USHER SYNDROME COALITION

Government Relations Strategy

How you can be an advocate

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Why be an advocate?

U.S. and Global Impact

Currently, there are no treatments or cure

Exceptionally challenging times

Promising research in taking place across the country

Urgent need for additional federal leadership and funding

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How can additional federal funding help?

Establish Regional Usher syndrome Centers of Excellence

Accelerate Research Funding for Finding a Cure and Improving Treatment

Expand and Spur On-going Pivotal and Promising Gene Therapy Work

Develop New Research Models to Evaluate Therapies with Emphasis on Retinal Degeneration

Usher Syndrome Coalition's 2020 advocacy goals

Identify and educate Members of Congress about goals

- Promote increased funding for Usher Syndrome research.
- Include "Usher syndrome" in the expansive list of medical conditions/diseases in Congressional annual spending bill.
- Request the Government and Accountability Office (GAO) to include Usher Syndrome in their investigation of the costs of undiagnosed and untreated rare diseases.
- Meet with leaders of key Executive Branch Agencies.
- Involve other relevant external stakeholders.

How can I get involved?

Write a personal note to your Senators and Member of Congress

- Find your Member of the U.S. House of Representatives here: https://www.house.gov/representatives/find-your-representative
- Find your Senators here: https://www.senate.gov/senators/index.htm

Call your Senator and Member of Congress

- U.S. Capitol Switchboard (202) 224-3121

Meet with Senators and Member in Congress in their home district office

- Make it personal. Tell them your story and why funding/research matters
- Get to know their staff. Schedule a meeting with DC or local staff

Identify and encourage other congressional advocates to help

- Raise Usher awareness with your state delegation of Members of Congress.
- Urge your Member of Congress or Senators to speak with Members of the Appropriations Committees for additional funding

Federal Engagement

Contact the Relevant House and Senate Committees

- Labor, Health and Human Services, Education, and Related Agencies Subcommittees in the Senate and House determine Usher Syndrome funding.
- Find out if your House Member or Senator is on the Subcommittee or any other Member in your state delegation.
- Organize a group letter signed by Members of Congress to the House & Senate Subcommittee leaders requesting increased funding for Usher Syndrome research.
- Use social media to expand your message (more later).

Urge enactment of H.R. 2620, the "Eye-Bonds", to provide $1 billion for treatments and cures of all causes of blindness and severe vision loss, including Usher syndrome.

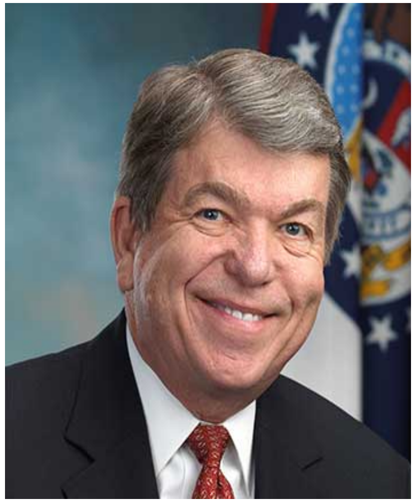
- Find the bill and cosponsors here:

Eye Bonds Bill - H.R.2620 - Faster Treatments and Cures for Eye Diseases Act

Who funds Usher Syndrome in Congress?

Senate Appropriations Labor, Health and Human Services, Education, and Related Agencies Subcommittee

Tom Cole	Rosa DeLauro
Ranking Member (R-OK)	Chairwoman (D-CT)



House Appropriations Labor, Health and Human Services, Education, and Related Agencies Subcommittee

Roy Blunt	Patty Murray
Chairman (R-MO)	Ranking Member (D-WA)

State Engagement

Identify and enlist the help of Governors, state and local legislative Leaders.

- Write, call, and meet with them to encourage their support.
- Ask your State leaders to speak with their Federal colleagues.
- Ask Governors to recognize Usher Syndrome Awareness Day, September 19, 2020. Example here:

https://www.usher-syndrome.org/our-story/news-and-media/ush-on-capitol-hill/august-2017-ask-your-state-to-recognize-usher-syndrome-awareness-day.html

Media

Write, write, write.

- Create blogs
- Write an op-ed about the need for more research funding
- Contact editorial writers of your local newspaper and request a meeting.
- Write letters to newspapers in support of increased funding
- Ask stakeholder partners to write letters to newspapers

Use social media – Facebook, Twitter, etc.

- Create Usher Syndrome hashtags
- Write personal stories
- Participate in local events and post about it
- Work with the Coalition to amplify coordinated messaging

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Grassroots Engagement

Gather supporters from stakeholder groups.

- Research facilities, colleges, universities, doctors, scientists.

Ask friends, family, local groups to write, email or phone Legislators.

Publicly recognize Legislators who are leaders.

Keep supporters and your community informed by sending action alerts and updates.

Participate in a Walk 4 Hearing:

https://www.usher-syndrome.org/take-action/walk4hearing2020.html

Volunteer

Volunteer for the Coalition

- This is about building a community to ensure a cure becomes a reality.

What are the Coalition's priority needs?

- Social media outreach.
- Become a USH Ambassador and be a resource providing information to individuals & families living with Usher syndrome Join their mailing list.
- Utilize your skills – marketing, development, finance, audit.

Contact

Usher Syndrome Coalition:

https://www.usher-syndrome.org/about-the-coalition/

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