

CGA-IGC Newsletter Spring Edition

Dear CGA-IGC Member,

Have you been wondering what's new with CGA-IGC over the last few months and what to expect this summer? Read on for updates from the CGA-IGC's Education, Research, DEI and Communications & Membership Committees as well as how a featured member and their organization are working hard to make a difference in the Lynch syndrome community.

Education Committee Updates

The CGA-IGC 2022 Webinar Series 4

The Education Committee has organized an exciting 2022 webinars series, including:

- Caring for our LGBTQI+ Patients, presented by Sonali Paul, MD
- State of the Art in Colorectal Cancer Prevention for Lynch Syndrome Patients, presented by Swati Patel, MD MS, in partnership with the American College of Gastroenterology (ACG)
- Challenges in Pediatric Polyposis Conditions, presented by Colleen Flahive, MD and Kami Wolfe Schneider, MS, CGC, in partnership with the North American Society of Pediatric Gastroenterology, Hepatology & Nutrition (NASPGHAN)
- Clonal Hematopoiesis in Clinical Cancer Genetics, presented by Kelly Bolton, MD, PhD

To see more information about past and future webinars, please click here.

Monthly Journal Scans with a Journal Club Podcast

The monthly journal scan created by the Education Committee is a valuable resource that will save you time and keep you current. To access the monthly journal scan, <u>click here</u>. We have added a special alerts section to let you know when major updates to society and national guidelines have been released.

You can now also access a journal club podcast featuring an interview with one of the authors of a recently published journal article that is of interest to our membership. The first podcast of the year was released on March 3, 2022 and features an interview with Dr. Bronwyn Bedrick.

- **Episode 1:** Creating Breast and Gynecologic Guidelines for Transgender Patients with BRCA Mutations, featuring **Bronwyn Bedrick, MD, MSCI,** Johns Hopkins Hospital, Department of Obstetrics & Gynecology.
- Episode 2: "EUS-based Pancreatic Cancer Surveillance in BRCA1/BRCA2/PALB2/ATM
 Carriers Without a Family History of Pancreatic Cancer", featuring Bryson Katona, M.D.,
 PhD, Director, Gastrointestinal Cancer Genetics Program & Assistant Professor of
 Medicine at the Hospital of the University of Pennsylvania; and Jessica Long, MS, CGC,
 Division of Hematology—Oncology, Department of Medicine at the University of
 Pennsylvania.
- Episode 3: Coming June 20th! Evaluation of Urinalysis-Based Screening for Urothelial Carcinoma in Patients With Lynch Syndrome Matthew F Kalady, MD, Division of Colon and Rectal Surgery, The Ohio State University Wexner Medical Center, Columbus, Ohio. & Mohammad Ali Abbass, MD, Department of Surgery, Northwestern University, Chicago, Illinois.

If you haven't already listened to them, you can access the podcast series here

Stay tuned for more webinars, podcasts, and journal scans this year!

Research Committee Updates

2022 Upcoming Clinical Practice Survey

With inspiration from the lively debate between Heather Hampel, MS and Matt Yurgelun, MD on universal germline genetic testing for colorectal cancer during the annual meeting, the 2022 CGA-IGC Clinical Practice Survey will further explore this proposal. Your participation is greatly appreciated and will help us to further define pros, cons, and barriers to universal testing. **Keep an eye out for the survey which will go live on May 31st and make sure to participate!**

2020 Clinical Practice Survey Data Published

<u>Data</u> from our 2020 Clinical Practice Survey were published earlier this year in the Journal of Genetic Counseling.

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Patterns of germline and somatic testing after universal tumor screening for Lynch syndrome: A clinical practice survey of active members of the Collaborative Group of the Americas on Inherited Gastrointestinal Cancer

Rachel Hodan¹ | Linda Rodgers-Fouche² | Sanjeevani Arora³ | Mev Dominguez-Valentin⁴ | Priyanka Kanth⁵ | Bryson W. Katona⁶ | Kathryn A. Mraz²,8 | Maegan E. Roberts² | Eduardo Vilar¹0 | Cynthia M. Soto-Azghani¹1 | Randall E Brand¹2 | Edward D. Esplin¹3 | Kimberlv Perez¹4 |
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Updates to Member Resources

It's time for our annual update of <u>patient registries</u> and <u>GI Cancer Genetics Clinics</u> which are available on the public-facing CGA-IGC website. Accurate information will help facilitate access to these resources globally. Please click the following links to add to or update your registry or clinic information:

- GI Genetics Clinics: https://www.surveymonkey.com/r/ClinicDirectoryQuestions2022
- Patient registry list: https://www.surveymonkey.com/r/Registry2022

DEI Committee Updates

Inaugural Achievements

The CGA-IGC Diversity Equity and Inclusion (DEI) Committee has achieved a great deal during its inaugural year. In collaboration with the Education Committee, health equity focused journals have been added to CGA-IGC's journal scans. Additionally, in conjunction with the Communications & Membership Committee, the DEI Committee spearheaded a DEI focused hashtag (#CGA_DEI) to highlight DEI in cancer genetics on the @CGAIGC twitter. Furthermore, we created a health equity submission category for the 2021 Annual Meeting and led a community focused DEI session alongside providers and patient advocates.

What to Expect in 2022

We look forward to the upcoming year as we plan a number of exciting programs:

- Offering a Spanish-language based webinar in collaboration with the Education Committee
- Adding an LGTBQIA+ cultural competency training resource page to the CGA-IGC website. The included resource links will provide access to robust and comprehensive training modules that clinical staff and providers can complete and use towards CME/CEU and HEI credits.
- Actively expanding our membership demographic questions to capture the diversity of the CGA-IGC membership

Additionally, the DEI Committee continues to assist with planning of the 2022 Annual Meeting in finding accomplished speakers from diverse backgrounds to create a highly informative and inclusive conference.

The DEI Committee is excited to have exceptional new members to help us accomplish these projects. *Lauren Gima, MS, CGC* is a certified and licensed cancer genetic counselor at City of Hope in Duarte, CA. Her primary research interests are in hereditary GI cancer syndromes. *Charles Muller, MD* is a gastroenterology faculty member at Northwestern Medicine and has been a CGA-IGC member since 2018 including as a member of Communications & Membership Committee. His clinical and research interests are in cancer risk assessment in diverse populations. *Amie Blanco, MS, CGC*, is a genetic counselor and director of the cancer genetic

and prevention and hereditary cancer programs at UCSF. She has spent the majority of her clinical career caring for patients at risk for hereditary GI cancers. She is also the parent of a mixed-race child on the autism spectrum and has experience in building connections to foster inclusion and anti-racism.

Communication & Membership Committee Updates

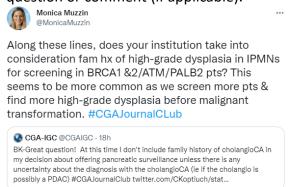
Twitter Journal Clubs

@CGAIGC Twitter Journal Clubs have been a great success thus far. Launched in 2021, the Communication & Membership Committee is excited to continue offering Twitter Journal Clubs in 2022. Most recently, **Bryson Katona**, **MD** and **Jessica Long**, **CGC** hosted a Twitter Journal Club on May 10th discussing their recent publication:

 Article: Katona BW, Long JM, Ahmad NA, et al. EUS-based Pancreatic Cancer Surveillance in BRCA1/BRCA2/PALB2/ATM Carriers Without a Family History of Pancreatic Cancer. Cancer Prev Res (Phila). 2021;14(11):1033-1040. doi:10.1158/1940-6207.CAPR-21-0161

Did you participate? We hope so. If not but you're interested in participating in the future, we've compiled a few tips regarding how to engage on Twitter during the next journal club:

- Create a Twitter account if you do not have one.
 - Pick a username that colleagues will easily be able to find if they're looking to connect with you on Twitter.
 - Add a professional headshot and brief bio to your profile.
- Follow @CGAIGC.
- Read the selected article in advance.
- Prepare questions and comments you have for the host in advance (maximum 140 characters per tweet).
- Be sure to log on to Twitter for the duration of the journal club to ask your questions and respond to others.
 - Monitor comments in real time by searching for #CGAJOURNALCLUB and selecting the "Latest" tab.
 - Include the journal club hashtag and the handle for the person/people you'd like to respond to your question or comment (if applicable).



Mentorship Program

The Communications & Mentorship Committee launched the CGA-IGC Mentorship program November 2021. Many mentor/mentee pairs have benefited from this new networking opportunity, the experience guiding a more junior colleague, and/or the direction and knowledge gleaned from their more senior colleague. Mentorship is essential for both personal success and career satisfaction. If for any reason you and your mentor or mentee have not managed to meet at least quarterly since this program launched, we encourage you to schedule your next Mentorship meeting today!

While the Mentorship Program was conceived during the pandemic and relied on mentor/mentee pairs to establish their connections virtually, it is impossible to replace the bonds that form during in-person interactions. Therefore, the Communications & Membership Committee aims to organize a formal in-person mentor/mentee meet-and-greet time during this year's Annual Meeting in Nashville, TN. Stay tuned for more details!

Colorectal Cancer and Lynch Syndrome Awareness

The CGA-IGC Communication & Membership Committee had an especially active month of March on Twitter doing our part to raise awareness about Lynch Syndrome and colorectal cancer. Some of our favorite posts were sharing the thoughts and ideas from CGA-IGC Council Members. Thank you to all CGA-IGC members for your contributions raising awareness online during March and beyond.



Membership Snapshot

Every year, we hope to grow our CGA-IGC community in both size and depth. Typically, our membership grows in spurts as people realize the benefits to membership throughout the year, such as the excellent webinars organized by the Education Committee. Our membership then rapidly grows as the Annual Meeting approaches. It will be interesting to see how membership patterns shift now that CGA-IGC offers a three-year membership option, which a great way to make sure you minimize gaps in CGA-IGC benefits. Here's a current snapshot of our community:

- Current members:
 - o 165 Allied Health Professionals
 - 76 Physicians and Scientists
 - o 22 Trainees
 - o 3 Emeritus
- @CGAIGC Twitter community: 1245 followers

CGA-IGC Member Highlight

Nominate a Member to Highlight!

Do you know a fellow CGA-IGC member who deserves recognition for the extraordinary things they do and/or for their efforts in increasing education and awareness of hereditary gastrointestinal cancer syndromes? We know that CGA-IGC is filled with such individuals and hope to highlight these members in future newsletters. To nominate a CGA member to be highlighted, please contact the Communications & Membership Committee via email.

Member Highlight: Dave Dubin with AliveAndKickn

About Dave

Dave Dubin is our first CGA-IGC member to receive this recognition. Many of you know Dave as he has had a table at our in-person Annual Meetings for many years and is very active in the hereditary GI cancer space. Dave is a 3-time Lynch syndrome cancer survivor and co-founder of AliveAndKickn (https://www.aliveandkickn.org/), a highly-informative and wonderful website and resource. Dave's mission in co-founding AliveAndKickn is to support and educate individuals as they navigate the intricacies of living with Lynch syndrome and other hereditary cancer syndromes. In addition to all of the work that Dave does through AliveAndKickn, we are thrilled to have him recently join the CGA-IGC Communications & Membership Committee.

AliveAndKickn Updates for 2021-2022

2021 saw some incredible advances in the work we do for the Lynch syndrome community including:

- The relaunch of the HEROIC Registry on the new LunaDNA platform
- The 2021 in-person <u>Living with Lynch Patient Workshop</u>
- Over 50 new episodes on <u>AliveAndKickn the Podcast</u>

Lynch Syndrome Patient Community Discussions: March-August, 2022

Each community discussion session will feature a Living with Lynch patient video followed by live discussions around each topic. Scheduled from March through August 2022, we will engage a moderator to facilitate conversation with patients, medical professionals and other experts, patient advocates, and online attendees. The Virtual Community Discussions will feature six (6) online sessions in 2022. More info and registration: https://bit.ly/3NsMTUX.

2022 Living with Lynch Participant Application

Applications are now open for the 2022 Living with Lynch Patient Workshop taking place September 15-18th, 2022 in Boston, MA which will feature presentations and Q&A by leading Lynch syndrome providers and researchers from Mass General Cancer Center. Approximately a dozen patients will be invited to participate in person. Applications are available to anyone that may be interested in participating in-person. Lynch syndrome patients can apply here: https://www.livingwithlynch.org/



We hope you have had a chance to check out the <u>LivingWithLynch.org</u> resource. The microsite features videos and photos of patients sharing how their Lynch syndrome diagnosis impacts them, their family, and their outlook on the future. AliveAndKickn and the Colon Cancer Coalition hope to help patients Living with Lynch make informed decisions about health and provide a community to relate to as they navigate future health needs.

In the News

Lastly, AliveAndKickn was featured in an article in Science Magazine about the incredible research being done on Lynch syndrome vaccines:

https://www.science.org/content/article/new-generation-cancer-preventing-vaccines-wipe-tumors-form.

As always, the Communications & Membership Committee will continue to keep you up-to-date on upcoming activities and recent accomplishments of CGA-IGC throughout 2022 with quarterly newsletters. Thank you all for continuing to bring passion, enthusiasm and brilliance to this community so we can better serve our patients and society.

Sincerely,

The CGA-IGC Communications and Membership Committee

Julie Moskowitz MS, CGC (Chair)
Charles Muller, MD (Co-Chair)
Fay Kastrinos, MD, MPH
Michelle Savage, MS, CGC
Danielle McKenna, MS, CGC
Giulia Martina Cavestro MD, PhD
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Michelle Springer, MS, CGC
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