



MAJOR INITIATIVES 2019 - 2020

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

Unrestricted gifts to the ACMG Foundation's Annual Fund help our Board of Directors and staff keep administrative costs down. 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 both the College and the Foundation is the establishment of a formal **Evidence-Based Guidelines (EBG) Program**. While we have developed guidelines on an ad-hoc basis for two decades, a more formal program is needed. Today, gene-related clinical care must be guided by the best scientific evidence. The infrastructure to ensure trustworthy guidelines is well-established and tested at ACMG. The Foundation 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 hire the necessary key experts to move this process forward, but more support is needed. 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 field. A Shire/Takeda **Residency and Fellowship Training** program has enabled 41 awardees (2006-2019) to receive up to two-years of specialty genetics training, but this marks the final year of funding for this grant. Pfizer Inc. has also been a key donor to our Fellowship Program. The Sanofi Genzyme **Medical Biochemical Genetics Awards** also ends in 2019 and 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 fighting to reauthorize the Newborn Screening Saves Lives Act and 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 several health coalitions in Washington.

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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 that might support key policy efforts.

Continuing Education Initiatives

ACMG offers several accredited continuing education courses for those in our field. 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 medical geneticists face. This year we are pleased to launch *The Dr. Michael S. Watson Genetic and Genomic Medicine Innovation Award* in honor of our long-time Executive Director. Receptions are planned to kick off the award and help build the fund. Corporate support is also welcome on a small or large scale. Evan and Cindy Jones have been key to the kickoff of the fund.

The ACMG Foundation Lifetime Achievement Award is supported by The Rimoin Family Fund and helps the Foundation recognized genetic leaders in 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 industry's positive impact on patient care and public health. This bootstrap effort could clearly use a founding sponsor and is set to grow. 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.

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- 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 genetic patients under physician 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.

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