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Experience Gained from the Development and Execution of a Multidisciplinary Multi-syndrome Hereditary Colon Cancer Family Conference

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Abstract
Genetic healthcare professionals provide genetic cancer risk assessment and follow-up care for patients facing hereditary cancers. To meet the needs of those affected by hereditary colorectal cancer, City of Hope and the Hereditary Colon Cancer Foundation collaborated to develop a "Family Day" conference. We describe the development of our conference based upon the Hereditary Colon Cancer Foundation's "Family Day" program model, with refinements completed using the Participatory Action Research theoretical framework, which incorporated input from conference participants and researchers. Thirty-one participants attended the conference, representing patients with, or families, friends, and caregivers of those with, multiple colorectal cancer predisposition syndromes, including Lynch, familial adenomatous polyposis, and juvenile polyposis. Participants who completed the feedback surveys ($n = 22$) were highly satisfied with the presentation content, ranking the keynote lecture on family communication the highest of the conference events. Participants also provided feedback regarding how to improve future conferences. In conclusion, we share our experience and provide guidance for developing a successful hereditary colon cancer predisposition patient and family conference.

Keywords Patient conference · Lynch syndrome · Genetic counseling · Familial adenomatous polyposis · Patient support

Introduction

Genetic cancer risk assessment (GCRA) identifies individuals at increased cancer risk due to personal or family history of cancer and/or genetic carrier status [1]. Key components of GCRA include facilitation of genetic testing, genetic counseling, psychological support, and personalized management recommendations [1]. In the USA, most GCRA consultations are completed in one or two appointments [2]. Therefore, there is a lack of opportunities to provide (1) longitudinal psychosocial assessment, (2) up-to-date information regarding personalized medical management, (3) information regarding advances in research, and (4) family resources to promote cascade testing of at-risk relatives.

Colorectal cancer (CRC) remains the second leading cause of cancer death in the USA, with approximately 140,250 new cases and 50,630 deaths each year [3]. Although the majority of cases are presumed sporadic, 5% are estimated to be due to a genetic predisposition that is usually inherited [4]. Historically, there has been a lack of support groups for patients facing hereditary colon cancer (HCC) [5, 6]. Most individuals with cancer predisposition syndromes are able to cope and adapt to living with their condition over time [7–9]. However, a portion of these individuals demonstrates ongoing anxiety and distress related to their positive genetic test results [5, 10, 11]. In addition, studies have shown that family communication after a positive genetic test result is a source of stress and can be challenging for the proband [12–14].

Ilana Solomon and Christina Rybak contributed equally to this work.

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The literature on patient conferences for HCC predisposition is sparse. Bannon et al. reported on their experience holding a conference specific for Lynch syndrome, but participant diagnoses did not include the full spectrum of HCC (Bannon et al.). The purpose of this paper is to describe our experience in developing and providing a HCC patient and family support (Family Day) conference. We report on conference development, implementation, and outcomes. To our knowledge, this is the first report detailing a conference that addressed multiple HCC syndromes. This descriptive analysis can be used to guide the development of future conferences and further identify the needs of HCC families.

Methods

Conference Inception and Design

The Hereditary Colon Cancer Foundation (HCCF) was founded in 2012 and is a non-profit organization serving the HCC community [15]. They contributed expertise in patient outreach, curriculum development, sponsorship, and conference planning during conference inception. The HCCF's Family Day program provided a curriculum framework that included topics, content, and learning outcomes.

The conference design was further informed by the Participatory Action Research (PAR) theoretical framework, which emphasizes a collaborative approach that directly engages participants in the research process [16] and a conversion of the results into new programmatic incentives [16]. PAR is distinct from other forms of research in that it focuses on meaningful involvement of participants in the research process and the co-generation of knowledge and problem solving to enable action [17].

Following the PAR framework, the conference agenda was informed by multiple sources: (1) a 42-item investigator-developed needs assessment survey, (2) the experience of the HCC Foundation in holding "Family Days" conferences, (3) feedback from the 2009 City of Hope Hereditary Breast and Ovarian Cancer patient conference [18, 19], and (4) data collected at the time of participant registration for the conference as part of a pre-conference needs questionnaire (Fig. 1). The overarching objective of the conference was to develop an agenda that met the needs of all stakeholders and provided content that was informative and supportive for those with HCC syndromes (Fig. 1). More specifically, we attempted to provide updated information on research findings for specific syndromes and establish a forum through which patients, families, and caregivers could connect.

The conference was held on a Saturday to accommodate patient work schedules. The conference was held in a large

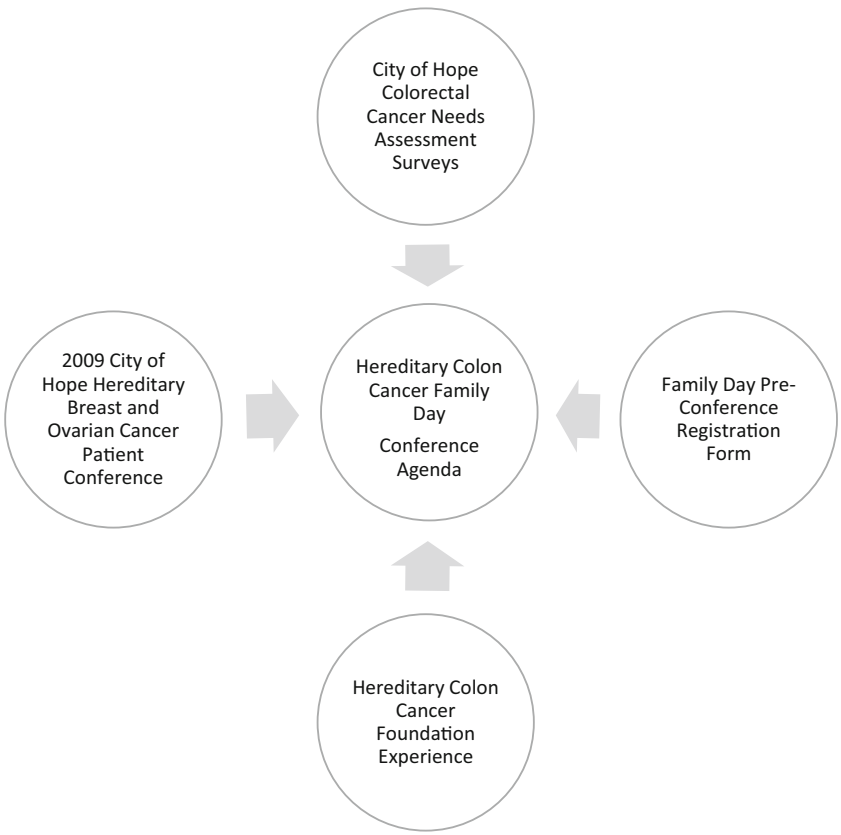

Fig. 1 Schema of the multiple sources that informed the development of the conference agenda

auditorium at the City of Hope. The finalized agenda (Table 1) included speakers from multiple disciplines including surgeons (gastrointestinal and gynecologic oncology), a medical oncologist, two geneticists, five genetic counselors, a nutritionist, and a nurse who specialized in meditation. Speakers were solicited from the City of Hope based on specialty and interest and requested to create short patient-oriented presentations. One outside speaker, a clinical psychologist who specializes in hereditary cancers, was invited to deliver a keynote presentation on family communication. Time was allotted after most sessions for questions, and participants were given index cards to write down any questions or thoughts that they were not comfortable asking. Breakfast and lunch were provided by industry sponsors. Non-profit organizations, such as the American Cancer Society, were invited to set up promotional booths to support the conference. Additionally, free time was allotted for patient networking and a guided meditation. All participants were given a survey packet with a goody bag at the start of the conference. The survey packet contained the agenda and surveys. Time was allotted at the beginning and end of the day for survey administration.

Population and Recruitment

Conference attendees were recruited using two sources. The first source was the City of Hope Cancer Screening and Prevention Program Network (CSPPN) registry, established in 1996, composed of patients seen for GCRA at the City of Hope and surrounding contracted network sites. The CSPPN patient registry database was queried for all living patients in California, Arizona, and Nevada with current addresses who carried a pathogenic or likely pathogenic mutation in *MLH1*, *MSH2*, *MSH6*, *PMS2*, *EPCAM*, *APC*, *MUTYH* (biallelic), *SMAD4*, *BMRP1A*, and *STK11*. The database was also queried for additional patients who had a clinical diagnosis of Lynch syndrome. In total, 155 CSPPN presumed living participants were mailed a "save-the-date" letter containing information about the conference and a website address for conference registration. This group included individuals (63% female) with known or suspected Lynch syndrome ($n = 125$, 80.6%), familial adenomatous polyposis ($n = 23$, 14.8%), juvenile polyposis ($n = 4$, 2.6%), or *MUTYH*-associated polyposis ($n = 3$, 1.9%); at least 61 (39.4%) individuals were known to have CRC at the time of the mailing.

The second source of recruitment included members of the HCC Foundation. Newsletters advertising the patient conference were emailed to 2210 HCC Foundation members on April 29, 2016, and 2323 members on June 30, 2016, successfully reaching 2057 and 2149 members, respectively. Additionally, the conference was promoted via social media to targeted groups on the HCC Foundation Facebook page four separate times and to the general HCC Foundation Facebook page and Twitter eight separate times.

Table 1 Conference agenda

9:30 am	Registration, exhibits, and continental breakfast			
10:30 am	Welcome			
11:00 am	Hereditary colon cancer: what is it? (*geneticist/oncologist*)			
11:45 am	Bio break			
12:00 pm	Colorectal cancer treatments (*medical oncologist*)			
12:15 pm	Family communication (*psychologist*)			
1:00 pm	Lunch, reflection time, and ask the experts exhibits			
	Concurrent sessions			
2:00 pm	Managing polyposis syndromes (*geneticist/gastrointestinal surgeon*)	Nutrition (*registered dietician*)	Teen talk (*genetic counselors*)	Introduction to meditation (*nurse practitioner*)
2:45 pm	Bio break			
2:00 pm	Managing Lynch Syndrome (*genetic counselor/gastrointestinal surgeon/gynecological oncology surgeon*)	Nutrition (*registered dietician*)	Teen talk (*genetic counselors*)	Introduction to meditation (*nurse practitioner*)
4:00 pm	Closing ceremony			
4:30 pm	Social time			
5:00 pm	Adjourn			

This table shows the presentations and timing of the Hereditary Colon Cancer Family Day at the City of Hope. Speaker backgrounds are written next to the talk title in italics

Instruments

Needs Assessment Survey

A 42-item investigator-developed needs assessment survey was analyzed for 223 individuals who underwent GCRA for HCC predisposition syndromes at the City of Hope Medical Center between 1997 and 2010. The survey included questions regarding patients' cancer-related health status, screening and management behaviors, family communication, GCRA knowledge retention, cancer distress, and barriers to care.

Conference Surveys

On the day of the conference, all participants over the age of 18 were eligible and invited to complete the conference survey.

All conference materials and surveys were approved by the City of Hope Internal Review Board (IRB). Two separate surveys were provided: (1) to request conference feedback and (2) to administer research questions designed by the City of Hope conference organizers and the HCC Foundation. The research questions were organized into three distinct sections. Section 1, which participants were asked to complete prior to the first presentation, consisted of 11 questions regarding baseline knowledge about colorectal cancer. Section 2 consisted of 7 demographic questions and 18 questions focused on the genetic testing experience and family communication. Section 3 consisted of 5 Likert scale questions soliciting feedback on the general conference experience, as well as each individual presentation. Conference feedback, section 2, and section 3 were all administered at the end of the conference.

In addition to the research survey, a voluntary reflection time activity took place during the midday break. Reflection questions were designed by the clinical psychologist and administered as a therapeutic activity. Large sheets of white butcher paper with the reflection questions were hung on the wall, and participants were invited to write their responses during the break and throughout the day.

Findings/Results

City of Hope Population Needs Assessment

Review of the 42-item needs assessment survey data showed a 75% response rate, with 144 surveys completed within an average of 3.5 years post-GCRA for HCC syndromes. Most respondents were female (65%), affected with cancer (81%) and/or affected with colorectal cancer (72%). The majority of respondents (61%) had pursued genetic testing. Of these, 42% had a pathogenic finding in a HCC predisposition syndrome gene, most commonly in a Lynch syndrome gene. A significant subset (23%) of patients indicated that thoughts of cancer interfered with daily life/activities at least once per week, suggesting a need for ongoing psychosocial support and resources.

Qualitative analysis of all responses ($n = 59$) to open-ended questions assessing the helpfulness of GCRA provided additional useful insight for conference agenda development. Respondents expressed interest in learning about new developments in genetic testing, cancer screening, treatment, and preventive strategies. Carriers of pathogenic variants described difficulty finding providers with sufficient knowledge about managing hereditary predisposition to colon cancer and revealed that they felt a burden to educate their local physician regarding their predisposition. A desire was stated for genetics visits beyond the results disclosure to clarify implications for family and medical management. The majority of patients ($n = 49$, 83%) reported a positive influence of GCRA on cancer genetics knowledge and family communication.

Pre-conference Survey

Fifty-four participants pre-registered for the conference. Fifteen of 54 (28%) pre-conference questionnaire respondents expressed interest in learning about new developments in genetic testing, cancer screening, treatment, and preventive strategies. Thirteen of 54 (24%) provided specific feedback on the pre-conference questionnaire regarding topics they would like to have addressed during the conference. These topics spanned several domains and included requests for updated cancer risk numbers, ways to mitigate risk, a review of inheritance, and information on advances in cancer surveillance, treatment options, and clinical trials. Two participants specifically indicated a wish to connect with other HCC families.

Conference Participant Demographics

Of the 31 (18.8%) participants who attended the conference, 3 participants did not pre-register. Participants represented patients, friends, family members, and caregivers affected by Lynch syndrome, juvenile polyposis syndrome, and familial adenomatous polyposis (FAP; see Table 2). Participants were mostly unaffected female adults ($n = 12$, 54.5%). Two children (ages 7 and 17) represented 6% of participants (Table 2).

Conference Survey Results (Feedback, Research Questions)

Twenty-two (76%) of 29 eligible participants completed conference surveys (Table 2). Eighteen participants answered all of the questions in the conference evaluation survey. Presentations were rated highly for overall quality and content, with "excellent" being the most frequently chosen rating for each talk and with none of the presentations being rated as "poor."

Table 2 Demographic and clinical characteristics of conference attendees who completed the participant survey

	N	%/range of respondents
All conference attendees	31	
Participants eligible to complete survey	29	93.5
Participants that completed the feedback survey	22	75.9
Age	46	19–68
Gender		
Female	17	77.3
Male	5	22.7
Race		
White	15	68.2
Black or African American	1	4.5
Asian	1	4.5
Other/ no response	5	22.7
Ethnicity		
Hispanic	5	22.7
Non-Hispanic	16	72.7
No response	1	4.5
Highest education level		
High School	5	22.7
Trade/technical school	4	18.2
Professional degree	0	0
College degree	11	50
Postgraduate degree	2	9.1
Hereditary colorectal cancer syndrome affecting you/someone in your life		
FAP/Gardner's syndrome	10	45.5
Attenuated FAP	2	9.1
Juvenile polyposis syndrome	1	4.5
Lynch syndrome	6	27.3
Unknown	1	4.5
HCC does not run in my family	2	9.1
Participant cancer history		
Personal history of 1 or more cancers	5	22.7
Colon	2	9.1
Colon and thyroid	1	4.5
Colon and gastric	1	4.5
Thyroid	1	4.5

Table 3 Results of conference Likert scale evaluations

Question		*N* (%)
Today's conference met my expectations	Strongly agree	15 (75)
	Agree	5 (25)
	Disagree	0
	Strongly disagree	0
	Unsure	0
	No response	2 (9.1)
The topics covered issues that I am interested in	Strongly agree	14 (73.7)
	Agree	5 (26.3)
	Disagree	0
	Strongly disagree	0
	Unsure	0
	No response	3 (13.6)
I will be able to use information I learned today in the future	Strongly agree	16 (80)
	Agree	4 (20)
	Disagree	0
	Strongly disagree	0
	Unsure	0
	No response	2 (9.1)
I will be able to use resources I gained today	Strongly agree	15 (75)
	Agree	5 (25)
	Disagree	0
	Strongly disagree	0
	Unsure	0
	No response	2 (9.1)
I would like to attend a conference like this again	Strongly agree	15 (75)
	Agree	4 (20)
	Disagree	0
	Strongly disagree	0
	Unsure	1 (5.0)
	No response	2 (9.1)

The most highly rated presentation for both overall quality and content was the keynote on family communication.

For the Likert scale question evaluating how the objectives of each talk were met, more than 70% of participants chose "strongly agree," and none of the participants chose the categories of "disagree" or "strongly disagree" (Table 3). Participants were also encouraged to share any open-ended responses or feedback (Tables 4 and 5). Results from the reflection time questions are summarized in Table 6. These responses highlighted the benefit of finding providers that are familiar with HCC and the contributions of family communication, engagement with healthcare providers, information-seeking, and positive attitude to adjustment to living with HCC.

Discussion

The Division of Clinical Cancer Genomics at the City of Hope and the HCC Foundation successfully collaborated to create a "Family Day" conference to meet the needs of patients, as well as their families, friends, and caregivers, who are facing HCC. Using the PAR methodology, we integrated data from multiple sources to generate a conference to meet the needs of (a) the HCC population as a whole and (b) the registrants, based on their specific questions during registration. Although there are reports on other patient conferences [18–20], to our knowledge,

Table 4 Event feedback summary table

Topic	Overall quality		Content		Positive feedback	Constructive feedback and suggestions
Hereditary colon cancer: what is it?	Excellent Good	17, 94.4% 1, 5.6%	Excellent Good	17, 94.4% 1, 5.6%	"Excellent engaged speaker" "Explanations were on a good accessible level and easy to understand" "Thank you for your passion and expertise! You rock!" "Very informative and easy to talk to"	
Colorectal cancer treatments	Excellent Good Fair	15, 83.3% 2, 11.1% 1, 5,6%	Excellent Good Fair	15, 83.3% 2, 11.1% 1, 5,6%	"Good presentation"	"Speaker spoke too fast" "Speaker kept it technical and went very fast"
Family communication	Excellent	19, 100%	Excellent	19, 100%	"Great presentation" "Speaker was very personable" "Provided a perspective that I did not have before" "Thank you for your discussion and enlightening me to some issues that our family has experienced!"	
Managing polyposis syndromes	Excellent Good Fair	14, 87.5% 1, 6.3% 1, 6.3%	Excellent Good Fair	14, 87.5% 1, 6.3% 1, 6.3%		"Gave good coverage, might have been good if they checked with each other on what they covered"
Nutrition	Excellent Good Fair	10, 58.8% 6, 35.3% 1, 5.9%	Excellent Good Fair	12, 70.6% 5, 29.4% –	"Great Presentation but not what I was looking for"	"Focused on ostomy portion of nutrition, would have liked a little more on J-pouch" "Didn't cover J-pouch as much as ostomy"
Managing Lynch syndrome	Excellent Good	7, 87.5% 1, 12.5%	Excellent Good	7, 87.5% 1, 12.5%		

Table 5 Overall commentary summary

Overall comments	Suggestions	Topics participants would like to see in the future
"Thank you- vendors were wonderful. Thank you for the food and lovely hospitality." "I no longer feel alone!" "Super excited to have attended today. Very informative and great speakers. Loved to meet other patients with HCC ad hear their stories." "Great job!" "I was very happy with everything, well planned and very informative"	"More time for sessions, limited groups and more Q & A options" "Better microphones" "Bigger mics, talk louder" "Include a handout explaining the meanings of the different bead/necklace colors (great idea!)" "Perhaps there could be a newsletter (annual or quarterly) attached to this conference?" "Encourage attendees to meet each other and share stories" "I would have liked if meeting people could have been facilitated but I know that takes time."	"Nutrition: that we need to do NOW to stop cancer or slow it down" "post surgery nutrition- tailored to individuals" "Future clinical trials and current trials" "Lynch" "Dealing with insurance" "Connecting with other survivors therapy" "Supplements that help replace minerals and vitamins lost due to lack of absorption" "Exercise (yoga) for healthy lifestyle without a colon" "Types of surgeries in detail- I had a port surgery and I think its so important to minimize surgical trauma for FAP patients." "How you can convince relative to obtain genetic testing." "More pediatrics"

Table 6 Reflection time questions

Question	Response (*n*)	Responses
1. What has helped you cope with your cancer risk?	5	"My husband, helping me see that it is better to know than not."
		"Family, My Dr.'s, Positive attitude"
		"Both my sister and I have it. Knowing there is someone going through the same stuff is awesome!"
		"Family support, research, and awesome doctors"
		"Finding online support groups like j-pouch.org (and in-person) j-pouch groups at St. Josephs"
2. What about your cancer risk has been the most difficult to cope with?	3	"The fact that our (my) daughter was diagnosed at 18 months old. The fear for her future is there daily."
		"The guilt of passing it on to my daughter."
		"Knowing my mom feels guilty, but won't talk about it."
3. Reflecting on how you have dealt with your cancer risk, what are you most proud of?	3	"Not settling for easy solutions, but seeking out the best solution"
		"My positive attitude"
		"Finding first-generation diagnosis online and helping the navigate everything"
4. What message would you give to someone who just found out they have a mutation associated with hereditary colon cancer?	5	"Consider all your options and get at least a second doctor's opinion with regards to the next steps."
		"Find support that you are comfortable with"
		"Get in touch with others with your same mutation- they can help you navigate challenges. Also, check out clinical trials."
		"Find doctors you trust- don't settle, even when its more convenient"
		"If you have to have your colon removed or any surgery where you'll have a colostomy or ileostomy, just know a big stoma that sticks out might not be as "pretty" but one close to your skin can be hard to manage"
5. What have you learned about yourself through coping with your cancer risk?	2	"My FAP does not define me!"
		"I grew up knowing about my risk, educating myself to better understand my mom. Ultimately, communication can solve most of my problems"
6. How has your family changed through learning about your cancer risk?	3	"We discuss each other's health and Dr.'s appointments openly"
		"More effort into learning about FAP and living a more positive lifestyle"
		"They learned how to steam veggies :)"
7. Some families use humor to help cope with challenges. Have you or your family found humor to be helpful in coping with cancer risk? In what ways?	2	"The family that scopes together stays together!"
		"Yes! Poop is always a funny topic!"
8. What has helped you talk to family members about cancer risk?	2	"Good communication. FAP has affected many of us."
		"FAP+ its manifestations are not taboo in our family."
9. What barriers have you run into talking with family members about cancer risk? What would help you overcome these barriers?	3	"Denial. Communication with my daughter"
		"Sometimes we come across gender differences that can be awkward to navigate discussion about."
		"My cousin doesn't like me and won't talk to me. I try to support him by speaking with his mom."
10. What are your favorite resources for HCC associated mutation carriers and/or cancer survivors?	3	"Social media, my support group, the internet"
		"Mom! She's the best researcher + support!"
		"F.A.P.ulous TV"

this is the first reported multi-syndrome HCC conference. As HCC syndromes are rare overall, many institutions may not have a large enough local patient population to devote a conference to a specific syndrome and creating multiple conferences is not likely to be logistically/financially feasible. Therefore, we hope that this report will provide a useful framework for other organizations seeking to create patient-focused multi-syndrome conferences.

A major goal of the conference was to meet the needs of the attendees by providing opportunities to attend both general HCC presentations and syndrome-specific talks (Table 1). To maximize time and provide participant flexibility based on their interests, condition-specific educational presentations were held concurrently with free time for patient networking and/or guided meditation. For instance, while the participants identifying with polyposis conditions were networking or experiencing a guided meditation, participants associated with Lynch syndrome joined lectures focusing on the care and management of their condition, and vice versa. The solicited suggestions for future conferences revealed areas for improvement, for example, adding more information on j-pouches during the nutrition talks. Participants also requested more opportunities to meet each other and connect, which suggests that future conferences should incorporate more social activities that promote interaction between participants. Other suggestions for future presentation topics were exercise, insurance issues, and nutritional supplements. Overall, the presentations were well received and highly rated for content and relevance.

Limitations to this study include a small sample size, both in conference attendees and those who completed the surveys. The low number of conference participants compared to those who registered was likely influenced by a local wildfire on the day of the conference that impacted neighborhood transit.

In conclusion, the favorable ratings demonstrate that the conference was highly successful and relevant to the participants. The PAR framework allowed us to gain valuable insight to inform future conferences for this population. We hope our experience can serve useful for others holding similar conferences.

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Compliance with Ethical Standards

Conflict of Interest Shawnie Bray and Travis H. Bray are co-founders of the Hereditary Colon Cancer Foundation. Ilana Solomon, Christina Rybak, Lily Van Tongeren, Lili Kuzmich, Kathleen Blazer, Bita Nehoray, Mariana Niell-Swiller, Karen Hurley, Jeffrey N. Weitzel, and Thomas P. Slavin declare that they have no conflict of interest.

Human Studies and Informed Consent Research participants included in this work were consented through an Institutional Review Board protocol through the City of Hope. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Animal Studies No animal studies were carried out by the authors for this article.

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