



**USHER 1F**  

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**COLLABORATIVE**

# **ANNUAL REPORT**

## **2020**

# USHER 1F COLLABORATIVE

## Mission Statement

Usher 1F Collaborative is a 501c3 nonprofit foundation whose mission is to fund medical research to find an effective treatment to save or restore the vision of those with Usher Syndrome type 1F.

## Operating Highlights

### Community Projects

While 2020 shifted activity online, we saw a number of successful campaigns executed throughout our community. These projects include: Roses for Vision, Foodies for Vision, Anna's Race for a Cure, Giving Tuesday Now, Giving Tuesday, and the many individual birthday fundraisers on Facebook. Our first Usher 1F InSight Series took place in December and was a great success!

### Partnerships

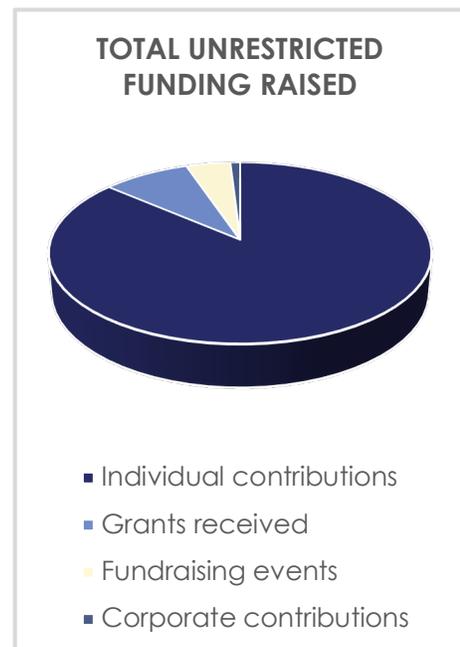
As a member of the **Chan Zuckerberg Initiative Rare as One** cohort (CZIRAO), the Usher 1F Collaborative has had access to some of the most forward-thinking individuals, and enriching conversations taking place in the rare disease universe. In addition to regular education and action within the network, CZIRAO invited us to participate in the 2020 Milken Institute Future of Health Summit. Participation in the virtual summit involved the Usher 1F Collaborative team in more advanced conversations, improving the strategy & work of the organization.

The Usher 1F Collaborative has worked to maintain our partnership with the **Usher Syndrome Coalition** through ongoing work enriching the Usher community at large.

## Financial Report

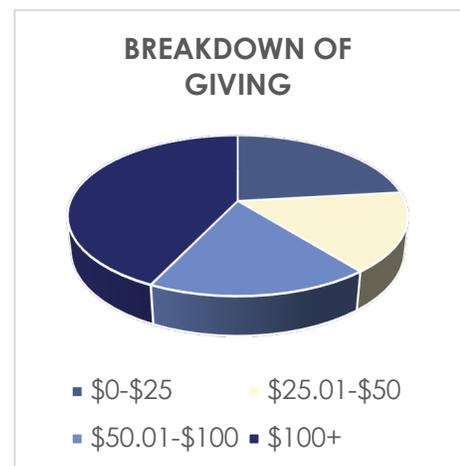
Total Raised \$1,224,058

- › Unrestricted \$759,058
  - › \$654,770 Individual contributions
  - › \$64,500 Grants received
  - › \$32,538 Fundraising events
  - › \$7,250 Corporate contributions
- › Restricted \$465,000
  - › Chan Zuckerberg Initiative



## Giving Breakdown

- › Total Gifts 549
  - › \$0.00 → 25.00: 127
  - › \$25.01 → 50.00: 88
  - › \$50.01 → 100.00: 98
  - › \$100 & up: 235
- › Average Giving
  - › \$2,448 average gift
  - › \$696 average gift (without restricted funds and highest individual donation)



- › Facebook Giving
  - › \$6,335 total
  - › \$52 average gift

## Total Grant Distribution \$305,000

- › Grants Given: 5
  - › Harvard Medical School: \$200,000 (\$100,000 x 2)
  - › University of Maryland: \$50,000
  - › University of Oregon: \$50,000
  - › Usher Syndrome Coalition: \$5,000

## Total Expenditures for 2020 \$495,056.40

- › Total expenditures from unrestricted funds \$337,735.54
- › Total % of unrestricted funds going to grants = 90.31%
  - › \$305,000 grants awarded / 337,735.54 expenditures

## Total Assets as of 12/31/2020 \$1,391,734

## Looking Ahead

### A Bright 2021

The coming year has many exciting projects on the horizon. We will be launching a laser focused initiative entitled **Ten to Cure**, enabling scientific breakthroughs and accelerating our path to a cure.

Our research continues with **5 gene therapies and 4 drug therapies in development!** In our ongoing pursuit of facilitating scientific research, this spring we will convene an international scientific research conference. Thanks to the funding of the Chan Zuckerberg Institute, we will have the resources to provide a world-class virtual symposium: **Therapeutic Strategies for Large Protein Coding Genes in Usher Syndrome, Thursday-Friday May 13-14, 2021**. Lastly, we look forward to continuing our InSight Series, enabling more community-based fundraising, and deeper work with partner organizations in 2021!

### Thank You!

We offer our deepest appreciation to each and every individual, foundation, and corporation who have joined in our pursuit of a cure for Usher Syndrome type 1F.

Through your investment in the Usher 1F Collaborative, you have brought light to an often-dark world. We also extend our most heartfelt gratitude to the scientists and researchers who inspire us on a regular basis! Looking forward to doing great things together in 2021.