Resources for Young Adults

Megan Lengel

Usher Syndrome Connections Conference
Introduction

• USH 1B
• Cochlear implant, oral English user (learned ASL as first language; moderately fluent)
• Bachelor of Science (Psychology & Sociology)
• USH Ambassador in VA and Young Adult Coordinator
Outline

• Objectives
• Statistics
• Resources
• Goals
• Wrap-Up
Objectives

• Get acquainted with what the USH Coalition provides for young adults

• Encourage young adults to participate and engage with the Coalition and each other
Statistics

- Lack specific statistics on young adults (18-28) with Usher
- Children ages 0-21:
  - Conservative estimate: 7,560
  - Liberal estimate: 25,200
- Employment age adults ages 18-62:
  - Conservative estimate: 11,000
  - Liberal estimate: 27,500
- USH Trust Registry: [www.usher-registry.org](http://www.usher-registry.org)
Coalition Resources

Young Adult Facebook Group
Y'all... I just watched “Crip Camp: A Disability Revolution” and I am REELING! Everyone NEEDS to watch this. Content warning for some disturbing images regarding Willowbrook. I knew about the institution but I was still a little taken aback at how brutal it was.

It’s on Netflix! WATCH IT. ❤️

I will check it out ASAP!

It is really good but the one thing I would warn people on not only the scenes at Willowbrook but some of the terms that are used in the film. It is amazing with work from the people in the film.
Coalition Resources

Young Adult Facebook Group

• Social & informative environment
• Keep informed about USH and young adult-related issues
• Open to EVERYONE
• How to join?
Coalition Resources

“Just for Young Adults”

• USH Blogs

• Webinars: “Educational Considerations for Students with Usher Syndrome” and “Starting a National Dialogue on Finding Children with Usher Syndrome”

• Contribute by filling out the comment box
WANT TO CONTRIBUTE TO THE YOUNG ADULT PAGE?

First Name (Required)
Last Name (Required)
Email (Required)

Type your experience here or upload a document below.

Upload file
No file selected
Click or drag here to add files

SEND
Coalition Resources

USH Blogs

• Open to all young adults to post as guest bloggers
SEEING IS BELIEVING: MY COLLEGE EXPERIENCE WITH USHER’S 1B

Megan Lengel, a recent college graduate and young adult with Usher syndrome, has offered to share with us her valuable experience attending college while dealing with Usher syndrome.

by Megan Lengel

College is insane. Even for someone without Usher syndrome, it can be the most hectic few years of life. The pressure seems to come from everywhere in college; students are expected to figure out their futures, form lifelong friendships, and make solid strides in their careers before graduation. For those with Usher (including me!) the pressures can increase tenfold with the added
Coalition Resources

USH Blogs

• Open to all young adults to post as guest bloggers
• Email info@usher-syndrome.org to add posts
Coalition Resources

USH Talks

• Hub of informational videos, community stories, and research updates
• USH Talks video podcast on iTunes
• View full catalogue on Panopto
Coalition Resources

All content is available on usher-syndrome.com
Goals

• Virtual support group meetings
• Encourage active engagement in Facebook group
• Google Classroom
• NCDB
• Next in-person conference: Breakout Sessions
Virtual Support Group

- Monthly
- Expand types of group meetings
- Special group meetings for specific demographic needs
Facebook Group

• “Guest” Facebook group takeovers
• Diversify content
• Regular posts about USH topics
• Open to ideas!
Google Classroom

• Resource collecting hub
• Place to share ideas for advocacy, new programs, and to encourage collaboration
• Accessible to more people
National Center on Deaf-Blindness

• Usher-specific literature review of existing materials
• Conducting a small number of interviews
• Goals:
  • Increase “child find” of kids with Usher, birth – 21
  • Identify and/or create materials
  • Identify or create trainings for all state DeafBlind project staff
Next In-Person Conference

- Young Adult-specific Breakout Session
- Will ask for input
Objectives

• Got acquainted with what the USH Coalition provides for young adults

• Encouraged young adults to participate and engage with the Coalition and each other

• Discussed goals for expansion
Contact Information

• Email: ambassador.va1@usher-syndrome.org
• Facebook profile: Megan Lengel
Reminder!

• Young Adult live meet-up later in week!
• Friday, July 10th
• 5 – 6 PM EST
• Bring questions!