ASHG 2021 President Gail Jarvik, MD, PhD: Comments to NIH and OSTP ARPA-H Listening Session August 11, 2021

Thank you for the invitation to join you today. My name is Gail Jarvik and I am a board-certified clinical medical geneticist and researcher, and the head of the Medical Genetics Division at the University of Washington in Seattle. I am here today in my capacity as President of the American Society of Human Genetics, or ASHG.

ASHG is the primary professional membership organization for human genetics specialists worldwide. Our nearly 8,000 members around the world are researchers, medical geneticists, genetic counselors, and others with an interest in the field of human genetics. ASHG's vision is that people everywhere realize the benefits of human genetics and genomics research, and we pursue that vision through year-round scientific programming for our members, educational and professional development opportunities, and advocacy at the federal level.

This is an exciting time in the field of human genetics. Advances in our field are contributing to all areas of health and biomedicine, from the evolution in cancer treatments, to the earlier diagnosis of rare diseases, to the development of gene therapies. Our ability to rapidly deploy genome sequencing technologies developed by the human genetics community continues to make it possible for the scientific and health community to respond to the COVID-19 pandemic.

These advances in human genetics and genomics, and the health, societal, and economic benefits they bring to our country, are made possible by strong, sustained federal investments in biomedical research, especially funding for the National Institutes of Health.

ASHG is grateful to the Biden Administration for proposing such a bold and historic funding level for NIH in Fiscal Year 2022, ensuring that, while establishing ARPA-H, the NIH remains able to support its core portfolio of fundamental biomedical research. Success in advanced research and development efforts like those envisioned for ARPA-H rely on these continued investments in basic biomedical science. We are excited to learn more about how ARPA-H will complement this core portfolio. One opportunity is for ARPA-H to fund programs that have impact across diseases. Through our experience with the Human Genome Project, our community has seen firsthand how major investments in use-inspired, breakthrough research – like those promised by ARPA-H – can benefit human health.

As NIH considers how ARPA-H will fit into the existing biomedical research ecosystem, we urge you to consider these important points:

- **First**, that diversity, equity, and inclusion be at the core of ARPA-H's mission, both with respect to its scientific priorities and its workforce.
- From all levels of the research workforce to the public's participation in research, increasing diversity is essential if we are to deliver health advances that will benefit all patients. Workforce diversity will require investment in training.
- ASHG appreciates the progress NIH is making in increasing diversity in biomedical research, such as through All of Us and the UNITE Initiative, and strongly recommends that the strides made by those programs are continued in ARPA-H.
- **Second**, that ARPA-H makes a commitment to responsible global data sharing.
- It's important to ensure that the results and data generated by ARPA-H are available to the larger biomedical research community, while also protecting participant privacy.

- The human genetics and genomics research community is a leader in leveraging large-scale data to transform science and medicine, and we would be happy to work with you on embedding robust data sharing policies into ARPA-H's structure and processes.

- In closing, we are excited to see how ARPA-H will leverage the progress made in human genetics and genomics research to date and how this initiative could improve health and medical outcomes for all.
- Thank you again for the invitation to speak today, and we look forward to continuing to work with you as ARPA-H takes shape.