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USHER SYNDROME
COALITION

CONNECTING THE GLOBAL USHER COMMUNITY

USH Advocacy on Capitol Hill: Script, June 11-12, 2025

Note: *Typically each meeting is 20 minutes max (check your invite to see how much time you have). If meeting in a group, coordinate to determine who will be doing the intro/definition/ask and divide your time to tell the stories.*

Dear USH Champions: We are so happy you are here to tell your story! Your story is truly the most important part of our trip to the Hill. Please feel free to modify this script to meet your vision abilities and comfort level in the meeting.

If you'd like to know more about why we are making this "ask," check out the end of this document under "The One-Pager Explained." If the staffer with whom you are meeting has additional questions about legislation, please direct them to Krista Vasi (they should have her contact as she is copied on all meeting invites) or take the questions down and pass on to Krista for follow-up.

Contents:

The Script

Intro: Thank you, [*Whomever you are meeting with*] for taking the time to meet with me/us on behalf of the Usher Syndrome Coalition. [I/We] [am/are] here today to discuss Usher syndrome and the need to advance research towards treatments and a cure and advocate for greater attention within NIH. The members of the Usher Syndrome Coalition are meeting with

House: the staff of Appropriations Chair Cole, LHHS Appropriations Chair Aderholt and Ranking Member Rosa DeLauro's to share our stories and r**equest critical research funding in the amount of $50,000,000.**

Senate: the staff of Appropriations Chair's Collin's, LHHS Appropriations Chair Capito and Ranking Member Baldwin's to share our stories and r**equest critical research funding in the amount of $50,000,000.**

[I/we] want to share with you a little bit about Usher syndrome, my story, and what our "ask" is.

My name is [*NAME*], I am [*Age*], I have been living in [*State*] for [*x*] number of years and I have (*relationship to person with*) Usher syndrome.

What is USH: Usher syndrome is a rare disease with no current treatment or cure that affects hearing, vision and balance. It affects at least 25,000 people in the United States and more than 400,000 worldwide. There are three types of Usher syndrome based on genotype (1, 2, and 3), characterized by the degree of hearing loss, the age of onset and rate of vision loss, and the presence or absence of balance problems. The hearing loss ranges from mild loss to total deafness. The vision component is known as retinitis pigmentosa which causes a loss of peripheral vision, night blindness and may lead to total blindness. Some children may be diagnosed at birth, but others may not be diagnosed until school age or later, impacting education, employment, and quality of life. In our state, there are ***an estimated x to x number of people*** with Usher syndrome (insert your state's USH prevalence estimates located at the end of this document).

Personal: I [or loved one*] was diagnosed with USH type [x] when I was [x] years old. Share your diagnosis story. 3-4 sentences about what it was like finding out & any fears/anxiety it brought forth.

Tell a personal story about a struggle/challenge that USH has had in your life. 3-4 sentences.

*If talking about a loved one who is not with you, bring an 8x10 picture to show the Member or staffer. This helps the Members of Congress put a face to the name and makes the story more personal.

Example:
When Peggy tells her story she may say: "I may do okay now, but will I see my girls walk across the graduation stage? Will I see them get married? Will I see my future

grandchildren? How do I ever reconcile the grief I feel from the burden I will put on my family? Society? I know I shouldn't feel that way, but I do."

We need the reps/senators to be moved to the point of doing something about it. There is no shame in what we are asking. There is no shame in people crying while telling their story.

The Problem: While there are solutions to manage hearing loss, *[for example I wear hearing aids, or I use ASL, or I wear a cochlear implant]* there are no FDA-approved treatments for the vision loss caused by Usher syndrome. We want to change that!

Our Ask: We are asking for your support in increasing NIH/NEI (National Eye Institute) funding to $50,000,000 in the FY2026 appropriations bill for the U.S.H.E.R. (Usher Syndrome Healthy Eyes Restoration) Research Program. This increased funding could lead to as many as three promising clinical trials, accelerate research and bring us much closer to a cure.

[Please refer to the gold text box on the One-Pager.]

(The following information provides additional details and justification. Take or leave as much as you want depending on the time you have and your comfort level with discussing the information.

We request support to direct the NIH to enhance and prioritize Usher syndrome research at NEI. Sufficient federal funding is needed to accelerate critical research: **we are asking for $50,000,000 in the FY2026 appropriations bill for NEI for Usher syndrome vision-related research.** This will supplement and not supplant existing NIH-supported research activities.

Closing:

Why should the [Rep./Senator] want to help? (Help the Member relate to the big picture)

- A cure for Usher syndrome might also mean a cure for other inherited retinal diseases.
- While the Usher community is small, there are 100,000 in the US with retinitis pigmentosa, 1.5 million worldwide
    - Nearly 500,000 new diagnoses of low vision this year
    - A recent Johns Hopkins study shows that low vision and blindness will more than double in the next 30 years, with 2.3 million people expected to be blind and more than 9.5 million living with low vision
- For those of us diagnosed with Usher syndrome, life goes on, but at what cost?
    - Due to limited public awareness, those affected with Usher syndrome may suffer from depression, anxiety, isolation, loss of independence

- A cure could help alleviate the financial burden the federal government faces to provide care for those with low vision diseases
- The annual economic burden of vision disorders in the U.S. is estimated at $199.6 billion in 2025 (medical, nursing home, loss of productivity) (National Alliance for Eye and Vision Research)
  - According to Prevent Blindness, **that number will jump to $385 billion by 2032 and $717 billion by 2050.**

It is heartbreaking knowing that my [or my loved one's] condition will only continue to get worse because there is no treatment but that can change with Congressional and Federal Government support.

Our Ask - in Closing:

For House Members

We would like you (if it is the Member you are meeting with) -or- we would like your Member (if it is the staff you are meeting with) to please include FY2026 direct vision loss research funding of $50,000,00 for the U.S.H.E.R. program at NIH/NEI in order to prevent vision loss in young Usher syndrome patients and the restoration of vision for Usher syndrome patients with significant or total blindness. We would like to leave you a copy of the Usher Syndrome Coalition's community sign-on letter highlighting the need for immediate action to cure vision loss caused by Usher syndrome. (If you have submitted written testimony to House LHHS, you may leave this behind, as well).

We truly hope to have the support of [Representative…]. Thank you for your time.

For Senate Members:

We would like you (if it is the Member you are meeting with) -or- we would like your Member (if it is the staff you are meeting with) please include $50,000,000 in direct funding for Usher syndrome research at NEI for the Usher Syndrome Healthy Eyes Restoration (U.S.H.E.R) Research Program in your FY2026 Appropriations Priorities. This increase in vision loss research funding will lead to the prevention of vision loss in young Usher syndrome patients and the restoration of vision for Usher syndrome patients with significant or total blindness. We would like to leave you a copy of the Usher Syndrome Coalition's community sign-on letter highlighting the need for immediate action to cure vision loss caused by Usher syndrome. (If you have submitted written testimony to Senate LHHS, you may leave this behind, as well).

We truly hope to have the support of [Senator …]. Thank you for your time.

The One-Pager Explained

The information below is not part of your script, but provides some background information if you are interested.

What is the difference between the bill and the report language we are asking our Representatives and Senators to include?

Appropriations

Appropriations are annual decisions made by Congress about how much money the federal government agencies like the National Institutes of Health receive, as well as identifying funding priorities.

Report Language

Report language is essentially additional directions that accompany the funding amounts that are often included in appropriations bills. While report language is not legally binding, it is generally followed by agencies like NIH.

When does this bill get passed?

June/July - necessitating these meetings for inclusion of the language now.

Supplant vs. Supplement

Supplant - take the place of (replace)
Supplement - add something to complete a thing (add to)
We do not want to take funds from other worthy causes. We want to be considered just as important as other rare diseases.

Translational Research

Research aimed at translating results in basic research into results that directly benefit humans.

Funding Background

The inclusion of specific report language in appropriations bills to provide $50 million in funding in the budget of the National Institutes of Health (NIH) is essential to accelerating and advancing research to finding a cure. In the past the Usher Syndrome Coalition has supported efforts to include language urging NIH to make Usher syndrome a higher priority, but funding for USH research has remained flatlined.

Despite the inclusion in appropriations bills for four years (FY2014-FY2018) of report language urging NIH to make Usher syndrome a higher priority and make regular updates on the actions taken to prioritize USH, no meaningful updates on Usher syndrome were reported by the National Eye Institute in their Congressional Justifications.

Tracking Funding Levels for Usher Syndrome Research is Difficult
Until early 2015, there was no way of knowing how much money NIH invested in Usher syndrome research. Through the efforts of the Usher Syndrome Coalition, Usher syndrome has been added as a new category in the NIH Categorical Spending list, the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC).

While the past four years of RCDC reports (FY2018-FY2022) show funding levels for Usher syndrome ranging from $14 million to $18 million, this is misleading and erroneous. Close examination of these projects receiving these funds reveals that Usher syndrome is not a primary research priority for the majority of these allocated funds. **The actual average annual funding for projects that prioritize Usher syndrome has been closer to only $7 million/year.**

Estimated Range of Number of People with Usher Syndrome by State (As of 2023)

State	If USH prevalence = (4.4/100000)	If USH prevalence = (17/100000)
AL	225	868
AK	32	124
AZ	320	1237
AR	133	513
CA	1739	6717
CO	253	979
CT	159	615
DE	43	166
FL	945	3651
GA	467	1805
HI	62	241
ID	79	304
IL	558	2154
IN	296	1144
IA	139	536
KS	128	495

KY	197	760
LA	205	790
ME	59	229
MD	266	1028
MA	303	1172
MI	439	1698
MN	248	959
MS	131	506
MO	270	1043
MT	47	182
NE	85	329
NV	136	524
NH	60	231
NJ	391	1510
NM	92	356
NY	856	3307
NC	461	1783
ND	34	130
OH	514	1987
OK	174	673
OR	186	717
PA	563	2176
RI	47	180
SC	227	875
SD	39	150
TN	300	1161
TX	1342	5186
UT	141	545
VT	27	106
VA	376	1451
WA	335	1295
WV	79	305
WI	256	990
WY	25	98

***The Usher Syndrome Coalition's mission** is to raise awareness and accelerate research for the most common genetic cause of combined deafness and blindness, while providing information and support to individuals and families affected by Usher syndrome. Learn more at www.usher-syndrome.org*