

Mission

The mission of the Raymond A. Wood Foundation is to drive research and advocate for treatment outcomes to improve quality of life for hypothalamic-pituitary brain tumor survivors.

Vision

To ensure that hypothalamic-pituitary brain tumor survivors live a life unburdened by the impact of disease.

www.rawoodfoundation.org

Experience Drives Change

Transforming lived experience into research, advocacy, and better treatments.



A Message from Our Board Chair

**Dear Friends, Families, and
Supporters of RAWF,**

This year brought real momentum for the Raymond A. Wood Foundation and the hypothalamic-pituitary brain tumor community we serve.

The highlight of our year came November 15–16, 2025, when RAWF held its in-person board meeting alongside our Pituitary Brain Tumor Family Conference in Philadelphia. Our board used the gathering to reconnect in person and align on priorities for the year ahead. At the conference, more than 100 patients, caregivers, researchers, clinicians, and sponsors came together for a weekend that delivered valuable information and resources. Most importantly, the gathering gave families the rare chance to connect with and share their stories with others who understand. Roundtable

discussions were a highlight of the weekend, including a particularly meaningful community conversation on grief and resilience that stayed with all of us. Our board was grateful to sit alongside these families and hear directly what matters most to them.

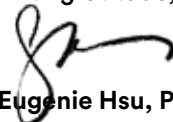
We're also proud that data from our Hypothalamic-Pituitary Brain Tumors Patient Registry contributed to two scientific publications this year:

"Treatment Priorities in Craniopharyngioma: Perspectives of Survivors and Caregivers" and "Advancing Understanding of Hyperphagia in Craniopharyngioma." These publications reflect what the Registry was built for: putting the patient and caregiver voice directly into the research priorities we, at RAWF, set.

Alongside this progress, we continued advancing our at-home sodium meter initiative and strengthened partnerships with clinicians, industry, and regulators working on treatments for hypothalamic obesity and related conditions.

None of this is possible without you: our patient and caregiver community, donors, Scientific Advisory Board, clinical partners, staff, and volunteers. Thank you for standing with us this year, and for all that's still ahead.

With gratitude,



Eugenie Hsu, PhD
Board Chairperson,
Raymond A. Wood Foundation

Eugenie Hsu pictured with son, Alex, a craniopharyngioma survivor.



Our Leadership

BOARD OF DIRECTORS



Yasmine Asaad



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Board Chair



Erin Centofani, MBA
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Josh Blumenthal
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Joan Saperstein, MD



Othman Ouenes
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Gabriel Rodriguez
MBA, PHR



Marci Serota



Ethan Schilling, PhD



Amy Wood
Executive Director, Founder



Malika Kelly
Outreach Coordinator



Nathalie Kayadjanian, PhD
Scientific Director



Kirstin Shreuders
Registry Coordinator



Meghan A. Wood,
MEd, MPA
Development Officer



Itiola Akingbola
Fundraising Coordinator



Jason Burris
Support Group Moderator



Holly Gainsboro
Grief Support Specialist



Michele Blacksborg,
MS, BSN, RN
Nurse Advocate

VOLUNTEERS

Scientific Advisory Board



M. Jennifer Abuzzahab, MD
Endocrinology,
Children's Hospitals and
Clinics of Minnesota



Ulla Feldt-Rasmussen,
MD, DMSc
Endocrinology,
Rigshospitalet, Copenhagen
University Hospital



Soma Sengupta, MD, PhD,
FRCP, FAAN, FANA
Neuro-oncology,
UNC School of Medicine



Christian Roth, MD
Endocrinology,
Seattle Children's Research
Institute



Cassie Kline, MD
Neuro-oncology,
Children's Hospital
of Philadelphia



Lewis Blevins, MD
Endocrinology,
California Center for Pituitary
Disorders, UCSF Health



Sadhana Jackson, MD
Investigator, NINDS, NHI



Shana McCormack, MD, MTR
Neuroendocrinology,
Children's Hospital of
Philadelphia

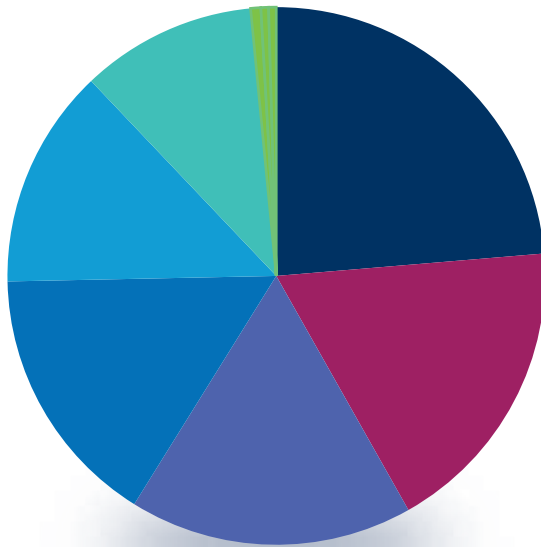


Ashley H. Shoemaker, MD,
MSCI
Endocrinology, Vanderbilt
University Medical Center



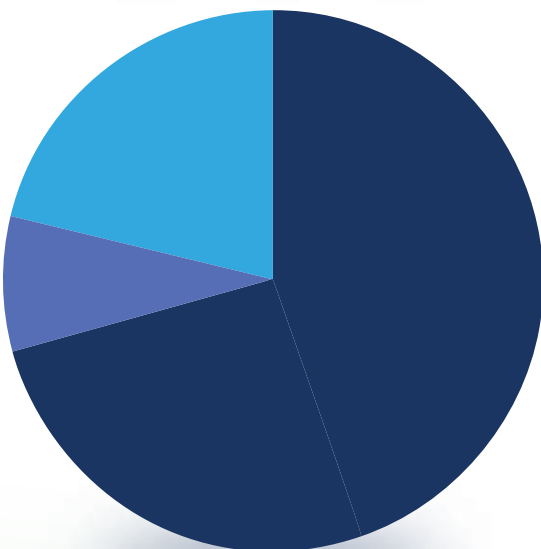
Jeffrey Wisoff, MD
Director of Pediatric
Neurosurgery, NYU Lagone
Health

Impact by the Numbers



Total Revenue \$734,504.95

- Corporate Sponsorships - 24%
- Unrestricted Giving - 18%
- Sodium Meter Device Development - 17%
- Fundraising Events - 16%
- Board Giving - 13%
- Foundation Grants - 11%
- Other - 2%



Total Expenses \$831,461.62

- Programs - 71%**
Patient Registry, Publications, Sodium Meter Development, Education, Patient & Caregiver Support, Outreach, Communications
- Operations - 21%**
Staff, Administration, Technology, Professional Services
- Fundraising - 8%**
Donor Relations, Events, Campaigns, Partnerships

Cash in Reserves \$546,636

RAWF strategically drew on reserves this year to fully fund multiyear research and program commitments. Strong cash reserves ensure this investment doesn't compromise long-term sustainability.

Turning Strategy into Change

FY 26 marked the first year of RAWF's new three-year strategic plan and set a clear direction for the next chapter of our work. Guided by the priorities of patients and caregivers, we advanced research and innovation, strengthened advocacy for recognition and treatment access, expanded education and global connections, and invested in the long-term sustainability of the foundation. Across each priority, our work reflected a common purpose: connecting patient experience with the data, partnerships, resources, and action needed to improve care and quality of life.

GOAL: Advance Research, Innovation & Clinical Care

PROGRESS ON GOAL:

We strengthened the foundation for patient-centered research and innovation. We advanced the Hypothalamic-Pituitary Brain Tumors Patient Registry by adding Spanish and French translations, implemented CRID functionality to support future data linkage, and continued planning for broader international and disease representation. Patient and caregiver treatment-priority analysis was completed, helping identify future research needs grounded in lived experience. We also moved the at-home sodium meter closer to reality, advancing Phase 1 validation, whole-blood cartridge testing, and development of the integrated disposable chip while beginning to address future regulatory and commercialization pathways.

GOAL: Strengthen Advocacy &

Access to Treatments

PROGRESS ON GOAL:

RAWF expanded its role in advancing recognition, access, and better treatment for hypothalamic conditions. We continued advocacy for access to targeted therapies, contributed to efforts to establish diagnostic criteria and ICD-10 recognition for acquired hypothalamic obesity, and provided patient experience data to the Canadian Drug Agency to inform treatment-access decisions. RAWF also met with FDA representatives to communicate patient perspectives and the urgency for treatment in acquired hypothalamic obesity, while continuing to build registry evidence around patient-centered outcomes. These efforts are helping bring lived experience into the systems and decisions that shape care.

GOAL: Expand Community Engagement & Education

PROGRESS ON GOAL:

In FY 26, we expanded opportunities for patients and caregivers to learn, connect, and participate in the work shaping their community. RAWF developed a partnership with the French Craniopharyngioma Association in support of registry translation efforts to expand registry participation. Educational programming expanded through the launch of a Uscreen video streaming platform, webinars and patient panels, and the FY2026 Pituitary Brain Tumor Family Conference. We also began producing new videos focused on hypothalamic syndrome, arginine vasopressin deficiency, and acquired hypothalamic obesity.

GOAL: Enhance Financial & Organizational Sustainability

PROGRESS ON GOAL:

FY 26 brought important investments in the long-term strength of RAWF. We welcomed two new board members, established a Patient Advisory Committee to deepen patient and caregiver participation in decision-making, secured executive coaching support, and formally began succession planning. At the same time, we continued growing corporate and industry relationships while strengthening major-donor and institutional engagement. Strategic planning around the sodium meter also expanded to include governance, commercialization, partnership, and future fundraising considerations, helping ensure that growth and innovation remain aligned with responsible stewardship of the foundation's resources.

With patients and caregivers continuing to guide our priorities, we are building on what we learned, strengthening the partnerships that make progress possible, and pursuing the changes our community needs most.

FY 26 Key Highlights

July
2025



Finalized RAWF's FY2026–FY2029 Strategic Plan, establishing new priorities for research, advocacy, community engagement, and sustainability.

Renewed RAWF's executive council participation with the Children's Brain Tumor Network (CBTN).

- Amy Wood shares progress on the sodium meter project on The Pickle Jar Podcast.

August
2025



- Welcomed Sean Turbeville to the RAWF Board of Directors.

September
2025



- Kicked off the DC's Dancing Stars fundraising campaign.

Provided a handheld blood analyzer to a family managing AVP-D, supporting safer monitoring at home.

October
2025



- Participated in the DC's Dancing Stars Gala, raising awareness and support for RAWF's mission.

November
2025



Hosted the Pituitary Brain Tumor Family Conference, bringing patients, caregivers, clinicians, researchers, and advocates together for education and connection.

- Held an in-person RAWF board meeting in Philadelphia.

December
2025



- Received \$116,000 from the DC's Dancing Stars campaign to support RAWF's mission.

January
2026



- Participated in Rare Disease Week to elevate the needs of the hypothalamic-pituitary brain tumor community.

Reached key sodium meter development milestones, including progress on test cartridge development and validation.

- Provided an additional iSTAT handheld blood analyzer to a family managing AVP-D.

Co-sponsored Rhythm Pharmaceuticals' webinar A Path to Diagnosis: Provider and Patient Perspectives on Acquired Hypothalamic Obesity.

February
2026

March
2026

Published research examining patient and caregiver treatment priorities and hyperphagia in craniopharyngioma, advancing understanding of the challenges that matter most to the community.

➤ Participated as a charity partner in the United Airlines NYC Half.

Submitted patient-experience input to support Canadian review and access considerations for IMCIVREE® (setmelanotide) in acquired hypothalamic obesity.

A Landmark Moment for Acquired Hypothalamic Obesity

On March 19, 2026, the FDA approved IMCIVREE® (setmelanotide) for adults and children ages 4 and older with acquired hypothalamic obesity, making it the first and only FDA-approved therapy specifically for aHO.

RAWF helped bring the patient perspective into the path toward this milestone through clinical-trial awareness and recruitment, patient-centered education, advocacy for treatment access, and the collection and sharing of lived-experience data.

May
2026

➤ Launched Benign Is Not Fine, raising awareness of the lifelong consequences of so-called “benign” brain tumors and generating \$62,908 in support.

Marked the second anniversary of the Hypothalamic-Pituitary Brain Tumor Patient Registry.

Welcomed Jennifer Chastain and Gabriel Rodriguez to the RAWF Board of Directors.

June
2026

Expanded the Patient Registry internationally with French and Spanish translations, increasing opportunities for global participation.

➤ Participated in Momentum: The MC4R Pathway Summit, strengthening connections across research, clinical care, industry, and advocacy.



In Their Own Words

Meaningful research considers the experiences of the patients and caregivers living with its impact every day.



KATHLEEN ON LIFE AFTER TUMOR TREATMENT:

"...it's a life sentence because it really has affected me for life."



ERIN ON LIFE WITH HO & HYPERPHAGIA:

"The hyperphagia was just, it's extremely socially isolating."



MARIA ON HER DAUGHTER'S FATIGUE:

"After the surgery, she is very weak—almost helpless—and sleepy all day; she is constantly dozing and lacks the energy to do anything."

Turning Patient Voices into Scientific Progress

In just two years, the lived experiences shared by patients and caregivers through the Hypothalamic-Pituitary Brain Tumors Patient Registry have translated into published research turning patient-reported data into evidence that is advancing scientific understanding, informing clinical care, and helping shape future therapies.

Research That Matters

This year, data from the Patient Registry contributed to two peer-reviewed publications, with a third manuscript currently under scientific review.

- **Treatment Priorities in Craniopharyngioma** identified the symptoms that matter most to survivors and caregivers, highlighting the need for therapies that address hypothalamic syndrome, cognitive challenges, emotional lability, and excessive thirst (polydipsia).
- **Advancing Understanding of Hyperphagia in Craniopharyngioma** provided new insights into one of the disease's most challenging symptoms and introduced tools to measure hyperphagia in both clinical practice and future clinical trials.
- A third study, conducted in collaboration with Rhythm Pharmaceuticals, is currently under review; it examines fatigue, another top priority identified by the community.

Together, these studies demonstrate how patient and caregiver experiences are driving research priorities and helping ensure that future treatments address the outcomes that matter most.



Supporting Therapeutic Innovation

This year also marked a historic milestone with the FDA approval of **IMCIVREE®**, the first treatment approved for hypothalamic obesity.

Throughout the drug development process, RAWF worked to ensure the patient perspective was represented in conversations with industry partners, including Rhythm Pharmaceuticals. We remain committed to engaging with pharmaceutical companies developing therapies for hypothalamic-pituitary disorders while maintaining our role as a trusted, patient-centered, and neutral advocacy organization.

Expanding the Global Patient Voice

To make our research more representative of the global community, the entire Hypothalamic-Pituitary Brain Tumors Patient Registry is now available in English, French, and Spanish.

By removing language barriers, RAWF is increasing participation, strengthening the diversity of patient experiences represented in research, and improving the quality and generalizability of future scientific discoveries.

Scientific Leadership

RAWF continues to strengthen its partnerships with leading clinicians and researchers around the world.

This year, we convened the fourth annual meetings of both our

Scientific Advisory Board and Registry Advisory Board. These experts reviewed our research portfolio, provided strategic guidance, and helped ensure our scientific initiatives remain rigorous, relevant, and centered on the needs of patients and families.

Advancing Innovation: At-Home Sodium Meter Development

RAWF continues to advance the development of an at-home sodium meter designed to help individuals safely monitor sodium levels from home. This year marked a significant milestone with the successful development and validation of the device's proprietary cartridge, bringing the technology one step closer to clinical use.

The project is being developed through a collaboration between Giner, Inc., the research and development firm leading the engineering efforts; Children's Hospital of Philadelphia; and the Raymond A. Wood Foundation. The current phase of development is being funded by RAWF, reflecting our commitment to investing in innovative solutions that directly address the unmet needs of our community.

Designed to improve the lives of survivors living with chronic sodium imbalances, the technology also has the potential to benefit patients with other conditions requiring frequent sodium monitoring. As development continues, RAWF remains committed to making this innovation accessible, affordable, and impactful for patients and families.



HYPOTHALAMIC-PITUITARY BRAIN TUMORS
CRANIOPHARYNGIOMA
PATIENT REGISTRY

Patient Registry Advisory Board



Johan de Graaf
Survivor
Chair of the Dutch Pituitary
Foundation
Netherlands



Shuang Liu, Ph.D.
CEO and Founder
ConSynance Therapeutics, Inc.
USA



Shana McCormack, MD, MTR
Scientific Director of the
Neuroendocrine Center
Division of Endocrinology and
Diabetes
Children's Hospital of



Hermann Muller, MD
Department Head, Pediatrics and
Pediatric Hematology and
Oncology
Klinikum Oldenburg | Germany



Lynn Mathies
Survivor & Student MSc
Neuroscience and Cognition
Utrecht University
Netherlands



Bradley Richards, Ph.D.
Caregiver, Assistant Professor
York University Toronto
Canada



Theresa Strong, Ph.D.
Director, Research Programs
Foundation for Prader-Willi
Research | USA

Building Community & Expanding Care

Bringing Our Community Together

One of the year's defining moments was the 2025 Pituitary Brain Tumor Family Conference, held November 15–16 at the Children's Hospital of Philadelphia (CHOP). More than 100 survivors, caregivers, researchers, clinicians, and industry partners gathered for a weekend dedicated to education, connection, and hope. Centered on the theme "Together in Knowledge, Stronger in Community," the conference combined expert-led educational sessions with meaningful opportunities for families to connect with others who truly understand their journey.

Attendees heard the latest updates on clinical research, tumor treatment, endocrine care, hypothalamic obesity,

financial advocacy, and emerging therapies. The weekend also featured survivor and caregiver roundtable discussions, strategic research updates from RAWF, and a powerful fireside conversation on grief that created space for honest dialogue, healing, and resilience. For many families living with these rare conditions, the conference was more than an educational event. It was an opportunity to build lifelong connections, exchange experiences, and discover they are not alone.

Expanding Access to At-Home Care

This year, RAWF distributed four handheld blood analyzers to families across the United States, helping caregivers monitor sodium levels from home with greater confidence.

These devices are already improving quality of life by reducing unnecessary emergency room visits, preventing avoidable hospitalizations, and supporting faster, more informed medical decisions at home.

To strengthen the program, volunteer nurse Michele Blacksberg joined the initiative, providing personalized training, troubleshooting, and ongoing support to families using the analyzers. Her expertise has made this innovative program even more accessible and effective.

Strengthening Peer Support

Throughout the year, RAWF continued to provide safe, welcoming spaces where survivors and caregivers could learn from one another, share experiences, and find encouragement.

In FY2026, RAWF continued to offer two distinct monthly support groups designed to meet the unique needs of our community. Caregiver support groups, led by Board Chair Dr. Eugenie Hsu, provided a compassionate space for caregivers to share experiences, exchange practical advice, and support one another. Survivor support groups, led by Jason Burris, created a welcoming environment where survivors could connect with peers who understand the challenges of living with a hypothalamic-pituitary brain tumor.

Recognizing that grief is often an overlooked part of survivorship, RAWF also expanded support by offering individualized grief sessions with Grief Support Specialist Holly Gainsboro. These one-on-one conversations provide compassionate guidance for individuals and families navigating anticipatory grief and loss, ensuring that every member of our community has access to support when they need it most.



Making Every Mile, Moment, and Gift Count

The strength of RAWF has always been our community. This year, survivors, caregivers, families, volunteers, corporate partners, and supporters turned their passion into action by organizing creative fundraising initiatives that advanced research, expanded patient support, and increased awareness of hypothalamic-pituitary brain tumors. From peer-to-peer campaigns and athletic challenges to community partnerships and personal acts of generosity, every effort helped move our mission forward while inspiring others to join the cause.

Rally for Research: Benign Is Not Fine

In May, during Brain Tumor Awareness Month, we launched our inaugural Rally for Research: Benign Is Not Fine peer-to-peer fundraising and awareness campaign. This initiative empowered survivors, caregivers, families, and supporters from around the world to come together in support of groundbreaking research, patient resources, and advocacy while raising awareness about the lifelong impact of craniopharyngioma and other hypothalamic-pituitary brain tumors.

Sixteen fundraising teams participated in a friendly competition, inspiring generosity from 135 donors across the globe. Together, they raised \$37,907.55, unlocking a \$25,000 matching gift from an anonymous donor and bringing the campaign's total impact to \$62,907.55.



DC's Dancing Stars Gala

RAWF was once again selected as a beneficiary organization in the 2025 DC's Dancing Stars Gala. Dancers Michael "Brownie" Brown and Adriana Foncesca brought heart and energy to the dance floor, with Brownie taking home the coveted Mirror Ball Trophy. The event raised a record \$116,000 for our mission, and we cannot wait to see what our dancers do next year!



A Birdhouse with Meaning

Lindsay, a 36-year-old from North Carolina, started If You Had Wings NC to share her love and talent for building bird houses. Each month, Lindsay builds a birdhouse, accepts donations, and gives the proceeds to a meaningful charity. After learning

her boyfriend, Jonathan, was diagnosed with a hypothalamic-pituitary brain tumor, her charity of choice was clear. She so generously raised **\$3,100** to support RAWF's mission and programs. What an honor!

Preston Cares

Our friends at Preston Automotive Group hosted a week-long campaign for RAWF and donated \$50 for every car sold at their Pittsville, Maryland location. RAWF has been a proud partner in this annual campaign since 2021, with donations now totaling over \$79,000. Amazing!



NYC Half Marathon

Seven runners took on the 2026 NYC Marathon with Team RAWF and raised nearly \$20,000 for our mission, a new event record. The team solicited more than 150 donors from across the country and each took on 13.1 miles to raise critical funds. We are proud to be a charity partner in this event and look forward to expanding our reach to races across the country.

Fundraise for RAWF

Let's discuss ways to get involved. Contact development@rawoodfoundation.org and a member of our team will be in touch.

Improving Life After a Hypothalamic-Pituitary Brain Tumor

Led by patients and caregivers, the Raymond A. Wood Foundation (RAWF) drives research and advocates for better treatment outcomes and quality of life for survivors of craniopharyngioma and other hypothalamic-pituitary brain tumors.

Born from Lived Experience

RAWF was founded in 2017 by parents who experienced firsthand the complex, lifelong challenges that can follow craniopharyngioma. They saw a critical gap: survivors were living with significant medical and quality-of-life challenges, yet there was no organization dedicated to advancing solutions for this community.

Putting Patients at the Center of Progress

Survivors and caregivers understand these conditions in ways that data alone cannot capture. RAWF brings their experiences and priorities into research, healthcare, and advocacy so that the questions being asked and the solutions being developed reflect what matters most to the people living with these conditions.

Turning Unmet Needs into Action

The effects of hypothalamic-pituitary brain tumors can extend far beyond tumor treatment, creating complex health challenges that last a lifetime. RAWF works with researchers, clinicians, industry partners, advocates, and families to address these gaps.

From patient-led research and global data collection to innovative technology, treatment access, education, and advocacy, we are building the evidence, partnerships, and solutions needed to improve care.

Lorem ipsum

A Future with Better Options

We envision a future in which people affected by hypothalamic-pituitary brain tumors have better treatments, more informed care, greater access to solutions, and the opportunity to live lives less burdened by the effects of disease.

Together, with patients and caregivers leading the way, we are working to make that future possible.



outreach@rawoodfoundation.org
www.rawoodfoundation.org



To support our work, please
consider making a gift today.

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