CGA-IGC Newsletter
Quarterly release: Q2

1. Helping Patients with Hereditary GI Cancer Predispositions in the Era of COVID-19

COVID-19 has turned the world upside down. Insomuch a flip of a switch, many have suspended air travel, choose to stay in our homes in isolation, and wear masks to the grocery story. At one point, we had no toilet paper. Six months ago, any prophecies of a virtual visit dominant healthcare system would've been dismissed. Remarkably, in a matter of days to weeks, and in an effort to maintain social distancing to prepare for a COVID-19 surge and maximize access for necessary non-COVID-19 visits, many of our office visits have been postponed. We have to risk stratify emergent encounters from urgent and routine. Risk stratification is a concept we all who work with hereditary cancer syndromes know far too well in. Yet now, there is an added decision layer to an already complex algorithm. *Can you delay a Lynch syndrome surveillance colonoscopy? By how long? What about a genetic appointment for a college student whose brother was recently diagnosed with FAP? And rectal bleeding in an otherwise asymptomatic 65 year old JPS patient with emphysema – would you feel comfortable bringing him in for a workup?* Each of our practices have devised creative ways to answer these challenging questions. And though there may not be the perfect answer, participation in organizations such as the CGA-IGC, hospital meetings, re-review of the literature, and long-term relationships with our patients (and their families) have helped and will continue to help us navigate these waters.

We are interested to see what you are doing at your institutions for the care of these patients. Please send any thoughts to Dr. Gautam Mankaney at MANKANG@ccf.org.

- Do you do telehealth?
- For patients scheduled for an endoscopy or surgery, are you delaying them? If so, how do you decide by how long to delay the procedure for?

We will collect and share your responses in our next newsletter. Stay tuned!

2. The Resurgence of Telemedicine

Among the many interventions employed by our healthcare community over the past several months to adapt to the realities of the COVID-19 pandemic, the widespread adoption of telemedicine services has been crucial to continued provision of essential services to our patients while keeping our providers and patients safe. Acknowledging telemedicine services as essential, CMS granted an 1135 waiver on March 6, 2020 to expand coverage of telehealth services during the pandemic. Genetics services, with the capability to provide virtual

counseling and at-home genetic testing, are well suited to a telemedicine delivery platform. In addition to providing essential genetics service during the current pandemic, more widespread use "telegenetics" in the future could expand access of genetics services in underserved populations and enable improved access to remote family members with more efficient cascade testing. Notably, services by genetic counselors are not covered under the current CMS waiver. As outlined by the recent NSGC Statement on Telehealth, expansion of coverage by GC services by CMS is needed to enable expanded delivery of these essential services, both during the pandemic and beyond. The success of telemedicine during the pandemic has shown that it is likely here to stay as a part of our routine medical practice, and recognition of genetics services within this expansion will be crucial.

3. Education committee update

The CGA-IGC 2020 Webinar Series Continues

The second webinar of the year aired in March and featured Dr. Laura Valle discussing data regarding emerging genes POLE/POLD1 and RNF43. If you missed the live event, you can watch a recording here: Webinar Series 2: Inherited G... | CGA-IGC (cgaigc-members.com)

The next webinar will also feature new genes, ***MSH3*** **and** ***NTHL1***. Tune in on **Wednesday, May 27 at noon ET** to learn more about these genes from **Dr. Richarda de Voer**.

Stay tuned for details regarding the remaining three webinars that will occur in the second half of the year. We are busy finalizing dates for these topics:

Pancreatic cancer surveillance

featuring Dr. Randall Brand

Gastric cancer surveillance

featuring Dr. Bryan Curtin

Challenging Cases

featuring an expert panel

Register for the series here Webinar Series 2: Inherited G... | CGA-IGC (cgaigc-members.com)

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 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, **click here**.

> Last month, we debuted the journal club podcast. From time to time, the journal scan will include a link to a short podcast featuring an interview with one of the authors of a recently published journal article that is of interest to our membership. **The first two episodes are now available!** The first podcast features **Brandie Heald Leach, MS, CGC**, discussing the **CGA-IGC position statement on multi-gene panel testing for colorectal cancer and polyposis**, published online in Familial Cancer in March. The second podcast features **Leah Biller, MD**, discussing **a multi-institutional cohort of therapy-associated polyposis**, published in Cancer Prevention Research in March. If you haven't already listened, you can access these podcasts here: https://www.podomatic.com/podcasts/cga-igc

4. Research committee update

The Research Committee has continued their efforts to compile and update hereditary cancer registry information. This database has recently been updated with international registries from Argentina to Australia. The Registries page is available on the CGA-IGC website and can be found here: https://www.cgaigc.com/findaregistry

Recent Highlighted CGA-IGC Member Publications:

Detection of DNA mismatch repair deficient crypts in random colonoscopic biopsies identifies Lynch syndrome patients.

Brand RE, Dudley B, Karloski E, Das R, Fuhrer K, Pai RK, Pai RK.

Fam Cancer. 2020 Apr;19(2):169-175. doi: 10.1007/s10689-020-00161-w.

PMID: 31997046

https://www.ncbi.nlm.nih.gov/pubmed/31997046

Molecular pathology of Lynch syndrome.

Cerretelli G, Ager A, Arends MJ, Frayling IM.

J Pathol. 2020 Apr;250(5):518-531. doi: 10.1002/path.5422. Review.

PMID: 32141610

https://www.ncbi.nlm.nih.gov/pubmed/32141610

Low Rates of Genetic Counseling and Testing in Individuals at Risk for Lynch Syndrome Reported in the National Health Interview Survey.

Faust N, Muller C, Prenner J, Lee SM, Kupfer SS.

Gastroenterology. 2020 Mar;158(4):1159-1161. doi: 10.1053/j.gastro.2019.11.297. Epub 2019 Dec 6. No abstract available.

PMID: 31816299

https://www.ncbi.nlm.nih.gov/pubmed/31816299

Health Care Provider Perceptions of Caring for Individuals with Inherited Pancreatic Cancer Risk.

Underhill ML, Pozzar R, Chung D, Sawhney M, Yurgelun M.

J Cancer Educ. 2020 Feb;35(1):194-203. doi: 10.1007/s13187-019-01623-1.

PMID: 31701425

https://www.ncbi.nlm.nih.gov/pubmed/31701425

5. Member Highlights

We're excited to present this new section of our CGA-IGA Newsletter, an entire section dedicated to YOU, our members. We know our CGA-IGC community works hard all year round, so we want to know what you've accomplished recently. This could include anything focused on hereditary gastrointestinal cancer from events or conferences you've organized to successful fundraisers or grant funding but isn't limited to those categories. **Please, tell us about your success!** This month, we're excited to share some exciting news about member, Dena Goldberg:

> After realizing the amount of misinformation surrounding genetic medicine, Dena is now working full time on creating media to make genetics more fun, familiar and relatable. She founded her personal brand, Dena DNA (DenaDNA.com) with the mission to spread awareness of medical genetics and medical genetics services to the general public through media and marketing techniques not typically used by the medical community. She is utilizing Instagram, Twitter, Facebook, Youtube and TikTok to reach a broad audience and is launching her new Youtube web series on May 15th with new episodes on Fridays. If you want to support this fellow CGA-IGC member, you can subscribe to her Youtube channel, follow her social media accounts, and share her content.

6. Genetics in the News/Media

The news has been dominated by updates about COVID-19, leaving hereditary cancer largely out of headlines the last few months, but luckily, hereditary cancer has not been wholly forgotten by main stream media. Most of us are likely spending more time at home than usual during this pandemic, which may mean spending more time with family, on house projects or personal development, but hopefully some genuine R&R as well. If you're seeking out ways to sneak a bit more science into your life while relaxing, you may want to consider watching a

documentary about the CRISPR gene-editing technology called *Human Nature* that debuted in March 2020. It includes lay explanations of the science, interviews with the pioneers of this technology, and presents ethical questions that could spur interesting conversations among your stay-at-home companions, whoever they may be. If you've already seen *Human Nature*, perhaps you'll cue up the new PBS series *The Gene* in your down time which also debuted recently which is based on a 2016 book by the same name written by Siddhartha Mukherjee. While it's entirely possible you won't learn anything new from either of these documentaries, it is important for all of us to stay up-to-date on the information circulating broadly to the public about genetics and the ethical questions society is pondering in this realm.