

USHER SYNDROME  
COALITION

# Advocating for Usher Syndrome Research Funding

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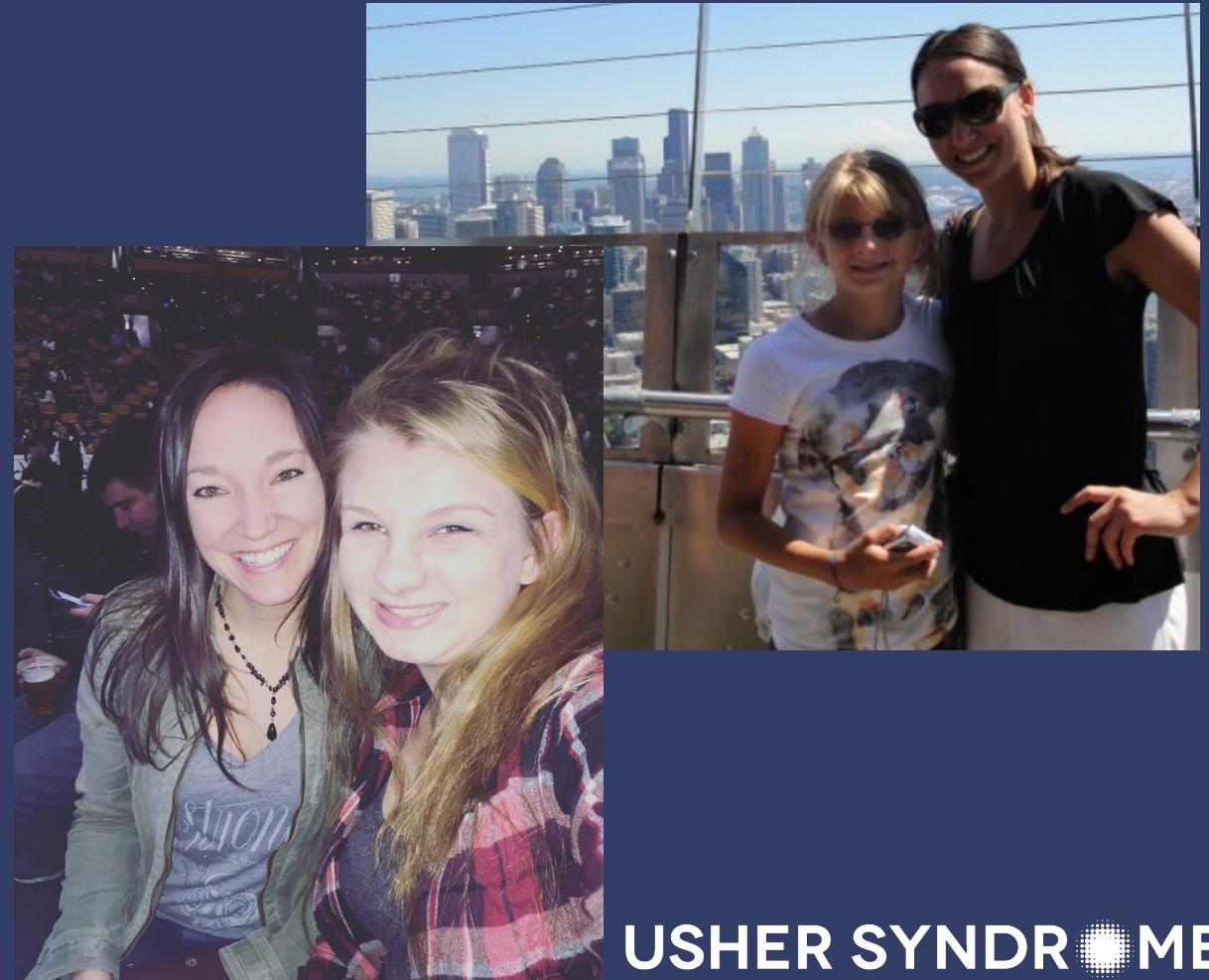
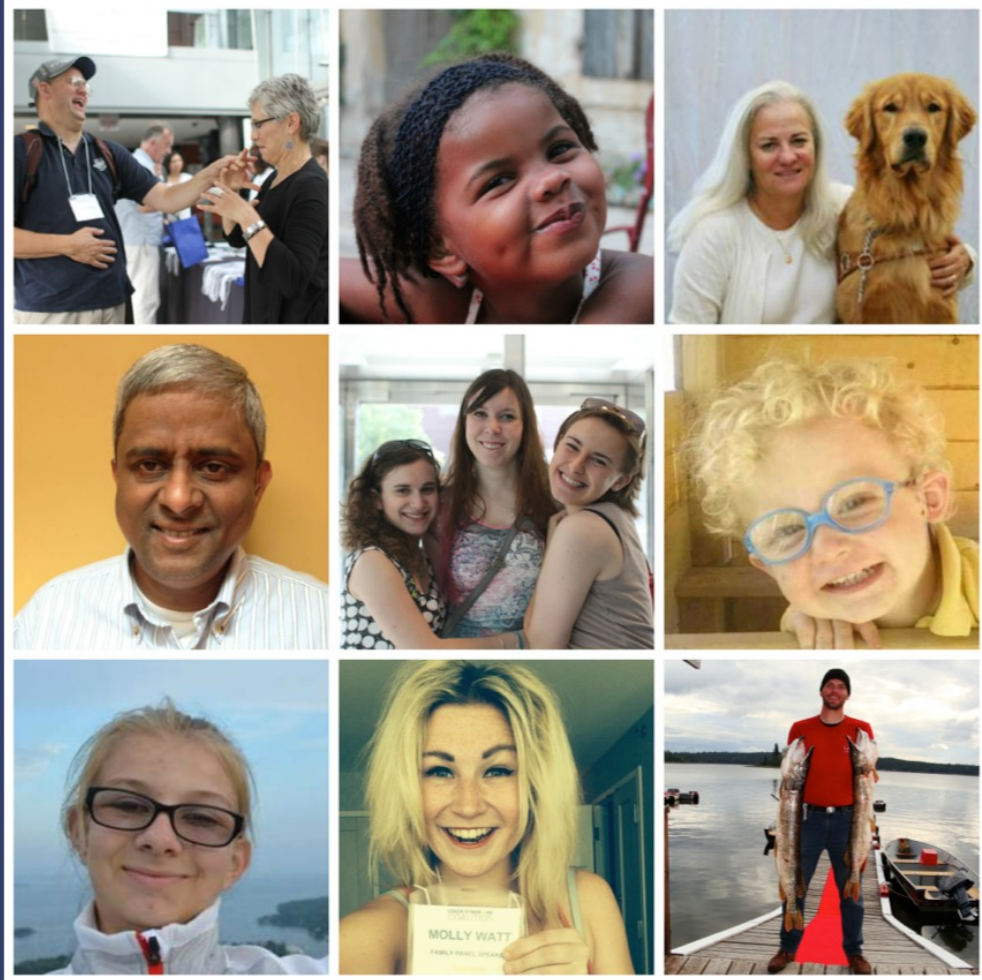
Executive Director, Usher Syndrome Coalition

14th Annual USH Connections Conference

July 8-9, 2022

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# USH Family



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# What is Usher syndrome?

- Most common genetic cause of combined deafness and blindness
- Usher syndrome impacts three major senses in the body:
  - **Hearing:** Hearing loss can be present at birth or develop shortly after.
  - **Vision:** Progressive loss of vision called Retinitis Pigmentosa, starting with night blindness and low peripheral vision (“tunnel vision”)
  - **Balance:** Vestibular issues are present in some genetic subtypes
- 13,000 to 56,000 people affected in the U.S. (over 400,000 worldwide)

# Usher Syndrome Coalition

## Who we are:

- Exclusively focus on Usher syndrome, worldwide, for all ages, all types
- We provide information, resources and support
- We do not fund research
- Bridge the gap between research community and Usher community (USH Trust)
- Goal: Identify and support every person in the world with Usher syndrome

Currently no cure for Usher syndrome. The Usher Syndrome Coalition aims to change that.

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# Overview of Today's Topics

- Where We Started:
  - Advocacy in Action, our milestones
- Where We Are Today:
  - Our USH Champions
- Where We Go From Here:
  - How you can get involved

# Where We Started

- The Gap:
  - We need more federal funding for Usher syndrome research
  - We need to make it happen in a way that doesn't impact the current research being done on other rare diseases.

# Where We Started

- Usher syndrome affects roughly the same number of people in the United States as ALS and Huntington's Disease
- Usher syndrome research receives only a fraction of the funding received by other deserving disease areas

## 📍 **ALS**

👤 15,000-20,000 AMERICANS

💰 AVG \$79.5 MILLION/YEAR

## 📍 **HUNTINGTON'S DISEASE**

👤 ~30,000 AMERICANS

💰 AVG \$46 MILLION/YEAR

## 📍 **USHER SYNDROME**

👤 13,000-56,000 AMERICANS

💰 AVG \$17.5 MILLION/YEAR

# Advocacy Milestones: 2013 and 2014

- 2013: USH Coalition begins advocating on Capitol Hill
  - Educating Members of Congress & staff about Usher syndrome
- 2014: USH Coalition advocates for inclusion of report language in Congressional spending bills (Appropriations)
  - Report language **from Committee** (LHHS) **to NIH** to prioritize Usher syndrome research
  - e.g.: “The Committee urges NEI to put a higher priority on Usher syndrome, the leading cause of deaf-blindness.” - **Senate FY2015 Labor, Health and Human Services, and Education (LHHS) funding bill**



# Advocacy Milestones: 2015-2017

- 2015: USH Coalition works with the President's Office of Management and Budget (OMB) to get Usher syndrome added to NIH Categorical Spending List
  - **Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)**
- 2015: Third Saturday in September entered into the Congressional Record as Usher Syndrome Awareness Day.
  - Proclamations in 20 states
- 2015-2017: USH Coalition ensures inclusion of report language in FY2016 through FY2018 LHHS Appropriations Bills

# Advocacy Milestones: 2020-2021

- 2020: Reactivated outreach to Members of Congress
- 2020: Launched USH Champions
- 2021: Rep. McGovern (D-MA) and Sen. Wyden (D-OR) placed statements in the Congressional Record acknowledging Usher Syndrome Awareness Day
- 2021: Met with key staff on important House and Senate Committees that approve spending for government agencies like the National Institutes of Health (NIH)

# Why do we care about Appropriations Bills?

- **Appropriations:** annual decisions made by Congress about how much \$\$ the federal government agencies receive as well as identifying funding priorities.
- **Report language:** additional directions that accompany the funding amounts are often included in Appropriations bills – While it is not legally binding, it is generally followed by agencies (e.g. NIH).

# Congressional Justifications and NIH

- U.S. House Committee on Appropriations
  - House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (LHHS)
- U.S. Senate Committee on Appropriations
  - Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (LHHS)
- NIH receives funding through an annual appropriations bill
  - Must be approved by House and Senate, signed by the President

# National Institutes of Health (NIH)

- **NIH** is made up of 27 Institutes and Centers, each focusing on particular diseases or body systems
- Key institutes for Usher syndrome:
  - National Eye Institute (**NEI**)
  - National Institute on Deafness and Communication Disorders (**NIDCD**)

# Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies (LHHS)

Senate Majority Members (Democrats)	Senate Minority Members (Republicans)
<b>Patty Murray, Washington, <i>Chair</i></b>	<b>Roy Blunt, Missouri, <i>Ranking Member</i></b>
Richard Durbin, Illinois	Richard Shelby, Alabama
Jack Reed, Rhode Island	Lindsey Graham, South Carolina
Jeanne Shaheen, New Hampshire	Jerry Moran, Kansas
Jeff Merkley, Oregon	Shelley Moore Capito, West Virginia
Brian Schatz, Hawaii	John Kennedy, Louisiana
Tammy Baldwin, Wisconsin	Cindy Hyde-Smith, Mississippi
Chris Murphy, Connecticut	Mike Braun, Indiana
Joe Manchin, West Virginia	Marco Rubio, Florida
Patrick Leahy, Vermont, <i>Ex Officio</i>	

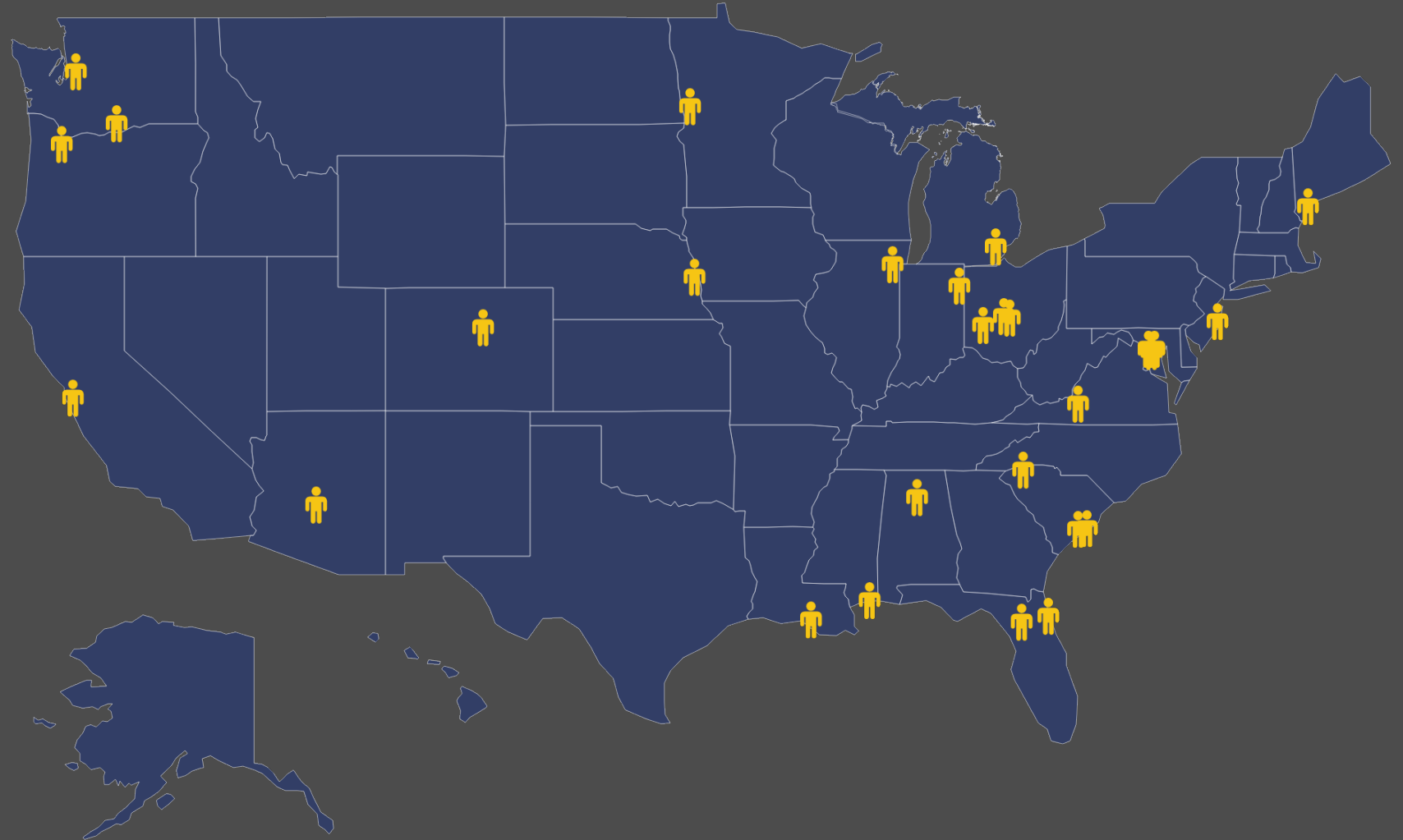
# House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies (LHHS)

House Majority Members (Democrats)	House Minority Members (Republicans)
<b>Rosa DeLauro, Connecticut, Chair</b>	<b>Tom Cole, Oklahoma, Ranking Member</b>
Lucille Roybal-Allard, California, Vice Chair	Andy Harris, Maryland
Barbara Lee, California	Chuck Fleischmann, Tennessee
Mark Pocan, Wisconsin	Jaime Herrera Beutler, Washington
Katherine Clark, Massachusetts	John Moolenaar, Michigan
Lois Frankel, Florida	Ben Cline, Virginia
Cheri Bustos, Illinois	
Bonnie Watson Coleman, New Jersey	
Brenda Lawrence, Michigan	
Josh Harder, California	

# Where We Are Today

28 USH  
Champions in  
20 states and  
28 districts

- Alabama
- Arizona
- California
- Colorado
- Florida
- Florida
- Illinois
- Indiana
- Louisiana
- Maine
- Maryland
- Maryland
- Maryland
- Michigan
- Minnesota
- Mississippi
- Nebraska
- New Jersey
- Ohio
- Ohio
- Ohio
- Oregon
- South Carolina
- South Carolina
- South Carolina
- Virginia
- Washington
- Washington





	City	State	Senators	House Member
1	Hanceville	Alabama	Richard C. Shelby (R) and Tommy Tuberville (R)	Robert B. Aderholt (R)
2	Cave Creek	Arizona	Kyrsten Sinema (D) and Mark Kelly (D)	David Schweikert (R)
3	Palo Alto	California	Dianne Feinstein (D) and Alex Padilla (D)	Anna G. Eshoo
4	Denver	Colorado	Michael Bennet (D) and John Hickenlooper (D)	Diana Degette (D)
5	Saint Augustine	Florida	Marco Rubio (R) and Rick Scott (R)	John H. Rutherford (R)
6	Gainesville	Florida	Marco Rubio (R) and Rick Scott (R)	Kat Cammack (R)
7	Bridgeview	Illinois	Tammy Duckworth (D) and Richard Durbin (D)	Marie Newman (D)
8	New Haven	Indiana	Mike Braun (R) and Todd Young (R)	Jim Banks (R)
9	Berwick	Louisiana	John Kennedy (R) and Bill Cassidy (R)	Clay Higgins (R)
10	Old Orchard Beach	Maine	Susan Collins (R) and Angus King (I)	Chellie Pingree (D)
11	Hyattsville	Maryland	Benjamin L. Cardin (D) and Chris Van Hollen (D)	Steny H. Hoyer (D)
12	Kensington	Maryland	Benjamin L. Cardin (D) and Chris Van Hollen (D)	Jamie Raskin (D)
13	Laurel	Maryland	Benjamin L. Cardin (D) and Chris Van Hollen (D)	Anthony G. Brown (D)
14	Canton	Michigan	Debbie Stabenow (D) and Gary Peters (D)	Haley M. Stevens (D)
15	Rothsay	Minnesota	Amy Klobuchar (D) and Tina Smith (D)	Michelle Fischbach (R)
16	Ocean Springs	Mississippi	Cindy Hyde-Smith (R) and Roger Wicker (R)	Steven Palazzo (R)
17	Omaha	Nebraska	Ben Sasse (R) and Deb Fischer (R)	Don Bacon (R)
18	Beachwood	New Jersey	Robert Menendez (D) and Cory Booker (D)	Andy Kim (D)
19	Dublin	Ohio	Sherrod Brown (D) and Rob Portman (R)	Jim Jordan (R)
20	Fairborn	Ohio	Sherrod Brown (D) and Rob Portman (R)	Michael Turner (R)
21	Columbus	Ohio	Sherrod Brown (D) and Rob Portman (R)	Troy Balderson (R)
22	Gladstone	Oregon	Jeff Merkley (D) and Ron Wyden (D)	Kurt Schrader (D)
23	Awendaw	South Carolina	Lindsey Graham (R) and Tim Scott (R)	Nancy Mace (R)
24	Charleston	South Carolina	Lindsey Graham (R) and Tim Scott (R)	James Clyburn (D)
25	Taylors	South Carolina	Lindsey Graham (R) and Tim Scott (R)	William Timmons (R)
26	Roanoke	Virginia	Tim Kaine (D) and Mark Warner (D)	Ben Cline (R)
27	Issaquah	Washington	Patty Murray (D) and Maria Cantwell (D)	Kim Schrier (D)
28	Bickleton	Washington	Patty Murray (D) and Maria Cantwell (D)	Jaime Herrera Beutler (R)

# USH Champions and their Members of Congress

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# Where We Go From Here

1. Usher Syndrome Awareness Day is Saturday, September 17, 2022
  - Can YOU come to Washington, DC for a day on Capitol Hill?
  - The House and Senate are in session the week leading up to our USH Day
  - Meet your Members of Congress September 13, 14 or 15!
2. If you can't come to DC, visit your Members' District Offices on September 14<sup>th</sup> and meet with staffers!
3. Go virtual: Send an email, a letter, or tweet your Members!
4. State Proclamations: Ask your governor to proclaim September 17 as Usher Syndrome Awareness Day

# Your Next Steps

- Sign up to become an USH Champion:
  - <https://bit.ly/USHchampion>
- Email Krista at [k.vasi@usher-syndrome.org](mailto:k.vasi@usher-syndrome.org) if:
  - you can go to Washington, D.C. September 13, 14, or 15
  - you know anyone in government or have valuable contacts.
  - you have experience or expertise in advocacy
- Ask your governor to proclaim Usher Syndrome Awareness Day

# Thank You!

- Website: [www.usher-syndrome.org](http://www.usher-syndrome.org)
- Krista Vasi, MPA, Executive Director: [k.vasi@usher-syndrome.org](mailto:k.vasi@usher-syndrome.org)
- Nancy O'Donnell, Director of Outreach: [n.odonnell@usher-syndrome.org](mailto:n.odonnell@usher-syndrome.org)
- Julia Dunning, Program Coordinator: [j.dunning@usher-syndrome.org](mailto:j.dunning@usher-syndrome.org)
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