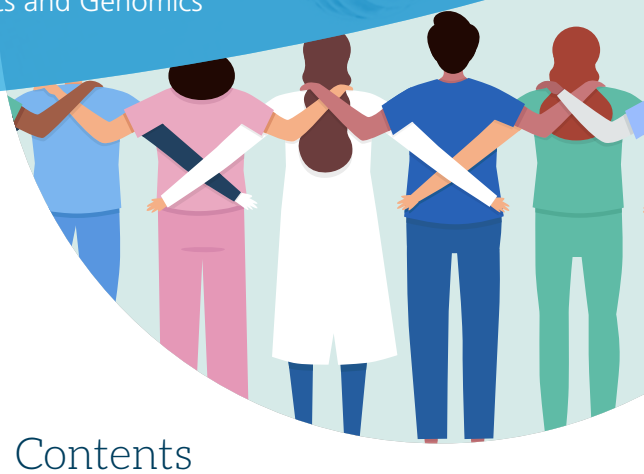
Advocacy Edition | Fall 2021

THE ACMG Medical Geneticist

The Newsmagazine of the American College of Medical Genetics and Genomics



Letter From the President

In 1869, *The Daily Cleveland Herald* quoted lawyer-poet John Godfrey Saxe* that "Laws, like sausages, cease to inspire respect in proportion as we know how they are made." This admonition would seem to be at odds with strategy number three of the ACMG Strategic Plan that states we will, "Advocate for the specialty to increase its visibility in the eyes of the public, regulators, health systems and payers." This issue of *The ACMG Medical Geneticist* focuses on the College's ongoing efforts to realize this strategic objective.

The political system is broken, so why bother?

It's difficult to avoid cynicism about the political process given the high degree of polarization that currently exists. While it sometimes seems as if there is no common ground between the political camps, the reality is that there is strong bipartisan support for science in general and medical science in particular. Major initiatives such as the Precision Medicine Initiative, the Cancer Moonshot, the All of Us program, and others have moved through Congress with relatively little opposition. Overall spending on science has increased under both Republican and Democratic administrations. While the College is primarily focused on clinical care, not research, the investment in research has accelerated the translation of advances in genetics and genomics into clinical care. Many College Fellows have generated evidence of clinical utility and improved outcomes that led to guidelines about the use of this information in clinical care, which in turn informs the development of rules, policies, and procedures that enhance access to these interventions. The importance of these activities is reflected in major legislative efforts such as the Newborn Screening Saves Lives Reauthorization Act, the Expanded Genetic Screening Act, the Medical Nutrition Equity Act, and many others that help the patients we care for. Despite our small size, we have a reputation as the 'go to' organization for matters concerning use of genetics in clinical care. We are frequently contacted by Congressional and Administrative staff soliciting our opinions on genetic and genomic topics that will be the subject of proposed legislation or rulemaking. These efforts result in legislation that is more likely to be aligned with the ACMG mission, vision, and values and promote our strategic initiatives. We also engage with the third branch of government, the Judicial, when court cases that impact genetic medicine, such as gene patents, are adjudicated.

Politics is local

Not all legislation or policy takes place at the national level. At any given time, actions in state houses have implications for the inclusion of genetics and genomics into clinical care. The challenge for the ACMG

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From the **Editor-in-Chief**

This edition of the Newsmagazine offers a plethora of information to support our theme of Advocacy. In the Q&A feature (page 4), President-elect Susan Klugman, MD, FACMG, explains how ACMG collaborates with the AMA to advocate for medical genetics. If you have any questions about how the AMA is supporting genetics or how we benefit from AMA membership, Susan offers that information in a clear and articulate form.

An article on page 10 describes how ACMG collaborates with other organizations to achieve our federal advocacy goals. ACMG may agree with an organization on one issue and disagree with the same organization on a different issue, but this does not impact the ability to work together to influence federal policy. A list of legislation pertaining to healthcare and genetics in the 117th Congress is provided on page 14. While most of these bills may not become laws, it is important to recognize that Congress is attentive to issues related to genetics.

Sheila Dobin, PhD, FACMG, Chair of the AGA Committee, has contributed an outstanding article - "Advocacy as a Daily Exercise." What is advocacy? How do you advocate? What are the costs of not advocating? These questions are answered here with astute and thoughtful comments and examples. Sheila also discusses the health benefits of advocacy. Advocating for a cause of importance to you promotes the cause and benefits your well-being – a win/win situation.

There is much more advocacy content for you in this edition, and I want to mention two articles focusing on diversity, which also fall under the broad umbrella of advocacy. The first article (page 13) presents the results of a 2019 survey distributed by ABMGG showing a lack of racial and ethnic diversity in the current clinical genetics workforce. To address this challenge, ACMG and ABMGG are working with other organizations to increase awareness of careers in medical genetics and genomics and are developing plans to interface with under-represented populations. The second article (page 9), is a summary of the Health Disparities in Medical Genetics Symposium presented in May. The symposium, which was planned by the DEI Committee, consisted of two sessions: "Raising Awareness about Health Disparities in Genetics" and "Opportunities to Reduce Health Care Disparities in Genetics through Education and Research." The program was excellent, and I encourage anyone who missed it to access it through the Genetics Academy.

Until next time –

Katy

Katy Phelan

Katy Phelan, PhD, FACMG, Editor
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is we don't have the resources to monitor activities in all 50 states, D.C., and territories. Focusing efforts to develop processes like the Recommended Uniform Screening Panel (RUSP), which provides information and evidence to states that manage their individual newborn screening programs, is an example of how the College can have an impact at the state level. We are also looking to develop a clearinghouse of state legislative activity to help our members identify initiatives in their state that could impact their practice, allowing them to effectively advocate within their state.

What can I do?

To achieve optimal outcomes, it is important for each and every one of us to advocate for genetics and genomics. Considering the current political environment, it's understandable to think that 'my' voice doesn't make a difference or won't be heard. In reality, elected officials are sensitive to what their constituents think about issues. In many cases, they may hear from only a handful of constituents on a given issue, so your opinion may influence their position. So, what can we do to make sure the ACMG voice is heard? Consider the following:

- Monitor ACMG communications for advocacy opportunities and contact your elected officials in support of the ACMG position.
- When the state legislative activity clearinghouse becomes available, check for activity in your state that you and your colleagues can engage in.
- If you become aware of an issue that you think impacts the practice of genetics and genomics, contact the ACMG advocacy staff (advocacy@acmg.net) with your information and concerns.
- Volunteer to serve on the ACMG Advocacy and Government Affairs Committee, or another ACMG committee that develops statements and guidelines that are used to support our advocacy efforts.

Thank you for all you do for the ACMG and for the patients we care for. Together, we can work to create a better environment for our patients and for us. I look forward to working with all of you.

Marc S. Williams, MD, FACMG
President

*This quote is frequently misattributed to Bismarck—thanks to the Quote Investigator site for their scholarship on its origin.

Meet ACMG's Newest Staff Members

Molly Caisse
NCC Project Coordinator

Molly joined ACMG in April 2021 as the project coordinator for the National Coordinating Center for the Regional Genetics Networks (NCC). Before joining NCC, Molly assisted with the coordination of research projects related to gastroenterology and health care quality improvement. She received a Bachelor of Arts in Psychology from the University of Massachusetts Amherst in 2018 and is currently pursuing a Master of Public Health with the University of New England.

After a couple of months with NCC, Molly said, "I have very much enjoyed my first few months working with the NCC and ACMG team. I am excited to continue to learn more about the field of public health genetics and to expand my public health career."

Barry Eisenberg, MS
Communications Manager

Barry joined ACMG as communications manager in late June. A strong writer and social media strategist, he received his bachelor's degree in English from The College of Wooster and a master's degree in Communications from Boston University. A native of Maryland, Barry comes to ACMG from the National Resident Matching Program and has had previous communications roles at the American Academy of Nursing, MedStar Washington Hospital Center, and the Plastics Industry Association. With more than 20 years of association experience, he brings a wealth of knowledge in media relations, public affairs advocacy, and meetings marketing. Barry stated, "I am eager to help build increasing awareness of genetics and ACMG, and to learn about the growing number of ways the field is developing new therapies for genetic disorders."

Raquel Fernandez
ClinGen Coordinator

Raquel began her role as ClinGen coordinator in May 2021. She joined ClinGen after working as the manager of the Molecular Lab at CVPath Institute, where she studied and curated sudden cardiac death variants associated with hypertrophic cardiomyopathy, as well as the impact of the COVID-19 virus on the heart. Raquel holds a B.S. in Cell and Molecular Biology, with a minor in Molecular Biology, Biochemistry, & Bioinformatics from Towson University, in addition to an A.A.S. in Biotechnology from Montgomery College. She has worked in both private and non-profit organizations in molecular biology and aspires to become a genetic counselor. Raquel reflects, "I can't think of a better place to grow than ACMG! It's inspiring to be working alongside experts in the field, and I look forward to supporting ClinGen's efforts and learning every step of the way!"

Gabrielle Jenkins, MSPH
Methodologist

Gabrielle joined the ACMG Foundation as a methodologist in May 2021. Her role involves providing methodological support for ACMG's Evidence-Based Guidelines (EBG) program. Gabrielle is an epidemiologist by training, with more than a decade of experience designing, planning, and analyzing public health and epidemiologic research. She has worked at academic research institutes and pharmaceutical companies examining health factors, national guidelines, and policies that impact population health. Gabrielle is a PhD candidate in the Department of Epidemiology at the University of North Carolina at Chapel Hill and will be defending her dissertation later this year. She is also a D.C. native. "I am excited and humbled to join the ACMG team, and eager to contribute to ACMG's EBG program."

Galata Tona
NBSTRN Data Engineer

Galata joined ACMG's Newborn Screening Translational Research Network (NBSTRN) team as a data engineer in May of 2021. Prior to working with NBSTRN, Galata was a Python developer working with the United States Coast Guard (USCG), where he was tasked with developing machine learning (ML) models to help the USCG manage recruitment and retention. He holds a master's degree in International Development from the University of Pittsburgh. One of his goals at NBSTRN is to develop models that make data visualization simpler and streamlined, by incorporating sophisticated ML processes and tools. He has experience working in Python, JavaScript, RDS and NoSQL databases. Since joining NBSTRN, Galata says, "I am thrilled to work with such incredibly smart individuals who are changing the lives of countless families by supporting groundbreaking research and making it available to the public."

Collaborating with the American Medical Association to Advocate for Medical Genetics

In a recent interview exclusively for *The ACMG Medical Geneticist*, Susan Klugman, MD, FACMG, FACOG; ACMG President-Elect; and Director, Division of Reproductive and Medical Genetics at the Albert Einstein College of Medicine and Montefiore Medical Center described how the American Medical Association (AMA) benefits medical specialty associations, like the ACMG; how ACMG members benefit from the AMA; and how our participation in the AMA House of Delegates (HOD) advances causes that are important to the field of medical genetics and genomics.

ACMG Medical Geneticist: What is the AMA Federation of Medicine, and why is it important for medical specialty associations like ACMG to be members?

Susan Klugman (SK): The AMA Federation of Medicine is a member organization that consists of more than 120 national medical specialty societies , including ACMG, and state medical associations. Each society appoints representatives to the House of Delegates (HOD). The number of delegates per society is determined by the size of the society's membership, similar to the way the US House of Representative is apportioned by population per state. Additionally, states and other organizations send their own delegates to the HOD, and there are also resident and medical student sections. In total, there are more than 600 voting delegates in the HOD, and each has a corresponding alternate delegate. Within the HOD, resolutions are introduced, discussed, and voted upon. The resolutions become policies that guide AMA's initiatives on various topics including state and federal legislation. In fact, many of the healthcare laws passed in Congress have been initiated on the floor of AMA's House of Delegates.

AMA Federation members give medical specialty associations a voice to influence AMA policies and guide their positions for federal and state legislation. But any delegate can introduce a resolution to the HOD, including medical students and residents. And because ACMG is a member of the AMA Federation, AMA often reaches out to directly seek

> **"Many of AMA's policies do, in fact, impact medical geneticists, directly and indirectly. In the past the AMA has been instrumental in coverage and reimbursement for genetic tests. They have a Code of Medical Ethics that includes genetic testing and counseling, protection of genetic test results, and reproductive decision-making."**

ACMG's advice on genetics-related legislation. AMA also often supports ACMG positions on certain topics and asks ACMG to reciprocate.

The AMA is the largest group of physicians in the country and is a very influential lobbying organization. AMA's mission is to promote the art and science of medicine and the betterment of public health. The AMA represents physicians in courts and state and federal legislative bodies across the nation, advocating for patient care and confronting public health crises.

ACMG: Does ACMG send delegates to the AMA meetings, and what happens at the meetings?

SK: ACMG has one delegate and one alternate delegate. Delegates must be AMA members and elected or selected by their sponsoring organization, and it is suggested that one member be involved in the organization's governance. Delegates should communicate with the board of their sponsoring organization as well as their membership and advocate for colleagues' views. Delegates should also advocate for their patients and to improve health care in general. For ACMG, I am the current delegate and Louanne Hudgins, MD, FACMG is the alternate delegate. Delegates attend two meetings a year, one in June and one in November. Some of the state medical associations also have geneticists in their delegation, but they are technically representing their state. The meetings are very busy with hundreds of resolutions for review and many meetings to discuss revisions. Some of the resolutions pertain to genetics, but many are broad and involve general health care and the practice of medicine. For the two most recent HOD meetings (which were virtual), the resolutions focused primarily on COVID-related issues, telehealth, and healthcare equity. In previous years the resolutions have ranged from resident education to e-cigarettes to confronting obesity. The meetings are very exciting! There are also reports from AMA's seven councils which provide information and recommend policies to the HOD on various issues impacting patients and physicians. I find the council on Science and Public Health particularly interesting.

> **"AMA also supports continuing medical education through their . Much of the content of the EdHub is the result of AMA's collaborations with other medical specialty organizations, and the ACMG is currently working with them to post some of our genetics offerings designed for non-genetics healthcare providers. This will greatly expand the exposure of these ACMG educational offerings."**

ACMG: How does AMA support improved integration of genetics in medicine? Do they advocate for federal policies that impact medical geneticists?

SK: Many of AMA's policies do, in fact, impact medical geneticists, directly and indirectly. In the past, the AMA has been instrumental in coverage and reimbursement for genetic tests. They have a Code of Medical Ethics that includes genetic testing and counseling, protection of genetic test results, and reproductive decision-making. Their Council on Science and Public Health has also published numerous reports and recommendations on genetics issues such as genetic discrimination, genome editing, and payment and coverage for genetic medicine.

Additionally, AMA has helped our colleagues by starting a precision medicine initiative where a high priority is the establishment of a Genomic Payment Advisory Group

(GPAG). Once active, this group will provide subject matter expertise to the AMA to guide their efforts to address issues that impact genetic and genomic testing.

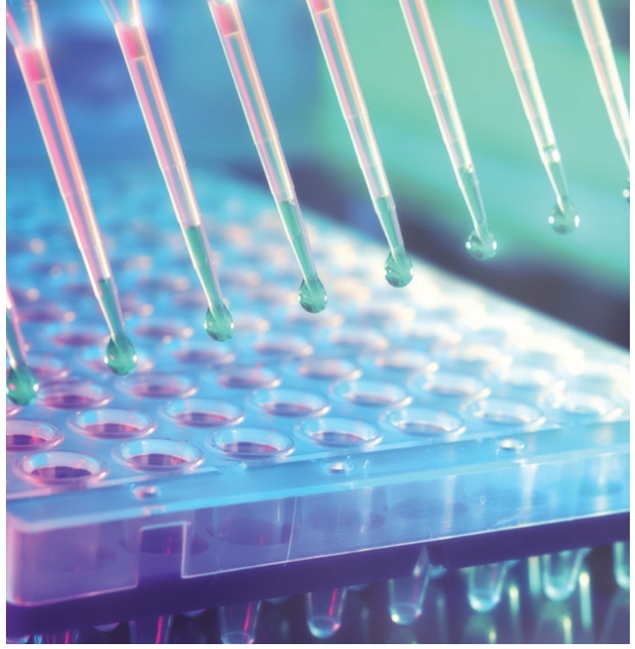
AMA also supports continuing medical education through their EdHub. Much of the content of the EdHub is the result of AMA's collaborations with other medical specialty organizations, and the ACMG is currently working with them to post some of our genetics offerings designed for non-genetics healthcare providers. This will greatly expand the exposure of these ACMG educational offerings.

Lastly, the AMA advocates and lobbies for a range of state and federal policies related to genetics. They advocate for appropriate coverage and reimbursement for physicians, including medical geneticists, and medical tests, including genetic and pharmacogenetic tests. In the past, AMA actively lobbied for federal legislation directly related to genetics such as the 21st Century Cures Act and the Genetic Information Nondiscrimination Act. Most recently, they have engaged with members of Congress about legislation aimed at improving coverage of various genetic services as well as broader topics that greatly impact genetic services such as telehealth, prior authorization, and reducing regulatory burdens.

> **"Because we are a member of AMA's federation, we can directly influence AMA policies and advocacy initiatives by introducing and voting on resolutions in the HOD. This includes policies on laboratory issues such as regulation of laboratory-developed tests and medical coding for clinical tests, so the benefits apply to all medical geneticists."**

ACMG: How do ACMG's members benefit from the College's membership with AMA?

SK: Because we are a member of AMA's federation, we can directly influence AMA policies and advocacy initiatives by introducing and voting on resolutions in the HOD. This includes policies on laboratory issues such as regulation of laboratory-developed tests and medical coding for clinical tests, so the benefits apply to all medical geneticists. And any ACMG member can always reach out to me with suggestions for new resolutions. In addition, AMA will reach out to ACMG directly to seek our advice on genetics-related issues, including state and federal legislation. While ACMG focuses primarily on issues directly related to genetics, we rely on AMA to take the lead for broader issues in medicine that still impact our field such as affordable access to healthcare, truth in advertising, and medical billing and coding. Requests from the AMA are often received by the ACMG office and fielded by Michelle McClure, PhD, ACMG Public Policy Director and CEO Max Muenke, MD, FACMG. If support is requested, the statement/request is summarized and passed on to the ACMG Board of Directors. In some instances, a request may also be reviewed by ACMG's Advocacy and Government Affairs Committee or another relevant committee before being sent to the Board of Directors. Requests for support can come in all forms, but most often we are being asked to sign onto a letter or statement. There can be weeks where we receive numerous requests ranging from CPT coding to mandatory vaccinations.



ACMG: Why should physician members of ACMG also become individual members of AMA, and how can they become more involved with the AMA?

SK: The AMA offers a variety of resources to its individual members, including educational and professional resources, webinars, invitations to special events, and opportunities to participate in AMA workgroups and member surveys. There are also other benefits such as discounts on insurance, cars, gym memberships, car rental and travel. Many of our ACMG physician members are also members of the AMA. In fact, it does not cost ACMG members anything extra to be a member of both! ACMG membership is only $430 if you are also a member of the AMA ($420 membership fee) whereas ACMG dues for non-AMA members is $830. The reason for this is that ACMG must have a certain percentage of AMA members represented among our physician voting membership in order to maintain our place in the HOD. So, AMA membership benefits individuals, ACMG, and the specialty of medical genetics as a whole.

CEO CORNER

Dear Members of the ACMG Family, Friends, and Colleagues,

"If you want to go fast, go alone. If you want to go far, go together." This African proverb is true for every aspect of what we do at ACMG, but probably more so for advocacy. Not only is advocacy the focus of my column, but also of this entire issue and of ACMG's Strategic Plan Update, which aims "to advocate for the specialty to increase its visibility in the eyes of the public, regulators and payers." The team that contributes to ACMG's advocacy includes volunteers on various committees (Advocacy and Government Affairs and Economics of Genetic Services, as well as committees that develop position statements and guidelines e.g., DEI, SELI, Lab QA, PP&G, Therapeutics), the entire ACMG membership, and, of course, our staff under the leadership of my colleague Dr. Michelle McClure, ACMG's public policy director. We also collaborate with numerous other provider and patient organizations with shared goals.

While we often think of government affairs, advocacy encompasses so much more. Advocacy is the act of supporting a cause or attempting to influence an outcome. ACMG strives to improve health care through the responsible application of genetics and genomics, and there are numerous aspects of our strategic plan designed to achieve that outcome. Here are some of the topics from our strategic plan that I am particularly passionate about: diversity, equity and inclusion; education; and workforce development. Following our 2019 US medical genetics workforce study (https://www.nature.com/articles/s41436-021-01162-5) I have initiated ACMG's Workforce Development and Optimization Committee, now led by Dr. Cynthia Powell, FACMG. Together with Dr. Mimi Blitzer, FACMG from ABMGG, we have outlined initial areas and proposed long-term solutions in our Invited Comment entitled; "Become an Ambassador to Recruit the Next Generation in Genomic Medicine" (currently in production for publication in ***Genetics in Medicine***). ACMG also participates in a larger workforce effort together with colleagues from ASHG, ABMGG, NSGC, and NHGRI with the long-term goal of increasing awareness of our field.

Life-long learning is paramount for all healthcare professionals to provide optimal patient care. Educating medical students in medical genetics and genomics can be a challenge, especially in those medical schools that do not have board-certified clinical or laboratory geneticists on their staff. In response, ACMG is considering a program to pilot in three medical schools with a virtual lecture series by volunteer geneticists. Lastly, we have had discussions with senior leadership from one of four Historically Black Colleges and Universities (HBCUs) with medical schools interested in starting a medical genetics and genomics residency and fellowship program at their institution.

Please contact Dr. Michelle McClure and/or me for more information on ACMG's advocacy. Enjoy reading this issue of *The ACMG Medical Geneticist*.

Warm regards,

Max Muenke

Maximilian Muenke, MD, FACMG

The National Coordinating Center for the Regional Genetics Networks (NCC), a cooperative agreement between ACMG and the Health Resources and Services Administration (HRSA), works to improve access to genetic services for underserved populations.

One way NCC works to accomplish this mission is to provide information about the genetics policy landscape across the country to genetics providers and individuals and families.

Check out the new or updated resources we have developed as a part of the Genetics Policy Hub to the right.

For questions, please email Megan Lyon (mlyon@nccrcg.org).

GPH
Genetics Policy Hub
An Initiative of the National Coordinating Center for the Regional Genetics Networks

UPDATED RESOURCES

Our newest resource is the Genetics Policy Hub Twitter account. Get the most up-to-date information about proposed legislation and regulation at the state and federal level by following @GeneticsPolicy!

Are you not on Twitter but would like to see what genetics policies are being proposed in your state? No problem! Check out our interactive map that highlights proposed regulation and legislation at https://nccrcg.org/regtrack/.

The State Medicaid Genetics Policies Database collects written policies from each state's Medicaid program to better understand coverage of genetic services for Medicaid patients. This database was recently updated to include the latest information from each state Medicaid program. Check it out at https://nccrcg.org/lift/state-medicaid-genetics-policies/.

Finally, we are excited to announce that all of these tools and more will be available on a new, fully integrated website later this fall. Be notified when this website launches by following NCC across social media at @nccrcg.

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.

2021 Updates in Health Disparities in Medical Genetics Symposium

Unequal access to health care and worse health outcomes have been documented for racial, ethnic, and gender minorities compared with White individuals. A workgroup from the ACMG DEI Committee planned the first-ever ACMG symposium on healthcare disparities in Medical Genetics. Thanks to unrestricted educational grants from Myriad Women's Health and Bionano Genomics, registration and CME/CEU credits were free. The symposium was presented in May and moderated by Fuki M. Hisama, MD, FACMG, and Cinthya Zepeda, PhD, FACMG. Those who missed it live, may access the program through the Genetics Academy at www.acmg.net until 2023*.

The first session was entitled "Raising Awareness about Health Disparities in Genetics." Edwin Lindo, JD, from the University of Washington opened the session with an amazing historical overview of "The History of Race Medicine." This was followed by talks focused on disparities affecting women's health. There was an outstanding presentation on disparities in prenatal care by Dr. Judette Louis, chair of OB-GYN at the University of South Florida, and another on genetics services for hereditary breast ovarian cancer, particularly among Black women, by Dr. Tuya Pal from Vanderbilt University.

The second session was entitled "Opportunities to Reduce Health Care Disparities in Genetics Through Education and Research." Laura Amendola, MS, genetic counselor and scientist at the University of Washington, described her group's research on improving genetic counseling for historically underserved patient populations. Shoumita Dasguspta, PhD, from Boston University presented her work on implicit bias regarding disability. Justin Hentges, acting director of engagement for the National Institutes of Health *All of Us* Program, discussed the aims of the most diverse health database in history. *All of Us* is an ongoing, innovative research effort to enroll one million participants, mostly from underrepresented groups in biomedical research, to collect many types of information over time–including genomic data to improve human health. A unique aspect of the program is the ongoing relationship with the participants, who are true partners.

Fuki M. Hisama, MD, FACMG, who co-moderated the symposium, was quoted as saying, "The Diversity Symposium was a home run and exceeded all of our expectations! I want to thank all of our outstanding speakers and our sponsors. Over 450 people registered for the symposium, which proves there is a high level of awareness and interest in diversity and equity issues among our community."

"The Diversity Symposium was a home run and exceeded all of our expectations! I want to thank all of our outstanding speakers and our sponsors. Over 450 people registered for the symposium, which proves there is a high level of awareness and interest in diversity and equity issues among our community."

*Note – Dr. Lindo's presentation available for viewing through Aug. 31, 2021.

Collaborating to Achieve Our Advocacy Goals

ACMG is ambitious with our goals to advocate for federal policies to improve the use of genetics in medicine. We act on a wide range of issues, including patient access to genetic services, billing and coding, appropriate regulations for laboratory testing, coverage and reimbursement for genetic services, and funding for public health programs like newborn screening. But successfully changing or influencing federal policies is not easy, and we certainly do not achieve our goals by acting alone.

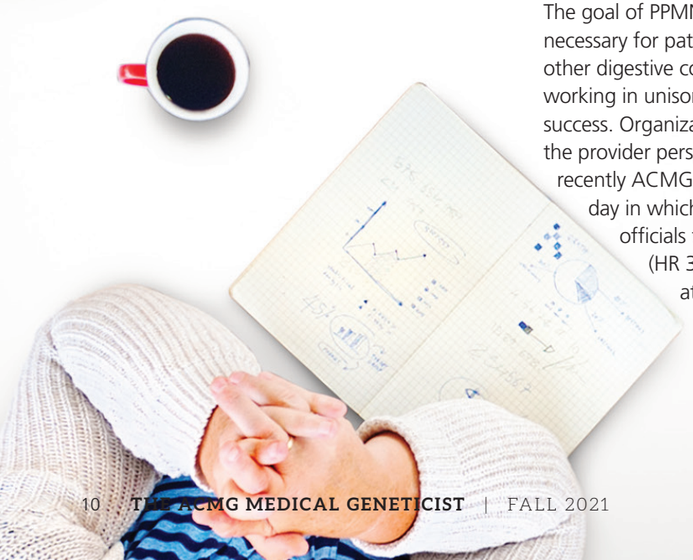
Collaboration is a critical tool in advocacy. For ACMG, building networks of allies with shared interests is an important part of our strategy. We work with numerous patient organizations, medical associations, laboratory organizations, genetic testing companies, pharma companies, academic institutions, human rights organizations, and a variety of other professional organizations as needed to achieve desired outcomes. For example, the Patients and Providers for Medical Nutrition Equity (PPMNE) is a formal coalition consisting of more than 40 patient and provider organizations. The goal of PPMNE is to improve access to medical foods and formulas necessary for patients with inherited metabolic conditions and certain other digestive conditions. While patients have their own stories to tell, working in unison towards a shared goal increases the likelihood of success. Organizations like ACMG support these patient voices by adding the provider perspective and reinforcing the patients' message. Most recently ACMG's advocacy team participated in a congressional advocacy day in which hundreds of patients met virtually with their elected officials to ask them to support the Medical Nutrition Equity Act (HR 3783 / S 2013). ACMG and other provider organizations attended these meetings to emphasize a united patient and provider message. We also utilized our resources to facilitate the virtual meetings for patient advocates representing a variety of conditions. While we still have a lot of work to do to get this legislation passed, we have made tremendous strides as a result of the coalition's collective and coordinated efforts. (More information about the PPMNE can be found at www.nutritionequity.org.)

ACMG's advocacy portfolio covers a variety of issues impacting genetics in medicine, so we collaborate with different groups depending on the topic. In fact, it is not uncommon for organizations to work together on one issue and then oppose each other on another. For most organizations, each issue is evaluated separately and handled professionally so that opposition on one topic does not impact our ability to work together on another. For example, ACMG recently expressed our support for the Verified Innovative Testing in American Laboratories (VITAL) Act (S 1666) which has been openly opposed by some organizations we are currently collaborating with on other issues, such as patent eligibility reform.

"Regardless of the situation, working together with other organizations is necessary to achieve our federal advocacy goals. It reinforces our message and expands our outreach capabilities. But we cannot measure success in the number of letters sent or meetings held. Success is realized when policies are implemented or modified to improve healthcare, even if those changes are incremental."

Success with our advocacy program sometimes requires that we work to find a compromise with those who disagree with our position. For example, part of ACMG's strategic plan includes efforts to allow for reimbursement of laboratory geneticists' professional interpretation of genetic tests. We know that some notable medical associations currently have concerns about this goal. We could easily move forward and introduce legislation anyway, but we would certainly encounter major challenges to passing such legislation. Therefore, we must engage with these organizations ahead of time to ensure that our language is not opposed. Not only does this increase our likelihood of success, but it also reinforces the respect we have for our professional colleagues.

Regardless of the situation, working together with other organizations is necessary to achieve our federal advocacy goals. It reinforces our message and expands our outreach capabilities. But we cannot measure success in the number of letters sent or meetings held. Success is realized when policies are implemented or modified to improve healthcare, even if those changes are incremental. At ACMG, we know that advocacy successes are not ours alone. We could not achieve our federal advocacy goals if not for our numerous collaborators, and we appreciate their time and support.



Building Partnerships to Advance Clinical Curation: The ClinGen Stakeholder Partnership Working Group (WG)

by **Laura V. Milko, PhD**
Deborah I. Ritter, PhD
Annabelle M. Frantz, BS
Aleksandar Milosavljevic, PhD
Michael S. Watson, MS, PhD, FACMG on behalf of the ClinGen Stakeholder Partnership WG

As of July 2021, over 4,400 genes have been implicated in human diseases (omim.org) with more than 750 million genetic variants identified in individuals (gnomad.broadinstitute.org). The task of accurately associating variants with human diseases is vast and labor intensive, requiring evidence-based, standardized, and scalable approaches. The National Institutes of Health (NIH)-funded Clinical Genome Resource (ClinGen), of which ACMG is a proud partner, has developed robust standards and infrastructure to enable international collaborators to share data and expertise. ClinGen's multidisciplinary Expert Panels span numerous disease areas to provide transparent and trusted classifications of clinically relevant genes and variants. Variant pathogenicity classifications are recognized by the Food and Drug Administration (FDA) as clinically valid for use by laboratories and manufacturers.

The ClinGen Stakeholder Partnership Working Group (SPWG) engages stakeholders interested in accelerating and scaling ClinGen's expert curation. Stakeholders include commercial genetic testing laboratories, medical device and pharmaceutical companies, genomics and informatics developers, healthcare insurers, professional medical associations interested in diseases related to their specialty, and genetic disease patient support groups. The SPWG is responsive to feedback on ClinGen's portfolio of activities to better understand and support the priorities of its diverse stakeholders.

The SPWG is building new partnerships with patient advocacy groups and professional medical societies to address the needs of patients and clinical specialists through advancement of the ClinGen expert curation ecosystem. An exploratory collaboration with the Children's Tumor Foundation is assessing interest in developing a Neurofibromatosis Expert Panel. ClinGen also has an ongoing sponsorship of the ClinGen Myeloid Malignancy and Platelet Disorders Expert Panels by the American Society of Hematology. The SPWG welcomes communication from all ClinGen stakeholders and looks forward to engaging with others with an interest in ClinGen's work. For those interested in potential partnership opportunities, please contact stakeholder_partners@clinicalgenome.org.

Minding the Gap: Understanding the Diversity Gap in Medical Genetics and Genomics

by **Matthew Taylor MD, PhD, FACMG, Secretary, ABMGG, University of Colorado, Anschutz Medical Campus** and **Miriam G. Blitzer, PhD, FACMG, Chief Executive Officer, ABMGG**

In 2019, ABMGG distributed an electronic survey to all practicing diplomates to support the ACMG and National Coordinating Center for the Regional Genetics Networks in a collaborative evaluation of the current makeup and activities of the US clinical genetics workforce [published 2021 PMID: 33941882]. Focused on clinical geneticists involved in direct patient care, the study represented an update from the last major workforce survey (2003) and was motivated both by a desire to understand any changes in the practicing clinical genetics workforce and to prepare for future demands and opportunities. From the survey results received from nearly 500 clinical geneticists, racial and ethnic diversity in the current clinical genetics workforce is less than that measured across the US physician population. The survey found that 79% of clinical geneticists reported their race or ethnicity as White, with only 11%, 8%, and 1% reporting as Asian, Hispanic, or Black, respectively. With fewer than 20% of respondents identifying as non-White, the data highlight the fact that recruitment and retention of non-White physicians to the clinical genetics specialty substantially lags behind the reported 44% non-White makeup of active US physicians in general. In particular, continued demographic trends toward an increasing percentage of non-White individuals in the US will likely further highlight disparities between the clinical genetics workforce and the diverse population they serve. This survey also noted that clinical geneticists are predominately concentrated at academic medical centers, highlighting that access to clinical genetic services outside of major metropolitan areas may be challenging to some patients and communities.

In order to better understand and address diversity challenges in the medical genetics and genomics community as a whole, the ABMGG is urging ALL diplomates, regardless of specialty, to include or update these demographic data in their ABMGG diplomate portal. This information will complement the existing clinical workforce survey data, which had a response rate of 40% among those who received the survey. In addition, the ABMGG is engaging both clinical and laboratory trainees to capture demographic data from the next generation of medical geneticists. Finally, the ABMGG, working with ACMG and other medical genetics organizations, has prioritized plans to increase exposure to the field of medical genetics and genomics among undergraduates, graduate students and medical students as well as develop strategies to interface with under-represented communities and populations.

Diplomates can update their demographic and contact information in their portal through the ABMGG website at http://www.abmgg.org/ or email abmgg@abmgg.org.

Legislation in the 117th Congress

After the COVID-19 pandemic resulted in a very disrupted 2020, the 117th US Congress is mostly back to business as usual. Healthcare is a major priority for many, and we're seeing significant attention to issues such as telehealth, physician workforce, and disparities in health care. For example, Congress has introduced dozens of bills related to telehealth, such as the CONNECT for Health Act of 2021 (HR 2903 / S 1512) and the Telehealth Modernization Act (HR 1332 / S 368). We are also seeing increased attention on issues directly related to genetics such as access to genetic screening and testing, privacy of genetic information, and use of genetic testing during immigration. The table below lists several bills that may be of particular interest to medical geneticists, and this list will undoubtedly increase in length. For instance, ACMG has been in contact with multiple congressional offices who are developing bills to improve coverage of and access to genetic testing for specific patient populations such as critically ill pediatrics or patients diagnosed with rare cancers. While members of Congress often seek out ACMG's input, it does not necessarily mean that we will establish a position on their bill.

Keep in mind that the majority of these bills likely will not become law. In fact, in the past few sessions less than 5% of introduced bills were passed. Nonetheless, it is clear that Congress is beginning to pay more attention to issues related to genetics, which means it is more important than ever for medical geneticists and organizations like ACMG to engage with and educate Congress about genetics. ACMG members can do this on their own by reaching out to their elected officials about specific bills or other issues in genetics for which there may be a legislative fix. They can also engage by volunteering for relevant ACMG committees or workgroups, responding to ACMG calls to action for specific legislation, and engaging with your own institution's government affairs team to encourage their support on ACMG positions.

Newborn Screening Saves Lives Reauthorization Act of 2021 (HR 482 / S 350)	Would reauthorize newborn screening programs administered through CDC, NIH, and HRSA; would require a National Academy of Medicine study on modifications to newborn screening
Expanded Genetic Screening Act of 2021 (HR 1439)	Would require Medicaid programs to cover noninvasive genetic prenatal screening for all pregnant patients regardless of age or other risk factors
Reducing Hereditary Cancer Act of 2021 (HR 4110)	Would allow Medicare to cover cancer genetic screening and preventive surgeries as recommended by NCCN guidelines
Medical Nutrition Equity Act of 2021 (HR 3783 / S 2013)	Would require public and private payers to cover medical nutrition for patients with inherited metabolic conditions and certain other digestive conditions
Access to Genetic Counselor Services Act of 2021 (HR 2144 / S 1450)	Would recognize genetic counselors as Medicare providers and permit them to bill under the physician fee schedule
Verified Innovative Testing in American Laboratories (VITAL) Act (S 1666)	Would clarify that LDTs are regulated solely by CMS through CLIA; would require public meetings to discuss needs for CLIA modernization
Verifying Accurate, Lead-edge IVCT Development (VALID) Act (HR 4128 / S 2209)	Would clarify that FDA has the authority to regulate all LDTs; would create a new FDA regulatory pathway for in vitro clinical tests which would treat LDTs and manufactured tests the same
Ending the Diagnostic Odyssey Act of 2021 (S 2022)	Would create a Medicaid state option for coverage of whole genome sequencing in children with a suspected genetic or undiagnosed condition (additional related bills expected soon)
Reunite Every Unaccompanied Newborn Infant, Toddler and other children Expeditiously (REUNITE) Act (HR 530)	Would require DHS and HHS to promulgate regulations to expedite reunification of families separated during immigration, including emphasis on protections to be implemented when genetic testing is needed to reunite families
End Child Trafficking Now Act (HR 2219 / S 903)	Would require that genetic testing be performed to verify family relationships for anyone crossing the border with a child
Protecting Personal Health Data Act (S 24)	Would require ONC and FTC to promulgate regulations to strengthen privacy and security protections for personal health data, including genetic information, collected or used by direct-to-consumer companies, wearables, and other consumer devices not generally covered by HIPAA
Protect Act (S 322)	Would add new provisions, including ones related to preexisting conditions and genetic discrimination, to HIPAA for private health insurance plans

Information is current as of August 2, 2021. Inclusion on the table above does not reflect presence or absence of an ACMG position. For questions, please contact ACMG's policy team at advocacy@acmg.net.

Application Launched for 2022-2024 NIH-ACMG Fellowship in Genomic Medicine Program Management: Deadline is December 1, 2021

ACMG Foundation for Genetic and Genomic Medicine
Better Health Through Genetics™

The NIH-ACMG Genomic Medicine Program Management Fellowship was established in 2017 as a partnership among ACMG and four agencies of the National Institutes of Health (NIH) - the National Human Genome Research Institute (NHGRI), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute on Minority Health and Health Disparities (NIMHD), and the All of Us (AoU) Research Program. "The NIH-ACMG Genomic Medicine Program Management trains future leaders in fields of genomic medicine and program management. I am delighted that ACMG and various NIH Institutes and Programs have partnered to collaborate on this important mission," stated Max Muenke, MD, FACMG, CEO of ACMG, when asked about the program.

This two-year fellowship seeks to increase the pool of health practitioners trained in managing research and implementation programs in genomic medicine, which ACMG considers to be the use of genomic information as part of an individual patient's clinical care. This supports strategy two of the ACMG Strategic Plan, which is to secure and expand the professional workforce of medical genetics and genomics (Clinical Geneticists, Laboratory Geneticists) and keep it viable.

The application for the 2022-2024 Fellowship was launched September 1, 2021, and applications will be accepted through December 1, 2021. Two fellowships are awarded annually and administered primarily by the ACMG, in collaboration with a fellowship committee of NIH representatives. During the fellowship, each fellow will have the opportunity to work at a participating NIH agency for 3-month rotations as an associate program director and/or as an assistant to program leaders in the NIH Intramural Research Program.

When asked about the importance of this program, Teri Manolio, MD, PhD , director of the Division of Genomic Medicine at the National Human Genome Research Institute stated, "We see this fellowship as a critical partnership between ACMG and several NIH partners to develop leaders capable of implementing new genomic medicine programs at NIH and at academic centers and organizations nationwide."

Education Offerings in 2021 Have Been Outstanding and Diverse

by **Jane Radford, MHA, CHCP**
ACMG Director of Education

ACMG GENETICS ACADEMY

Education programming has been exceptional in 2021. The ACMG Genetics Academy pivoted to more e-learning offerings when the pandemic hit in March 2020, and we have continued to support our remote learners' needs with more live webinars, recorded content, and a new Qbank. Highlights for 2021 have been the *ClinGen Somatic Cancer and VICC Virtual Molecular Tumor Board Case Series, 2021 ACMG Genetics and Genomics Review Course, LGG Mentored Cases in Molecular Genetics and Genomics and Cytogenetics and Genomics, LGG Foundational Specialty Training Courses,* and the *2020 and 2021 ACMG Clinical Genetics Meeting Digital Edition*. We offer CME credits for other activities that are hosted in the ACMG Genetics Academy, including the *NCC Knowledge Nugget Series: SMA ACT Sheet* and the *ABMGG Longitudinal Assessment Program CertLink* self-report module.

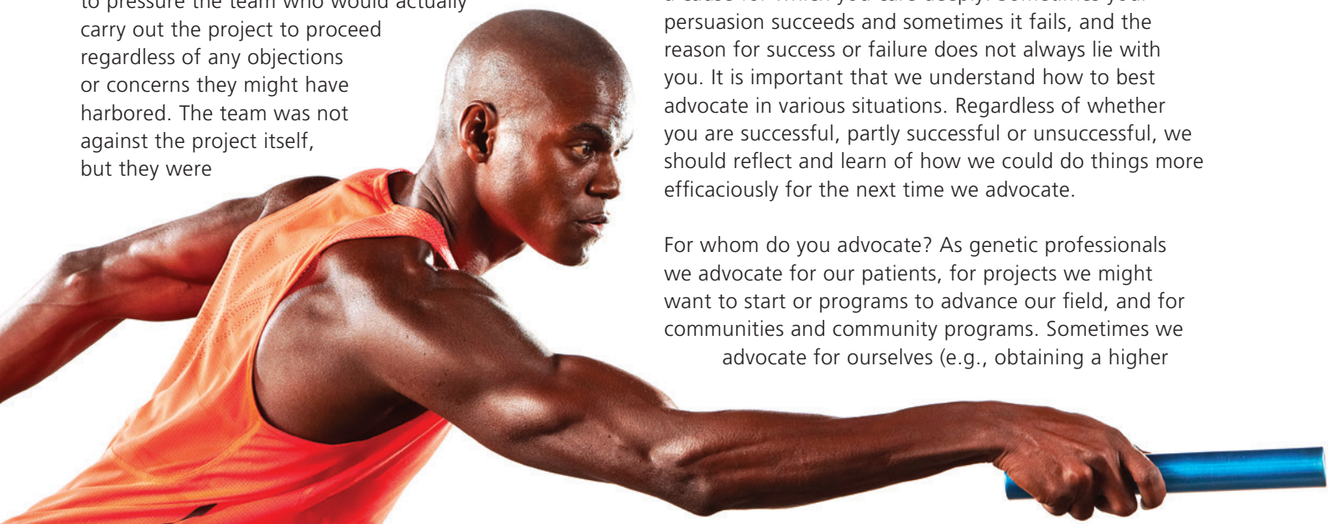
We currently have 6,600 learners accessing over 180 courses in the ACMG Genetics Academy. Members make up 30% of the learners, and we have a large outreach to genetic counselors, students, and trainees. ACMG is very grateful to our incredible faculty for their contributions in programming. Their expertise, energy, and willingness to fill the education gaps for our learners has been outstanding. It truly is a team effort as supporting our members and education outreach are paramount to the College's mission.

Advocacy as a Daily Exercise

by **Sheila M. Dobin, PhD, FACMG**
Chair, Advocacy and Government Affairs Committee

Advocacy is like exercise; some people practice daily and some engage weekly, monthly, or yearly. It is a rare person who never speaks on behalf of others. You advocate for your family, often without being aware of it. You advocate for your patients and your institution. Despite the daily experience you have advocating for yourself and others, it is true that we can all improve with training. As with training and exercise, the more you do it, the more effective and joyful advocacy becomes.

Let me start by sharing a story. Leaders of a company described a Principal Investigator (PI) of a proposed project as a "visionary." He could describe his vision for a project and was adept at communicating that vision to his company's C-suite. He was able to convince many others of the importance of his project, and he was even able to gain the interest of outside investment firms without any evidence to support the likelihood of success. This possibility of funding for the project together with his promises caused the leaders to support his visions whole-heartedly. It also led him to pressure the team who would actually carry out the project to proceed regardless of any objections or concerns they might have harbored. The team was not against the project itself, but they were concerned by the lack of coordination, leadership and details for the project. Two years into it, things began to fall apart. The PI complained that the project was not progressing fast enough. The research team executing the project was concerned about the quality of their research due to lack of clarity of procedures and asked to pause sample testing while they better defined the research protocols. The team was called into numerous meetings where they "felt like they were being called to the principal's office". Finally, a meeting was held with the PI, the research team executing the project, the project manager, the VP overseeing this research endeavor and a manager from the finance department. Despite the concerns repeatedly voiced by the team, the attitude of the PI and the VP at the end of the meeting was "just get it done". Individuals working on the project now feel they have no choice but to move at a faster pace regardless of the quality. They will address issues as they arise and proceed even though results from early sample testing may be unreliable.



Now you might be asking, what does this have to do with advocacy? This story has many elements of advocacy that worked and many elements of advocacy that did not. From this story and those from your own ventures into advocacy, we can learn how to do it better.

There are multiple definitions of advocacy. One of my favorites is the ability to persuade others to care about a cause for which you care deeply. Sometimes your persuasion succeeds and sometimes it fails, and the reason for success or failure does not always lie with you. It is important that we understand how to best advocate in various situations. Regardless of whether you are successful, partly successful or unsuccessful, we should reflect and learn of how we could do things more efficaciously for the next time we advocate.

For whom do you advocate? As genetic professionals we advocate for our patients, for projects we might want to start or programs to advance our field, and for communities and community programs. Sometimes we advocate for ourselves (e.g., obtaining a higher salary or more resources for our department). The ACMG Advocacy and Government Affairs Committee advocates on behalf of the College's membership and their patients.

How do you pick your causes and when do you advocate? You advocate when you identify a problem and think that there is a solution to that problem. In the example above, the PI was able to identify a need and had a solution that would improve patient care. He was able to advocate for his vision. To advocate appropriately, you must be passionate about a project, idea or issue. The PI in the scenario had that passion. There may be multiple things that you are passionate about. Perhaps it is laws passed by federal or state legislators. Perhaps it is causes such as the environment or food insecurity or dietary needs of our genetic patients. We are often passionate about multiple things, but you may not be able to successfully advocate for numerous causes, issues or ideas by yourself. Consider being a strong advocate leader in one area, then you can support colleagues who advocate for your other interests such as through monetary means or letters of support. In the case above, the PI had one project he was passionate about and to which he dedicated his time. For the issue that you select to become an advocacy leader in, learn everything you can about it including who the stakeholders are for that issue. Gather as many different viewpoints on the issue as you can.

How do you advocate? Have an "elevator speech" ready - be able to explain your cause and your passion within two minutes. Advocacy takes time, work and planning. Convincing others what might be best and worthy of their time may take multiple introductions. One of the best advocates I knew was often described as a horse fly, continually buzzing and biting at the horse until they got a reaction. The PI had this tenacity. Have a good story line that people can relate to... In the scenario I provided, the PI did well. He had a good story to tell. Do not give up when someone says your idea for something will not work. Instead ask them to share with you what they see as obstacles to success. In the example, the researcher did not want to hear about obstacles. Once you know the obstacles, you can design solutions and go back and present to the individuals with issues again.

You must also get the right people on board. In the case of the researcher, having the support of the C-suite was crucial, but you also need people to work on the project. Not only do you need the "worker bees," but you need their support. Find individuals who are as interested in the project as you are, and ask them to be part of the team. In addition, you need to listen to them, respond and give solutions. John Daly, in his book entitled *Advocacy: Championing Ideas and Influencing Others* writes "Whoever the source, effective advocates don't ignore input. Instead, they assess when in the development cycle inclusion is optimal." He also reminds us to not forget the home team. "Advocates know it is crucial to make sure they have continued support of their home team—the team of people who do all of the basic work on the idea." This is what an advocacy leader must be able to do to keep their project afloat. You must be an active listener and respond to concerns. In the example, the PI was not an active listener nor did he respond to concerns with possible solutions. The individual just wanted the project to be done, regardless the cost.

What are the costs of advocating versus not advocating? The obvious cost of not advocating is that your voice won't be heard on an issue important to you. If that issue moves in the wrong direction or is resolved negatively, individuals affected will be hurt and you will wish you had done more. If we feel that it is too much trouble to advocate, there is a cost. We will not be able to benefit society or specific individuals. In their 2005 paper *Pursuing Happiness: The Architecture of Sustainable Change*, Sonja Lyumbomirsky et al. theorized that there are three causes of happiness. One of those is intentional activity which accounts for 40% of happiness. Advocacy is an intentional activity. Eric S. Kim et al., in their 2020 article *Volunteering and Subsequent Health and Well Being in Older Adults: An Outcome-Wide Longitudinal Approach*, concluded "participants who

volunteered ≥ 100 hours/year (versus 0 hours/year) had a reduced risk of mortality and physical functioning limitations, higher physical activity, and better psychosocial outcomes (higher: positive affect, optimism, and purpose in life; lower: depressive symptoms, hopelessness, loneliness, and infrequent contact with friends)." While this study was done in individuals over 50, I would submit to you that advocacy work has a positive result in individuals younger than 50 as well. Besides the personal benefits, success in your advocacy efforts may help one or more individuals through programs or legislation.

Advocacy can also undermine positive attitudes if used incorrectly, such as with bullying. In the above example, the PI and VP bullied those who had to carry out the plans. Thus, the outcomes had the negative effect of individuals "just giving up", feeling depressed, and not being heard. In their 2015 paper *Arrogance in the workplace: implication for mental health nurses*, Michelle Cleary et al. wrote "Advocacy and empowerment can be undermined and relationships adversely impacted, including the achievement of positive consumer outcomes". For advocacy to work, all individuals involved with advocating for a cause must be given a voice.

Will your advocacy efforts always be successful? Of course not. It is a mantra that 50-70% of projects fail. Why would we think it would be different in the world of advocacy? If efforts were unsuccessful or partially unsuccessful, would you get the personal benefits of advocating or would the issue you were advocating for be impacted? It may not feel very good when advocacy fails. Did the failure lead to a depression rather than happiness or did it lead to giving up or a resolve to do more? That is a personal issue on how we deal with failure. On the other hand, we may not know immediately whether our efforts had an impact on the issue or not. We need to examine why things are failing. In your advocacy efforts, was it the timing, were other voices "louder", or were there external pressures, monetary or political pressures?

When the Advocacy and Government Affairs Committee writes comments for pieces of legislation, we must look at the broader picture. Does it fit with the mission of ACMG, can our comments be misinterpreted by others, is the topic of importance to our members, and are the comments based on evidence rather than personal opinion? Even when all things are in our favor and we have submitted the comments, the bill may not make it through the legislative session. Sometimes that is the end, but sometimes that bill comes up in the next legislative session and we must start again.

> **"When the Advocacy and Government Affairs Committee writes comments for pieces of legislation, we must look at the broader picture. Does it fit with the mission of ACMG, can our comments be misinterpreted by others, is the topic of importance to our members, and are the comments based on evidence rather than personal opinion?"**

Finally, I would like to say a word about ethics. While we may believe very strongly in an idea, project or person that we are advocating for, it does not give us license to make up evidence. In our story, the PI was able to get financial groups interested because the individual presented unknowns as facts. These incidents made everyone on the team feel vulnerable and unethical, and the team voiced these concerns repeatedly. Remember, any evidence you present must be true and credible.

In reality, the PI was a very good advocate for his vision. The individual communicated his excitement, was able to get the C-suite on board, and secured startup funding. The PI repeated the vision often and stayed on message. The PI, however, failed to bring the team along, listen to and answer their concerns, and was not ethical when providing evidence for the project.

My hope is that regardless of the level you have been exercising your advocacy, you will now be armed with new knowledge that will help you advocate more effectively.

NBSTRN Commemorates Newborn Screening Awareness Month with Virtual Summit

by **Ross Wiebenga, BS, Marketing Analyst; Kee Chan, PhD, MBA, Scientific Strategy Manager;** and **Amy Brower, PhD, Associate Project Director, Co-Principal Investigator**

The first annual NBSTRN Virtual Summit was held in September 2020, in recognition of Newborn Screening Awareness Month. The focus was to highlight cutting-edge newborn screening (NBS) research. Speakers from across the United States shared their work and expertise with topics ranging from machine learning in NBS to a deliberative community engagement model for constituent involvement in NBS programming. The virtual event provided a forum for sharing inspiring developments in the world of newborn screening and helped to spread excitement throughout the NBS research community, interest groups, and the general public.

The event attracted more than 500 listeners from across the United States and the world and allowed for direct communication between NBS stakeholders and frontline researchers. Fostering dialog and engagement is important for the NBSTRN as we work to support NBS research efforts. The sharing of discoveries and innovations helps build partnerships throughout the NBS community and drives advocacy to expand the reach of NBS. Shared support can often lead to synergistic research collaboration and legislative changes that benefit state NBS programs, families and patients, health care teams, and researchers.

In September 2021, NBSTRN will host another summit – this time with the theme of "innovations from technology, advocacy, and clinical care." The NBSTRN 2021 NBS Summit will be held September 1-3, marking the beginning of Newborn Screening Awareness Month, a celebration of newborn screening technology and lifesaving efforts.

Help drive NBS advocacy by becoming a member of NBSTRN. Visit NBSTRN.org to learn how you can support NBS research.

Steven T. Warren, PhD, FACMG

by **Judith L. Fridovich-Keil, PhD**
Stephanie L. Sherman, PhD
Michael J. Gambello, MD PhD

The human genetics community lost a giant, and a friend, on June 6, 2021 when Steven T. Warren, PhD passed away following a courageous and private battle with myotonic dystrophy type 2. He was 67.

Steve was born in Detroit and trained at Michigan State University, majoring in zoology as an undergraduate and completing his PhD in human genetics. Early on, Steve recognized the value of combining basic science with medical genetics and volunteered at Henry Ford Hospital to gain clinical experience. After completing postdoctoral studies at the University of Illinois in Chicago, and at the European Molecular Biology Laboratory in Heidelberg, Germany, Steve joined the faculty at Emory University in 1985. There, Steve quickly emerged as a star, earning international recognition for leading his team to discover the unstable CGG repeat as a novel mechanism of disease underlying Fragile X Syndrome. Steve rose through the ranks and served as founding chair of the Department of Human Genetics. As chair, he folded the existing Division of Medical Genetics into the newly formed basic science department and encouraged cross talk and interdisciplinary training. Steve remained a vital part of the Department until the time of his death.

During his long and illustrious career, Steve not only made seminal contributions to the science of human genetics but also advanced the field through extraordinary professional service. He was president of the American Society of Human Genetics and Editor-in-chief of the society's journal. Steve was a founding fellow of the ACMG.

Steve received numerous professional awards. He was honored by both the American Association for the Advancement of Science and the American Academy of Arts and Sciences. He was elected to both the National Academy of Medicine and the National Academy of Sciences. He received the March of Dimes Colonel Harland Sanders Award for Lifetime Achievement and was named to the Hall of Honor by the National Institute of Child Health and Human Development.

Steve's groundbreaking science and leadership in human genetics are known worldwide, but those of us fortunate enough to work with Steve at Emory also recognized his many personal qualities that made him such a beloved colleague and chair. Steve led by example. He applauded our successes and gave pep talks when we stumbled. Steve was especially supportive of young faculty and went out of his way to help those balancing the demands of family and career. He will be dearly missed.

ADVOCACY

ACMG AT WORK ON BEHALF OF MEMBERS AND PATIENTS

ACMG stays hard at work advocating for the responsible application of genetics and genomics in healthcare. Examples of policy priorities include:

- **CODING FOR GENETIC SERVICES**
  Supporting the creation of new codes for genetic services and advocating for appropriate reimbursement by payers.
- **NEWBORN SCREENING**
  Advocating for federal funding to support and expand newborn screening throughout the United States.
- **PAYER COVERAGE OF GENETIC SERVICES**
  Improving coverage of genetic sequencing services, noninvasive prenatal screening, telegenetics, and more.
- **REIMBURSEMENT FOR LABORATORY SERVICES**
  Pursuing recognition of laboratory geneticists and reimbursement for the laboratory interpretations they provide.
- **ACCESS TO THERAPIES**
  Supporting policies to improve patient access to therapies such as those requiring public and private payer coverage of medical foods.
- **REGULATION OF LABORATORY-DEVELOPED TESTS**
  Working closely with Congress and other stakeholders to support regulatory frameworks appropriate for laboratory-developed tests.
- **EDUCATING LAWMAKERS ABOUT GENETICS & GENOMICS**
  Helping lawmakers better understand genetic and genomic medicine and how it is impacted by their proposed policies.
- **AND SO MUCH MORE!**

Get involved!
Learn more at www.acmg.net/advocacy.

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