

MAJOR INITIATIVES 2019 - 2020

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

Unrestricted gifts to the ACMG Foundation's Annual Fund enable the Foundation to carry out its mission in support of the educational and clinical initiatives of the ACMG. The flexibility of these donations also enables us to pivot and meet new opportunities as they arise. Donors may also give to the programs below in a targeted manner.

Evidence Based Guidelines

The largest initiative of the College, supported by the Foundation, is the establishment of a formal **EvidenceBased Guidelines (EBG) Program**. While we have developed guidelines on an ad-hoc basis for two decades, evidence-based guidelines will be critical to ensure that genomic approaches are adopted across the spectrum of medical care. The infrastructure to ensure these guidelines is well-established and tested at ACMG. The Foundation has established a dedicated **Evidence-Based Guidelines Fund**, and a formal ACMG Board-approved **selection and topic vetting process** sits within the College. The Foundation has secured a \$200,000 seed grant from Illumina to enable the College to begin hiring the necessary experts to move this process forward, but more support is needed to address the broad need for guidelines in our rapidly growing field. Our goal is to secure \$5 million in the next four years for guideline development. A program document is available for interested partners.

Expanding the Medical Genetics and Genomics Workforce

It is critical that we continue to attract young medical professionals to the genetics and genomics workforce. A Shire/Takeda **Residency and Fellowship Training** program has enabled 41 awardees (2006-2019) to receive up to two-years of specialty genetics training. Pfizer Inc. has also been a key donor to our Fellowship Program. The Sanofi Genzyme **Medical Biochemical Genetics Awards** also has trained an additional 19 genetic scientists. Since 2011, the **Summer Genetic Scholars Program** has given 122 medical students hands-on experience in our field at nearly two dozen participating universities around the nation. We are grateful that BioMarin has helped us to fund 20 Summer Scholar awards last year. And thanks in part to Illumina, we provided **Travel Grants** enabling 17 medical students to attend our 2019 annual meeting. The Foundation is seeking interested corporate partners to both continue and expand these important efforts. Annually, \$800,000 is needed to fund these workforce development initiatives.

Educating Policy Makers

ACMG's public policy team is advocating for reauthorization of the Newborn Screening Saves Lives Act and has held educational briefings on genetics and genomics topics on Capitol Hill. Staff members regularly educate policy makers on the complex issues in medical genetics and advocate for federal funding bills that invest in our field. Keeping ACMG members informed of opportunities to weigh in with the Centers for Medicare and Medicaid Services or Congress is key as we fight together for reimbursement changes, comment on proposed federal regulations, and partner with health coalitions in Washington. Because of our recent work, Congress directed the U.S. Government Accountability Office to assess workforce issues around medical genetics specialties. Contributions to the Foundation's general fund make this work possible. Staff are also exploring grant funding to support key policy efforts.

Continuing Education Initiatives

ACMG offers several accredited continuing education courses in genetic and genomic medicine. We welcome corporate underwriting or support from individuals willing to sponsor a series of our video-based Genomic Case Conferences, CME Credit courses, or to help us launch a new goal of producing educational and informative classes for the non-geneticist community. QIAGEN and Illumina have sponsored our education programs; additional support would enable us to expand this work.

Attracting National Attention

National Awards recognize brilliant leaders, bring attention to our field, and highlight the many issues faced by medical geneticists.

This year we are honored to launch *The Dr. Michael S. Watson Genetic and Genomic Medicine Innovation Award* in honor of our long-time past Executive Director. Evan and Cindy Jones generously helped kickoff the fund early in 2019, as did receptions in Mike's honor held in both Bethesda and Houston.

The ACMG Foundation Lifetime Achievement Award is supported by The Rimoin Family Fund and helps the Foundation to recognize leaders in genetic and genomic medicine. The Rimoin Fund still accepts donations.

PerkinElmer supports another media-worthy program: *The Annual Day of Caring*. For several years they have enabled the Foundation to provide hundreds of individually customized bicycles to children who live with genetic conditions. The bike give-away is held at ACMG's annual meeting.

A new staff-led initiative is our *Medical Genetics Awareness Week*. Launched last year, it shined a spotlight on our field's positive impact on patient care and public health. This bootstrap effort is set to grow with further support from a founding sponsor. Attendees at our annual meeting and geneticists around the world created more than three million media impressions in more than 35 countries. A seed donation for the week would help strengthen awareness efforts, build media kits, and link patients to the effort, not to mention the positive impact for the brand of a corporate donor.

Leveraging ACMG's National Reach

The American College of Medical Genetics and Genomics is a key partner on three major federally funded projects that draw on the talents of industry, government, and nonprofit partners:

- The **Newborn Screening Translational Research Network** (NBSTRN) aims to improve the health outcomes of newborns with genetic or congenital disorders. NBSTRN's database provides investigators and researchers access to robust data on newborn screening.
- The **Clinical Genome Resource** (ClinGen) is a National Institutes of Health- funded effort. ClinGen's experts are curating variants to build an authoritative central database that defines the clinical relevance of genes and variants. The work advances precision medicine and research.
- Since 2004, the College has administered The **National Coordinating Center** (NCC) for the Regional Genetics Network (RGN) under a cooperative agreement from the Health Resources and Services Administration (HRSA). Focused on improving access to genetic services for medically underserved populations, the NCC, along with seven RGNs and a Family Support Center, engages in education, health care policy, and telemedicine. NCC also offers clinical decision support tools. Our "ACT Sheets" aid providers in referring and informing patients with genetic disorders under their care.

Limited federal funding restricts the scope of these projects, and ACMG staff often uncover gaps where added support of key areas could independently advance genetic and genomic medicine.

Other Opportunities Abound

By becoming a sponsor of The *ACMG Medical Geneticist* member newsmagazine (\$10,000 annually) or our *ACMG in Action* monthly ezine (\$15,000 annually), corporate donors receive increased market penetration among our highly skilled membership.

Support these and other 2019 initiatives with a general contribution. Visit ACMGfoundation.org and click the "Donate" button on the website, or Text "DNA" to 56512 from your c: