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[International Symposium on Usher Syndrome and Sixth Annual Usher Syndrome Family Conference](https://tndeaflibrary.nashville.gov/event/international-symposium-on-usher-syndrome-and-sixth-annual-usher-syndrome-family-conference-07-10-2014)
[\(<https://tndeaflibrary.nashville.gov/event/international-symposium-on-usher-syndrome-and-sixth-annual-usher-syndrome-family-conference-07-10-2014>\)](https://tndeaflibrary.nashville.gov/event/international-symposium-on-usher-syndrome-and-sixth-annual-usher-syndrome-family-conference-07-10-2014)

This is an in-person event.

Event Date

Thu, Jul 10 2014, 12am CDT - 2 days

Joseph B. Martin Conference Center at Harvard Medical School
77 Avenue Louis Pasteur
Boston, MA 02115
United States

[View on Google Maps](#)

<https://google.com/maps?q=77%20Avenue%20Louis%20Pasteur%20Boston%20MA%2002115%20US>
)

Contact Name

Krista Vasi

International Symposium on Usher Syndrome: July 10-11, 2014

6th Annual Usher Syndrome Family Conference: July 12, 2014

International Symposium on Usher Syndrome | History in the Making

The Coalition for Usher Syndrome Research presents the Third International Symposium on Usher Syndrome in conjunction with the Sixth Annual Usher Syndrome Family Conference in Boston, Massachusetts at the Joseph B. Martin Conference Center at Harvard Medical School.

The International Symposium on Usher Syndrome will convene on July 10-11, 2014 bringing together researchers, clinicians, geneticists and specialists to examine the latest research and developments in Usher Syndrome. The meeting will enable the exchange of ideas and knowledge among different disciplines in order to facilitate new research and progress that focuses on Usher Syndrome.

The annual Usher Syndrome Family Conference will convene on July 12, 2014 bringing together professionals with those affected by Usher Syndrome. This unprecedented combination of events is expected to engage the largest number of constituents in the history of the Usher Syndrome community.

About Usher Syndrome

Usher Syndrome is the leading cause of deaf-blindness in the world. Approximately 45,000 Americans are affected by this genetic disorder. 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 a progressive vision disorder known as retinitis pigmentosa (RP). Initially, they will develop 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.

While there are currently no universally agreed upon treatments for Usher Syndrome, there are a number of treatments nearing clinical trial that could potentially help people with Usher Syndrome.

About the Coalition

Based in the United States, the Coalition for Usher Syndrome Research is a 501(c)3 non-profit organization dedicated to helping families cope with Usher Syndrome while working diligently to find a cure. Our goal is simple: Provide hope to families with Usher Syndrome.

The Coalition counts a number of leading institutions and researchers among its members. In the United States, member institutions from coast to coast bring their expertise and commitment to the work of the Coalition, collaborating with partners and researchers from some of the finest international organizations in the world. In short, the Coalition for Usher Syndrome Research strives to be the most comprehensive source of information on Usher Syndrome and the tremendous efforts being made to find a cure.

REGISTRATION: [Download Form](#)

<https://custom.cvent.com/618E72E57A474629BDEF48F0174EC5BA/files/event/a6ce433211264d6299c6e21872a91c12/b6554eb611504a71979b2154200e48de.pdf>

ABSTRACT SUBMISSION: [Click here for guidelines and to submit an abstract](#)

<http://www.cvent.com/events/international-symposium-on-usher-syndrome/custom-18-a6ce433211264d6299c6e21872a91c12.aspx>

ACCOMMODATIONS

All Hotel Reservation Deadlines: June 4, 2014

Group rates are available at the following hotels:

The Midtown Hotel, 220 Huntington Avenue, Boston. The Midtown Hotel is a 10 minute taxi ride, or 4 stops on public transportation (the “T”) from the Martin Conference Center. To reserve, use Block Code “USHERSYN” to book online at: www.midtownhotel.com (<http://www.midtownhotel.com>), or call The Midtown Hotel’s Reservations Department directly at +1-617-262-1000, or +1-800-343-1177 and identify the block name: “Usher Syndrome Conference.” Rates: \$159 single/double, \$169 triple, \$179 quad.

The Inn at Longwood Medical, 342 Longwood Avenue, Boston. The Inn at Longwood Medical is a 5 minute walk from the Martin Conference Center. Online reservations can be made at www.innatlongwood.com (<http://www.innatlongwood.com>), select “Check Availability,” “Special code” then use Group Code: USHE0709. Or call the Hotel’s Reservations Department directly at +1-800-467-2378 or +1-617-731-4700 and refer to the “Usher Syndrome Conference 2014.” Rates: \$200 One Bed, \$209 Two Beds, \$209 Handicap Accessible.

The Colonnade, 120 Huntington Avenue, Boston. The Colonnade is a 10 minute taxi ride, or 4 stops on public transportation, from the Martin Conference Center. Rates: \$269 single/double, \$299 triple,

\$329 quad. To reserve, contact Krista Vasi at k.vasi@usher-syndrome.org (<mailto:k.vasi@usher-syndrome.org>) or +1-978-637-2625.

SESSION TOPICS

International Symposium on Usher Syndrome

Diagnostics, Epidemiology and Population Genetics

Functional Genetics

Phenotypes and Natural History

Preclinical Studies

Therapy and Clinical Trials

Panel Discussion: Funding Usher Syndrome Research

Usher Syndrome Family Conference

Diagnosis

Gene Therapy 101

Psychological Aspects: Words from the professionals

Psychological Aspects: A patient journey

CONFIRMED SPEAKERS

Zubair Ahmed, PhD (Cincinnati Children's Hospital, Ohio, USA)

Kumar Alagramam, PhD (Case Western Reserve University, Ohio, USA)

Maria Bitner-Glindzicz, MD (University College London, United Kingdom)

Hanno Bolz, MD (Bioscientia, Center for Human Genetics, Ingelheim, Germany)

Connie Cepko, PhD (Harvard Medical School, Boston, USA)

Dominic Cosgrove, PhD (Boys Town National Research Hospital, Nebraska, USA)

Arlene Drack, MD (University of Iowa, Iowa, USA)

Mark Dunning (Coalition for Usher Syndrome Research, Boston, Massachusetts, USA)

Anne Fulton, MD (Boston Children's Hospital, Massachusetts, USA)

Margaret Kenna, MD, MPH (Boston Children's Hospital, Massachusetts, USA)

William Kimberling, PhD (University of Iowa, Iowa, USA)

Hannie Kremer, PhD (Radboud University Nijmegen Medical Centre, Netherlands)

Jennifer Lentz, PhD (Louisiana State University, Louisiana, USA)

José M. Millán, PhD (Unidad de Genética, Valencia, Spain)

Ilene Miner, LSCW (Gallaudet Research Institute, Washington, DC, USA)

Claes Möller, MD, PhD (Audiological Research Centre, University Hospital, Örebro, Sweden)

Kerstin Nagel-Wolfrum, PhD (Johannes Gutenberg Universität Mainz, Germany)

René Pellerin (The Unstoppable, Vermont, USA)

Christine Petit, MD, PhD (Institut Pasteur, Paris, France)

Eric Pierce, MD, PhD (Massachusetts Eye and Ear, Boston, USA)

Heidi Rehm, PhD (Harvard University, Boston, Massachusetts, USA)

Stephen Rose, PhD (Foundation Fighting Blindness, Maryland, USA)

Anne-Francoise Roux, PhD (Hôpital Universitaire, Montpellier, France)

José-Alain Sahel, MD, PhD (Institut de la vision, Paris, France)

Nizar Smaoui, MD (GeneDX, Maryland, USA)

Edwin Stone, MD, PhD (University of Iowa, Iowa, USA)

Luk Vandenberghe, PhD (Massachusetts Eye and Ear, Boston, USA)

Richard Weleber, MD (Oregon Health and Science University, Oregon, USA)

Monte Westerfield, PhD (Institute of Neuroscience, Oregon, USA)

Uwe Wolfrum, PhD (Johannes Gutenberg Universität Mainz, Germany)

Region

[National \(https://tndeaflibrary.nashville.gov/event-region/national\)](https://tndeaflibrary.nashville.gov/event-region/national)

Select the state where your organization or point of contact is located.

Massachusetts

Email Address

[k.vasi@usher-syndrome.org \(mailto:k.vasi@usher-syndrome.org\)](mailto:k.vasi@usher-syndrome.org)

No

Event Type

[Conferences \(https://tndeaflibrary.nashville.gov/event-types/conferences\)](https://tndeaflibrary.nashville.gov/event-types/conferences)

Event Website

<http://www.cvent.com/events/international-symposium-on-usher-syndrome/event-sum...>

<http://www.cvent.com/events/international-symposium-on-usher-syndrome/event-summary-a6ce433211264d6299c6e21872a91c12.aspx>

The state(s) you choose will also populate that state(s) calendar.* After you create an event, use the "Clone" tab to duplicate the event on additional dates.

GEO Location

POINT (-71.102726 42.338315)

Updated: January 27, 2014 5:13pm CST

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