

INITIATIVES 2021

The American College of Medical Genetics and Genomics & the ACMG Foundation

ACMG Foundation's Donor-Funded Efforts

UNRESTRICTED GIVING

The ACMG Foundation's Board approved a \$280,000 goal for "unrestricted" gifts in 2021. These corporate and individual donor dollars are not committed to any one effort, allowing our Foundation's leadership and the Board of ACMG to **accelerate core efforts, explore innovative new programs, or build up rainy-day reserves**. Unrestricted dollars are vital when the unexpected occurs. In response to the COVID-19 pandemic, unrestricted dollars helped keep our staff safe by temporarily closing our Maryland Headquarters. The funds were also decisive in revamping our 2020 *and* 2021 in-person Annual Meetings into fully-remote conferences.

RESTRICTED DONATIONS

Workforce Development

The number of medical genetics experts needed to diagnose and treat patients with genetic disorders has fallen chronically short of demand for decades. Consequently, attracting talented medical professionals to the genetics and genomics workforce remains a core objective of the ACMG Foundation. Since 2006¹, Takeda Pharmaceuticals, Sanofi Genzyme, and Pfizer have helped our Foundation fill the workforce pipeline. Together, they have provided more than \$4,600,000 in support of our **NEXT GEN Scholarships**. Those funds provided a combined **sixty-years** of highly specialized genetics training to qualified medical experts. Programs currently include a two-year Clinical Laboratory and Medical Biochemical Genetics and Genomics Residency, a two-year Clinical Genetics Residency Training Award, and a one-year Medical Biochemical Genetics Subspecialty Fellowship. Our 2020 awardees exhausted this programs' final reserves and 2021 will be a rebuilding year.

Other workforce programs include our **Summer Genetic Scholars Program**, which has enabled 130 medical students to gain hands-on medical genetics experience at nearly two dozen participating universities around the nation. With their 2020 support, BioMarin also helped some Scholars attend our Annual Meeting at no cost. Finally, **Travel Grants** were most recently funded by Illumina and sent dozens of curious medical students to our Annual Meetings (granted, in pre-COVID times). We hope to reactivate travel sponsorships in 2022.

Public Policy and Advocacy

ACMG's public policy and advocacy team ensures our views are presented and understood by key decision-makers in Washington and beyond. While we partner with like-minded medical organizations, health coalitions, and national patient groups, our DC staff often take a leadership role. Staff work directly with our members to develop and advocate for policies that promote the responsible application of genetics and genomics in healthcare. Examples of our team's current efforts include:

- Working with the US Congress and federal agencies to improve access to, and coverage of, genetic services and therapies such as telegenetics, medical nutrition, genetic testing, and prenatal screening;
- Advocating for new codes for genetic services and appropriate payer reimbursement policies;
- Supporting policies to authorize and fund critical public health programs, such as reauthorization of the Newborn Screening Saves Lives Act; and
- Educating policymakers by hosting briefings for members of the US Congress, drafting letters and regulatory responses to health agencies, or developing other resources to guide policymakers.

¹ Our Next Gen awards were first funded by Shire Pharmaceuticals, which later merged with the Japanese company, Takeda.

Continuing Education Programs

ACMG offers many accredited continuing education courses in genetic and genomic medicine. Educational grants have contributed to the development of new educational classes and symposium for medical professionals. Donors have also helped ACMG produce video-based Genomic Case Conferences, CME accredited courses, and informative videos that explain complex technical issues to the public or non-genetics specialized medical staff.

Evidence Based Guidelines

Building upon two decades of ad-hoc guideline development experience, the ACMG Foundation launched a formal **Evidence-Based Guidelines (EBG) Program** in August of 2019. Corporate and individual donations to the new EBG Program in 2020 exceeded half a million dollars, making it one of the largest initiatives of the College. Our fundraising goal for the EBG Program in 2021 is an ambitious \$700,000.

Evidence-based guidelines ensure that genomic best practices are adopted across the medical field. Guidelines aid payors, providers, and patients in making science-based decisions. Our infrastructure ensures trustworthy guidelines and includes the Foundation's dedicated **Evidence-Based Guidelines Fund** and the College's formal **selection and topic vetting process**. Illumina, Perkin Elmer, BioMarin, Invitae, Horizon and many individuals have given generously over the past two years. Find more information at www.acmgfoundation.org/ebg.

National Awards, Events, and Media Opportunities

Our annual awards and media events bring attention to the distinguished work of our awardees, showcase pioneers in our field, and highlight the positive impacts of our profession. These, along with our professional publications, give corporate sponsors a great way to showcase their brand while supporting genetic medicine.

- *The Dr. Michael S. Watson Genetic and Genomic Medicine Innovation Award* honors ACMG's founding Executive Director and recognizes a pioneer with less than a decade of service in our field.
- *The ACMG Foundation Lifetime Achievement Award*, supported by the Rimoin Family Fund, honors steadfast and long-standing leaders in genetic and genomic medicine.
- *The Annual Day of Caring* has provided hundreds of individually customized bicycles to children who live with genetic conditions. The bike give-away is generally held at ACMG's annual meeting and has been supported most recently by Perkin Elmer.
- *Medical Genetics Awareness Week* is entering its third year and spotlights our field's positive impact on patient care and public health. Geneticists at our annual meeting and around the world created more than three million media impressions in more than 35 countries in its first year alone. A corporate sponsor would help the ACMG Foundation move this staff-driven program to the next level.
- Sponsor our *ACMG Medical Geneticist* (printed) or *ACMG in Action* (online) and reach our members.

Leveraging ACMG's National Reach

Since 2004, ACMG has administered the federally-sponsored **National Coordinating Center (NCC)** for the Regional Genetics Networks (delivering genetic services to medically underserved populations) and the **Newborn Screening Translational Research Network (NBSTRN)**. The College is also a key partner in the **Clinical Genome Resource (ClinGen)**. Through NBSTRN and ClinGen, our staff members work with advanced databases and in the field of gene variant curation. Each program provides ACMG a unique perspective of the gaps health care providers face when delivering medical care in the genetics or genomics space. **ACMG's "ACT Sheets"** are just one noteworthy byproduct. They aid non-genetics providers in referring and informing their patients with genetic disorders. We hope to expand our library of disease-specific Act Sheets and revise dated material.

Become a Corporate Partner today. See "Our Partnerships" at ACMGFoundation.org