

# ACMG In Action

Essential Updates: Member News You Can Use



March 2020

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## ***Upcoming Events***

**ACMG Genomics Case**

## **ACMG Announces Cancellation of the 2020 ACMG Annual Clinical Genetics Meeting Due to Continuing Spread of COVID-19 and Growing Concerns over the Health and Well-Being of Participants: Cancellation Deemed to Be the Most Responsible Action at This Time**

As you saw over the weekend, after careful deliberations, the leadership of the American College of Medical Genetics and Genomics (ACMG) has made the difficult and unprecedented decision to cancel the upcoming 2020 ACMG Clinical Genetics Meeting scheduled for March 17-21, 2020 in San Antonio, Texas.

“We deeply regret any inconvenience caused by cancellation of the ACMG meeting and we share your disappointment, but we believe this is the most responsible course of action to protect the health and well-being of attendees and the patients they serve, presenters, exhibitors, staff, vendors and all those engaged in the conference,” said Max Muenke, MD, FACMG, chief executive officer of the ACMG.

The American College of Medical Genetics and Genomics had been continuously monitoring the latest information from the [Centers for Disease Control and Prevention](#), [World Health Organization](#) and [US Department of State](#) on the spread of the novel coronavirus disease COVID-19. In addition to restrictions on international and domestic travel; ACMG leadership had become aware over the last 48 hours of a rapidly increasing number of travel bans being imposed on employees by healthcare institutions and companies across the US, along with rising concerns that travel to large group gatherings is not judicious from a public and personal health perspective.

ACMG President Tony Gregg, MD, FACMG said, “This decision was especially hard because so many have spent countless hours planning and preparing to attend our meeting in San Antonio. I would like to especially thank Dr. Jennelle Hodge and the program committee, along with the many speakers and session leaders who ensure that each annual meeting harbors best in class educational opportunities. Our meeting in San Antonio was on track to be one of the best ever. Thank you! The support and commitment by industry is also recognized as being pivotal to the success of the ACMG Annual Clinical Meeting. Of utmost importance,

## Conference

2:00–3:00 PM EDT

March 25, 2020

RENEW  
MEMBERSHIP

## Website Links

[ACMG](#)

[ACMG Foundation](#)

[ACMG Meetings Website](#)

[ACMG Education Center](#)

[NBSTRN](#)

[NCC](#)

[ClinGen](#)

[GIM](#)

however, is the health of our attendees and the health and safety of the patients we serve.”

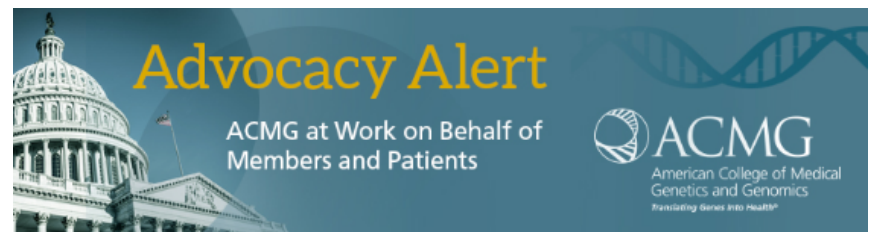
The ACMG staff and Board of Directors is considering rescheduling a meeting in San Antonio in August (25-29, 2020) that can facilitate the educational needs of our members. We will provide an update as soon as information becomes available.

ACMG asks for your understanding and patience as we work through the complex and immense logistics of this extraordinary and difficult circumstance. **We ask you to please not call or email the ACMG office at this time while details are sorted out and decisions are made.**

Note – if you booked your hotel through ACMG’s official housing partner, CMR, **please do not contact them or the hotels directly at this time.** ACMG will be notifying them of the status and they will be sending cancellation confirmations to all attendees and exhibitors with reservations.

Please continue to watch our meeting website at [www.acmgmeeting.net](http://www.acmgmeeting.net) for updates as they become available. Exhibitors and registrants will receive emails from ACMG with further information within the next 10-14 days.

## ACMG Advocacy Updates



## VALID Act of 2020 Introduced in US Congress

On March 5th, 2020, US Representatives Larry Bucshon, MD (R-IN) and Diana DeGette (D-CO), and Senators Michael Bennet (D-CO) and Richard Burr (R-NC), introduced bipartisan, bicameral legislation to reform the regulatory framework for in vitro clinical tests (IVCTs), which includes laboratory-developed tests (LDTs). The legislation, titled the Verifying Accurate Leading-Edge IVCT Development (VALID) Act of 2020, reflects many aspects of the VALID Act Discussion Draft that was released in 2018. The legislation would create a new definition under the Food, Drug, and Cosmetic Act for IVCTs which would include all LDTs. Under this framework, all LDTs would be subject to regulation by the US Food and Drug Administration (FDA) unless certain criteria for exemption were met.

As noted elsewhere in this month’s *ACMG in Action* ezine, ACMG recently published an updated [position statement](#) on the risk categorization of LDTs. This updated statement will help to guide our response to legislators about the framework proposed in the VALID Act. Over the coming weeks ACMG will be performing a detailed assessment

of the VALID Act of 2020, and we will continue to provide updates as the legislative process continues.

### **The Advisory Committee on Heritable Disorders in Newborns and Children Is back!**

In the January 2020 edition of our *ACMG in Action* ezine, we notified members of ACMG's efforts to get the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC or the Committee) reinstated. Specifically, ACMG joined 60 other provider and patient organizations in requesting that Secretary Azar reinstate the ACHDNC as a secretarial (aka, discretionary) advisory committee. See our letter [here](#). This was followed by additional outreach to Secretary Azar and others at the Department of Health and Human Services (DHHS), as well as a coalition-initiated petition effort administered by a few patient advocacy organizations. Thanks to these coordinated advocacy efforts, we are pleased to announce that the ACHDNC will be reinstated as a discretionary advisory committee starting March 20, 2020. See the Federal Register notice [here](#). Additional information about the ACHDNC can be found [here](#). We are relieved to know that the critical work of the Committee will be able to proceed while we continue to work with Congress to encourage passage of the full Newborn Screening Saves Lives Reauthorization Act that expired on September 30, 2019.

### **Just Published: Updated ACMG Position Statement on Risk Categorization for Oversight of LDTs**

In case you missed it, the ACMG recently published "[Risk Categorization for Oversight of Laboratory-Developed Tests for Inherited Conditions: An Updated Position Statement of the American College of Medical Genetics and Genomics \(ACMG\)](#)." This document was developed by a joint workgroup of the Laboratory Quality Assurance and Professional Practice and Guidelines Committees.

The statement proposes a framework to guide federal agencies, policymakers and other stakeholders. For a number of years, the prior version of this position statement has been a critical component of ACMG's advocacy with the Food and Drug Administration (FDA), Centers for Medicare and Medicaid Services (CMS) and Congress on the topic of thoughtful regulatory oversight of laboratory-developed tests (LDTs). As you have read in the Advocacy Update section in this issue of the *ACMG in Action* ezine, this new publication coincides with recent increased legislative interest in the regulation of LDTs.

The workgroup considered analytical and healthcare-related risks and implications of laboratory testing of constitutional genetic information in a variety of contexts to develop its proposed approach. It then categorized testing for inherited conditions using a three-tiered risk-based system founded on two elements. The first element is consistent with the typical FDA determination of testing-associated risk and aligns risk with medical decision making based on the test results and the clinical significance of an erroneous result. The second element considers factors that impact

analytical performance and the likelihood of an erroneous result based on methodology. While the authors acknowledge that novel technologies for an otherwise lower risk clinical application could temporarily place that test in a higher risk category until additional experience with the methodology is gained, the model specifies criteria defining each level of risk and identifies mitigating factors that could potentially lower the chance of inappropriate or harmful clinical action based on the test result.

**The College gratefully acknowledges Sarah T. South, PhD (Workgroup Chair); Michelle McClure, PhD (Workgroup Co-Chair); Caroline Astbury, PhD; Michael T. Bashford, MD; Judith Benkendorf, MS; Edward D. Esplin, MD, PhD; Kristin G. Monaghan, PhD; Devin Oglesbee, PhD; V. Reid Sutton, MD; and Michael S. Watson, PhD for volunteering their time and expertise to complete this update within a very short timeframe.**

### **Why Are You in Medical Genetics? Share Your Inspiration during Medical Genetics Awareness Week**



What was your inspiration for pursuing a career in medical genetics? What about your job makes you excited to go to work every day? ACMG invites you to help us celebrate the 2nd annual [Medical Genetics Awareness Week](#) by telling everyone on social media, in your own words, why you love being in medical genetics.

If you love taking videos on your cell phone, you can post your statement as a short video. Just a short clip of 60 seconds is all you need to tell viewers why you are in medical genetics and to encourage them to share their stories.

Video not your thing? Then use our “Why I’m in Medical Genetics” [graphic](#) or one of the other Medical Genetics Awareness Week graphics in our [Resource Tool Kit](#) to illustrate a post for your social media page. We also invite you to break out your inner graphic designer and create a graphic of your own for your statement about why you love medical genetics.

And be sure to tag [@TheACMG](#) and include one or more of our Medical Genetics Awareness Week [hashtags](#) so we can find and share your posts!

### **ACMG Welcomes 67 New Members**

ACMG welcomes and congratulates its 67 new and newly certified members. There has never been a more exciting time to be a part of this field and we encourage current members of the College to invite friends and colleagues to join and help grow the medical genetics and genomics field. Thank you to all our members who make important contributions

and the work of the College possible through your membership, support and involvement.

### **Fellow Members**

Abdulrazak Alali, MD, FACMG  
Adnan Alsadah, MBBS, FACMG  
Blake Atwood, PhD, FACMG  
Houriya Ayoubieh, MD, FACMG  
Joshua J. Baker, DO, FACMG  
Emily Black, MD, FACMG  
Nicole J. Boczek, PhD, FACMG  
Colyn C. Cain, PhD, FACMG  
Perry Chan, PhD, JD, MBA, FACMG  
Jennifer Cohen, MD, FACMG  
Natario Couser, MD, FACMG  
Taraka Donti, PhD, MS, FACMG  
Carolina Galarreta Aima, MD, FACMG  
Paul Hillman, MD, PhD, FACMG  
Saumya S. Jamuar, MD, FACMG  
Rama D. Kastury, DO, FACMG  
Emilie Lalonde, PhD, MS, FACMG  
Benson Lee, DO, FACMG  
Kristen N. Lee, MD, FACMG  
Harry Lesmana, MD, FACMG  
Mauro Longoni, MD, FACMG  
Jerry Machado, PhD, MS, FACMG  
Maksym Misyura, PhD, FACMG  
Danielle C. Monteil, MD, FACMG  
Chaya N. Murali, MD, FACMG  
Mesaki K. Ndugga-Kabuye, MD, FACMG  
Elizabeth A. Normand, PhD, FACMG  
Mersedeh Rohanizadegan, MD, MPH, FACMG  
Carey Ronspies, MD, FACMG  
Bianca E. Russell, MD, FACMG  
Brian Shayota, MD, MPH, FACMG  
Jessica Smith, MD, FACMG  
Brandon Stauffer, PhD, FACMG  
Allison C. Tam, MD, FACMG  
Bo Yuan, PhD, FACMG  
Amy Yuen, MD, PhD, FACMG

### **Associate Members**

McKinsey Goodenberger, MS, CGC  
Kory L. Keller, MGC, MS, CGC  
Phuong My Le, MS, CGC  
Jerica Lenberg, MS, CGC  
Tara M. Short, MS, CGC  
Melisa A. Siegler, MS, CGC  
Heather N. Witt, MGC

### **Affiliate Members**

Norma J. Arciniegas-Medina, MD  
Rebecca R. Blackwell, MSN  
Angela J. Gruber, PhD

Minhua Liao, MGC  
Andrea Viator Murphy, MS  
Deepa S. Rajan, MBBS  
Laura J. Rear, DNP  
Julie Voeller, MD  
Huan T. Vuong, MD  
Hannah E. Williams, MPH

#### **Candidate Fellows**

Benjamin A. Hilton, PhD  
Meng Su, PhD

#### **Trainee Members**

Angella Charnot-Katsikas, MD  
Laura Dillon, PhD  
Xiaolan Fang, PhD  
RaeLynn Forsyth, MD  
Jennifer M. Gass, PhD  
Emily Shelkowitz, MD  
Moin U. Vera, MD, PhD, MS

#### **Student Members**

Md. Abul Kalam Azad, BS  
Ryan Thomas Foley, BA  
Arielle Majka, BA  
Melissa J. Reeves, MS  
Matthew Strein, BS

Do you know someone who should join ACMG? Please tell them to visit our [Join ACMG web page](#).

### **Sarah Elsea, PhD, FACMG Is Elected to the Board of Directors of the ACMG Foundation for Genetic and Genomic Medicine**



In case you missed it, Sarah H. Elsea, PhD, FACMG, professor of molecular and human genetics at Baylor College of Medicine and senior director of biochemical genetics at Baylor Genetics, was recently elected to the board of directors of the ACMG Foundation for Genetic and Genomic Medicine. The ACMG Foundation is a national nonprofit foundation dedicated to facilitating the integration of genetics and genomics into medical practice. The board members are active participants, serving as advocates for the Foundation and for advancing its policies and programs. Dr. Elsea was elected to a two-year term starting immediately.

ACMG Foundation President Bruce R. Korf, MD, PhD, FACMG said, "It is our pleasure to welcome Dr. Sarah Elsea to the ACMG Foundation



Board of Directors. Dr. Elsea's experience in medical genetics and commitment to the mission of the College will add greatly to our ability to support clinical and educational activities on behalf of our members and the public."

About being elected to the ACMG Foundation Board of Directors, Dr. Elsea said, "As we focus toward defining targeted treatments for both rare and common disease, we have an increasing need to translate genetics in healthcare. The mission of the Foundation to support and foster the training and education of medical geneticists and to enhance community education and awareness of genetics and genomics is at the heart of my work. I am both honored and delighted for the opportunity to support the ACMG Foundation Board of Directors, and I look forward to working with the Foundation to advance these goals."

To learn more about Dr. Elsea and the ACMG Foundation board, [click here](#). To view a complete roster of the ACMG Foundation Board of Directors, [click here](#).

### Now Showing on TheACMGChannel: New "Careers in Genetics" Videos



One of the key strategies in ACMG's new strategic plan is to secure and expand the professional workforce of medical genetics and genomics. In support of this aim, ACMG offers a variety of opportunities geared toward students, trainees and others who are early in their careers. These opportunities include free student membership in the ACMG; reduced membership dues for young professionals; student-, trainee- and early-career-oriented educational programming and mentorship and networking activities; ACMG Foundation awards that recognize excellence or support medical genetics training or travel to the ACMG Annual Clinical Genetics Meeting; opportunities to participate on ACMG committees; and much more.

ACMG also offers programming on its YouTube channel that is specifically geared toward student, trainee and early-career followers. This month, ACMG added four new videos to the *Careers in Genetics Series* [playlist](#) on [TheACMGChannel](#). These videos are recordings of presentations from a session entitled "Careers in Medical Genetics and Genomics—An Informational Session for Students and Trainees" that were filmed during the ACMG Annual Clinical Genetics Meeting in Charlotte, North Carolina. This annual interactive session provides students and trainees the opportunity to learn more about various career pathways in medical genetics and genomics. ACMG thanks the presenters in these newest videos: Julie Jones, PhD, FACMG; Heather Byers, MD, FACMG; Erin Rooney Riggs, MS, CGC; and Miriam G. Blitzer, PhD, FACMG.

To watch these and all ACMG's other videos on YouTube, visit [TheACMGChannel](#) and the *Careers in Genetics Series* [playlist](#).

## March 2020 GenePod: Should All Breast Cancer Patients Get Germline Genetic Testing?



Is more better? As the cost of genetic testing plummets, allowing more people to get testing of more genes, researchers and clinicians are asking: who should get tested, and for what? One recent study suggested that all breast cancer patients should get genetic testing. But does the evidence support this approach? In a recent [ACMG](#)

[statement](#) published in *Genetics in Medicine (GIM)*, the statement's authors weighed the evidence for *BRCA1/2* and other germline genetic testing in patients with breast cancer and recommended points for clinicians to consider. On this month's episode of [GenePod](#), *GIM*'s monthly podcast, host Cynthia Graber talks with Dr. Tuya Pal, associate director for cancer health disparities at the Vanderbilt University Ingram Cancer Center and first author of ACMG's recent statement, and Dr. Susan Domchek, director of the Basser Center for BRCA at the University of Pennsylvania and author of a [commentary](#) on the ACMG statement, about the evidence, gaps in current knowledge, and how to improve testing rates among high-risk patients.

## ACMG Social Media Highlights

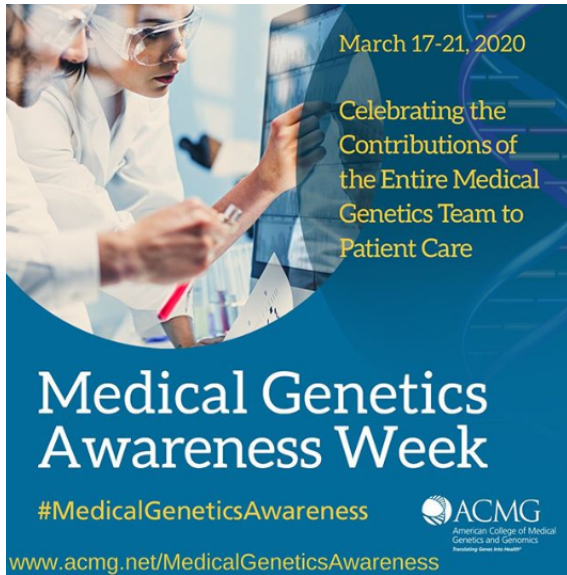
ACMG's social media pages engage thousands of people each month and keep followers up to date on educational programs and other activities of the College and ACMG Foundation. ACMG also hosts a private, members-only group on LinkedIn that offers members exclusive news and opportunities such as invitations to comment on new draft ACMG documents, calls for engagement in College and Foundation activities and programs, and advance notification of new ACMG statements and guidelines and news releases.

ACMG's portfolio of social media pages includes:

- @TheACMG on [Twitter](#);
- @theacmg on [Facebook](#);
- @theacmg on [Instagram](#);
- TheACMGChannel on [YouTube](#);
- ACMG Annual Clinical Genetics Meeting on [LinkedIn](#);
- a public company page ACMG - American College of Medical Genetics and Genomics on [LinkedIn](#); and
- a private, members-only group American College of Medical Genetics and Genomics (ACMG) on [LinkedIn](#).

We invite you to follow ACMG on social media and be a part of the conversation. A sampling of our recent social media posts illustrates the variety of news and information we share on social media.





March 17-21, 2020

Celebrating the  
Contributions of  
the Entire Medical  
Genetics Team to  
Patient Care

# Medical Genetics Awareness Week

#MedicalGeneticsAwareness

ACMG  
American College of Medical  
Genetics and Genomics  
Advancing Science. Improving Health.

[www.acmg.net/MedicalGeneticsAwareness](http://www.acmg.net/MedicalGeneticsAwareness)

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theacmg Join ACMG March 17-21, 2020 for #MedicalGeneticsAwareness Week as we celebrate the contributions of the entire #medicalgenetics team to #patientcare and #publichealth. Learn more at [www.acmg.net/MedicalGeneticsAwareness](http://www.acmg.net/MedicalGeneticsAwareness) #genetics #genomics

♡ 💬 📌



#RareDiseaseDay  
[rarediseaseday.org](http://rarediseaseday.org)

RARE IS  
MANY

RARE DISEASE DAY®

29 FEBRUARY 2020

theacmg

theacmg ACMG applauds all those who work every day to care for and improve the lives of patients and families living with rare diseases. #RareDiseaseDay [www.rarediseaseday.org](http://www.rarediseaseday.org)

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Genetics in Medicine features collections of subject-specific articles on a number of specialties. Check out our new collection on Genomic Variant Interpretation and more focusing on [#neurology](#) [#obstetrics](#) [#oncology](#) [#pediatrics](#) [#publichealth](#)  
<https://lnkd.in/d2p-d46>



### Don't Let Your Membership Benefits and Discounts Expire!

***The 2020 membership renewal deadline was January 31, 2020 but there's still time to renew and avoid late fees. Renew today.***



ACMG's online renewal system is a fast, easy and secure way to renew your ACMG membership instantly and receive immediate payment confirmation. The online system accepts Visa, MasterCard, Discover and American Express payments. If you prefer to pay by check or by fax, download a 2020 Dues Renewal Form [here](#). Renewal by phone is also available. Call us at 301-718-9603.

Renew today to avoid interruption of membership services and benefits. Membership payment must be current in order to register at the member rate for the ACMG Annual Clinical Genetics Meeting, receive member discounts in the Genetics Academy and access the ACMG Members Only sections of the ACMG website.

**Don't Forget!** *Genetics in Medicine*, ACMG's official journal, is going green. Online access and free downloads will remain the same for members, but if you wish to continue receiving a print copy of the journal

you will need to add the print subscription cost when submitting your renewal payment.

Questions regarding membership renewal can be sent to [membership@acmg.net](mailto:membership@acmg.net).

### **Mark Your Calendar for the Next ACMG Genomics Case Conference**



Wednesday, March 25, 2020, 2:00 PM – 3:00 PM EDT

This month's engaging topic is "Telegenetics Consults and Resources at Your Fingertips" and is hosted by experts from the National Coordinating Center for the Regional Genetics Networks (NCC).

[Register Now!](#)



American College of Medical Genetics and Genomics | 7101 Wisconsin Avenue, Suite 1101, Bethesda, MD 20814

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