



CGA-IGC Newsletter

1. Presidential Welcome

It is with immense gratitude and humility that I begin my tenure as CGA-IGC President. This past year has posed challenges from every corner. I am in awe of the servant leadership and vision that our 2020-2021 President, Randall Brand, exhibited as a steward of our organization through trying times. Despite multitude challenges, we credit him with putting on an outstanding annual meeting with over 350 registrants from around the world and fostering continuing growth of our organization.

We are stronger than ever on all fronts.

CGA-IGC has seen tremendous growth over the past several years with the support from our management firm, PACE. Many of you had the pleasure of interacting with **Megan Fowler** and **Tom Saenz** from PACE and can attest to their commitment to CGA. Although we are saddened to announce that PACE will no longer be supporting CGA-IGC, we are delighted to introduce you to the Kenes Group. **Evelyn Zuberbuhler** will be supporting our year-round society activities and communications. **Pinar Akbulut** is our annual meeting project manager, who leads a team of experts including, Lara Volkan (scientific content), Muzaffer Komek (sponsorship contact), Neyir Utugen (registration & accommodations) and Defne Caglar (marketing). Please welcome them when you get a chance.

The 2021 annual meeting could not have happened without the countless hours dedicated by the 2020-2021 Meeting Planning Committee chaired by Dr. Brand. I thank **Matthew Yurgelun, Rachel Pearlman, Jill Genua, Gregory Idos, Aimee Lucas, Aparajita Singh, Jose Perea, Maureen Mork, Nykole Sutherland** and **Michael Hall**. I thank the Research Committee for showcasing the outstanding research submitted and catalyzing collaborative research efforts during the meeting. I also thank our Diversity, Equity & Inclusion Committee for elevating unique voices and experiences at the meeting.

I extend my deepest thanks to those who support our organization, without whom the annual meeting could not have taken place.

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The true ground swell of strength in our organization comes from the many members who volunteer their time and expertise as CGA-IGC committee members and leaders. In addition to their invaluable contributions to the CGA-IGC annual meeting, our committees curate outstanding educational content, research resources and mentorship/collaborative opportunities throughout the year.

These resources and professional opportunities make CGA-IGC stand out as *the* premiere society dedicated to hereditary GI cancer syndromes.

Don't miss what we have in store for 2022. As a thank you, we are offering discounted membership for those who sign up for three consecutive years. Renew now!

[Renew Now](#)

I am indebted to my predecessors for being able to take the helm at a time when CGA-IGC is healthier and more impactful than ever. It is my goal as your president to expand our reach and impact as a society and elevate all voices within our organization. Our strength is in our diversity of thought and experience. I look forward to working with our committees to expand our successful programs and to develop new endeavors to continually increase the value of your membership and to expand CGA-IGC's international footprint.

I extend a heartfelt thank you to committee members rolling off and an energetic welcome to new members. If you have any suggestions for topics for our newsletters, webinars, podcasts or twitter journal clubs, please contact me, any of our council members, or our committee chairs.

I cannot tell you how proud I am of CGA-IGC. Our organization is comprised of exceptional professionals whom I know have met every challenge, twist, and turn of the past two years with compassion, commitment, creativity, kindness and grace. I am honored to lead this group and will make it my mission to usher prosperity and growth over the next year.

Swati G. Patel, MD, MS
2021-2022 CGA-IGC President



2. Important Dates for 2022: Mark your Calendars!

As the end of 2021 approaches, we have a lot to look forward to and work to do in 2022. Put these dates in your work calendar now along with a few reminders in the weeks/months leading up to them so you do not miss any of these important deadlines or make other plans during the annual meeting.

- **Abstract Submission and Annual Meeting Registration:** Opens April 1, 2022
- **Abstract submission deadline:** July 11, 2022
- **CGA-IGC Fund Grant submission deadline:** September 9, 2022
- **Annual CGA-IGC meeting:** November 11-13, 2022, in Nashville, TN

3. Policy & Advocacy Updates: CGA-IGC has a Voice!

We thank CGA-IGC members who responded to our call to support the proposed Medicare for a Merit-based Incentive Payment System (MIPS) measure requiring hospitals to track and report their universal tumor screening for Lynch syndrome. We are happy to report that the measure has moved on to the next stage of approval, in large part because of widespread support from our organization and members.

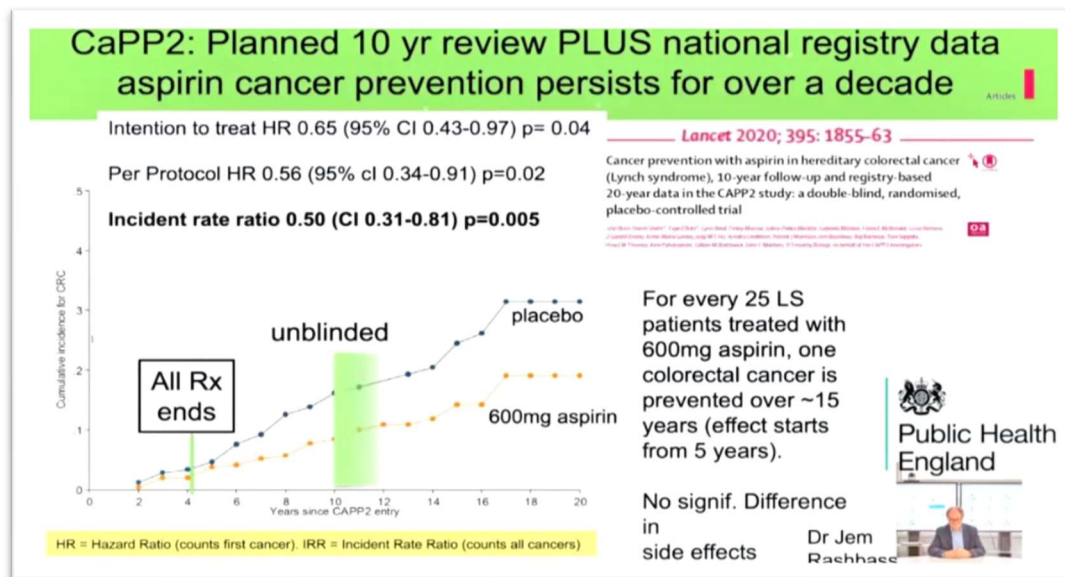
We also thank CGA-IGC members who joined us in nominating “Lynch Syndrome-Related Cancers: Risk Assessment, Genetic Counseling, and Genetic Testing” as a New Topic to be reviewed by the United States Preventative Services Task Force (USPSTF). We have been informed that this topic has been added to the list of preventive services under consideration by the USPSTF. If approved, this designation will significantly improve coverage for genetic counseling and genetic testing services.



4. Highlights from the 2021 Annual CGA-IGC Meeting

The CGA-IGC annual meeting is always one of the can't-miss meetings for anyone caring for patients with hereditary gastrointestinal cancer syndromes or scientists researching these patient populations or conditions. The 2021 meeting was no exception. The schedule was packed full of relevant, innovative presentations. The communications committee will continue to highlight abstracts from this meeting through Twitter in case you missed any of this important content. Here are a few highlights from the meeting, but we encourage you to return to the Crowd Compass app to review any content you may have missed.

- **Sir John Burn** shared new data from the CaPP2 study, revealing long-term CRC chemoprevention effect of aspirin for patients with Lynch syndrome after 5 years. However, we still need more risk/benefit data to determine the optimal aspirin dose.



- Attendees found **Dr. Iris Romero's** talk on gender identity and expression incredibly useful. Dr. Romero shared how provider language and knowledge as well as clinic environment impact patients with Lynch syndrome from the LGBTQ community. It is reassuring to know that gender affirming hormones do not increase the risk for Lynch syndrome associated cancers.

LGBTQ Terminology

Language *What you say*

- Avoid language that assumes gender identity and sexual orientation
- Allow patients to choose their own terms and you use them
- Use **preferred** names and pronouns that patient asks you to use

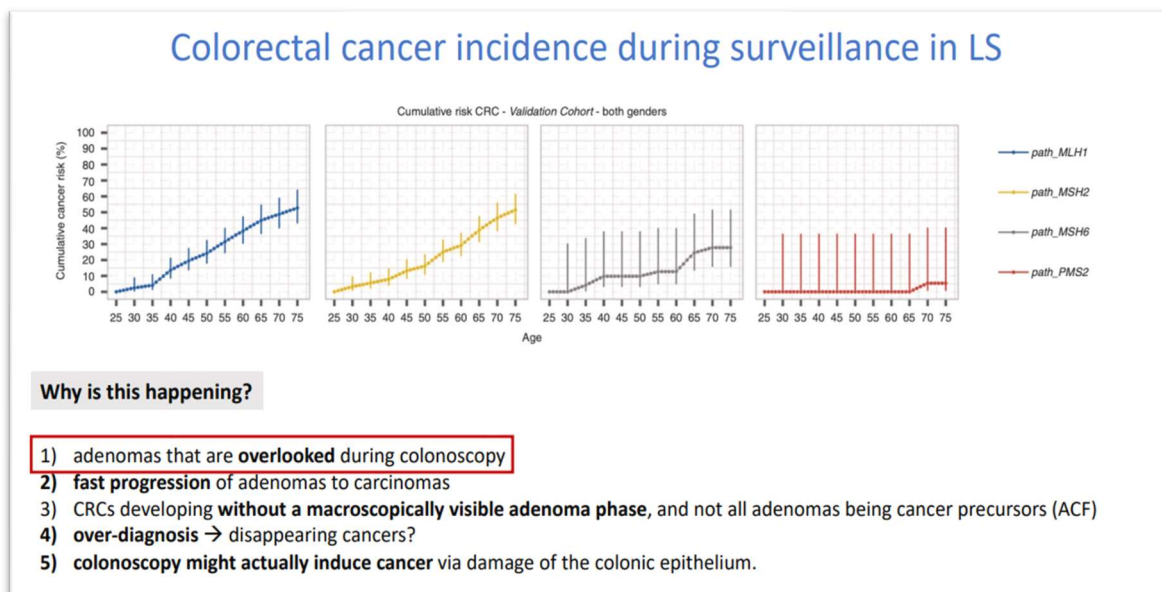
Knowledge *What you know*

- Avoid relying on patient to educate you
- Do not focus on sexual and gender identity if it is not relevant
- Avoid asking questions to satisfy your own curiosity

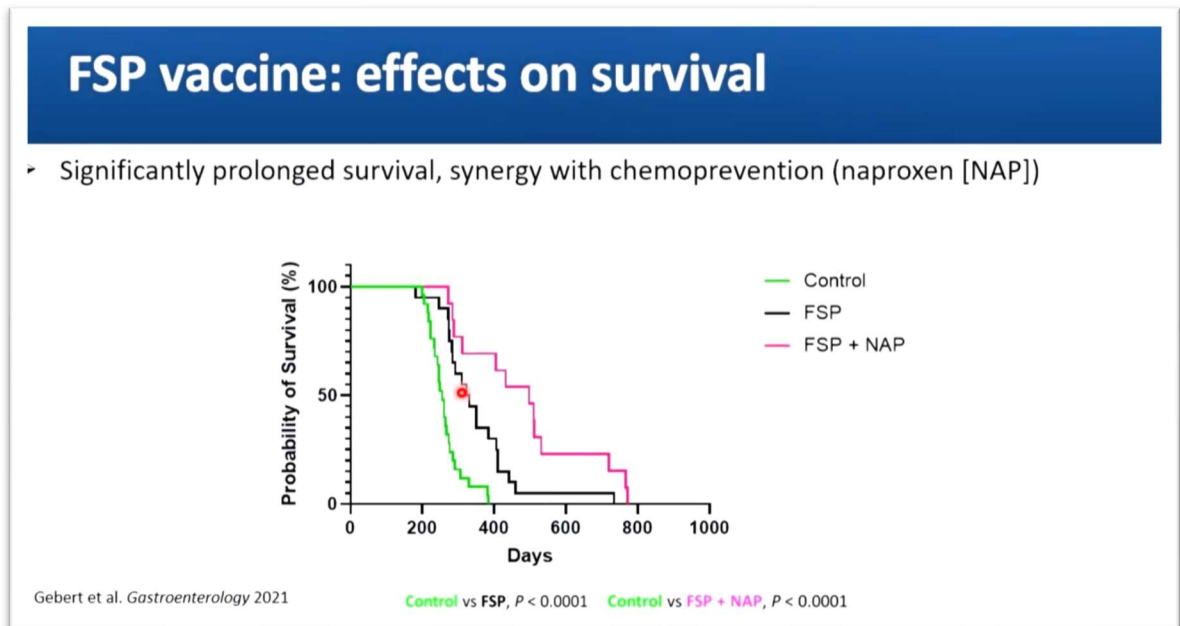
Environment *What you show*

- Imagery, representation, and signage
- Train staff across continuum of care

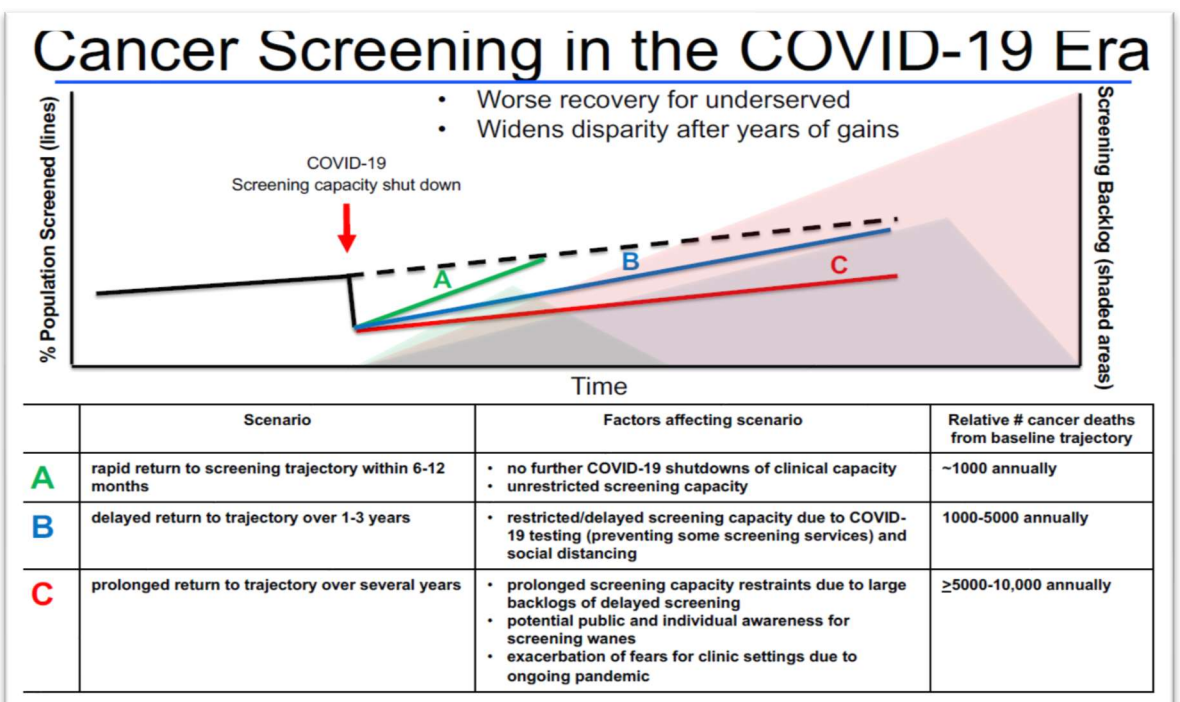
- Dr. Frank Balaguer** presented on why the incidence of CRC is still high in patients with Lynch syndrome. Figuring out *why* is the first step to addressing the problem and decreasing CRC incidence in the future.



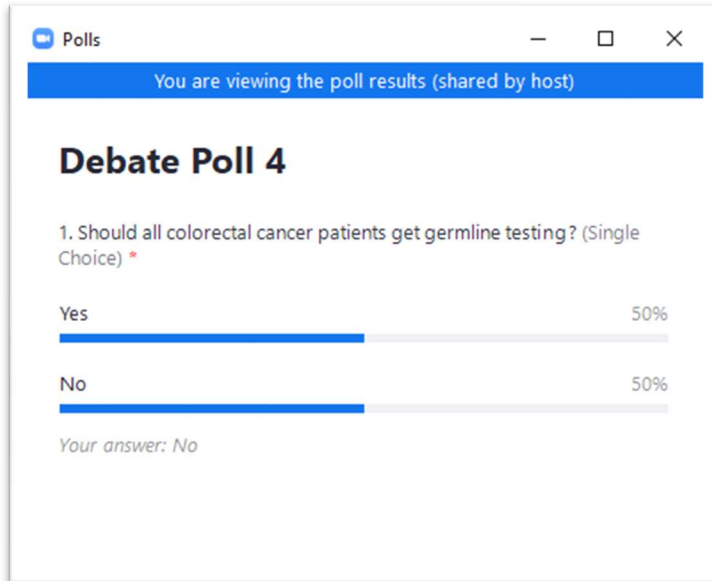
- **Dr. Matthias Kloor** shared promising survival data on vaccinations for Lynch syndrome which was further improved when combined with naproxen.



- **Dr. John Carethers** showed how the impact of COVID-related drops in cancer screening could be profound, with excess mortality likely experienced disproportionately by the underserved.



- **Heather Hampel, CGC and Dr. Matt Yurgelun** engaged in a hotly contested debate on whether we should offer universal gene panel testing for all patients with colorectal cancer. After a wonderful and thoughtful debate, the results showed that CGA-IGC participants who responded to the poll were equally split – 50/50!



- **Dr. Anirban Maitra, MBBS** was this year's recipient of the Bert Vogelstein Lectureship. Here we see the inspiring quote he keeps on his computer that is important for us all to remember!



- **Rachel Pearlman, CGC** reminded us of the flaws and limitations of the current algorithms used for detecting patients with Lynch syndrome.

Other Limitations of The Algorithm: OCCPI Pearls

- 6.3% (9 of 144) of those with lynch syndrome would have been missed based on the current UTS algorithm.
 - 6 had an MMR-proficient tumor (four PMS2 and two MSH6)
 - 2 had constitutional MLH1 hypermethylation
 - 1 was absent MLH1/PMS2 with MLH1 hypermethylation (PMS2)
- 8% of cases with non-methylated MMR deficiency also had a non-MMR pathogenic variant (*CHEK2*, *PALB2*, ect).
- Had UTS been the only method used to screen patients with CRC for germline assessment, 38.6% of those with a PGV in a cancer susceptibility gene or constitutional hypermethylation would have been missed.

Pearlman et al. JCO Precis Oncol 5:779-791

- **Dr. Andrea Holowatyj, PhD, MS** described how racial and ethnic disparities are amplified when looking at outcomes of early-onset colorectal cancer. There is still so much we do not yet understand, and more studies are needed.

Disproportionate burden of EAOCCRC across population subgroups

- Distinct racial/ethnic patterns by age at early-onset CRC diagnosis
- Racial/ethnic disparities in early-onset CRC outcomes are amplified

Holowatyj et al. Nature Reviews Cancer 2021

- **Dr. Nicolette Rodriguez, Dr. Greg Idos, Sonia Margarit, CGC, Dr. Daniel Pineda-Alvarez, Pardeep Kaurah, PhD, CCGC, Dr. Sonia Kupfer, Candace Henley, Linda Rodgers, CGC, and Charite Ricker, CGC** engaged in a wonderful panel discussion on Diversity, Equity and Inclusion: We have to “work together to synergize efforts towards the same end goal → saving lives”.



The communications committee will continue to keep you up-to-date on upcoming activities and accomplishments of CGA-IGC throughout 2022 with quarterly newsletters. However, this quarter we had so much exciting news to share with you, we have decided to send out a second newsletter in January 2022. Keep an eye out for the January newsletter edition, which will include updates from the CGA-IGC Fund, updates from the Research, Education, DEI and Communication Committees, and introductions to the newest members on each of these committees.

Best wishes for the new year!

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
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 Warren Stopak Student
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 Nicholas Bartell MD
 Claudio Heine MD
 Kimberly Hilfrank MS, MPH



Evelyn Zuberbuhler was born in Switzerland and moved with her family to New Zealand as a child. She spent part of her working life in Geneva, Switzerland. Working in the medical non-profit field since 2001 and with Kenes Group since 2009, she loves working as an Association Manager and seeing professional medical societies grow and thrive. She is a keen garden festival attendee, hiker, reader of print material and traveler.



Pinar Akbulut started working on conferences during her university years and continued in this career after graduating with a bachelor's degree in Business Administration. Now, with her 15+ years of experience, she is a senior project manager at Kenes Group where she organizes conferences around the world. She is also in the process of getting a second degree in sociology. Besides her work life, she is a pet mom and owns a beautiful golden retriever girl named "Parfé" (meaning "parfait" or perfect in English). She loves to walk and play with Parfé, reading and traveling. She loves photography and considers herself an amateur photographer. She is an advanced scuba diver and is working on becoming a scuba diving trainer.