

Dear HD Reach Community,

It's been quite the year and it's certainly not over yet.

As a community supported organization, we want to provide you – the reason we exist and why we are able to exist with a brief report on how HD Reach used its resources to deliver on our promise to help improve the quality of life of people impacted by HD. All metrics are based on January 1 – October 19:

Supporting

"I'm just so glad to know there is someone I can call and talk to about all of this. My family has been dealing with this for years and I'm glad there is someone who understands that I can reach out to."

- 58 personal sessions with social worker for social support
- More than 16,000 people have directly or indirectly received knowledge and support



Support Groups - In the Covid-19 era, we transitioned to online meetings. Staff provided tech support to help ease the transition to Zoom and guest speakers were invited to reduce Zoom fatigue.

- 37 Support Group meetings were held in Raleigh, Charlotte, Winston-Salem and Wilmington with 169 participants

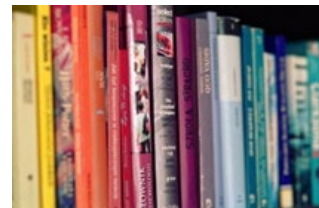
Check-ins – Calls are being made to active and past clients to offer assistance and companionship during the lockdowns and restrictions.

Connections Project was initiated to link people together for regular chats. Our goal by the end of the year is to create 10 Connections; six have been made to date.

Educating

"I never thought about how some of this was connected until I watched the videos. Now things are beginning to make more sense."

- 9,346 views of the educational pages on website
- 37 personal sessions with social worker regarding disease education



Educational Conference - The *Your Road to Wellness and Resilience* accomplished the following:

- Extraordinary line-up of experts including Dr. Bruce Compas, Dr. Mary Edmonson, Dr. Victor Sung, Dr. Bonnie Hennig-Trestman, Dr. Robert Trestman and many others
- 91 participants in the live presentation
- 416 independent views of 12 videos
- 81% of participants rated the content as "Very Useful"

- Movement Disorder Foundation rebroadcast the keynote presentation to their audience in partnership with HD Reach
- Unfortunately, we couldn't bring everyone into a room together to forge the "you are not alone" feeling and build new friendships. We're determined to create more community building opportunities in 2021.

Educational Workshops - Provided educational workshops and videos to directly address issues found at the intersection of caregiving during a pandemic.

- 9 people attended the first two workshops (participation is limited to increase interaction)
- 73 people have viewed short videos with helpful tips

Genetic Testing

"It made a big difference going through the Decision Path before getting tested. I'm definitely better prepared and have recommended that my sister go to HD Reach too."

- 6 participants and their testing partners have gone through the Decision Path and Anonymous Genetic Testing process
- Each participant that took part in the survey indicated that they were satisfied with the process.



Collaboration and Research

- HD Reach is presenting two research posters at the Huntington Study Group Conference.
 - "Confidential Genetic Testing in a Non-Medical Setting: Protocol Development," written and presented by Dr. Bonnie Hennig-Trestman
 - "Layers of Loss: A Scoping Review of Huntington's Disease Caregivers' Spiritual Distress and Coping Strategies." The academic leader is Dr. Buddy Marterre, MD, MDiv at the Wake Forest University School of Medicine
- Debbi Fox-Davis is on the Advisory Council of the University of South Carolina Huntington's Disease Society of America COE



Connecting and Community Building

"Until I saw everyone sitting together in one room, I had no idea there were so many people in my situation. It changed my attitude about this and made me realize, I'm not alone."

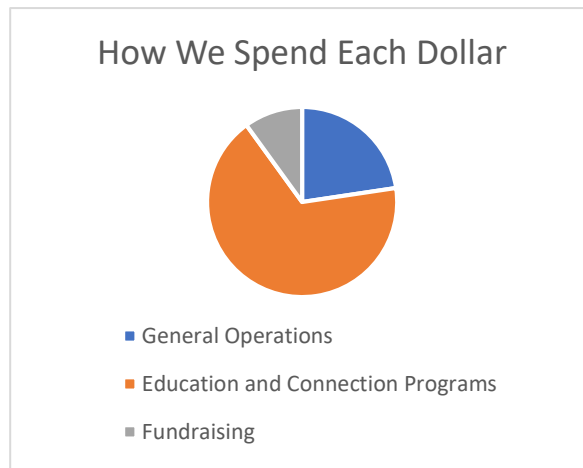
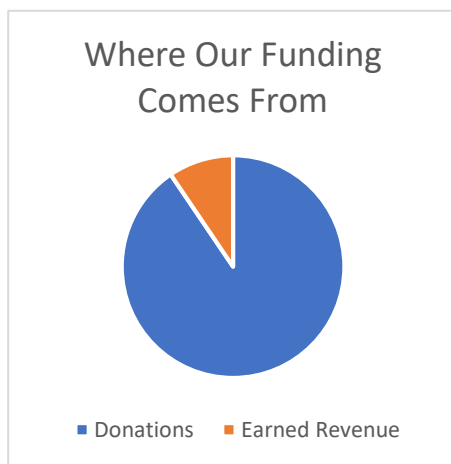
Pathway Program - Creating a snowball effect of family members telling family members that they could live better with the help of a supportive community is one of our key goals. In August 2019, we launched the Pathway program to learn about our clients' needs, fears, hopes and concerns. We want to know how to serve each client better and want to extend our reach to their family and friends.



- 89 people have taken the Pathway Program survey to identify and clarify needs.

Beehive Project is in development but will ultimately build upon our efforts to strengthen the feeling of community, connect HD Reach to people previously unconnected and reduce isolation for more people.

Financial Highlights



Operational Highlights

- 9 Amazing staff members; 3 full-time, 6 part-time
- 7 Dedicated Board Members
- 23 Volunteers donated 628 hours
- Transformed into an Office-without-Walls to operate more economically and provide flexibility in order to keep experienced staff.

