

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

Coalition Resources

Young Adult Facebook Group

Group by Usher Syndrome Coalition

Young Adults Living with Usher Syndrome

Private group · 123 members



██████████ is 😊 feeling motivated.

Admin · May 4 at 9:36 AM · 🌐

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. ❤️

👍❤️ 5

8 Comments · Seen by 50



Like



Comment

View 1 more comment



██████████

I will check it out ASAP!

Love · Reply · 4w



1



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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.

Like · Reply · 4w



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About

Greetings and welcome to the Usher Syndrome Coalition's Young Adult Corner. This page was curated by Jessica Chaikof a senior at Wheaton College... [See More](#)



Private

Only members can see who's in the group and what they post



Visible

Anyone can find this group



General Group

Popular Topics in Posts

USH Conference (1)

volunteer opportu...

college (1)

Support Group (0)

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?

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

YOUNG ADULTS BLOG

View all posts from young adults living with USH:

OCTOBER 1, 2019

SEEING IS BELIEVING: MY COLLEGE EXPERIENCE WITH USHER'S 1B

SEEING IS BELIEVING: MY COLLEGE EXPERIENCE WITH USHER 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!