HOPE is wishing something would happen.

FAITH is believing something will happen.

COURAGE is making something happen.

OUR MISSION

Hope for Hypothalamic Hamartomas (hopeforthh.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.

WELCOME

Founded in November 2009, Hope for Hypothalamic Hamartomas (www.hopeforthh.org) recently celebrated 10 years of service to HH patient and professional communities. Hope for HH’s creation as a 501c3 non-profit organization stemmed from each founding board member’s struggle to obtain timely diagnosis, medically accurate information and access to expert advice concerning prognosis, treatment and comorbidities. Bound by this rare brain tumor and complex epilepsy syndrome, the founding volunteers were determined to ensure that other families, newly diagnosed or managing HH over their lifetime would have a trustworthy, safe and welcoming place to turn for information and support.

In the space of a decade considerable progress has been made: the landscape for those now diagnosed is significantly more positive, with increased knowledge among medical experts, a greater number of expert centers experienced in and able to treat and manage HH throughout the world, and more - and more refined - surgical options. Yet the need for Hope for HH remains. Individual diagnoses are still delayed, or misdiagnosed. Best practice in identifying and treating HH varies widely from country to country, and from hospital to hospital.

While the range of surgical options has increased, along with the number of centers and surgeons able to perform these complex operations, not all treatment options are universally available, not all patients are good candidates for the available options, and research which could determine the long-term efficacy of the different surgical interventions is largely non-existent. We still do not understand what causes HH, how the various symptoms inter-relate with the HH itself, or how to prevent it.

We appreciate all the patients and families who make up our community and who have shared their journeys which are often heart-breaking, always inspiring, and which drive us on to do more. We are indebted to the medical professionals who dedicate their practice to caring for HH patients and who volunteer their time, skill and resources to improving understanding, treatment and symptom management. We admire and thank the internationally dispersed experts from many institutions who have made understanding HH a priority, and who provide a model for collaboration and partnership across systems and jurisdictions. The following pages highlight accomplishments as testament to what can be achieved by a small but highly-motivated group of skilled, passionate and thoughtful partners.

As we look to the future, we hope that understanding Hope for HH’s mission, history, accomplishments and goals will inspire and empower new members to get involved. Sustaining this organization – this valuable community resource – requires more enthusiastic volunteers and more dedicated advocates.

We hope you will help us commemorate Hope for HH’s ten-year anniversary by contributing however you can - involving your family, your friends, your community and your professional networks. Whether you support other families touched by HH, attend a family or professional conference, organise a fundraiser, make a financial donation, volunteer your time and talent, or participate in a survey, your participation is key to our continued success.

Thank you for putting the HOPE in hope for HH.

The Board of Directors
A hypothalamic hamartoma is a tumor-like, abnormal mass of tissue adjacent to the hypothalamus in the brain that develops at the fetal stage and is present at birth but may not be recognized until later in life. They are rare but can grow slowly and sometimes cause seizures, or at times may lead to obesity. The size and form of an HH can vary greatly from patient to patient as can the type and severity of its symptoms. In the majority of cases seizures are the first symptom recognised clinical symptoms of HH. HHs are central precocious puberty, and HH epilepsy and related neurobehavioral symptoms including developmental delay, cognitive impairment, and impulsive outbursts often described as rage behaviours. Approximately 40% of patients with epilepsy also have central precocious puberty.

HH IS RARE

It is currently estimated that symptomatic HH occurs in 1 in 200,000 children. This estimate is based on a prevalence study carried out in Sweden in 2004. In the intervening 15 years MRI imaging has improved and medical awareness of HH has broadened. Therefore, we suspect that symptomatic HH is currently being diagnosed in a smaller proportion of cases than was previously thought.

The cause remains unknown

The underlying cause of HH remains unknown. A review of medical literature suggests that over 95% of cases are sporadic, with no prior known family history and where the identified patient remains the only affected individual within the family. A defect in factors that regulate fetal development of the hypothalamus is thought to be the main likely cause. Less than 5% of cases are attributed to Parson-Hippple-Syndrome — a genetic abnormality that can also cause extra-fingers and toes, bifid epiglottis, Imperforate anus and kidney abnormalities. A research project initiated through Hope for HH is currently exploring HH for genetic abnormalities. Early results are promising and suggest that a genetic cause of HH may be present in a significantly higher percentage of patients than current thinking supposes.

Seizures & Other Co-Morbidities

Gelastic seizures are the hallmark of HH. Superficially they resemble laughter, but often appear subtly different from true laughter such that family members may struggle to distinguish between the two. They can be quite sudden and, particularly during infancy, may be mistaken for other conditions including colic and reflux. They can vary in frequency, with the most severely afflicted patients suffering many gelastic seizures per day and even per hour. The diagnosis of gelastic seizures is often complicated by co-occurring depression, personality disorder, and anxiety in up to 75% of these patients. Treatment is usually non-pharmacological, focusing on dietary, lifestyle and non-pharmacological management. Medication may be required in some cases. The characteristic symptom of epileptic HH patients is ‘rage behaviour’ which may be associated with poor frustration tolerance or lack of impulse control. Neuropsychologists and neuropsychological tests are used to conduct a research comnol. A working group of expert neuropsychologists and researchers is conducting a research comnol. A working group of expert neuropsychologists and researchers is conducting a research commenol. A working group of expert neuropsychologists and researchers is conducting a research comnol. A working group of expert neuropsychologists and researchers is conducting a research comnol. A working group of expert neuropsychologists and researchers is conducting a research comnol. A working group of expert neuropsychologists and researchers is conducting a research comnol.
CELEBRATING TEN YEARS OF GROWTH

Hope for HH incorporated as a nonprofit organization in 2009 and has operated for a decade, run exclusively by a small group of highly dedicated volunteers. Highlights through the years follow.

2009 Hope for HH is founded and incorporates as a 501c3 nonprofit organization.

2011 Electronic newsletter is launched. Hope joins other epilepsy and rare stakeholder coalitions including Vicen 20/20 and National Organization of Rare Diseases (NORD) to raise awareness of HH and rare epilepsy. Hope for HH Board Members faculty at the Institute of Medicine (IOM) Epilepsy Across the Spectrum conference. Drs. Rekate and Harvey of Hope’s MAR created a pedicure and published ten HH articles in Neurourogical Focus a special online supplement of the Journal of Neurosurgery edited by Dr. Rekate.

2013 Dr. Harold Rekate becomes MAR Chair. First research grant is funded. Organized the 2nd International Epilepsy Research Symposium in Paris, France. The first International Family Forum is convened in Marseille.

2015 Dr. Helen Cross becomes MAR Chair. 3rd Family Forum is organized in Houston, TX. Hope for HH—UK established as a charitable trust in the UK. Hope Board Member invited to speak at the twelfth European Gamma Knife Society Annual Congress in France.

2018 Celebrated 10 Year Anniversary. Launched the HH Cameradly patient/caregiver survey gathering insights from over 250 families about their HH side effects. Expanded outreach to Russia and surrogates through International Outreach Committee and volunteer Ramu V. Awarded our first Research Grant Pioneer Awards to Dr. Jeffrey Rosenthal, Dr. Harold Rekate and HHH co-founder and advocate Lisa Bailey. Reinaugurated Hope! Surgical Care and Care Bag with distribution at 2 hospitals.

2019 Delivered informational packets to all HH US families. Added 5 new MAR members including Drs. Karl, Seeley, Hildebrand, Jacobs-Lewin and Enriquez. Organized 4th International Symposium for HH in Washington, DC. Hope Board member speaks by invitation at an international medical symposium held in Marseille, France.

2017 Drs. Gallard, Berkovic, Oostman, Srinivas, and Wu join Hope’s MAR Award 2 research grants. Organized 5th Family Forum in Washington, DC. Launched Surgical Care and Care Bag programs. Organized a Facebook Live and webinar. Special supplement on HH published in Epilepsy comprising eleven peer-reviewed articles publishing 2013 and 2014 symposia. International multimodal—multinstitutional Comparative surgery post research study is launched. Hope Board Member invited to join UK National Policy Group addressing NIS funding of laser thermoradiation for HH.

2019 Launched volunteer program and onboarded new volunteers. Produced educational brochures on Myths and Facts, Caregivers Code, and Understanding HH. Graceful completion grants and report but findings. MAR publications in Epilepsia, Personalized Medicine, and Case studies take off. Year—round awareness campaigns across social media channels flourish. Hope for HH—UK joined EpiCARE for European advocacy and collaboration.

2019
GOAL #1: PROVIDE INFORMATION TO HH PATIENTS, CAREGIVERS, AND HEALTHCARE PROVIDERS

PROVIDING HIGH QUALITY DIGITAL & PRINT CONTENT. Early on Hope for HH launched digital and print resources designed to keep patients and professionals apprised of HH treatments, news, findings and discoveries, and to build community. The organization also partners with other patient advocacy groups to provide information on hot topics relevant to our families.

- 1,500 monthly Website visitors
- Weekly Blogs
- Daily Facebook, Twitter, Instagram posts
- Quarterly Electronic Newsletter
- YouTube videos on demand
- Facebook Lives & Webinars available across time zones and geographic boundaries
- Multi-Language Educational Brochures: Myths and Facts, Caregivers Guide, and Understanding HH
- Print Guides: Questions to Ask Neurologists, Neurosurgeons, About Gamma Knife Surgery, About Laser Surgery

STAFFING PATIENT SUPPORT. Dedicated volunteers provide one-on-one support via phone, email, text, Facebook posts and messenger to newly diagnosed patients and their families, as well as to families confronting new issues as patients mature. Our volunteers help answer questions, suggest referrals and resources, and lend a listening ear to patients and their caregivers around the world.

Until then, the organization works to realize five goals:

- Provide INFORMATION to HH patients, caregivers, and healthcare providers
- SUPPORT HH patients and caregivers
- Promote RESEARCH toward early detection, improved treatments, living with HH and cure
- Increase AWARENESS of HH, seizures, co-morbidities and Hope for HH
- Operate ALL VOLUNTEER ORGANIZATION (AVO) 501(c)3 virtually, legally, and efficiently

GOAL #2: SUPPORT HH PATIENTS AND CAREGIVERS

BUILDING COMMUNITY. Most HH families never meet another HH family face-to-face given how rare the disease is and how physically dispersed families touched by it are. To build community, Hope for HH launched a Family Forum program, planning long weekends filled with information, education, and bonding. Bringing together HH families has created life-long friendships and support networks among people that truly understand the HH journey.

4 Family Forums
Phoenix, AZ (2012)
Marseille, FR (2013)
Houston, TX (2015)
Washington, DC (2017)

Another Family Forum Coming 2021!
GOAL #3: PROMOTE RESEARCH TOWARD EARLY DETECTION, IMPROVED TREATMENTS, LIVING WITH HH AND CURE

CONVENING MEDICAL ADVISORY BOARD. Hope for HH is guided by a Medical Advisory Board comprising internationally-renowned experts and thought-leaders in their fields and in the fields of epilepsy and HH. All medical content on our website is overseen and approved by MAB members, who also direct our research strategies and programs. Neurologist and epileptologist Dr. John (Jack) Kerrigan of the Barrow Neurological Institute was Hope for HH’s inaugural MAB Chairman, followed by neurosurgeon Dr. Harold Rekate, also at BNI, and then Dr. Helen Cross CBE, Prince of Wales Chair of Childhood Epilepsy at NICH and UCL Lancair. Under Dr. Cross’ continued leadership the MAB spearheaded initiatives to adopt a worldwide consistent definition of HH and its recognition as a complex epilepsy syndrome, to create a paradigm for best practice in diagnosis and treatment, and through international cooperation and exchange to maximise research opportunities and programs.

FUNDING & SEEDING HH RESEARCH. Hope for HH has funded grants to support researchers, lab equipment, International Symposiums, and scientific conferences. Recent grants focused on functional Magnetic Resonance Imaging (fMRI) for surgical planning and the development of an animal model for HH. Hope for HH is currently working with 16 international institutes on a comparative effective profile to evaluate the efficacy of different types of surgery on seizures and other co-morbidities (side effects) in both the short and long term. Hope for HH also partners with American Epilepsy Society (AES) to identify Innovative young scientific investigators and new proposals to advance our understanding of HH. Hope for HH has helped seed partnerships with Duke University, Barrow Neurological Institute and University of Melbourne on genetic sequencing.

CONNECTING RESEARCHERS & CLINICIANS ACROSS BORDERS & DISCIPLINES. Every three years Hope co-organizes an International Research Symposium with a local host to gather the world’s foremost HH neurosurgeons, neurologists, epileptologists, geneticists, psychi- atrists, radiologists, neuroradiologists, endocrinologists and basic scientists. Each meeting focuses on a different theme. However, they are all highly praised for the opportunity to connect HH researchers and clinicians to exchange information and transfer knowledge. Symposia have increased our understanding of HH, disseminated best practices across borders, and helped identify new research challenges and opportunities.

LEVERAGING PARTNERSHIPS TO INCREASE HH UNDERSTANDING. Hope for HH joined the Epilepsy Organization and 30+ other rare epilepsy organizations in receipt of a $1M Patient-Centered Outcomes Research (PCORI) grant to build a rare epilepsy registry. Hope recruited nearly 100 HH participants and gained valuable insights about the prevalence of HH comorbidities, the usage of anti-epilepsy medications, and similarities HH shares with other rare epilepsies including a proclivity for rage and other behaviors.

GOAL #4: INCREASE AWARENESS OF HH, SEIZURES, CO-MORBIDITIES AND HOPE FOR HH

As a rare epilepsy, Hope relies on partnerships to increase awareness and improve policies for our families. Hope volunteers assume leadership roles in coalitions, partner with key stakeholders on policy, testify at key conferences, and promote HH awareness in popular media.

Leadership Roles
Worldwide

Partnerships with
Key Epilepsy Stakeholders

Testimony & Presentations at Key Meetings

Stories Shared on Primetime TV & Cable

Curing Epilepsy 2020

Institute of Medicine Committee on the Public Health Dimensions of the Epilepsies

XX Stereotactic & Functional Neurosurgery Conference

Interagency Collaborative to Advance Research in Epilepsy (ICARE) Working Group Meeting

NINDS Nonprofit Forum

Curing Epilepsies 2013:
Pathways Forward Conference

EpiCARE Annual General Meeting 2019
GOAL #5: OPERATE ALL VOLUNTEER ORGANIZATION (AVO) 501C3

Hope for HH is led by a volunteer Board of Directors comprised of five parents of HH sufferers. It is guided by a Medical Advisory Board comprised of 15 internationally recognized clinicians and researchers representing multiple institutions from around the world and disciplines in neurosurgery, neurology, genetics, neuropsychology, endocrinology and basic science. Efforts are supported by the generous donation of time and talent from exceptionally committed volunteers. Many caregivers and professionals have walked alongside us over the past decade and we appreciate their contributions. Hope for HH operates virtually without incurring the infrastructure costs of bricks and mortar. Funding raised supports information, education, and research.

BOARD OF DIRECTORS

- **Erica Webster**
  - President, Co-Founder
  - Director of Information

- **Lisa Soeby**
  - Vice-President, Co-Founder
  - Director of Operations

- **Kimberly Ranson**
  - Treasurer

- **Emma Nott**
  - Secretary, Hope For HH UK Affiliate Advisor
  - Director of Research and Awareness

- **Kathy Jenson**
  - Director of Support

MEDICAL ADVISORY BOARD (MAB)

- **J. Helen Cross, MD**
  - (MAB Board Chair, 2015-Present)
  - Great Ormond Street Hospital (UK)

- **Alexis Arzimanoglou, MD**
  - University Hospital, Lyon (FR)

- **William Davis Gaillard, MD**
  - Children’s National Hospital (US)

- **Daniel Curry, MD**
  - Texas Children’s Hospital (US)

- **Sonja G. Berzins**, MD
  - King’s College Hospital (UK)

- **Alexis Arzimanoglou, MD**
  - University Hospital, Lyon (FR)

- **Varina Boenink, MD**
  - Phoenix Children’s Hospital (US)

- **Oliver Oatman, DO**
  - Phoenix Children’s Hospital (US)

- **Jean Regis, MD**
  - Timone University Hospital (FR)

- **Andreas Schulze-Bonhage, MD**
  - University Hospital Freiberg (GER)

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  - University Hospital Freiberg (GER)

- **Hiroshi Shirozu, MD, Ph.D.**
  - Nishi-Niigata Chuo National Hospital (JAP)

- **Madison M. Boli, PhD, ABPP**
  - Children’s National Hospital (US)

- **Varina Boenink, MD**
  - Phoenix Children’s Hospital (US)

- **John F. Kerrigan, MD**
  - (MAB Chair, 2009-2012)

- **Jie Wu, MD, Ph.D.**
  - Barrow Neurological Institute (US)

EMERITUS

- **Harold Rekate, MD, (MAB Chair, 2013-2014)**

- **Jeffrey V. Rosenfeld, AM, Manash University (MAB)**

- **A. Simon Harvey, MD, Royal Children’s Hospital Melbourne**

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- **Madison M. Berl, PhD, ABPP**
  - Children’s National Hospital (US)

- **Julia Jacobs-Levan, MD**
  - Alberta Children’s Hospital (CAN)

- **Varina Boenink, MD**
  - Phoenix Children’s Hospital (US)

- **John F. Kerrigan, MD**
  - (MAB Chair, 2009-2012)

- **Jie Wu, MD, Ph.D.**
  - Barrow Neurological Institute (US)

PAST VOLUNTEERS

- **Margorie Bushby (Volunteer)**
  - Dawn Carnes (Board of Directors)

- **John Fulton, Ph.D., University of Utah**

- **Maya Lodish, MD, NIH**

- **Ilene Miller (Board of Directors)**

- **Julie Robinson (Volunteer)**

- **Wendi Tipps (Chair of Directors)**

- **Diane West (Volunteer)**

PRESENT VOLUNTEERS

- **Bradford Davis, Database Administrator**

- **Mike Conway, Digital and Print Design**

- **Roza Wu, International Outreach Chair**

- **Angela Donn, Patient Support & Awareness**

- **Traci Flanagan, Patient Support & Awareness**

- **Lauren Mellon, Writer, News Research, & Resources**

- **Lawrence Prossen & Kilpatrick Townsend, Pro-Bono Legal Advice**

- **Susanna Kather, Surgical Support Bags**
IT TAKES A GLOBAL COMMUNITY RAISING FRIENDS & FUNDS

Hope’s programs and services are ambitious and require both friends and fundraising. To that end, Hope has partnered with an affiliate in the United Kingdom. The UK Affiliate, founded by patients and caregivers, has spearheaded professional education and outreach, research symposiums planning, and advocacy for access to laser ablation and other novel interventions. Hope for HHL actively collaborates with groups of HHL patients on social media including HH Survivor Facebook, L’ESPOIR, Hamartome Hypothalamique Facebook (France), and Russian online community. Hope seeks to expand its international imprint in the years to come.

Hope income comes from our generous volunteers, donors, sponsors, and in-kind supporters. A special thanks to Wendi Tippins and the Mudrun Committee who launched and organized “M-o-oving Thru the Mud with London”. Their dedication and success inspired other walks and runs including Walk for Cailey and OrthoBethesda Chevy Chase (OBCO) Great Strides 5K, Facebook fundraising campaigns in memory of individuals we have lost and in honor of birthdays, anniversaries and other milestones provide critical support to continue the work of the organization.