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ACMG In Action

Essential Updates: Member News You Can Use

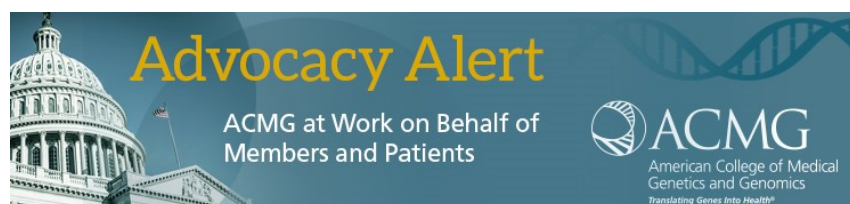


January 2021

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ACMG Advocacy Updates



ONC Information Blocking Rule Compliance Date Extended

In May 2020, the Office of the National Coordinator for Health Information Technology (ONC) finalized a new [interoperability and information blocking rule](#) in response to requirements included in the 21st Century Cures Act passed in 2016. The rule included numerous provisions impacting a variety of stakeholders, but most notable for many of ACMG's members is the requirement that test results be made immediately available to patients. An exception, referred to as the Preventing Harm Exception, was included in the final rule to allow for delayed release of results in specific situations for which immediate return of results would pose a risk of harm to the patient. As noted in ACMG's 2020 statement on [the interface of genomic information with the electronic health record](#), "the ability of patients to access genomic test results through the EHR in a timely manner must be balanced against the need for clinical interpretation and counseling related to the results and potential for patient harm." ONC's Preventing Harm Exception is particularly important for institutions returning genetic and genomic results. However, as genetic testing laboratories and provider institutions have begun to implement new policies in compliance with the final rule, many questions have been raised regarding the limitations of this exception.

[READ MORE](#)

ACMG Joins Effort to Assess and Enhance Genetics and Genomics Workforce Diversity

As part of ACMG's commitment to diversity, equity and inclusion, the College is joining together with the American Society of Human Genetics

Upcoming Events

2021 ACMG Annual Clinical Genetics Meeting: A Virtual Experience

April 13-16, 2021



Website Links

[ACMG](#)

[ACMG Foundation](#)

[ACMG Meetings Website](#)

[ACMG Education Center](#)

[NBSTRN](#)

[NCC](#)

[ClinGen](#)

[GIM](#)

(ASHG), the National Human Genome Research Institute (NHGRI), the National Society of Genetic Counselors (NSGC) and other leading organizations on an important initiative to assess and enhance workforce diversity and inclusion in human and medical genetics and genomics. This NHGRI-funded effort is part of a strategic priority to increase diversity in the genetics workforce.

An immediate area of focus will be collecting and standardizing existing workforce demographics data from the peer societies and from leaders of institutions that represent academia, clinical, government, industry, and policy fields. This project will focus on conducting original quantitative and qualitative research through data collection from relevant professional scientific membership communities and organizations through surveys. These findings will be used to assemble a benchmarkable report that can serve as a foundation for setting future goals and metrics. The College encourages members to participate in this important initiative by completing the survey when you receive it. To learn more about the Human Genetics and Genomics Workforce Diversity Initiative, [click here](#).

Google Scholar Page Showcases Citation Data for ACMG Publications

ACMG recently created a [Google Scholar page](#) that displays the number of citations for all statements, guidelines, technical standards and practice resources published by the College. These citation metrics demonstrate the value, importance and impact of ACMG publications.

Every document that has been published by the College is shown on the Google Scholar page and the order of entries begins with the most-cited document. There are hyperlinks for document "title," "cited by," and "year" to help customize the search for data. By clicking on the document title, a detailed page about the specific paper appears, which provides the opportunity to go directly to the document on *Genetics in Medicine's* website, the citation list, or related articles in the area of study. A citation chart is also displayed for the document. Clicking on the citation number provides a gateway to the list of published articles that have cited that specific ACMG document. When selecting year, the list starts with the most-recently published documents by ACMG.

[READ MORE](#)

ACMG Launches #IGottheShot Campaign to Encourage COVID Vaccination

ACMG is excited to announce the launch of a new public relations campaign to encourage people to get vaccinated against COVID-19. The #IGottheShot campaign will feature photographs of ACMG members getting the COVID-19 vaccine. The goal is to show examples of healthcare professionals safely getting vaccinated and in so doing encourage others to get vaccinated. ACMG kicked off the campaign last

week with social media posts featuring ACMG member Beth A. Pletcher, MD, FACMG and ACMG President Tony Gregg, MD, FACMG. Thank you, Beth and Tony, for kicking off the campaign in such terrific fashion!

If you have, or plan to take, a picture of yourself getting the COVID-19 vaccine, ACMG invites you to post your photos to your own social media pages along with #IGottheShot and #MedicalGeneticsAwareness, and a tag to @TheACMG. This will allow us to find and share your posts. Or you can email your photo and a brief quote to [Reymar Santos](#) and we'll share your photo and quote for you on ACMG's social media channels and in other ACMG publications—please be sure to include your social media handles, if you have any, so we can tag you in our posts.



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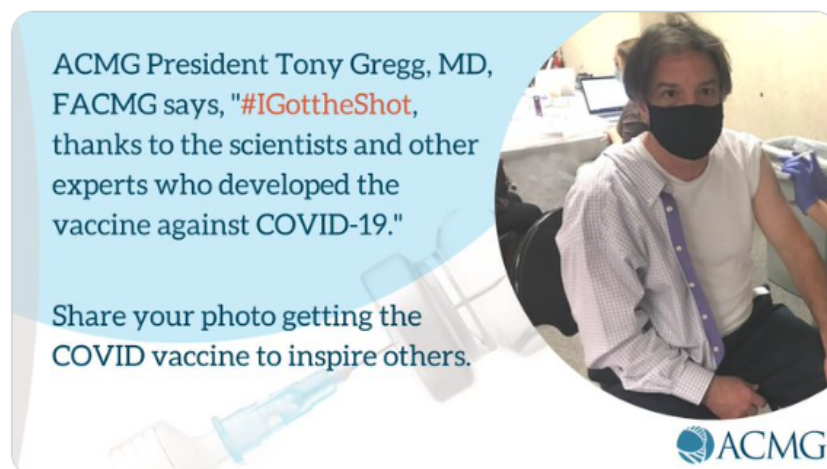
ACMG member Beth A. Pletcher, MD, FACMG says, "Be well, stay safe and have a wonderful 2021. Hold your loved ones close and roll up your sleeve!" Have you gotten your [#COVIDvaccine](#)? Post a photo with [#IGottheShot](#) & [#MedicalGeneticsAwareness](#) & be sure to tag [@TheACMG](#). [@pletcher_a](#)





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ACMG President Tony Gregg, MD, FACMG says, "[#IGottheShot](#), thanks to the scientists and other experts who developed the [#COVIDvaccine](#)." Have you gotten yours yet? Post a photo with [#IGottheShot](#) and [#MedicalGeneticsAwareness](#) — and be sure to tag [@TheACMG](#) so we can find your posts.



Third Annual Medical Genetics Awareness Week Set for April 13-16, 2021



ACMG will celebrate the third annual [Medical Genetics Awareness Week](#) April 13-16, 2021. The goal of Medical Genetics Awareness Week is to raise awareness of the invaluable contributions that medical genetics healthcare professionals make in the diagnosis, management and prevention of genetic diseases, and the difference these professionals make in the lives of patients and families.

We're already busy developing exciting new ways for people across the United States and around the world to unite in a shared recognition of the important work of medical geneticists. We are working on activities to attract students and trainees to careers in medical genetics and genomics; engage myriad groups and individuals in a common goal to increase the diversity and inclusion of our field; and shine a light on ACMG's advocacy efforts. Stay tuned for more information and plan now to join us April 13-16, 2021 in "Celebrating the Contributions of the Entire Medical Genetics Team to Patient Care and Public Health."

For all the latest information, follow ACMG on social media and join the conversation. You can find us on [Twitter](#), [Facebook](#), [Instagram](#), and [YouTube](#). Be sure to also check us out on LinkedIn, including our [public page](#), our private [members-only group](#), and our Annual Clinical Genetics Meeting [group](#).

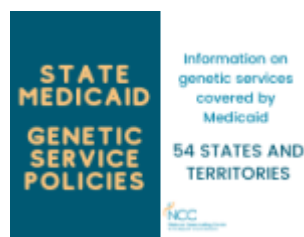
January 2021 GenePod: Is Newborn Screening for Metachromatic Leukodystrophy Coming Soon?



While newborn screening is gradually expanding in many states in the US and other countries to include some members of a class of diseases known as lysosomal storage diseases (LSD), there has yet to be a screening test available for one LSD called metachromatic leukodystrophy (MLD).

MLD is a rare neurogenetic condition that is often fatal and there is currently no widely available approved treatment. However, there are a number of promising therapies under development in ongoing clinical trials. Michael H. Gelb, PhD, professor of chemistry and biochemistry at the University of Washington, recently turned his attention to developing a newborn screening test for MLD, which he discusses on this month's episode of [GenePod](#), *Genetics in Medicine's* monthly podcast. Based on the results of more than 27,000 newborns screened for this [study](#), Dr. Gelb believes that a newborn screening test for MLD, upon completion of a second unblinded prospective study, could soon become part of the Federal Recommended Uniform Screening Panel.

NCC Update: State Medicaid Genetics Policies Database



Are you curious what your state's Medicaid program covers related to genetic services? If so, the National Coordinating Center for the Regional Genetics Networks ([NCC](#)), a cooperative agreement between ACMG and the Health Resources and Services Administration (HRSA), has the tool for you! Updated in November 2020, the NCC State Medicaid Genetics Policies database provides

information on the written policies of each state's Medicaid programs. Information within the database includes general coverage determinations, policies for children with special health care needs, and reimbursement policies on specific genetic tests. Explore the database by [clicking here](#).

If you have any questions about NCC or the State Medicaid Genetics Policies database, please contact NCC Senior Program Manager [Megan Lyon](#).

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Cooperative Agreement #UH9MC30770 from 6/2020-5/2024 for \$800,000 per award year.

This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

ACMG in the News

ACMG is proud to have participated in Mediaplanet's recent national Breast Health campaign, which was published in *USA Today*. This campaign advocates for increased funding for breast cancer research and better public education about risk factors and prevention. The campaign also highlights innovations in testing, treatment and aftercare, and elevates some of the leading voices among breast cancer "thrivers." ACMG was happy to contribute our medical genetics expertise to this broad campaign, which dispels common myths and spotlights the personal journeys and untold stories from survivors and thrivers including Olivia Newton-John and Amy Robach. To see the campaign, [click here](#). Be sure to check out the article by ACMG Vice President Clinical Genetics Susan Klugman, MD, FACMG, entitled "[Is There Evidence to Support BRCA and Other Inherited Breast Cancer Genetic Testing for All Breast Cancer Patients?](#)"

The National Institutes of Health (NIH) and *All of Us* Research Program recently [announced](#) that the *All of Us* program has begun to return genetic results to participants. In time, participants will receive pharmacogenetic information and information about genetic variants associated with increased risk for certain diseases. The *All of Us* program is basing their return of results on ACMG's secondary findings recommendations. ACMG's list is the only evidence-based, vetted list of genes for secondary findings and, as such, provides a valuable resource for research programs such as *All of Us* to refer to and study. However, it is important to note that the purpose of ACMG's list is to support analysis and interpretation of secondary findings generated from clinically indicated sequencing tests; the College does not advocate for the use of the list for population screening in the clinical setting as more research on population screening is needed, which programs like *All of Us* can provide.

ACMG is always interested in nominations for additions or deletions to the ACMG Secondary Findings Panel. For more information, see the [ACMG SECONDARY FINDINGS PANEL NOMINATION FORM \(to Add or Remove a Gene\)](#).

ACMG Welcomes 15 New Members

ACMG welcomes and congratulates 15 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 Member

Yiming Zhong, PhD, FACMG

Candidate Fellow Member

Marina T. DiStefano, PhD

Associate Members

Lila M. Aiyar, MGC, CGC

Kristy Lee, MGC, CGC

Megan Tucker, MS, CGC

Affiliate Member

Ravikumar Balasubramanian, MBBS

Trainee Members

Tiffany Guess, PhD

Merin Jose, MBBS

Aneta Kaczmarczyk, PhD, MS

Student Members

Kathryn Diamond Fosbenner, BS

Kathleen Gwilliam, BS

Arun Jacob, PharmD

Brianna Kristine Knode

Aditi Tayal

Brayden West

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

Accelerating Discoveries in Newborn Screening: New NBSTRN Website Designed to Support Researchers, Healthcare Professionals, State NBS Programs, Families and Advocacy Groups

The year 2021 begins with an exciting development for the Newborn Screening Translational Research Network (NBSTRN). Late last year, NBSTRN launched a new website designed to expand the tools and resources available to researchers, clinicians, state newborn screening programs, advocacy groups, parents and families. The improved website helps to realize NBSTRN's mission to foster collaboration among these stakeholders and facilitate newborn screening-related research to discover novel technologies, treatments and interventions.

A central goal for NBSTRN is to advance scientific and clinical understanding of conditions that are part of or candidates for nationwide screening. To support this goal, the new website features several data tools designed to provide secure access to millions of data points from groundbreaking studies and pilots available for data mining, visualization and secondary research. An update of the Longitudinal Pediatric Data

Resource (LPDR) includes de-identified, case-level, phenotypic and genomic data sets, and introduces two new data tools, the NBS Virtual Repository (NBS-VR) and the NBS Conditions Resource (NBS-CR). The NBS-VR provides national and state-level views of screening panels and disease incidence, where users can collaborate with state NBS programs to locate research samples and subjects. The NBS-CR provides a centralized resource of facts and statistics for both screened and candidate conditions and is designed to be an interactive resource for researchers, clinicians, parents and families to learn more about these conditions.

[READ MORE](#)

It's ACMG Membership Renewal Time—2021 Membership Renewal Deadline Is January 31, 2021



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 2021 Dues Renewal Form here](#). Renewal by phone is also available at 301-718-9603.

Renew your membership **by January 31, 2021** in order 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 ACMG Genetics Academy and access the ACMG Members Only sections of the ACMG website.

Don't forget! *Genetics in Medicine*, ACMG's official journal, has gone green. Online access and free downloads will remain the same for members, but if you wish to receive 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 the [ACMG membership department](#).

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Are you receiving ACMG emails on a regular basis? If not, visit your [ACMG Privacy Preferences page](#) to verify which types of communications you would like to receive.

We all get a lot of email! ACMG does not want to contribute to your email fatigue, so we ask you to choose which nonessential communications you receive. For example, on your privacy preferences page, you must opt in to receive communications about the ACMG Annual Clinical Genetics Meeting, ACMG Foundation, and ACMG educational opportunities. When making your selections, **you must check**

the box next to each topic about which you wish to receive email. If you do not explicitly opt in, you will not receive emails related to unselected topics.

If you have opted in to receive these or other member communications but are still not receiving our emails, we recommend asking your institution's IT department to "whitelist" communications from the ACMG (i.e., acmg@acmg.net). Many organizations protect their email systems by employing IP whitelisting. At its core, whitelisting is the addition of email addresses to a list of "acceptable senders," thereby explicitly granting permission to receive email traffic from those senders. Whitelisting ACMG will ensure that our messages will reach you.

If you need assistance with checking your ACMG privacy preferences, please email the [ACMG membership department](#) or call 301-718-9603.

2021 ACMG Annual Clinical Genetics Meeting Update



ACMG Annual Meeting Abstract Submission Deadline Extended One Week

ACMG has extended the Abstract Submission deadline by one week. Submissions will now be accepted until **Friday, January 15, 2021, 11:59 pm PT**.

The goals of the ACMG Annual Meeting are to present new scientific knowledge and provide attendees with research results and tools to translate genetic discoveries into state-of-the-art patient care. Abstracts selected as Platform Presentations will be presented in live streamed sessions during the meeting. Abstracts accepted as Posters will be presented as ePosters in a gallery format, available both during and after the meeting. Accompanying audio clips will be accepted for posters.

All accepted abstracts will be published in an online supplement of *Molecular Genetics and Metabolism*.

Visit the [abstract submission site](#) and start your submission. If you have already started the submission process, please [log in](#) to complete or make edits to your submission between now and the final deadline of January 15.

If you have any questions regarding abstract submission, please email them to the [ACMG education department](#).

Registration is now open!

Registration for the 2021 ACMG Meeting Virtual Experience is now open. The meeting will be brought to you through an innovative, interactive and engaging platform that will capture the excitement of being at the ACMG Annual Meeting. Learn, make connections and discover something new.

Visit the [ACMG Meeting Website](#) for meeting information and a link to the online registration site. Registration fees have been discounted by 30% over last year's fees but be sure to register by the Early Bird Registration Deadline of February 15, 2021 to save up to \$140.



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