



# N2Y NEVER TOO YOUNG FOR COLORECTAL CANCER

**PROGRAM UPDATE**

MAY 2022

# INTRODUCTION

## Mission & Vision

The mission of Colorectal Cancer Canada's (CCC) Never Too Young Program (N2Y) is to raise awareness and enhance patient support around early age onset colorectal cancer (EAO CRC) in Canada in order to decrease the number of young people diagnosed with advanced stage disease. N2Y is committed to spreading the message that young adults need to be screened earlier than age 50 if they have a family history of the disease or an associated hereditary syndrome.

N2Y envisions a future where no young person in Canada dies of colorectal cancer due to a lack of awareness, misinformation, testing delays or stigma. Young Canadians and healthcare providers will have the appropriate information to continue the fight against colorectal cancer with confidence and resilience.

## Program Goals

Increase awareness about EAO CRC in Canada, especially among those under 50

Improve patient support services for those with early onset colorectal cancer

Sensitize healthcare community on EAO CRC and patient realities

## Program Values

The N2Y Program is dedicated to:

- Increasing Canadians' awareness and understanding of EAO CRC
- Health promotion and cancer prevention
- Patient-centricity and empowerment in education, support, and advocacy efforts
- Multidisciplinary approaches to address unique needs of young patients
- Utilizing evidence-based research and best practices
- Advocating for appropriate and effective screening practices to increase early detection of CRC at any age
- National and international partnerships for innovation and sustainability

# VISION 2023

From 2019 - 2023, CCC's N2Y Program will raise awareness regarding EAO CRC and encourage appropriate screening practices, educate, empower and support patients, health care professionals and other care providers, create platforms for patient voices to be heard, advocate for clinical best practices, and foster communities of support.

By 2023, N2Y sets out to achieve:



**At least three additional EAO CRC clinics/programs in major Canadian cancer treatment centres based on best practices (e.g. Sunnybrook Young Adult Colorectal Cancer Clinic)**



**EAO CRC awareness campaign to educate Canadians under age 50 on risk, signs and symptoms**



**A best practices model for EAO CRC centres of excellence**



**EAO CRC information, patient stories and interactive content on a dedicated web page on the CCC website**



**N2Y toolkits in all major Canadian cancer treatment centers and CCC-affiliated support groups**



**EAO CRC social media content shared on CCC platforms 3x/month to sensitize online community**



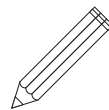
**Quarterly EAO CRC webinars to educate healthcare community and patients on EAO CRC and emerging CRC research and innovations**



**N2Y patient ambassadors for CCC events, blogging, supporting fellow N2Y patients, and representing young CRC patients**



**Web-based support platform for patients to share concerns, ask questions and obtain mutual support**



**N2Y survey of EAO CRC patients and caregivers regarding symptoms, diagnosis, treatments, and experiences**

## VISION 2023



**Young patient or loved one  
contacts CCC**

Patient connected to CCC support team to  
address queries and concerns

Educational materials provided  
upon request

Patient linked to specialized clinical or  
support services based on specific needs

Patient supported throughout  
cancer journey

Patient engaged for various  
opportunities to share their story,  
participate in studies, take on an  
ambassador role, etc.

**Patient is engaged and  
empowered to contribute  
to reducing overall  
colorectal cancer burden  
to individuals and society**

## PROGRAM DIRECTIONS

- 1 Develop program plan that is aligned with CCC's mission & vision & track its impact
- 2 Establish expert advisory panel of representatives across Canada
- 3 Integrate EAO CRC information across CCC activities & platforms
- 4 Develop and disseminate EAO CRC awareness materials & tools
- 5 Contribute to understanding EAO CRC in Canada
- 6 Enhance support services available for EAO CRC patients & loved ones
- 7 Increase profile of EAO CRC in health policy & practice

## PROGRAM PROGRESS



### Develop program plan that is aligned with CCC's mission & vision & track its impact

- Hired Program Manager (March, 2020)
- Conducted an external assessment to understand and identify best practices of other colorectal cancer organizations regarding EAO CRC nationally and internationally so that CCC efforts may be collaborative and innovative
- Prioritized N2Y program within CCC strategic plan and integrated N2Y messaging across other CCC initiatives
- Identified key opinion leaders (KOLs) across the country
- Defined program brand and determined program messaging
- Ongoing collection of preliminary KPIs



### Establish expert advisory panel of representatives across Canada

- Established core panel; ongoing efforts to expand and diversify



### Integrate EAO CRC information across CCC activities & platforms

- Increased communication about EAO CRC on social media
  - Featured during Colorectal Cancer Awareness Month and Young Survivors Week for 2018, 2019, and 2020.
- Enhanced EAO CRC information included in CCC website revamp, launched May, 2020.
- Met with web developers to plan N2Y web pages with unique features and content
- Sensitized hundreds of CCC event participants/guests across Canada about EAO CRC through N2Y information and patient speakers
- EAO CRC incorporated into CCC messaging about screening
  - Developed CRC Screening Roadmap infographic
  - EAO CRC materials included on The Giant Colon Tour, CCC table tops, Foods That Fight Cancer workshops
- Dedicated N2Y web page (May, 2021)

I WAS 34





#### Develop & disseminate EAO CRC awareness materials & tools

- Collection and curation of peer-reviewed research and gray literature to inform materials and communications
  - Discussion with and support of Dr. Jon Loree's (BC Cancer) research with MD Anderson
  - Attended Colon Cancer Foundation Annual EAO CRC Summit (May 2 - 3, 2019)
- Ongoing review of N2Y Informational Booklet
- Developed EAO CRC awareness poster
  - Distributed at Giant Colon Tours, CCC table tops, and through the Colorectal Cancer Student Association at York University
- Developed a downloadable family health history chart tool
- Ongoing investigation of platforms for leveraging CCC Clinical Research Updates online
- Met with colorectal cancer support group facilitator at Wellspring/Cross Cancer Institute (Edmonton) to discuss N2Y education materials for support groups
- Disseminated CAG (Canadian Association of Gastroenterology) screening guideline updates
- Attended EAO CRC awareness event and engaged organizers for future partnership opportunities
- N2Y Patient Toolkit developed (May, 2021)



#### Contribute to understanding EAO CRC in Canada

- EAO CRC is developed and expert review process is ongoing (expected launch August 2020).
- Ongoing compilation of patient coordinates for focus groups/consultation regarding education and support materials
- Conducted EAO CRC National Survey (fall, 2020) and generated and disseminated an accompanying report (January, 2021)



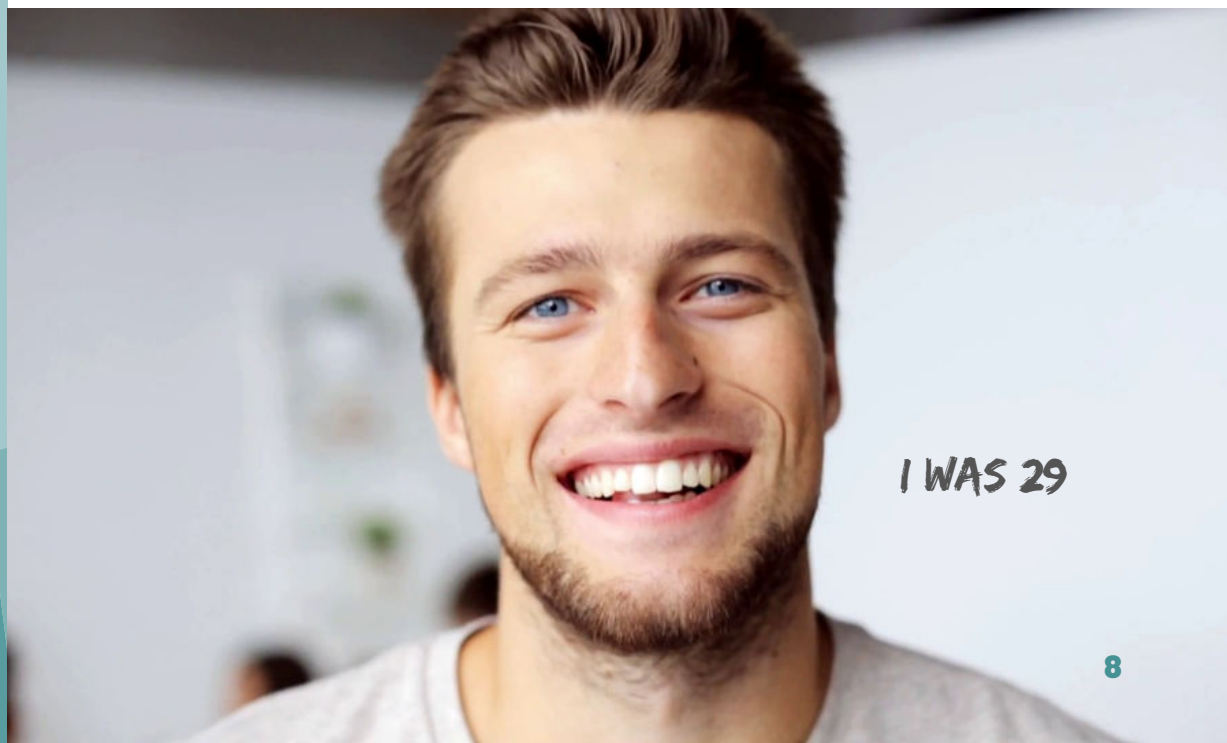
## Enhance support services available for EAO CRC patients & loved ones

- Ongoing EAO CRC patient support through CCC info-line
- Ongoing identification of centres of excellence regarding EAO CRC for advocacy and scale-up
  - Sunnybrook Young Adult Colorectal Cancer Clinic
  - Dana-Farber/Brigham Young-Onset Colorectal Cancer Centre
- Launch of EAO CRC national support group (February, 2021) bby CCC's Patient Support team



## Increase the profile of EAO CRC in health policy & practice

- Advocated for further research regarding screening at younger ages following the American Cancer Society's recommendation to lower the age of screening to 45 in the United States
- Represented EAO CRC issues at National Colorectal Cancer Screening Network meetings (NCCSN)



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## KEY PERFORMANCE INDICATORS

**10**



engaged young survivors have spoken about their journeys at our events

**1,900+**



people sensitized about EAO CRC at CCC Push for Your Tush events

**3**

per month



regular social media posts about EAO CRC

**10**



testimonials of young adults shared through social media

**20**



events/displays included N2Y materials

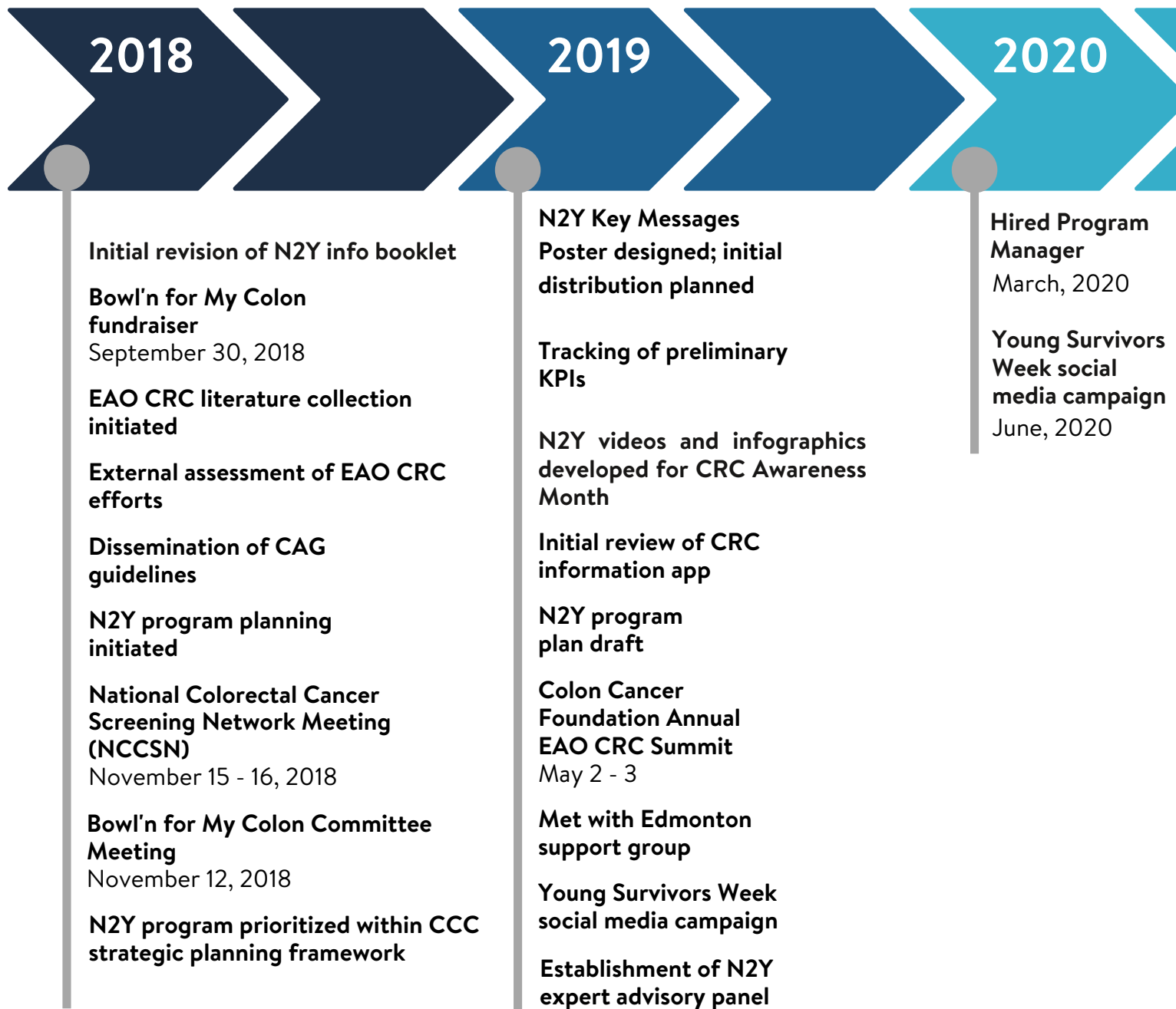
**6**



infographics/tools developed

## N2Y MILESTONES

In addition to providing individual patient support through the CCC info-line and continued communication regarding EAO CRC online and at public engagements, the N2Y Program has accomplished the following milestones:



2020

**Create N2Y survey questions for a Canadian context**

July/August, 2020

**Review questions with Expert Advisory Committee & edit draft**

August, 2020

**Launch GoogleForms survey and promote on all CCC channels**

September - October, 2020

**N2Y Survey data analysis and report creation**

December, 2020

**N2Y Survey report review by Expert Advisory Committee**

December, 2020

2021

**N2Y Survey disseminated widely to partners, stakeholders and via CCC channels**

January - February, 2021

**Developed N2Y Patient Toolkit**

March - April, 2021

2022

## NEXT STEPS

- Continue to expand N2Y content on dedicated webpage
- Attend and present at EAO CRC conferences to share N2Y survey results
- Review N2Y Patient Toolkit with Expert Advisory Committee
- Collaborate with Dr. Michael Kolber on Family Physician Screening Toolkit
- Begin the creation of the EAO CRC best-practices model

# MATERIALS & TOOLS

## HAVE YOU BEEN DIAGNOSED WITH COLORECTAL CANCER UNDER THE AGE OF 50?

SHARED EXPERIENCES OF DIAGNOSIS AND TREATMENT OF YOUNG-ONSET COLORECTAL CANCER IN AN ON-LINE COMMUNITY (STORY)

Participants are eligible to participate if they:

- Are 18 years or older
- Can communicate in English
- Have received a diagnosis of yCRC (diagnosed before the age of 50 years)
- OR have cared or/caring for someone with yCRC.

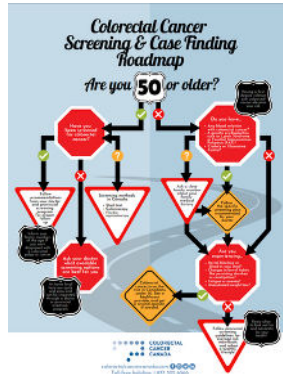
Your participating will involve:

- Share in writing your colorectal cancer story (approx. 30 minutes)
- Participants can enter to win one of two \$50 CAD giftcards

If interested in participating, please follow this link: <https://bit.ly/2V459Gj>

For more information, please contact the study coordinator at [louis.crouse@alumni.ubc.ca](mailto:louis.crouse@alumni.ubc.ca) or (504) 822-5497

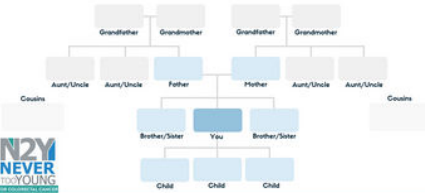
Engagement will be paid by social media through reporting, commenting, liking or following you personally directly you with the study. This is a UBC study undertaken by Dr. Mary De Vore



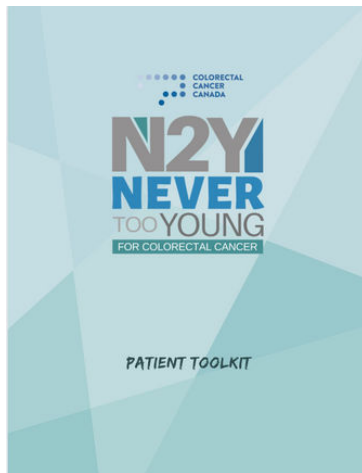
## KNOWING YOUR FAMILY HISTORY CAN SAVE YOU OR A LOVED ONE

Family history matters when it comes to your health. This is a tool to help you start a conversation with your family members about your family history of colorectal cancer. Only a health professional can counsel you about your risk for developing colorectal cancer.

1. For each blood relative below, note down any of the following health conditions and age of diagnosis: colorectal cancer, colon or rectal polyps, stomach or bowel problems, other cancers (endometrial, kidney, stomach, small intestine, liver), Crohn's or Ulcerative Colitis
2. Make copies of this chart for your family members and update regularly
3. Share this information with your healthcare professional



TOLL-FREE HELPLINE 1 877 502 6566 | COLRECTALCANCERCANADA.COM



**N2Y NEVER TOO YOUNG PATIENT & CAREGIVER SURVEY RESULTS**

Early age onset colorectal cancer poses unique barriers for Canadian patients. Here are some eye-opening statistics everyone needs to know.

- 54.2%** REPORTED TO LACK IN THE KNOWLEDGE ABOUT COLORECTAL CANCER
- LONGER THAN AVERAGE PATH TO DIAGNOSIS**
- 18% HAD NO FAMILY HISTORY**
- SURVIVORSHIP & OUTCOMES**
- IT'S TIME TO TAKE ACTION**
- READ THE FULL SURVEY RESULTS REPORT HERE**



## COLORECTAL CANCER IS NOT AN OLD PERSON'S DISEASE

Most colorectal cancer are being found among young and middle-aged individuals, who are more likely to die in a young age (50 and over). Young people are often diagnosed at a later stage because they aren't getting screened and doctors don't routinely screen cancer to develop in a young age.

## EARLY-AGE ONSET COLORECTAL CANCER

The Canadian Cancer Society recommends that those at average risk of colorectal cancer start participating in regular stool tests at age 50, while all people aged 75 and older be in constant communication with their doctor about screening. While these screening guidelines have worked to decrease the rate of colorectal cancer in people over 50, there has been an increased affliction rate in young adults. Young adults, especially those with a family



**Colorectal cancer is NOT an old person's disease**  
RATES OF COLORECTAL CANCER ARE INCREASING AMONG YOUNG & MIDDLE-AGED CANADIANS

**N2Y NEVER TOO YOUNG FOR COLORECTAL CANCER**

1. KNOW THE SIGNS & SYMPTOMS
2. KNOW YOUR RISK
3. EARLY DETECTION CAN SAVE YOUR LIFE

**N2Y NEVER TOO YOUNG FOR COLORECTAL CANCER**  
PATIENT & CAREGIVER SURVEY REPORT

PATIENT & CAREGIVER EXPERIENCES WITH EARLY-AGE ONSET COLORECTAL CANCER IN CANADA

JANUARY 2021

## PROPHETICO

- Symptoms: 6 Articles
- Diagnosis: 47 Articles
- Treatment: 30 Articles
- After Treatment: 7 Articles
- Prevention: 32 Articles
- Clinical Trials: 2 Articles
- Drug Info: 4 Articles
- Miscellaneous: 45 Articles

# EXPERT ADVISORY PANEL



**Darren Brenner, PhD**  
Cancer Epidemiologist  
University of Calgary



**Melyssa Aronson, MS, (C)CGC**  
Senior Genetic Counsellor  
Sanai Health System



**Prithwish De, MHSc, PhD**  
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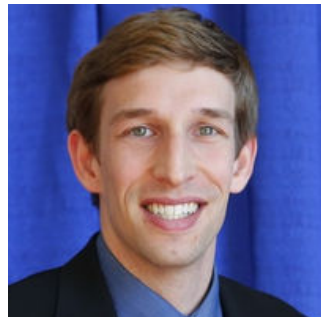
**Aneta Fishman, M.Ed**  
Survivor, N2Y  
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**Cathy Eng, MD**  
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# N2Y NEVER TOO YOUNG FOR COLORECTAL CANCER

#NEVERTOOYOUNG #N2Y



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Colorectal Cancer Canada (CCC) is the national Canadian not-for-profit corporation dedicated to colorectal cancer (CRC) awareness and education, support for patients and their caregivers, and advocacy on their behalf. CCC is comprised of dedicated volunteers, members, management and is governed by a national Board of Directors. A Medical Advisory Board, made up of top healthcare professionals in the field of colorectal cancer, provides counsel to CCC to ensure members are kept abreast of the latest medical advances in the diagnosis and treatment of the disease.

**Charitable Registration Number 86657 2423 RR0001**

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