CGA-IGC Newsletter
Quarterly release: Q1

1. *Welcome from the CGA-IGC President!*

Dear CGA-IGC Members,

In this first CGA-IGC newsletter of the year, I want to take the opportunity to welcome members old and new to what I expect will be an exciting year for the organization. The CGA was the first professional society I joined as a trainee, as well as the first professional society meeting that I ever attended, and has thus always been a special organization to me, personally. I am excited to continue working on your behalf this coming year, and wanted to give you a few updates on recent developments and exciting forthcoming events for the CGA.

I am thrilled to announce that the CGA's 24th Annual Meeting will take place Saturday, November 14 through Monday, November 16 at the Loews Vanderbilt in Nashville, TN. Our Meeting Planning Committee is hard at work putting together this year's program of events. To give you a small sneak peek, we're planning a multidisciplinary session on "FAP throughout the lifetime," which will include talks on pediatric, surgical, endoscopic, chemopreventive, and genetic counseling aspects from world-renowned experts on these various aspects of this complex syndrome. We're also planning novel efforts at the Annual Meeting to highlight research from "rising star" junior investigators who are making seminal contributions to cutting edge research on various aspects of inherited gastrointestinal cancer. Save the dates on your calendar now!

In addition, PACE Medical Communications, Inc. (headed by Tom Saenz) has been providing invaluable management services for the CGA since 2014, and I'm excited to report that we finalized a renewed 3-year contract with PACE to continue this fruitful partnership. Thanks in large part to PACE's support, we have been able to solidify the financial status of the CGA with a growing array industry sponsorship and cost-effective planning of the Annual Meeting and other efforts. This has helped us keep Membership fees down, while still expanding the array of year-round services offered to our members, including webinars, podcasts, and journal scans, not to mention our new, upgraded website (www.cgaigc.com). Furthermore, the additional sponsorship support has allowed us to keep costs (and, subsequently, registration fees) manageable at the Annual Meeting, while bringing in expert speakers from around the globe, increasing engagement with trainees, and adding in new features to the Meeting, such as the popular poster walks in 2019.

I'm honored and humbled to serve as the organization's president for the year, and I want to thank our Council – particularly immediate past-president Dr. Michael Hall and president-elect Dr. Randall Brand – for their countless hours of work and their vision for the organization's continued growth. I also want to thank the members of our various Committees for all of their

contributions to the diverse efforts of the CGA-IGC that make us the "go to" professional society for all aspects of inherited gastrointestinal cancer research, education, and patient care.

Lastly, I want to thank you, our members, for being the lifeblood of the organization. Specifically, we recognize that one of our critical strengths is our diversity of expertise as researchers and medical professionals. Along those lines, I want to take an opportunity to remind everyone of the CGA-IGC's ongoing support of our genetic counseling colleagues, including our formal organizational support of H.R. 3235, the Access to Genetic Counselor Services Act, designed to improve access to genetic counselors for Medicare beneficiaries. See https://www.nsgc.org/p/cm/ld/fid=678 for further details.

Simply put, my goal is to finish the year with CGA being in an even stronger position than it was when the year started. With all of your dedication, expertise, and enthusiasm, I know we can continue to expand the reach and impact of this world-class organization so as to one day end suffering from inherited gastrointestinal cancers.

Thanks for all that you do,
Matt

2. Genetics in the News

The *Wall Street Journal* published a provocative article that is best summarized by its title, "A Genetic Test Led Seven Women in One Family to have Major Surgery. Then the Odds Changed." The article describes the experience of a family who had risk-reducing surgery for what was initially thought to be a pathogenic BRCA-1 mutation, but then after several years, reclassified to a VUS. It describes the emotions felt by the family members throughout the process, beginning with the fear of breast and ovarian cancer, to one of regret for having "unnecessary" prophylactic surgery. The article highlights the complexity of hereditary cancer management. The CGA is comprised of many experts, including physicians, geneticists, psychologists, and registry managers, to name a few. We all know that medical decision-making and patient counseling for any one individual involves many minds, and we make recommendations based on the available evidence at the time. But, at the same time, just as we have witnessed the field of genetic medicine flourish in the last decade with the availability of NGS & multi-panel gene testing, that "evidence" can change. Though the unfortunate circumstance of the family is rare, and that many laboratories other than the one utilized for their testing continue to classify the mutation as pathogenic, this situation is likely to arise throughout our careers. The article is both humbling and a reminder to the occasional murky waters we still swim in as we strive to master precision medicine.

Link to original article: https://www.wsj.com/articles/seven-women-in-a-family-chose-surgery-after-a-genetic-test-then-the-results-changed-11576860210

3. Research Committee Update

We are pleased to report that an updated Registries page has now been published on the CGA website, listing patient Registries across North and South America (https://www.cgaigc.com/findaregistry). We invite you to review it, and if you find a Registry not listed that should be, please email ed.esplin@invitae.com or kimberly_Perez@dfci.harvard.edu.

For those interested in more information about starting a Registry, the Research Committee is preparing a handbook of resources for developing a Registry, coming soon.

Finally, here is a sampling of the research published by some of our CGA members:

Determining the clinical validity of hereditary colorectal cancer and polyposis susceptibility genes using the Clinical Genome Resource Clinical Validity Framework. Seifert BA, McGlaughon JL, Jackson SA, Ritter DI, Roberts ME, Schmidt RJ, Thompson BA, Jimenez S, Trapp M, Lee K, Plon SE, Offit K, Stadler ZK, Zhang L, Greenblatt MS, Ferber MJ. Genet Med. 2019 Jul;21(7):1507-1516. doi: 10.1038/s41436-018-0373-1. Epub 2018 Dec 7. PMID: 30523343

A functional assay-based procedure to classify mismatch repair gene variants in Lynch syndrome. Drost M, Tiersma Y, Thompson BA, Frederiksen JH, Keijzers G, Glubb D, Kathe S, Osinga J, Westers H, Pappas L, Boucher KM, Molenkamp S, Zonneveld JB, van Asperen CJ, Goldgar DE, Wallace SS, Sijmons RH, Spurdle AB, Rasmussen LJ, Greenblatt MS, de Wind N, Tavtigian SV. Genet Med. 2019 Jul;21(7):1486-1496. doi: 10.1038/s41436-018-0372-2. Epub 2018 Dec 3. PMID: 30504929

Diagnostic Yield From Screening Asymptomatic Individuals at High Risk for Pancreatic Cancer: A Meta-analysis of Cohort Studies. Corral JE, Mareth KF, Riegert-Johnson DL, Das A, Wallace MB. Clin Gastroenterol Hepatol. 2019 Jan;17(1):41-53. doi: 10.1016/j.cgh.2018.04.065. Epub 2018 Jun 30. PMID: 29775792

4. ***Education Committee Update***

The CGA-IGC 2020 Webinar Series Has Begun!
The first episode of this year's series aired last month and featured Dr. Rick Boland discussing a historical perspective on Lynch syndrome. If you missed the live event, you can watch a recording here: [include link to recording].
Stay tuned for details regarding 5 more webinars that will occur throughout the year. We are busy finalizing speakers and dates for these topics:

New genes - RNF43 and POLE/POLD1
New genes - MSH3 and NTHL1
Pancreatic cancer surveillance
Gastric cancer surveillance
Challenging Cases

Genetic Counselors: You can claim up to 6 category 1 contact hours for CEUs from this series for a fee of $25. If you miss a live event, you are still able to claim CEUs by viewing the recording and scoring 80% on a quiz.

Monthly Journal Scans with a New Twist
The monthly journal scan created by the Education Committee is a valuable resource and will save you time and keep you current. To access the monthly journal scan, click here.

In the coming months, keep an eye out for a new feature of the journal scans: from time to time, we will feature an article from the month through a podcast discussion with one of the authors!