Maine Chapter

INCORPORATED IN MAINE

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

Chapter Executive Director
Dee Kerry
dakerry@aap.net

30 Association Drive, Box 190
Manchester, ME 04351
office: 207-480-4185

www.maineaap.org
MAAP Facebook Page
Twitter: @MaineAAP

LD 1601, Resolve, To Establish an Advisory Panel To Study the Implications of Genome-editing Technology for the Citizens of the State

Good morning Senator Claxton, Representative Meyer, and members of the Committee on Health and Human Services Committee. My name is Jennifer Jewell and I am a resident of Portland, a pediatrician, a member of the Board of Directors of the Maine Chapter of the American Academy of Pediatrics, and a concerned citizen. I'm testifying this morning in support of LD 1601.

We can all agree that many human diseases are a direct result of a person's genetic code, meaning that despite healthy living and advantage, the diagnosis is inevitable even before birth. We live in an era when novel technology has provided a mechanism to cure a number of these diseases.

As a pediatrician, I have witnessed tragedy for children and families that are impacted with many of the disorders that genetic innovation may be capable of routinely curing in the extremely near future. I have seen:

- Toddlers with sickle cell disease suffering the lasting effects of an all-to-common stroke
- An adolescent who could walk and now is confined to a wheelchair, understanding that this is the beginning of the end of his life due to Duchenne Muscular Dystrophy
- Young adults with cystic fibrosis requiring double lung transplantation, hoping that their life expectancy is closer to 10 years, instead of the more typical five years
- The family devastated by the early death of a parent with Huntington Disease
- Patients of all ages knowing that total blindness is approaching.

While I can recall the impact of these conditions on specific patients and families, the contribution to the increase in health care expenses and in social support programs is unimaginable to me. Although I am not expert in other areas, I know that this genomic-editing technology can affect other species and our environment, too. Thereby, enhancing the lives of Mainers.

However, any new technology, especially ones that edit genetics, must be done with caution and with input from experts in ethics, medicine, research, public health, and the environment. My concern is about nefarious uses of these technologies to create biologic weapons and promulgate physical and cognitive traits that our society finds desirable. Therefore, genome-editing technology cannot be left to a single group of professionals. Instead, understanding the range of implications and establishing boundaries requires a transparent process to consider all short- and long-term implications of genome-editing. Establishing a panel, as described in LD 1601, does just that. I commend the authors and sponsors of LD 1601 on their thoughtful approach to including traditional and non-traditional partners that are impacted by genomic-editing.

I look forward to a day when I no longer sit in a room with a box of tissues, delivering the devastating news to a patient and family that a child has a disease resulting in a life of pain, physical suffering, and financial ruin. Being capable of curing these genetic diseases will positively impact individuals, families, communities, and our State in so many ways. Establishing the proposed Advisory Panel will allow this to be achieved in a comprehensive and ethical way.