

Resources for Usher Syndrome

The following resources are recommended by our speakers to provide more information on Usher syndrome, as well as support for those with Usher syndrome.

Usher Resources

Usher Syndrome in Louisiana

http://www.medschool.lsuhsu.edu/genetics/usher_syndrome1.aspx

Dr. Lentz's Laboratory

<https://www.medschool.lsuhsu.edu/neuroscience/lentz.aspx>

Usher Syndrome Coalition

<http://www.usher-syndrome.org>

Ush One See Foundation

<https://www.ushoneseesee.com/>

Usher 2020 Foundation

<http://www.usher2020.org>

Ava's Voice

<https://avasvoice.org/>

Usher Syndrome Society

<https://www.ushersyndromesociety.org/>

Usher Blog

<http://www.angelicears.blogspot.com>

Usher Syndrome Registry

<http://www.usher-registry.org>

Foundation Fighting Blindness

<https://www.fightingblindness.org/diseases/usher-syndrome>

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Genetics Information

Telephone Based Genetic Counseling through Informed DNA

<http://www.informedDNA.com> or call 800-975-4819

Find a Genetic Counselor through the National Society of Genetic Counselors

<http://www.nsgc.org> --Click on Find a Genetic Counselor

NCBI GeneReviews: Usher Syndrome Type I

<https://www.ncbi.nlm.nih.gov/books/NBK1265/>

NCBI GeneReviews: Usher Syndrome Type II

<https://www.ncbi.nlm.nih.gov/books/NBK1341/>

National Institutes of Health (NIH) Genetics Home Reference

<http://ghr.nlm.nih.gov/condition/usher-syndrome>

National Resources

Helen Keller National Center

<https://www.helenkeller.org/hknc/>

National Center on Deaf-Blindness

<http://www.nationaldb.org> (for state information, click on *Contact Your State DeafBlind Project*)

National Family Association for Deaf-Blind

<https://www.nfadb.org/>

I Can Connect, the National DeafBlind Equipment Distribution Program

<https://www.icanconnect.org/>

National Institute on Deafness and Other Communication Disorders

<http://www.nidcd.nih.gov/health/hearing/pages/usher.aspx>

U.S. Department of Education, Office of Special Education Programs IDEA

<http://idea.ed.gov/explore/view/>

ADA National Network

<https://adata.org/>

National Institutes of Health

<http://www.ushersyndrome.nih.gov/>

American Speech-Language-Hearing Association (ASHA)

<http://www.asha.org>

Louisiana Resources

Louisiana DeafBlind Project

<https://www.hdc.lsuhsu.edu/ladbp/>

Early Steps

<https://ldh.la.gov/page/139>

Louisiana Rehabilitation Services

https://www.laworks.net/WorkforceDev/LRS/LRS_Rehabilitation.asp

Disability Rights Louisiana

<https://disabilityrightsla.org/>

Families Helping Families

<https://fhfmgno.org/>

Louisiana Hands and Voices

<https://www.lahandsandvoices.org/>

Louisiana Commission for the Deaf

<https://ldh.la.gov/page/LCD>

Louisiana Association of the Deaf

<https://www.lad1908.org/>

Affiliated Blind of Louisiana

<https://www.affiliatedblind.org/>

National Federation of the Blind – Louisiana

<https://www.nfblla.org/>

Lighthouse Louisiana

www.lighthouselouisiana.org

Louisiana Association of the Blind

www.lablind.com

Louisiana Center for the Blind

www.louisianacenter.org

Training, Resources, and Assistive Technology Center

<https://www.uno.edu/trac>

Governor's Office of Disability Affairs

<https://www.gov.louisiana.gov/page/disability-affairs>