



USHER 1F
COLLABORATIVE

NEWSLETTER
June 2020



"Learning online is so much more of a challenge for Zachary. He cannot hear as well, see as well, and is struggling to learn to his potential." - Rachel & Jared

Living with Usher 1F During the Coronavirus

As the world navigates this unprecedented and challenging time, we are hyper aware of the additional burden placed upon those living with Usher 1F. The ways in which the world has adjusted during this global pandemic have been broad and swift. Unfortunately, this means that our community feels an extra impact.

We have heard from members of our community across the globe about their challenges at this time. Social distancing makes everyday interaction that much harder. Tactile communication used by the deaf-blind requires touch, which is now limited. While masks are helpful in reducing the spread of COVID-19, they muffle voices and render lip-reading impossible. Society just feels less accessible to those with Usher 1F in these times.

So many of us love to travel, but our community is hit especially hard by this aspect of shelter-in-place. For those dealing with the loss of vision, they are literally racing time to see all of the destinations they long to visit. While many of us have had to postpone planned trips, few have to worry as those with Usher 1F do if they will be able to see those places when travel resumes.

Most of us are now working from home; no matter what one's role may be, people are being asked to do more with fewer resources. With every meeting and class moved online, please be mindful of how that affects the Usher 1F community. Individuals' eyes are even more strained, as they not only have to pay attention, but many must actively read lips as well.

(cont'd)



"Because of the Coronavirus, I am losing my race against time to travel and see the world." -Anna



"The coronavirus has affected me by making me feel more isolated than I already am due to Usher 1F. - Jessica



"I fear that I won't get to explore and view beautiful sites before I lose my vision. Being unable to plan trips because of the coronavirus makes me angry, as my vision loss is not going to wait until COVID passes." -Dorie

Continued from cover page

Voices are muffled over the best internet connections, and visuals can be pixelated more often than not. Also, some members of our community are unable to use video conferencing software at all! Traditional support mechanisms offered by schools cannot be replicated when students are at home, leaving many without any of the support systems they are accustomed to. This, unfortunately, leaves students with Usher 1F not learning to their full potential!

Lastly, the vital work being done by researchers across the globe has been greatly affected. Many members of our community expressed concerns over delays caused by lab closures. Our researchers are proceeding where able while our labs are only permitted a skeleton crew. They are analyzing data and working on plans for when regular hours resume. Despite the slowdown, we have realized some exciting progress:

- First testing of gene replacement in our mouse model has begun
- Two types of gene replacement: split gene and mini gene are advancing at multiple labs
- Utilizing a bonus end of 2019 grant from the Ganz Family Charitable Foundation of Canada, our Oregon team is working to create an even better zebrafish model using advanced gene-editing techniques
- Establishment of a natural history study is ongoing

We are living in unprecedented times in a fragile world. Please be mindful of those around you and the circumstances in which we are all living. Take the time to reach out to fellow members of our community. While we cannot be together physically, let us connect digitally ♦



USHER 1F
COLLABORATIVE



Introducing Our New Logo

We would like to share our new logo, which resulted after months of discussion among Usher 1F patients, families, and Usher 1F Collaborative board members. We wanted a logo that was more symbolic of both Usher 1F and of our work for a cure. In addition, we wanted to recognize that, while the most prevalent Usher 1F mutation is one that runs among those of Ashkenazi Jewish descent, we also have several families working with us whose mutations are more rare though very much still Usher 1F. In addition, unfortunately, there are over 100 identified Jewish genetic diseases, and so we wanted our logo to be more specific to Usher 1F.

Our new logo contains three symbols:

1. An eye. It is the progressive vision loss of Usher 1F that we are working so hard to cure.
2. The eternal flame or eternal light: While a symbol from Judaism, it is one that is widely applicable to all with Usher 1F, for whom we want to keep light ever present.
3. DNA: The focus of our work is funding medical research to reverse or halt the effects on vision of the genetic mutations that cause Usher 1F.

We send a huge thank you to Rebecca Berman of Berman Branding, who designed our new logo pro bono, working patiently with us through several options and then countless design tweaks. ♦

Amplifying #Usher1F through Social Media & Amazon Shopping

We hope that you have connected with us through social media! Especially in these times, it is helpful to stay connected through these outlets. To amplify our mission, please share our social media content with your friends, family, and wider online community. There are many ways to participate: use the hashtag #Usher1F, invite your friends to like us on Facebook, retweet a tweet, or like an Instagram post. Additionally, we encourage you to share your own #Usher1F story with our online community through social media.

One more way that you can help out is through Amazon Smile! When you shop on Amazon by logging on through smile.amazon.com (instead of amazon.com), you are able to select a charity to be gifted a portion of the money that you spend. This does not cost the shopper anything and is a wonderful way to support Usher1F through your everyday shopping on Amazon! Simply search for and select "Usher 1F Collaborative" and it will be saved for each time you return to shop. ♦



Introducing Erica N. Miller

Having worked for a number of years in a number of client-facing roles both in the nonprofit world and the field of consulting, Erica is thrilled to join the Usher 1F Collaborative. In her new role, she will be responsible for building relationships with Jewish communities and other potential funders and collaborators throughout the country, coordinating fundraising efforts with private and corporate donors, and liaising with key stakeholders.

Erica was born and raised in Lower Merion, Pennsylvania (just outside of Philadelphia). Erica graduated from the American Jewish University with honors where she then matriculated in their graduate program studying Kabbalah, Hasidut, Jewish Law, and community organizing. She has spent time working both on Capitol Hill and as a social media coordinator for a national news food editor.

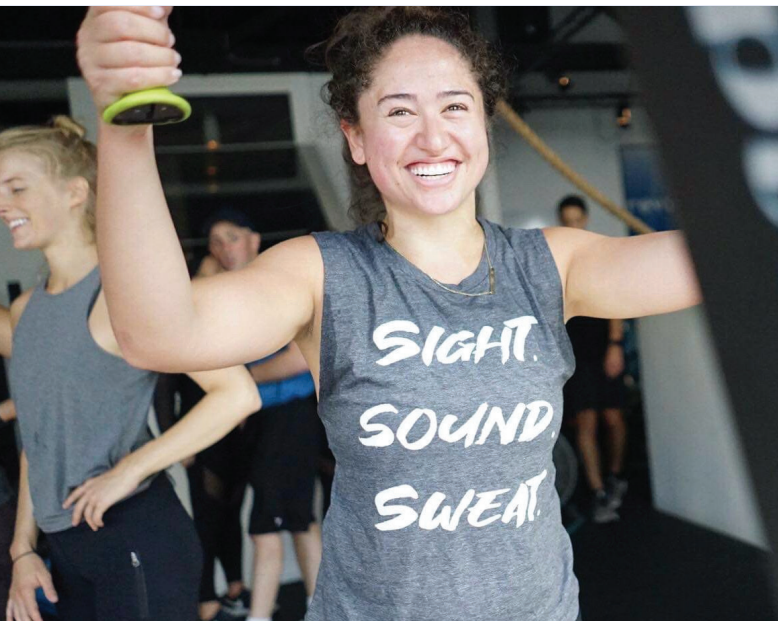
In her time working for the American Israel Public Affairs committee, Erica was responsible for everything from fundraising, to leadership development strategy, and event activation. At the bipartisan lobbying firm, she learned greatly about diplomacy and discretion.

Most recently, Erica saw how Fortune 500 companies function from the inside. At a boutique consulting firm,



she had both internal and client-facing responsibilities. Internally, she created a staff onboarding and training program. Externally, she was part of a team leading a large-scale audit and reformation of internal corporate educational systems.

Erica is thrilled to join the Usher 1F Collaborative and work towards a cure. Please do not hesitate to be in touch, as she loves meeting members of the community and hearing YOUR story! ♦



Dorie Shapiro – Usher 1F Ambassador

Dorie Shapiro has been involved with Usher 1F Collaborative since our founding. She has been a terrific and enthusiastic fundraiser. Most importantly, though, she provides a needed voice for our foundation, that of a person living with Usher 1F. In recognition of Dorie's contributions, we have made her our official Usher 1F Ambassador. Look to hear more from Dorie in the coming weeks. ♦

Dorie Shapiro at her Sight. Sound. Sweat fundraiser