

Giving Hope. Getting Answers.

Impact Report for 2020-2021

Giving Hope.
Getting Answers.

Hope for Hypothalamic Hamartomas

LETTER FROM THE BOARD

Board of Directors

Erica Webster
President

Lisa Soeby
Vice President

Kathy Jensen
Secretary

Kimberly Ranson
Treasurer

Emma Nott
Kristy DeBowes

Medical Advisory Board

J. Helen Cross, MD
MAB Chair (2015 - Present)
UCL Instit. of Child Health (UK)

Alexis Arzimanoglou, MD
Univ. Hospitals of Lyon (FR)

Sam Berkovic, MD
University of Melbourne (AU)

Madison M. Berl, PhD
Children's National Hospital (US)

Varina Boerwinkle, MD
Phoenix Children's Hospital (US)

Daniel Curry, MD
Texas Children's Hospital (US)

William Davis Gaillard, MD
Children's National Hospital (US)

Michael Hildebrand, PhD
Melbourne Brain Centre (AU)

Julia Jacobs, MD
Alberta Children's Hospital (CA)

Oliver Oatman, DO
Phoenix Children's Hospital (US)

Jean Regis, MD
Timone Univ. Hospital (FR)

Andreas Schulze-Bonhage, MD
University Hospital Freiburg (DE)

Hiroshi Shirozu, MD, PhD
Nishi-Niigata Chuo Nat. Hospital (JP)

Jie Wu, MD, PhD
Barrow Neurological Institute (US)

Kevin C.J. Yuen, MD
Barrow Neurological Institute (US)

Honorary Members

Simon Harvey, MD
Royal Children's Hospital (AU)

Jack Kerrigan, MD
MAB Chair (2009 - 2012)

Harold Rekate, MD
MAB Chair (2013 - 2014)

Jeffrey V. Rosenfeld, MD, AC, OBE
Alfred Hospital (AU)

The past two years have been profoundly unpredictable and have required the world to constantly find a new sense of 'normal'. Many nonprofits continue to face an uncertain future. However, Hope for Hypothalamic Hamartomas has not only continued to serve our community, but we have been able to expand in our support of novel HH research. We have always operated virtually, which keeps our overhead expenses low and allows us to reach an ever-expanding international community. It has always been and will continue to be, part of our mission to be excellent stewards of the donations entrusted to this organization.

Despite the worldwide lockdown, Hope for HH was able to keep our focus on improving the lives of individuals and families affected by HH. We were able to facilitate a broader, more extensive definition of HH as a syndrome, connect our international community through online Meet & Greet, and provide education through our virtual Patient Conference. Our Support programs continued through these difficult times, ensuring we provided the needed comfort to our community as they coped with the daily challenges of living with not only a complex syndrome but how that might be further complicated during a pandemic.

We are excited about the new opportunities 2022 brings, and look forward to achieving an even greater impact for our community and advancing critical research of Hypothalamic Hamartoma Syndrome.

The Hope for HH Board of Directors and our dedicated volunteers would like to thank our Hope for HH community for your unwavering support and generosity.

Warm Regards,
Hope for HH Board

WHO WE ARE

Hope for Hypothalamic Hamartomas (Hope for HH) is a volunteer-based nonprofit organization founded and run by parents of children with hypothalamic hamartomas (HH).

MISSION

Hope for Hypothalamic Hamartomas (HopeForHH.org) provides information, support and community to HH patients, caregivers and healthcare providers. We promote research into early detection, improved treatments, living with HH as a complex medical syndrome, and a cure.

CORNERSTONES



GOALS

- Provide **INFORMATION** to HH patients, caregivers, and healthcare providers
- **SUPPORT** HH patients, caregivers, and families around the world
- Promote **RESEARCH** toward early detection, improved treatments, living with HH, and a cure
- Increase **AWARENESS** of HH, seizures, comorbidities, and the Hope for HH organization
- **FUNDRAISE** to support our programs, services, and research
- Maintain the **OPERATION** of an All-Volunteer Organization (AVO) 501c3 virtually, legally, and efficiently

BOARD OF DIRECTORS



Erica Webster
President, Co-Founder



Lisa Soeby
Vice President, Co-Founder



Kathy Jensen
Secretary



Kimberly Ranson
Treasurer



Emma Nott
Director of Awareness



Kristy DeBowes
Board Member

VOLUNTEERS

- Whitney Barnett
- Mark DeBowes
- Angela Donn
- Lisa Garrn
- Tomas Lampo
- Damien McCann
- Michelle Swartz
- Roza Wu

RESEARCH

- Dr. Kevin Yuen, Professor of Medicine and Medical Director Barrow Pituitary Center, Barrow Neurological Institute, St. Joseph's Hospital, and Medical Center joined our Medical Advisory Board (MAB).
- Endocrine data from the HH Comorbidity Survey was featured as a poster '*Prevalence of Self-Reported Endocrine Comorbidities in Hypothalamic Hamartoma Patients: Data from the Hope for Hypothalamic Hamartoma Survey*' by Dr. Kevin Yuen, Dr. John F. Kerrigan, and Dr. Oliver Oatman at the 2020 Endocrine Society annual meeting.
- Hope for HH partnered with the Child Neurology Foundation (CNF) to conduct a brief survey '*The Diagnostic Journey*' to understand caregivers' experiences on their journey to a diagnosis, with the goal of finding ways to shorten the diagnostic odyssey.
- Hope for HH highlighted the new HH-focused clinical trial '*A Feasibility Safety Study of Benign Centrally-Located Intracranial Tumors in Pediatric and Young Adult Subjects*' which is currently underway at Nicklaus Children's Hospital in Miami, Florida.
- Hope for HH's Medical Advisory Board (MAB) established a special task force to draft clinical recommendations for the diagnosis, treatment, and long-term care of those with hypothalamic hamartomas. These recommendations will cover the spectrum of comorbidities associated with HH.
- In collaboration with ILAE and EpiCARE an interactive Hypothalamic Hamartoma e-learning module has been developed to educate the clinician in how to diagnose, treat and manage HH and its comorbidities.

'Helps you feel less isolated, nice to talk to others going through the same thing as there is no one that would understand the situation better.'

2021 Meet & Greet Attendee

RESEARCH HIGHLIGHTS



RESEARCH HIGHLIGHTS

RESEARCH

- Hope for HH awarded a \$50,000 grant to fund the collaboration between the University of Melbourne and Baylor College of Medicine with the focus on genomic profiling of HH-derived samples obtained during MRI-guided Laser Interstitial Thermal Therapy.
- A total of \$9,000 in multiple grants was awarded by Hope for HH to fund the shipment of HH tissue from Great Ormond Street Hospital and Alberta Children's Hospital to the University of Melbourne to be used for genomic profiling.
- The review publication '*Hypothalamic Hamartomas: Evolving Understanding and Management*' from the 4th International Symposium on Hypothalamic Hamartoma was published in the November 2021 issue of the Journal of American Academy of Neurology. Thank you to our Medical Advisory Board for their dedication and diligence in getting this work published.
- The HH Comorbidity Survey closed and work will begin in 2022 on drafting a publication. A total of 480 patients and caregivers from over 35 different countries participated in this initiative. Collaboration in research is crucial and we're so grateful to our Hope for HH community for answering this call.
- Hope for HH is part of a Transversal Working Group across the European Rare Disease Network, representing HH patients and other rare and complex epilepsies within EpiCARE, examining care and services in pregnancy and family planning for patients with a rare disease.

'The presentations and breakouts need to be longer. So much good stuff to learn!'

2021 Patient Conference Attendee



SUPPORT

Giving Hope.
Getting Answers.

- International Meet & Greet were hosted online to provide community members a place to connect through live, interactive video conferencing. We held five virtual events which provided an opportunity for many to meet 'face to face' for the very first time.
- Hope for HH hosted the 2021 Virtual Patient Conference. We had nine speakers and multiple breakout sessions covering: treatments, mental health, caregiver concerns, impact on the family, service dogs, executive function, and memory.
- Surgical Comfort bags were provided to those going for treatment through our partnerships with Phoenix Children's Hospital, Texas Children's Hospital, and Seattle Children's Hospital.
- Patient and family outreach and support were ongoing through email, phone, social media, and our new private Hope for HH Community Group on Facebook.

"We truly loved the surgical bag gift! It was such a sweet gesture that made our 2wks in the hospital helpful! The snacks came in handy when we couldn't leave the room. The books were a welcome addition since our fam reads every night. Mostly it was the thoughtfulness gesture that impacted us and helped us form lifelong friendships!"

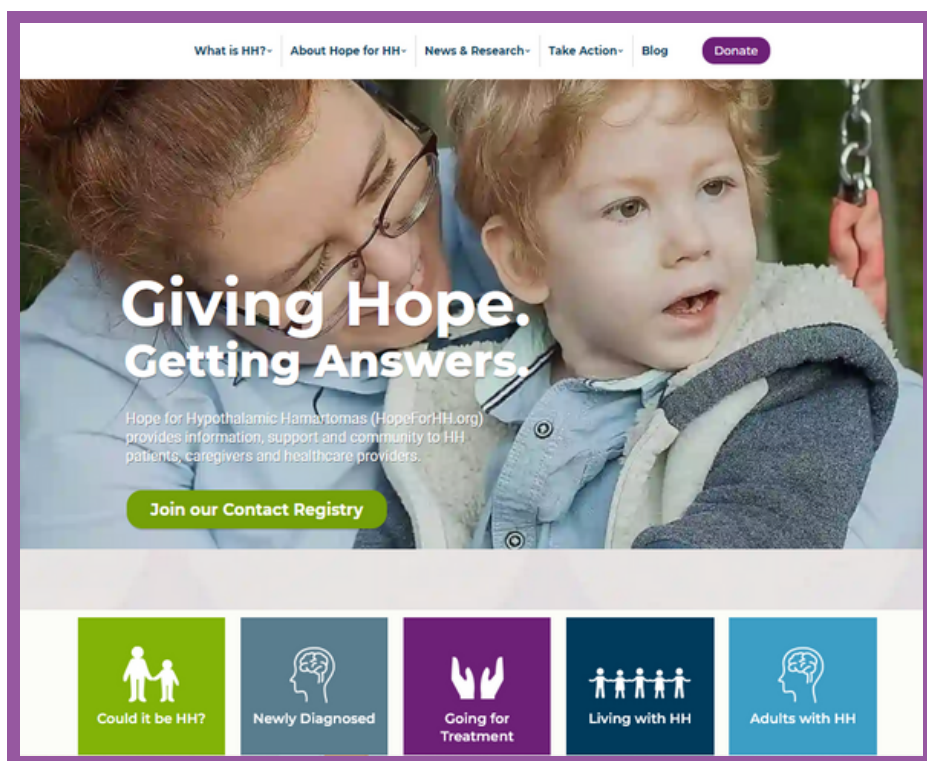
Surgical Support Bag Recipient

SUPPORT HIGHLIGHTS



INFORMATION

- Hope for HH expanded our information and resources to better support our growing international community in 2020. Many of our downloadable information pamphlets were translated into multiple languages.
- In 2020, we launched the inaugural International HH Awareness Month campaign to raise global awareness of this rare brain tumor, gelastic epilepsy, and the spectrum of comorbidities. This campaign reached an international audience of over 31,000.
- Our Facebook page grew by 16% as individuals connected to us throughout the pandemic in 2020 and 2021.
- Critical and timely HH information, research news, and event information were shared through our monthly newsletter.
- Our new website has launched in September 2021. The primary objective was to ensure we provided current information and resources for all stages of the HH patient journey from pre-diagnosis, diagnosis, treatment, and living as an adult after treatment. Also, to better support our international community, the website can now be translated into French, German, and Spanish.



AWARENESS

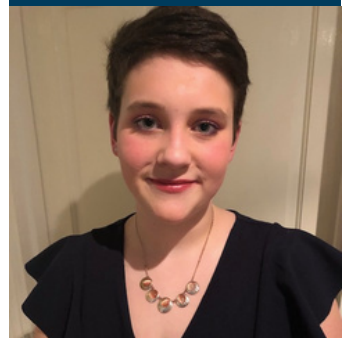
Giving Hope.
Getting Answers.

AWARENESS HIGHLIGHTS

- In collaboration with EpiCARE ePAG (European Patient Advocacy Group) and our Medical Advisory Board, several resources were developed for both patients and healthcare providers and are available on the Hope for HH website.
 - 'Hypothalamic Hamartoma Causing Epilepsy - Patient Journey'
 - '10 FAQ's: Patient and Caregiver' a leaflet for families.
 - 'Hypothalamic Hamartoma Syndrome - Information for the Healthcare Professionals' a leaflet for professionals.
- Hope for HH presented a poster at the European Conference on Rare Diseases in 2020 in collaboration with our Medical Advisory Board, Eurordis, and EpiCARE.
 - 'The Rare and Complex Epilepsies - Common Unmet Needs within the Patient Community'
- Hope for HH presented a poster at the 2020 EpiCARE Symposium.
 - 'Patient Advocacy bringing Laser to UK and Europe: Challenges and Opportunities'
- Hope for HH a poster at the American Epilepsy Society (AES) annual meeting in 2020.
 - 'Centralized Efforts Transforming Global Care The Ten-Year Impact of a Patient Advocacy Group - Medical Expert Partnership on Recognising and Treating a Rare and Complex Epileptic Brain Malformation Syndrome'
- Hope for HH awarded \$2500 grant to Child Neurology Foundation (CNF) for collaboration on the two-year education initiative to "Shorten the Diagnostic Odyssey in Children with Neurological Conditions".
- Erica Webster, Co-Founder and President, featured as a Rare Leader by Global Genes.
- Carrie Fulcher, Chair of Hope For HH United Kingdom Affiliate featured in Rare Revolution Magazine.

'It was beneficial being able to chat & listen to other parents'

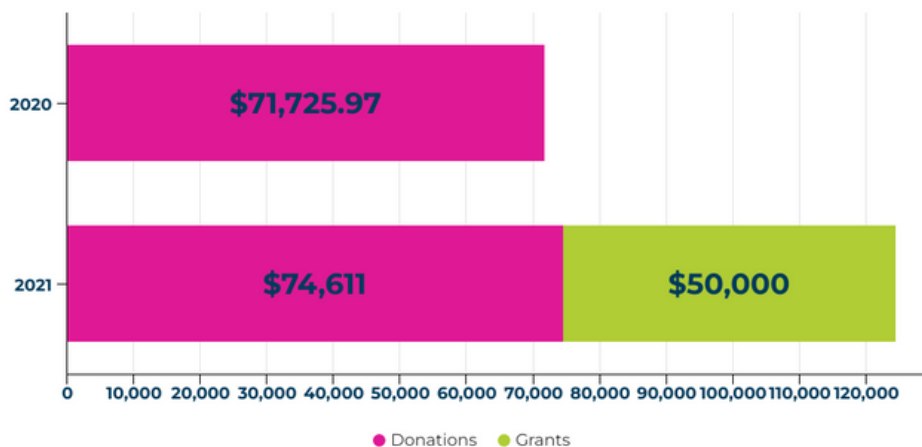
2021 Patient Conference Attendee



TWO YEAR SNAPSHOT

FINANCIAL HIGHLIGHTS

Income



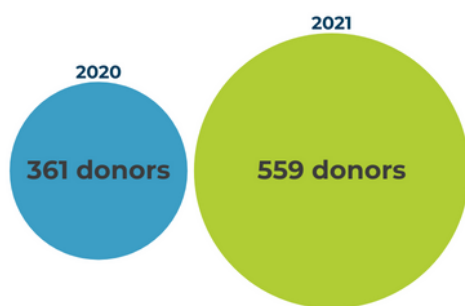
55%

of funds spent
went towards Research

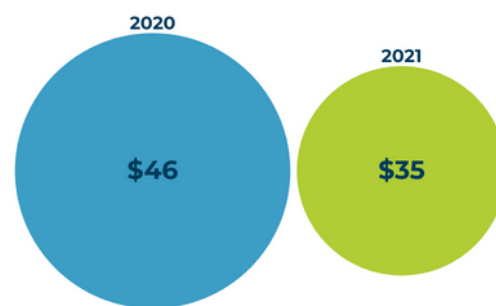
7%

of funds spent
went towards Operations

Number of Facebook Donations



Average Facebook Donation



ZERO

salary amount
Board Member and Directors

8000+

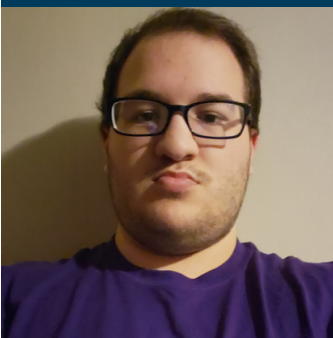
number of hours
Board Members volunteered

2.5%

of donors
giving more than \$500

\$16

amount raised
for each dollar spent on fundraising

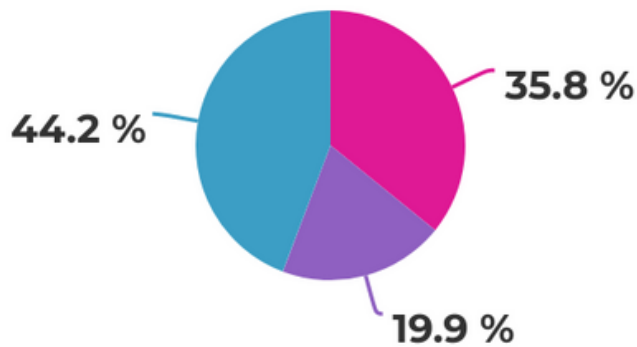


2020 FINANCIALS

Giving Hope.
Getting Answers.

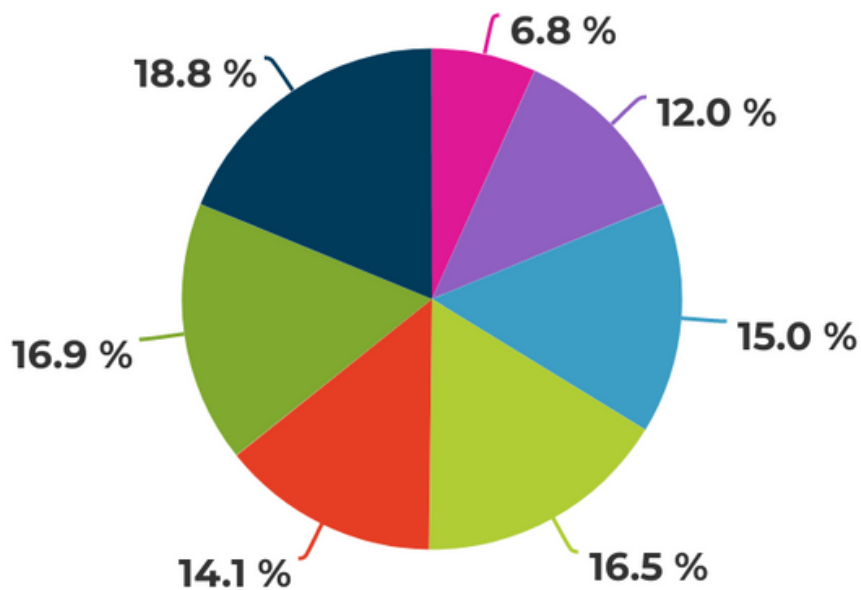
FINANCIAL HIGHLIGHTS

2020 Income



■ Business & Organization Donations ■ Individual Donations ■ Hope for HH Fundraisers

2020 Expenses



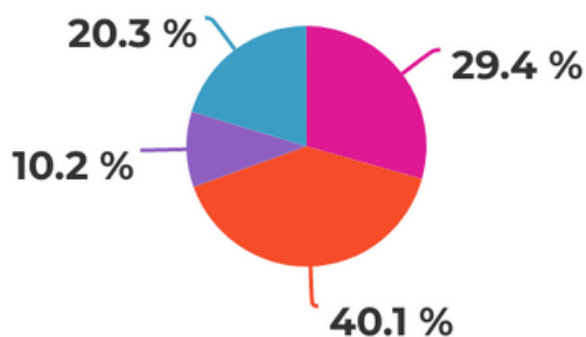
■ Support ■ Information ■ Operations ■ Finance ■ Awareness ■ Research ■ Fundraising



2021 FINANCIALS

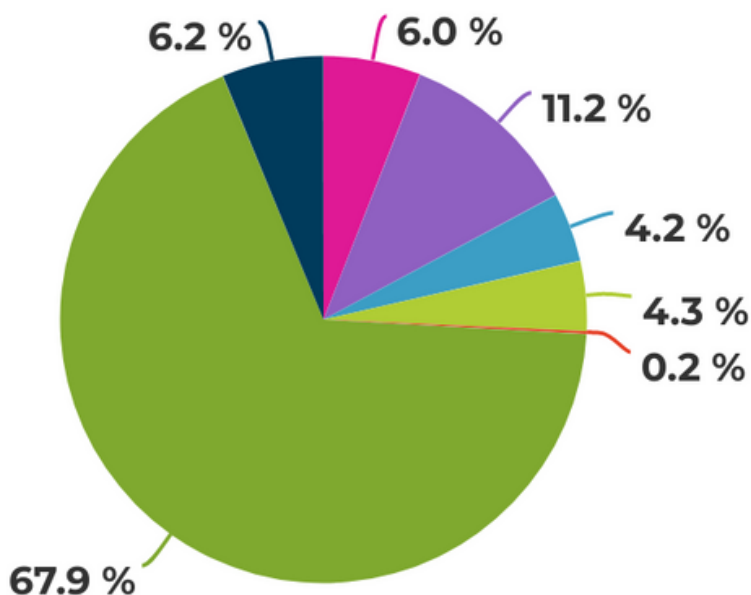
FINANCIAL HIGHLIGHTS

2021 Income



Business & Organization Donations Grants Individual Donations Hope for HH Fundraisers

2021 Expenses



Support Information Operations Finance Awareness Research Fundraising



OPERATIONS

- Over 8,000 volunteer hours from board members and volunteers were donated.
- Kristy DeBowes joined the Board of Directors.
- Hope for HH recruited new volunteers for our Operations, Information, and Finance Committees.
- Hope for HH contracted with a new website development and maintenance company for the website relaunched in 2021.
- Hope for HH contracted with a virtual meeting company to facilitate the 2021 Virtual Patent Conference.

“Look, careful identification of priorities and clever use of medical experts makes all the difference. For example, Hope for HH is run by maybe 5 or 6 individuals but the organization’s achievements are wholly disproportionate to their size. That’s because they hand-picked – and carefully use – a strong and diverse group of experts, and they use their energies wisely – focussing on the things that really make a difference, and according to their individual skill sets. The waves they make in the medical world are consequently strong and consistent. This ePAG could learn a lot from their structure and approach”

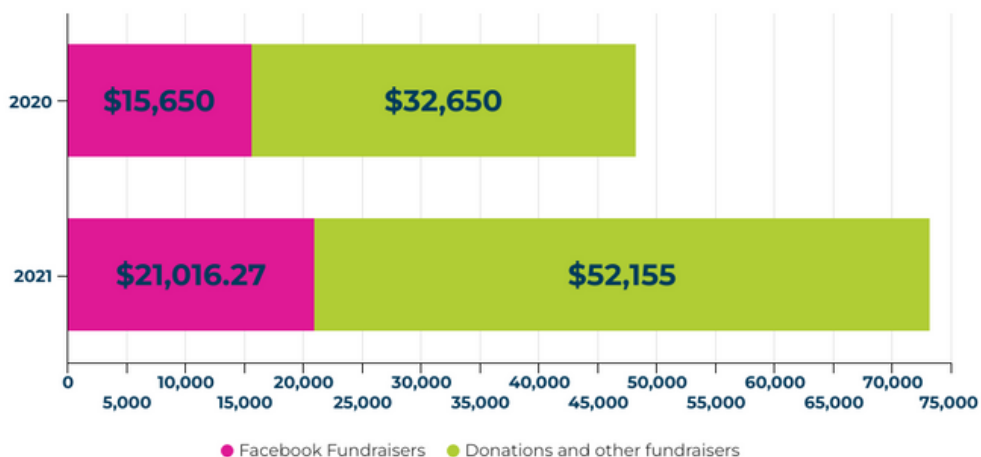
*Professor Alexis Arzimanoglou
EpiCare Coordinator
Hope for HH Medical Advisory Member*



COMMUNITY IMPACT

The achievements we make each year in completing our mission are not possible without the continued support of our community and their passionate fundraising efforts.

Community Fundraising and Donations



Each year we continue to see growth in support from our community for our Hope for HH fundraisers as well as individuals initiating their own fundraising efforts on Facebook or through individual fundraising events.

A few examples of the individual fundraising events include:

- hosting a Facebook fundraiser (59 fundraisers in 2020 & 2021)
- selling photography
- selling custom artwork
- selling an epilepsy children's book
- hosting a bunco night
- hosting a concert



COMMUNITY IMPACT

Giving Hope.
Getting Answers.

'It's 17 years since my daughter's diagnosis & this was the first time we've spoken to anyone who understands!'

2021 Meet & Greet Attendee

'This conference was a Godsend. We are going to become regular donors and follow the work of this amazing group much more closely! Thank you thank you thank you !!!'

2021 Patient Conference Attendee

'My husband and I would like to thank you for the HH-gift we received last March....in this period, far away from home (Netherlands), there were these little sparkles we received from others; especially the bag we received from the Hope for HH organization... As a coffee lover, I truly enjoyed every Starbucks coffee I had. Especially after short nights, this was a very welcome something. Thank you so much for this little light in a dark period.'

Surgical Support Bag Recipient

COMMUNITY IMPACT





Hypothalamic
Hope
 Hamartomas
 Giving Hope. Getting Answers.

PO Box 941
 Eagle, ID 83616

Email: info@hopeforhh.org
 Website: www.hopeforhh.org