

Usher Syndrome Coalition

63 Great Road, Suite 207

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www.usher-syndrome.org



July 26, 2018

The Honorable Pete Sessions
2233 House Rayburn Office Building

The Honorable Gus Bilirakis
2112 Rayburn House Office Building

The Honorable Fred Upton
2183 Rayburn House Office Building

The Honorable Sanford Bishop
2407 Rayburn House Office Building

Dear Cosponsors:

On behalf of the Board of Directors of the Usher Syndrome Coalition, I am writing to express strong support for H.R. 6421, the "Faster Treatments and Cures for Eye Diseases Act."

This legislation, which would allow for the creation of "Eye-Bonds," would significantly increase funding for translational biomedical research, the process of promising research moving "from bench to bedside," that will speed development of treatments and cures for all eye conditions, including inherited retinal diseases like retinitis pigmentosa (RP), the vision loss associated with Usher syndrome.

Usher syndrome is the leading genetic cause of combined deafness and blindness, affecting up to 50,000 people in the United States. Children with Usher syndrome are born with or develop hearing loss and may also be born with or develop vestibular issues which adversely affect their balance. Early in life, they will experience symptoms of RP, a progressive vision loss that often starts with night blindness, followed by a narrowing of the visual field, commonly known as "tunnel vision," leading eventually to complete blindness. Most individuals with Usher syndrome are legally blind by the time they are young adults.

The Usher Syndrome Coalition, a nonprofit organization representing the global Usher syndrome community, supports this legislation that will accelerate therapies and treatments for patients that can save sight and restore vision. The field of Usher syndrome research is in desperate need of funding to develop treatments and a cure for the vision loss associated with this insidious disease.

For many Americans, going blind is their greatest fear. A 2016 JAMA Ophthalmology article reported the findings of a well-characterized survey across all US ethnic and racial groups, concluding that good vision is key to one's overall sense of well-being, and ongoing research for vision and eye health is strongly supported.

Vision disorders currently have the fifth highest direct medical costs. Vision disorders and eye disease is estimated to cost the nation \$717 billion annually in inflation-adjusted dollars by the year 2050. This "Eye-Bond" legislation enables a novel funding mechanism to address this growing public health problem.

This innovative financial instrument uses low-risk investments that provide a route to:

- Leverage private sector dollars
- Make available new private capital to provide critical support for promising medical research projects making their way out of labs into clinical trials, and ultimately the patient's bedside.
- De-risk projects sufficiently that they would become commercially attractive to pharmaceutical and biotech companies.
- Fund small labs and university researchers who wish to translate their basic research.

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- Engage the National Eye Institute (NEI) within the National Institutes of Health (NIH) in selecting eligible projects—without incurring any risks or costs to NIH.

On behalf of the Usher Syndrome Coalition community, we commend each of you as Cosponsors of a creative approach to eradicating eye disease, for our family and friends seeking a cure today, and for future generations as well.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mark Dunning', with a stylized flourish at the end.

Mark Dunning

Chair, Usher Syndrome Coalition Board of Directors