USHER 1F
COLLABORATIVE

NEWSLETTER
Spring/Summer 2022

Victoria Butler-Sloss and her son Arum

Our Families Are Stepping Up!

By Melissa Chaikof

We want to give a big shoutout to some of our Usher 1F families who have stepped up to the plate to help us raise much-needed funds for research. For our 2021 Giving Tuesday and end-of-year campaign, we issued a challenge to our families to see who could raise the most. We send a big thank you to all of our families who participated but want to recognize our top fundraiser, Victoria Butler-Sloss, who raised $6105. From Giving Tuesday through the end of the year, we realized a total of $110,294 in donations and a grand total of $273,084 for the fourth quarter of 2021.

Zachary Root promoting Sight.Sound.Cycle @Home

Following their pre-pandemic fundraising success with Sight.Sound.Cycle fundraisers, the Root family of New Jersey, including ten-year-old Zachary, who has Usher 1F, spearheaded Sight.Sound.Cycle @Home, engaging riders on their Peloton bikes or participating in any type of workout on a Saturday morning in early April, all using the hashtag #Usher1F on the Peloton app. Over 100 registrants and countless donations and corporate sponsorships in support of the ride brought in $73,525 for Usher 1F research.

Jaime victorious approaching the Boston Marathon finish line with her sighted guide

On April 18, 2022, Jaime Recht, who has Usher 1F, realized a dream of hers when she ran the Boston marathon with the help of her sighted guides Gail Edwards and Troy Hemstreet. Jaime tirelessly reached out in the months prior to the marathon, seeking sponsors for her race to raise funds for Usher 1F research and succeeded not just in completing the 26.2 mile race but also in raising $5150. If you haven't seen it, check out the wonderful article about Jaime's race for a cure in the April 28, 2022, issue of the *Jewish Journal*. Visit Jaime's story on our website for a direct link.

On April 23, 2022, Dorie Shapiro, who has Usher 1F, held her second Sight.Sound.Sweat fundraiser in San Francisco. Challenging all of her friends not only to sign up to join her to work out at Project 13 Gyms but to also seek sponsorships themselves, she raised $9573 for Usher 1F research.

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Jaime and Rachel –

Their Experiences Growing Up Deaf with Usher 1F 20 Years Apart

Jaime Recht (L), Rachel Chaikof (R) with Rachel's mother

INTRODUCTION

At Usher 1F Collaborative, we have families with affected children who are babies all the way through adults with Usher 1F who are in their 80s. Our mission and our focus is on finding a cure for the vision loss of Usher 1F, but those with Usher 1F are also born profoundly deaf. With the advent of cochlear implants (CIs), which were FDA-approved for children in June 1990, childhood experiences growing up deaf changed. Now, 32 years later, some in our Usher 1F community are adults who were among the first children to receive CIs.

A long history exists of friction between the Deaf Culture and those in the oral deaf community. At Usher 1F Collaborative, it is important that we transcend these differences and all work together toward our common goal of a cure. Communication and understanding are key to realizing this goal.

Jaime Recht has Usher 1F. She is 56-years-old so grew up well before the advent of cochlear implants. Rachel Chaikof is 35 and, as a participant in the FDA clinical trial for the first multichannel cochlear implant, was one of the first 200 children in the U.S. to receive a CI. Recently, Rachel and Jaime had the opportunity to spend an evening celebrating Passover together in Boston. An understanding began to grow from this that we would like to share with others.

Both answered the same set of questions that focused on their acquisition of language and growing up deaf at very different times in terms of available technology.

QUESTIONS

1. **Describe how you gained access to language as a child. How much were your parents involved, and can you give some specific examples?**

   Jaime: I first went to Lexington School for the Deaf from 1967 through 1974 from age 2 to 9 in Manhattan. The school used a strictly oral method. Children would secretly sign to each other during break times and play time outside the classroom. I once showed my parents some of the signs I picked up from other kids, but my parents immediately stopped me and firmly told me not to do that again. The school also provided me some intense one-on-one speech therapy with audiological equipment. Despite all that, I refused to learn how to lipread, speak, read, and write.

   My parents finally gave in as I got older and decided to hire a tutor to teach all of us,including my younger deaf sister, sign language in order to prepare for my transfer to St. Francis de Sales School for the Deaf in Brooklyn. This school used the Total Communication method (signing and speaking simultaneously). I was finally exposed to sign language in the classroom setting in third grade. I remember being shown a picture of a bus in a picture book and then being shown a sign "bus." I made the connection between these two. After that, I immediately learned many more words, and then from there I finally got to learn how to speak a little.

   I would say my own stubbornness is what ended up showing my parents that I was a visual learner. I had worn hearing aids since I was a baby up until I was about 17 or 18. They simply did not do anything for me. It was just all sounds to me, nothing I could identify or recognize.

   At home we all used "sim-com", speaking and signing at the same time in Signed English as opposed to American Sign Language (ASL) even after I learned ASL. At least we were able to communicate with each other.

   Rachel: During the first two years of my life when I had no access to advanced hearing technology, I relied on lipreading, which my parents and Auditory-Verbal therapist taught me, and I also happen to have the natural ability to learn. However, I was able to learn only about 100 words. I then received a cochlear implant as part of a clinical trial at New York University in 1989 when I was two-years-old. I went from having very little access to language to having full access to complex language through listening with my cochlear implant. From age two to ten, my parents took me to Auditory-Verbal therapy weekly to learn how to rewire my brain to understand language through listening with my cochlear implant, and then my mom provided me therapy for one hour daily. Auditory-Verbal therapy involved playing with toys and communicating with listening and spoken language to learn not only words but also grammar. As the Auditory-Verbal Approach not only involves therapy but also bathing a deaf child in as much language as possible, my mom integrated the Auditory-Verbal Approach into everyday life by teaching me vocabulary while cooking, shopping, cleaning our home, playing games and going to parks. Through Auditory-Verbal therapy, I was able to learn to have conversations with ease on the phone and understand the television without the use of closed captioning.

2. **What type of school did you attend, mainstream or self-contained school for children who were deaf? How was this experience for you?**

   Jaime: It was all schools for the deaf for me including a university for the deaf, Gallaudet University. The best educational environment for me was being in a school with other deaf students using ASL. I was involved in a lot of activities as soon as I entered St. Francis, continued to Lexington and Gallaudet and beyond. I even got a role in a school play, I also got on honor rolls, etc. This was where I first saw how capable I am. I built up a lot of self-esteem and self-confidence, especially when I realized I was not as inferior as I thought and that there was nothing wrong with me. This is the proof that sign language and visual learning worked best for me. I can tell you I was happy as soon as I entered St Francis.

   Rachel: I attended mainstream schools all my life and learned alongside my hearing peers. My teachers and other students used assistive listening devices to ensure that I had equal access to hearing instructions and discussions. Moreover, I had phenomenal teachers of the deaf who not only worked with me to ensure that I had reasonable accommodations in the classroom but also worked one-on-one with me on my language skills to close my language gap since I was two before I received full access to language. I learned a second spoken language, participated in extracurricular activities, including holding leadership positions, achieved stellar grades and graduated with honors from middle school and high school.

3. **How easy was it for you to make friends at school? Were you able to communicate with your friends easily?**

   Jaime: Since I always went to school with deaf kids, it was never a problem communicating with them. Even at the oral school, we still often communicated with each other in signs during breaks and I also had play dates outside the school.

   National Association of the Deaf has a great youth program called Jr. NAD, which provided various activities including their famous Youth Leadership Camp (YLC). When I was in 8th grade, one deaf parent of a deaf student observed me and encouraged my mom that I join Jr. NAD where her oldest son was president. My mother and I went to an orientation meeting to learn about the program. I then started hanging around with other Jr. NAD kids, and it was the first time I started meeting other deaf kids outside St. Francis. I went on ski trips and other events with them. That was also where I learned ASL (as opposed to Signed English) before I even entered Lexington again in the fall of 1980, which had finally allowed sign language in their high school just a year before. At Lexington, I was involved in a lot of school activities, some in leadership positions. Some of the kids were also from the Jr. NAD group, so I already had the in. I was so grateful for the networking and experience Jr. NAD provided me.

   Rachel: During most of my schooling years, I was able to make friends easily and enjoy a social life by not only getting together in our homes but also at movies and restaurants, although I did face some bullying because of my disabilities during my later elementary school years. Those difficult years taught me to stand up against discrimination and advocate for myself as a person with disabilities.

4. **Did you ever feel frustrated because of your deafness or have difficulty communicating as a child?**

   Jaime: Yes, up until I was 9, my childhood was a very difficult and frustrating time for me, especially at Lexington School during my first time around. Starting at St. Francis and thereafter, I didn't have much problem communicating with kids, teachers, and staff. My deafness was not a barrier in these signing environments. I was finally in a better place mentally and emotionally.

   Rachel: Before I received a cochlear implant, I faced challenges with communication due to my limited access to language through lip reading. I loved going "bye bye." I was very determined from the start, and two photos of me at age three show me holding onto the doorknob with an angry look on my face, climbing the door to try to open it. I didn't understand why we couldn't go out. About six months later, I had a similar situation, but my language had advanced enough that my mom was able to explain to me that first we had to do something else, and then we could go bye bye. I understood and kept repeating it.

5. **What do you want parents today who are raising children who are deaf to know about and learn from your experiences?**

   Jaime: Parents need to remember the importance of an early language acquisition from the start, which is where ASL comes in. I am proud and happy that my parents let me grow and thrive since I was nine. Because of the way I was (and still am), I was constantly very motivated and involved, especially when the barriers were broken down for me. I graduated as salutatorian in my high school class and from Gallaudet University with a business degree. I'm currently a program analyst with the Federal Government. I'm a strong, independent woman with two adult sons. Parents need to know that deafness doesn't mean our futures are doomed to be miserable.

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I also want parents of deaf children to learn as much as they can about deafness and deaf culture, whether their children have a cochlear implant or not. One cannot just get their kids implanted and automatically expect them grow up just like them or hearing kids. They are all different so the parents need to learn as much as they can to be able to afford kids any opportunities available to them. ASL and my involvement in the deaf community were the best things for me mentally and emotionally since these are what gave me the education and confidence I needed in life.

Rachel: The first most important lesson from my experience is that parents must ensure that their deaf children have access to full language as soon as possible as it makes all the difference in the outcome of a deaf child's life. The second lesson is that parents should not underestimate the abilities of their deaf children. They should know that the sky is the limit, and deaf children can grow up to do anything they wish to do in life.

6. **If you had a chance to change how you were given access to language as a child, what would you change, if anything?**

Jaime: It would be ideal if I was exposed to ASL as an infant, which is why I strongly support early intervention because late language acquisition is a huge issue with deaf children of hearing parents who don't sign from the start. Written good English is still difficult for me as I acquired it rather late in my life. I know if cochlear implant technology was available when I was a baby, my parents would be one of the first to get me one. Nevertheless, I'm a proud deaf person who doesn't want to change anything regarding my own deafness.

Rachel: I would get bilateral cochlear implants no later than six months old, which would have decreased my time in therapy dramatically and enabled me to learn language more easily through listening in a variety of different situations. Today, combined with newer cochlear implant technologies and hearing with two cochlear implants (I received my second cochlear implant in my other ear when I was 17-years-old), my access to listening and spoken language has vastly improved and become even easier. I'm able to have conversations with ease in noisy environments, overhear people's conversations, including when I'm in a different room from where the conversation is happening, and understand the radio in the car and announcements at airports and on planes.

7. **How do you think it is different for babies born deaf today compared to your childhood?**

Jaime: Yes, it's so different today for deaf people. We now have access to closed captioned TVs, captioned movies, video relay service, smartphones with FaceTime, speech-to-text app, online ordering, etc. We are not as isolated and out of touch with mainstream hearing culture. And at the same time, we are more in touch with deaf people from all over the country and even the world thanks to social media. Also, most deaf schools dropped oral education philosophy because it simply and clearly doesn't work. Yes, there are a lot less communication, language, and cultural barriers now.

Rachel: Today, when deaf children receive cochlear implants in both ears at six months, they complete therapy by three-years-old and go on with life, thriving with advanced listening and spoken language skills. The first three years of a child's life are the most critical for access to full complex language as this determines the outcome of a child's life. It is extremely important for a child born deaf today to receive bilateral cochlear implants as soon as possible, preferably by six months so that they can have immediate access to full language. The sooner the child hears language, the sooner the child finishes therapy and is able to access language with ease. Because I didn't have access to full language until two-years-old and, moreover, I grew up hearing with only one cochlear implant, I didn't complete therapy until I was ten-years-old.

FINAL THOUGHTS

The common theme in both Jaime's and Rachel's experiences and thoughts is the importance of early acquisition of language. The first few years of life are the critical early language learning years and are also the years spent mainly with parents and primary caregivers. Regardless of approach, parents must be fully committed to imparting sophisticated language to their children. Cochlear implants have made it much easier for children born deaf today to successfully learn to listen and talk, but the ability to comprehend spoken language through hearing with their implants does not magically happen. While early implants have made it a much easier process, parents and caregivers need to invest the necessary time and effort. Similarly, if parents opt for ASL as their child's primary language, they must make the necessary effort to become fluent themselves in order to impart sophisticated language to their child.

Regardless of primary language, Jaime and Rachel have shown us that those with Usher 1F have experiences and priorities in common and can work together to find a cure for their vision.◆

Update on RUSH1F, Our Natural History Study

Anna participating in testing for RUSH1F

As shared in our newsletter a year ago, Usher 1F Collaborative has partnered with Foundation Fighting Blindness and the JAEB Center for Health Research for RUSH1F, our Usher 1F natural history study.

For rare diseases, a natural history study is a critical step in advance of a clinical trial. While most clinical trials include a treated and a control group (the latter given a placebo) to compare outcomes to determine efficacy, with rare diseases there are not enough patients to form two separate groups. We also don't want to put any Usher 1F patients through a clinical trial with the associated testing without giving them hope with an actual treatment. Thus, RUSH1F will provide the control group in advance. That is, RUSH1F clinicians and researchers will document and study natural progression of vision loss in the absence of treatment over a period of four years. This data will then be available for any future clinical trial to determine efficacy.

RUSH1F includes ten clinical research centers around the world:

- San Francisco, CA: University of California San Francisco
- Baltimore, MD: Johns Hopkins University, Wilmer Eye Institute
- Lexington, KY: University of Kentucky, Advanced Eye Care
- Toronto, Canada: University of Toronto, Hospital for Sick Children
- London, England: Moorfields Eye Hospital
- Paris, France: CHNO des Quinze-Vingts
- Radboud University Medical Center, Nijmegen, Netherlands
- Tuebingen, Germany: University of Tuebingen, Centre for Ophthalmology
- Jerusalem, Israel: Hadassah-Hebrew University Medical Center
- Basel, Switzerland: University Hospital Basel

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Meet Our New Board Member, Heather Rosenstein

Earlier this year, Heather Rosenstein joined our Usher 1F Collaborative Board as a Trustee. Heather is a partner with the Evergreen 21 Group at Morgan Stanley Private Wealth Management. She works with individuals, families, foundations, and entrepreneurs and is very engaged with the firm's socially responsible investment platform and Jewish values initiative. She graduated from the University of Rochester with a BA in Economics and Political Science and received her M.B.A. in Finance from Columbia Business School. She started her investment career working for a mutual fund and then spent 13 years at Gotham Asset Management as the co-Portfolio Manager of SaddleRock Partners, a long/short equity fund focused on the consumer sector.

Heather grew up next door to a parent of an Usher1F child, so she felt a personal connection to our mission, and she is excited to join the board, knowing that she can make an impact for those living with Usher 1F. We are delighted with the energy Heather brings to our organization.

Heather is also a board member of the American Jewish Committee (AJC), where she is actively involved with the Leaders for Tomorrow program. She and her husband Joseph Sarachek live in Scarsdale with their five children. ◆

Meet Our New Development Associate, Sarah Gauch

In January, Sarah Gauch joined the Usher 1F Collaborative team as our Development Associate and has already wowed us with her expertise, enthusiasm, and initiative. Sarah has dedicated the majority of her career towards raising critical philanthropic funds for the healthcare of individuals. She began her fundraising career at Muscular Dystrophy Association before moving on to Inova Children's Hospital in Fairfax, Virginia. Sarah has worked with donors of all levels and has collaborated on every aspect of fundraising, including foundation and corporate giving, major gifts, and special events.

Through her professional experience, and as the parent of children with disabilities, Sarah brings a special interest in children's access to quality healthcare and education. Sarah earned a bachelor's degree in Economics from the University of Virginia, and currently lives in Richmond with her husband and four children.

She is thrilled to take on this role with Usher 1F Collaborative and is most excited to work with families and donors as we seek to expand our fundraising initiatives. ◆

Families Stepping Up! *continued*

Dorie (bottom row front and center) and her Sight.Sound.Sweat teammates and supporters

Together, these four individual fundraising campaigns raised $94,353, which is enough to fund one of our research labs for a year. If these stories have inspired you, please join us. No one of us alone can realize enough funding for a cure, but all of us working together will make it happen. Imagine what we can accomplish if all of our families pitch in. No fundraiser is too small, and we will support you in any way that you need, creating your online fundraising page, processing donations, promoting your event on social media, and more. ◆

Natural History Study *continued*

Participant visits began in the fall of 2021 when the University of California San Francisco began seeing patients, and other sites soon followed. All ten centers are now either up and running or will be very shortly. For this first year, two visits are required, an initial screening visit and, once qualified for the study, a longer visit. After that, visits will be once a year for three more years. The study budget includes an amount for reimbursing patients for travel expenses to the site nearest their home.

Enrollment is approaching the number of patients needed, but we are not there yet. We send a huge thank you to those who have already signed up and gone for their appointments. If you have not yet signed up, please do so. Participating will benefit you/your child and all with Usher 1F. We are all in this together! ◆

Meet Our Social Media Interns, Haley and Vi

Social media intern
Haley Guerrero

Social media intern
Vi Ho

If you follow us on social media, then you have noticed our more frequent postings that are also more creative and colorful. Haley Guerrero and Uyen-Vi Ho are graduating seniors at the University of Connecticut, majoring in communications. After participating in a semester-long project initiated by their professor, Tyler Page, PhD, to develop a strategic communications campaign for Usher 1F Collaborative, we opted to take advantage of their knowledge about our cause and their skills. ◆