELLE SURANSKI
Ms. Denelle Suranski born and raised in Pittsburgh, PA. She is an event coordinator for Allegheny County, Parks and Recreation division and currently enrolled in Carlow University pursuing a degree in Human Resources Management. She is also stage II rectal cancer survivor diagnosed with Lynch Syndrome, MSH2. Denelle is a 2019 On the Rise model for the Colon Club and delighted to be a 2019 EAO-CRC faculty member of Colon Cancer Foundation.

THOMAS K. WEBER, MD, FACS
Dr. Weber is Director of Surgical Oncology, Northwest Region, Northwell Health and Medical Co-Director of Cancer Genetics at Northern Westchester Hospital, Northwell Health. Through 2017, Dr. Weber was Academic Professor of Surgery at the State University of New York at Downstate. As Chief of Surgery at VA New York Harbor Health Care System, Brooklyn Campus Dr. Weber led major initiatives to improve operating room productivity, surgical quality improvement and enhanced multidisciplinary training and care for the surgical patient at the Brooklyn VA Medical Center. In addition, he successfully led multiple new innovations including the establishment of a genetic counseling service, Surgical Telemedicine, implementation of a surgical simulation center, enhanced postoperative pain control templates and improved communication between surgical teams and waiting family members during extensive surgical procedures. To enhance quality assurance and surgical outcomes he designed an objective analytic analysis of response and completion times of ancillary service response to requests from the surgical service including radiology, cardiology and infectious disease. He also led the full integration of the Manhattan VA Surgical Service into the Brooklyn VA Medical Center following the Hurricane Sandy evacuation of all Manhattan VA patients and staff to the Brooklyn Campus on October 28th, 2012 and their return to Manhattan 6 months later in May 2013.

KANA WU, MD
Dr. Kana Wu is a trained physician and chronic disease epidemiologist and a Principal Research Scientist at the Harvard T. H. Chan School of Public Health. Her research focuses on studying relationship between diet and lifestyle and cancers, particularly prostate cancer, breast cancer, colorectal cancer and colorectal adenoma. To gain more insight into the etiology and pathways underlying carcinogenesis, she is currently conducting multi-disciplinary studies to assess whether associations between risk factors and colorectal cancers differ by molecular subtypes or genetic susceptibility. Another focus of her current research is to examine the role of early-life exposures on colorectal neoplasia. She has authored or co-authored over 185 peer reviewed publications.
Susan has been an indomitable patient advocate and tireless researcher since the moment her 17-year-old daughter Jessica Joseph was diagnosed with Colorectal Cancer (CRC) in December 2016.

Since then, Susan has devoted herself to her daughter’s care and to finding answers to the question, How Did This Happen?

Jessica died in May of 2018, 17 months after her initial diagnosis. Over the course of her illness, Jessica became a fierce advocate for early detection and treatment of CRC. Her courage in the face of her diagnosis and prognosis, were inspiring to all who knew her, and thousands more who never did.

Over the course of the last two and a half years, Susan’s mission has been to continue Jessica’s legacy through advocacy and awareness. Since Early Onset CRC may often be missed or misdiagnosed in its early stages, Susan has been working to educate parents, caregivers and young people in her community that CRC is not as the adage suggests, “an old man’s disease”. Central to her advocacy work, is helping to change these core beliefs. She has helped impress on younger populations the need to pay attention to their bodies, their lifestyle, and their habits.

But the one statement that kept pushing Susan, as a caregiver and more importantly, as a mom, was the statement from Jessica’s care team, experts from some of the leading cancer centers in the country, who collectively expressed the answer to the “WHY” question, or at least part of it.

“We KNOW it’s environmental.”

Susan has dedicated herself to looking at the environmental and epigenetic factors that may have impacted Jessica’s health, and potentially the development of her cancer. From early exposures that increase the body burden of chemicals, to lesser known factors that may be quietly increasing the risks and incidence of inflammatory diseases affecting the microbiome.

Susan spent most of her professional career in marketing and public relations as a VP of the global communications firm Hill and Knowlton, where she advised CEO’s, Fortune 500 companies and foreign governments. In the healthcare arena her clients included Bayer, SmithKline Beecham, Johnson & Johnson, DuPont Pharmaceuticals, Bristol-Myers Squibb (BMS), and Novartis Pharmaceuticals. Susan developed and executed national and international media campaigns, corporate and employee communications, community relations and product launches, including Advanced Wound Care for Johnson and Johnson. Susan also handled public affairs and communication for BMS Medical Imaging and Field Operations for Medical Affairs/Government Relations. The BMS imaging product line included Cardiolite®, the world’s leading cardiac perfusion agent, (Kit for the Preparation of Technetium Tc99m Sestamibi for Injection), Thallium-201 (Thallous Chloride Tl 201 Injection) and TechneLite® (Technetium Tc99m Generator) and Definity® (Vial for Perflutren Lipid Microsphere Injectable Suspension. One of her favorite projects was coordinating the media launch of the iconic U.S, Postal Service Breast Cancer Awareness stamp which has raised more than 87 million dollars since its inception.

As a Registered Foreign Agent, Susan has advised Botswana, Chile, China, Finland, Italy, Israel, Spain, Macedonia and Indonesia on issues relating to tourism, trade policy and foreign direct investment.

She holds a B.A. from Middlebury College in Political Science and International Affairs and a Certificat from L’Université D’Aix en Provence Aix, France.

She has authored by-lined articles published in More, Glamour, Self, Pregnancy, Southern Living, Fitness, & Psychology Today.

She lives in Richmond, Virginia with her two sons, Jordan (22) and Jonah (17).

Dr. Ronit Yarden is the Director of Medical Affairs at The Colorectal Cancer Alliance. She is responsible for the research funding program Chris4Life and the Alliance intramural population health research.

Dr. Yarden received Her PhD in Molecular Biology and Biochemistry from Georgetown University after a Master in Science in Immunology and an undergraduate degree in Biology from Tel Aviv University in Israel. She recently completed a Master in Health System Administration from Georgetown University.

She obtained her post-doctoral training in genomics at The National Human Genome Research Institute at NIH. She subsequently moved to Israel to establish her own lab and became an Independent investigator at the Sheba Medical Center that is affiliated with Tel Aviv University. After 7 years in Israel, Dr. Yarden moved back to Georgetown University and was a professor at the School of Nursing and Health Studies and a Full Member of the Lombardi Comprehensive Cancer Center.

Dr. Yarden’s research focused on hereditary breast cancer and understanding how cancer cells respond to environmental and metabolic challenges that affect DNA stability with the ultimate goal of developing strategies for prevention and improved cancer treatments as well
as molecular epidemiology of breast cancer. She is also an innovator in development of small molecules that inhibit DNA repair.

Dr. Yarden’s basic and translational research was funded by multiple foundations and government agencies. She has authored multiple publications in prestigious peer-reviewed journals such as Nature Genetics, Proceedings of National Academy of Science, USA and others. She serves as a review editor in the journal Frontiers Cancer Endocrinology.

MATTHEW YURGELUN, MD
Dr. Matthew Yurgelun is a gastrointestinal medical oncologist at the Dana-Farber Cancer Institute affiliated with both the Gastrointestinal Cancer Center and the Cancer Genetics and Prevention Program. He has a longstanding special interest in studying the diagnosis, phenotypes, and management of patients with Lynch syndrome and other hereditary gastrointestinal cancer syndromes. His current research includes studying the benefits and limitations of using widespread multi-gene panel testing – rather than criteria-based targeted genetic testing – in the evaluation of patients at risk for hereditary cancer syndromes.
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 PhD1; Robin Dubin2; Dave Dubin2
1Albany College of Pharmacy and Health Sciences, Albany, NY; 2AliveAndKickn, Haworth, NJ
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% reporting having had a diagnosis of colorectal cancer with an average age of 42 at diagnosis; 23.2% of female respondents reporting 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 reporting 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 (EAOCRC): Findings from an international cross-sectional online survey
Mary A. De Vera, PhD1; Khalid Saad El Din, BSc (Honours)1; Halle Dau, MPH1; Helen McTaggart Cowan, PhD2,3; Sharlene Gill, MD, MPH, MBA2,4, Jonathan Loere, MD, MS2,4
1University of British Columbia Faculty of Pharmaceutical Sciences, Vancouver, Canada; 2BC Cancer, Vancouver, Canada; 3Simon Fraser University Faculty of Health Sciences; 4University 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, and reason for cancer), treatment (e.g., others’ experiences with treatment), and survivorship (e.g., reason for cancer), treatment (e.g., others’ experiences with treatment), and survivorship (e.g.,
Results: As of March 11th, 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.,

Conclusion: Findings from our online survey show 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 |
|---|---|---|---|---|
| Information needed | Information not needed | Information need has been met | Information need has not been met* |
| 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 (96.38) | 27 (3.42) | 135 (19.69) | 628 (80.31) |
| Risk for family | 784 (97.27) | 22 (2.73) | 375 (47.77) | 409 (52.17) •• |
| Research/trials | 704 (89.91) | 79 (10.09) | 161 (22.87) | 543 (77.13) |
| Specialized tests | 747 (94.36) | 43 (5.44) | 221 (29.39) | 526 (70.61) •• |

Information need among respondents currently undergoing 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 |
|---|---|---|---|
| Complementary treatments | 192 (93.66) | 13 (6.34) | 30 (15.63) | 162 (84.38) •• |
| Clinical trials | 189 (94.30) | 11 (5.50) | 30 (15.87) | 159 (84.13) |
| Chances of cancer coming back | 180 (90.45) | 19 (9.55) | 58 (32.22) | 122 (67.78) •• |
| Exercise and physical activity | 194 (96.52) | 7 (3.48) | 77 (39.69) | 117 (60.31) |
| Nutrition and diet | 201 (97.57) | 5 (2.43) | 71 (35.32) | 130 (64.68) •• |
| Bowel activity | 206 (100.00) | 0 (0.00) | 95 (47.98) | 103 (52.02) |
| Others’ experiences with treatment | 191 (94.55) | 11 (5.45) | 59 (30.89) | 132 (69.11) •• |

Information need among respondents who have completed treatment for CRC

| 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 |
|---|---|---|---|
| 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) | 224 (58.64) •• |
| Bowel activity | 381 (97.94) | 8 (2.06) | 154 (40.42) | 227 (59.58) |
| Others’ experiences after treatment | 337 (93.61) | 23 (6.39) | 93 (27.60) | 244 (72.40) •• |

Information need among all respondents on impacts of CRC on life

| 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 |
|---|---|---|---|
| Sexual activity | 669 (87.45) | 96 (12.55) | 235 (35.13) | 434 (64.87) •• |
| Fertility | 553 (97.19) | 35 (2.81) | 167 (29.31) | 342 (70.69) |
| Work | 596 (77.5) | 173 (22.5) | 254 (42.62) | 250 (57.38) |
| Parenting | 395 (53.38) | 345 (46.62) | 145 (36.71) | 250 (63.29) |
| Mental health | 714 (92.49) | 58 (7.51) | 227 (31.79) | 487 (68.21) •• |
| Bowel activity | 767 (100.00) | 0 (0.00) | 262 (35.69) | 472 (64.31) |
| Long-term side effects of treatment | 715 (96.46) | 50 (6.54) | 164 (22.94) | 551 (77.06) •• |

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

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Departments of Surgical Oncology, Gastrointestinal Medical Oncology, Clinical Cancer Prevention, Pediatrics, Health Services Research 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=235) YO-CRCs did not differ in these genes, but left-sided YO-CRCs were more frequently mutated in TPS5 (65.8 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; 1 Ronit Yarden, PhD, MHSA 2
1Manager of Never Too Young Program, 2Director 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

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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 consecutives 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, MHSA1; Kimberley Newcomer, BS, CPPN2

1Director of Medical Affairs, 2Manager 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.