

# **Family History & Early Onset Colorectal Cancer Task Group**



*Pre-Annual Meeting Task Group Informational Webinar  
2018 Updates / 2019 Planning*

October 17, 2018  
2:00 p.m. EST



## **Agenda**

- Welcome & Introductions
- Task Group Charge
- Accomplishments
- Current projects
- Possible topics for annual meeting task group session
- Q&A



## Task Group Co-Chairs

- Paul Schroy, MD, MPH  
*Boston University School of Medicine*  
*Director of Clinical Research, GI Section*
  
- Dennis Ahnen, MD  
*University of Colorado School of Medicine,*  
*Director of Genetics Clinic Gastroenterology of the Rockies*
  
- Steve Itzkowitz, MD  
*Icahn School of Medicine Mount Sinai*  
*Professor of Medicine and Oncological Sciences Director, GI Fellowship Program*



## ***Charge:***

- The charge of this task group is to identify key issues and areas of need around familial and early onset colorectal cancer for the purpose of identifying opportunities for the Roundtable to be a catalyst for change.



## Task Group Themes

- Help clinicians systematize the identification of patients at familial risk and recommendation of early diagnostic evaluation of those presenting with symptoms of CRC at any age.
- Improve EHRs to help facilitate needed screening and/or counseling recommendations for patients with a family history.
- Increase clinician-patient and intra-family communication about familial/heritable risk.
- Improve “on time” screening for the 50 to 55 population, according to recommended guidelines.
- Address the increase in CRC in young adults through strategic interactions with key stakeholders and thought leaders.



## FY18 Projects (December 2017)

- Help finalize, disseminate and validate the Risk Assessment and Screening Toolkit
- Write Summary of EAO CRC Symposium
- Organize FH Symposium at EAO CRC (April 2018)
- Identify strategies for optimizing communication about advanced adenomas – Develop Working Group
- Work with NCCRT to change narrative regarding on-time screening
- Complete the darn Delphi Survey, analyze the data, share results with the NCCRT and ACS CAN and submit for publication
- Ask NCCRT to convene and facilitate a meeting of leaders of Primary Care Organizations to discuss EAO CRC.
- Again participate in National Family Health History Day via Twitter (Thanksgiving)



## FY18 Accomplishments

- Completed and disseminated the Risk Assessment and Toolkit and corresponding webinar.
- NCCRT EAO CRC Summit Follow-up (hosted December 7, 2017)
  - Summary report released at 2018 Annual Meeting
  - Manuscript draft near completion and to be reported on at 2018 Annual Meeting
- Developed Advanced Adenomas (AA) Working Group to identify strategies for optimizing communication about AA
  - Met regularly; set work group action plan; early progress and successes
- Participated in Colon Cancer Challenge Foundation 2018 EAO CRC Summit
  - Hosted a pre-conference session and discussion
- Lifted ACS CAN EHR Recommendations to NCCRT Steering Committee for endorsement
- Looking forward to promoting National Family Health History Day



# Risk Assessment & Screening Toolkit

## Toolkit Goal

To bridge the existing knowledge gap and to provide a step-by-step, detailed tool for practices that are dedicated to improving their processes in the collection of family history and acting on that information according to recommended guidelines.

## Objectives

1. Conduct a multi-faceted needs assessment to:

- discover best practices in CRC screening for at-risk populations
- identify key drivers influencing successful CRC screening programs

2. Develop a comprehensive toolkit to recommend steps on creating a system that helps primary care practices:

- Identify patients at increased/high risk based on personal and family history
- Apply screening guidelines based on risk
- Refer high risk patients to genetics
- Recognize and rapidly diagnose patients presenting with a CRC “alarm” sign or symptom

## *RISK ASSESSMENT AND SCREENING TOOLKIT*

— TO DETECT FAMILIAL, HEREDITARY, AND EARLY  
ONSET COLORECTAL CANCER —



# Risk Assessment & Screening Toolkit

- The Risk Assessment and Screening Toolkit includes:
  - ▣ Full Guide
  - ▣ Quick Start Guide
  - ▣ Sample Risk Assessment & Screening Algorithm
  - ▣ Interactive Table of Contents for Individual Section Download
  - ▣ Web friendly version available at Jackson Lab website
  - ▣ Corresponding Webinar
  
- **Promising Start to Dissemination**
  - ▣ Nearly 500 downloads
  - ▣ More than 1,100 visits to resource page and webinar page
  - ▣ 600+ visits to the screening algorithm (about 400 downloads)



## RISK ASSESSMENT AND SCREENING QUICK START

— TO DETECT FAMILIAL, HEREDITARY, AND EARLY ONSET COLORECTAL CANCER —



## **Annual Meeting Workshop Details**

***Risk Assessment and Screening To Detect Familial,  
Hereditary And Early Onset Colorectal Cancer:  
Putting Knowledge Into Action***

**Thursday, November 15 3:30 PM – 5:00 PM**



# 2017 EAO CRC Strategy Session

*(December 6, 2017)*

- **What:** NCCRT convened a strategic meeting to focus on the concerning trend of young-onset colorectal cancer.
- **Participants:**
  - 30+ attendees- experts/stakeholders
  - Funding from ACS, Colon Cancer Challenge Foundation, Entertainment Industry Foundation, National Colorectal Cancer Research Alliance
- **Purpose:** To assess how the NCCRT and its member organizations could most effectively align to address the issue

## **Objectives:**

- Review the current practice and research in the field and what we think we know.
- To identify things that can/should be done now based on what we know
- To define some of what we need to know (causation, identification, course, prevention)
- Begin developing a strategic plan and hypothesize a research agenda around these issues.



# 2017 EAO CRC Strategy Session

*(December 6, 2017)*

## Follow up:

- ❑ Meeting summary released at 2018 Annual Meeting (pending formatting)
- ❑ Manuscript draft near completion and reported on at 2018 Annual Meeting
- ❑ Hosted a pre-conference session and discussion at 2018 EAO CRC Summit



DONALD AND BARBARA  
ZUCKER SCHOOL of MEDICINE  
AT HOFSTRA/NORTHWELL

### SCHEDULE

APRIL 26, 2018

SPECIAL SYMPOSIUM: TRANSFORMING FAMILY HEALTH HISTORY ASCERTAINMENT AND COLORECTAL CANCER: PREVENTIVE SERVICES IN PRIMARY CARE: AN UPDATE FROM THE NCCRT FAMILY HISTORY EARLY AGE ONSET TASK GROUP

4:00 – 4:30 PM

REGISTRATION

4:30 – 4:35 PM

Opening Remarks: Thomas K. Weber, MD, FACS, Northwell Health, Colon Cancer Foundation

4:35 – 4:45 PM

Overview and Introduction to the National Colorectal Cancer Roundtable (NCCRT) and the Family History Early Age Onset Colorectal Cancer Task Group

Dennis Ahnen, MD, AGAF, FACP, University of Colorado School of Medicine

Paul Schroy, III, MD, MPH, Boston University School of Medicine



## **Annual Meeting Session Details**

**Strategies for Addressing Early Onset CRC: An  
NCCRT Report**  
Jan Lowery, PhD

**Friday, November 16 8:35 AM – 8:55 AM**



# Advanced Adenoma Working Group

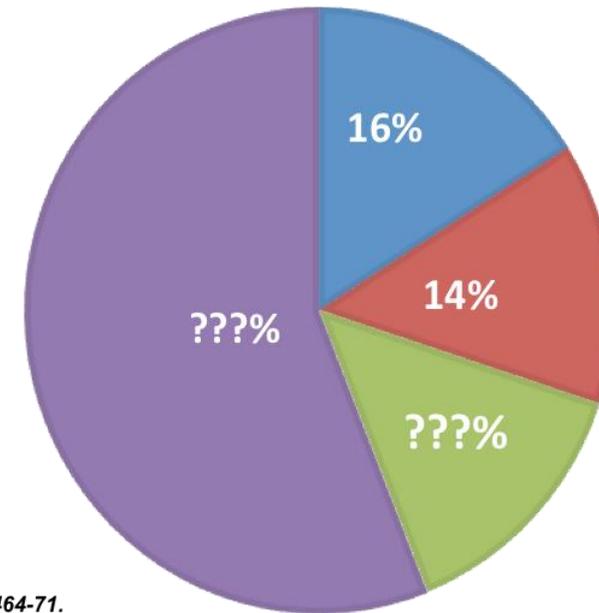
**Chairs:** Christine Molmenti, PhD, MPH, Jordan Karlitz, MD, & Jennifer Kolb, MD

**Rationale:** Finding of advanced adenoma increases CRC risk in patients and their FDRs but... only GI's know this- unique opportunity/ethical responsibility

## Initiatives & Progress:

1. Prevalence of **advanced adenomas (AAs)** among FDRs of early age onset colorectal cancer probands
  - Funding secured for feasibility study
2. Development of advanced adenoma brief
  - Draft in-progress: tools to assist GIs
  - Identifying patients with AAs
  - Keep abreast of the AA guidelines
  - Inform pts with AA patients about risks (pt and FDRs)
  - Facilitate communication of risk/recommendations for their family members

■ Hereditary ■ FDR with Colorectal Cancer ■ FDR with Advanced Adenoma ■ Sporadic



>30% of patients with EAO CRC might have been eligible for earlier screening

JAMA Onc. 2017;3(4):464-71.



# Delphi Survey

## □ Progress

- Transition from “Broad Consensus” to “Expert Consensus”
- Completed third or fourth iteration of the survey.
- Completed final? Revisions
- In field prior to annual meeting

## □ Consensus items thus far

- **Goal-** ID patients who should be referred for further risk assessment and those at higher than average risk and need more intense screening
- **Data elements-** FDRs and SDRs, age of cancer dx, all cancer types that would change screening, entered as discrete elements in searchable fields, importable from FH tool and patient portal, updated whenever new information becomes available



## Consensus Items (continued)

- **Links to Decision Making-** capacity to alert increased risk of hereditary cancer syndrome, for elevated cancer risk or need for different screening, provide links to current screening guidelines based on FH and generate best practice alerts for cancer screening for high risk pts
- **Development Process-** Elements of FH section should be guided by national standards, standardized across EHRs incorporated centrally by EHR vendors and updated by vendors as recommendations change
- **Incentives-** *Completing/Maintaining FH* section should be tied to performance measures for cancer screening. *Referral* of appropriate patients for genetic counseling/testing should be expected as part of high quality care



## FY19 Projects

- Strengthen plans for dissemination and evaluation of the Risk Assessment and Screening Toolkit in partnership with Jackson Lab
- Act on recommendations from the EAO CRC strategy meeting.
- Continue to work with ACS CAN on EHR vendor improvements on family history collection .
  - Requested endorsement of recommendations from NCCRT (pdf attached)
- Sustain momentum of work of advanced adenomas working group – addressing research gaps & importance of family communication.
- Priority focus on “on time” screening, with divergent guidelines. (Utilize take-away lessons from NCCRT Guideline Summit)
- Complete the Delphi Survey.



# FY20 Project Plan

## Early thoughts ...

- ▣ Ongoing support for Risk Assessment and Screening Toolkit
  - Validation / Field Testing
  - Modernizing – Instructional Design
  - Corresponding one pagers?
  - Marketing Plan
- ▣ Stakeholder Engagement
  - Convening Primary Care Organizations (or engage PCP leadership societies)
  - Implementation science experts, Oncologists
- ▣ NCCRT summit re: New ACS guideline
  - Should our TG take lead in monitoring, developing resources for early age screening option



## FY20 Project Plan

### Early thoughts cont. ... (What else?)

- ▣ Concerted Educational Campaign earliest possible diagnosis for providers and public
- ▣ Engage appropriate stakeholders to develop a strategic plan for graduate and post graduate education about the importance of family history, risk assessment and existing guidelines



To be continued on  
Wednesday, November 14, 2018  
5:00 to 6:30 p.m.

Sheraton Inner Harbor  
Baltimore, MD  
*See you there!*



# Questions & Suggestions?