

FY 2025 IMPACT REPORT

JULY 2024 – JUNE 2025

Driven by *Purpose,* Powered by *Progress*

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.



Our Progress and Vision

We aspire to leverage every opportunity to expand our reach, develop new resources, and ensure survivors and their families receive the support they need, guided by ethical collaboration with research and corporate partners.

Dear Friends and Supporters,

This past year, the Raymond A. Wood Foundation made significant strides toward our mission. With your support, we turned hope into action—delivering critical tools, advancing research, and expanding care.

We placed handheld blood analyzers directly into the hands of survivors like Levi, Grace, Lennox, Elder, and Sabrina—decreasing the disease management burden for families. We also launched grief and teen support groups, ensuring that patients and caregivers are never alone in their journeys.

On the research front, Executive Director Amy Wood and Scientific Director Dr. Nathalie Kayadjanian represented RAWF at the Chan Zuckerberg Initiative Science in Society meeting. Amy attended the International Symposium on Neuro-oncology and the Children's Brain Tumor Network Summit, while Nathalie attended the advanced global collaboration with experts and craniopharyngioma families that took place in France. Most importantly, we launched a groundbreaking patient registry study focused on the real-world challenges survivors face and the treatment priorities that matter most.

These efforts are fueled by a growing community of champions. From Staci and Abby Memmensheimer's grassroots Music Bingo fundraiser, to the successful DC Dancing Stars Gala, to the use of my painting (The Art of Surviving Craniopharyngioma)

as an advocacy tool on Capitol Hill during Rare Disease Week, all efforts amplified our mission and inspired others to act.

Yet there is still so much more to be done. Every gift—large or small—brings us closer to a future in which survivors have the tools, treatments, and support they need to thrive. We invite you to join us in this work and make an impact that will last a lifetime.

With gratitude,

Eugenie Hsu,
Ph.D.

Chair, Board of Directors

Dear Friends and Supporters,

As I reflect on FY2025, I am enormously grateful for what we have achieved together. This was our first year outside of the Chan Zuckerberg Initiative grant, and with that came many uncertainties about how we would sustain our fundraising. Thanks to the unwavering support of our community, donors, and corporate partners, we not only persevered but succeeded.

On a personal note, our family faced some of the hardest challenges yet. Alex endured multiple

hospitalizations this year and received two new diagnoses, adding to the ongoing complications caused by his original tumor and its treatment. These experiences have been a stark reminder that for many of us, diagnosis and surgery are not the end of the journey—they are only the beginning of a long and complex road.

Through it all, I have been deeply proud of our dedicated team and board. Their strength, leadership, and commitment allowed the foundation to continue moving forward during the times I had to step away to focus on Alex's health.

It amazes me to think about how far we've come—from an initial goal of raising \$15,000 to purchase a handheld blood analyzer for another family to building an organization that is driving research, advocacy, and real solutions for survivors. My hope is that we will continue to grow and drive solutions until the day comes when families like ours no longer face these challenges.

With gratitude,

Amy Wood
Executive Director



Our Leadership

RAWF's dedicated board members, staff and volunteers are the driving force behind our mission. They tirelessly work to support individuals and families affected by brain tumors through fundraising, awareness campaigns, and research collaborations, leaving a lasting impact on our community.

FY 2025
BOARD OF
DIRECTORS



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Board Chair



Dean Carson, PhD
Research Chair



Ethan Schilling, PhD
Treasurer



Christine Selko
Secretary



Marci Serota, RDN



Josh Blumenthal



Joan Saperstein, MD



Yasmine Asaad



Othman Ouenes



Erin Centofani



Scott Coven, DO, MPH

FY 2025
STAFF



Amy Wood
Executive Director, Founder



Nathalie Kayadjanian, Ph.D.
Scientific Advisor



Malikah Kelly
Outreach Coordinator



Jamie Ping
Outreach & Communications
Manager



Kirstin Shreuders
Registry Coordinator



Meghan A. Wood, MEd, MPA
Development Officer,
Major Gifts

FY 2025
VOLUNTEERS



Jason Burris
Support Group Moderator



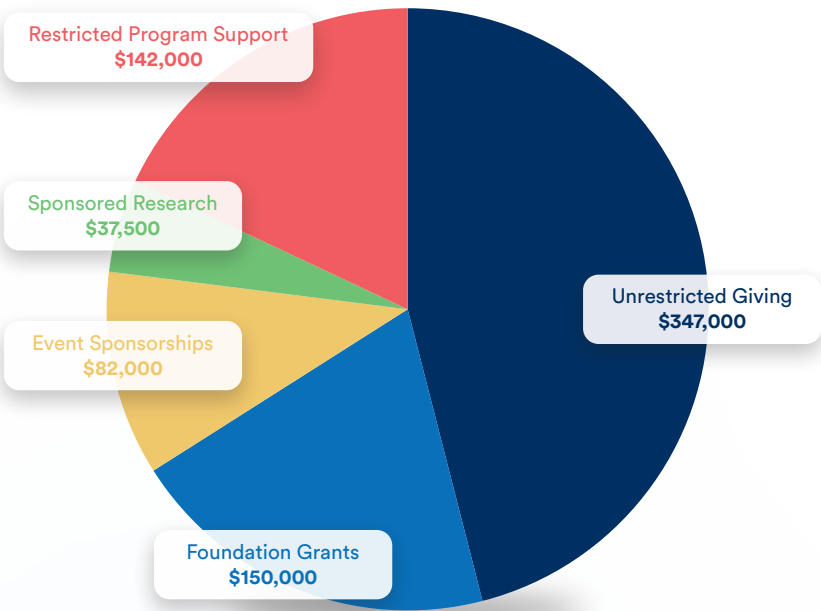
Holly Gainsboro
Grief Support Specialist



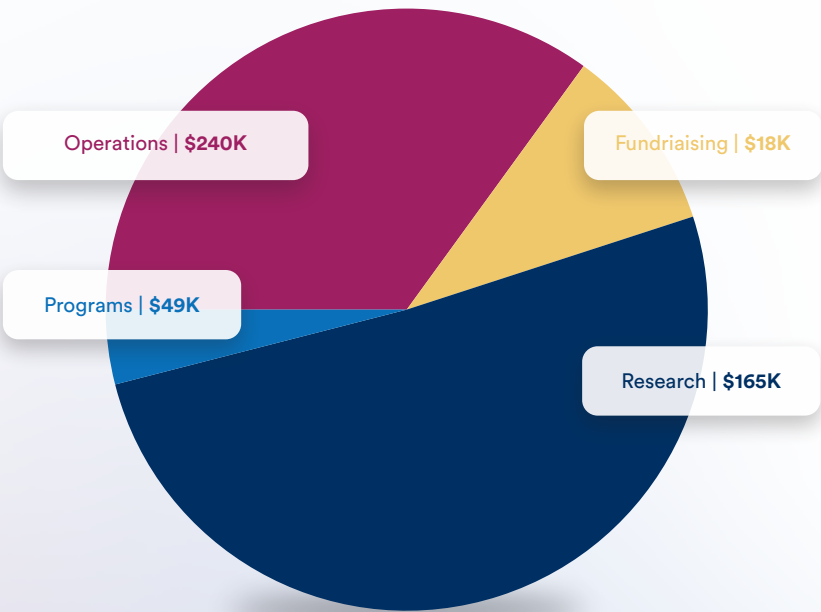
Michele Blacksborg, MS, BSN, RN
Nurse Advocate

Impact by the Numbers

Total Revenue:
\$760,451



Total Expenses:
\$472,000



Carryover into FY26: \$546,636

*RAWF maintains a strong carryover to fund multiyear projects and ensure sustainability. Over one-third of RAWF’s annual spending directly funded research including our patient registry, strategic studies, and sodium meter development. Community programs, outreach, and essential operations were sustained with lean administrative costs and a strong commitment to impact.

Progress on Goals

Now in the final year of our three-year strategic plan, the Raymond A. Wood Foundation continues to turn strategy into measurable action—driving forward initiatives that address the real-world challenges faced by survivors and caregivers of hypothalamic-pituitary brain tumors. In FY2025, our focus was on deepening our research infrastructure, enhancing direct support for families, and ensuring sustainability for the future.

GOAL: Improve Treatment & Quality of Life

PROGRESS ON GOAL: We made significant progress advancing tools that directly improve patient outcomes. This year, we expanded the Hypothalamic-Pituitary Brain Tumor Patient Registry, launching two new surveys focused on hyperphagia and eating behavior.

These data tools are shaping our understanding of treatment impact and daily life challenges. We also provided multiple handheld blood analyzers to families managing arginine vasopressin deficiency, ensuring access to safer care at home, and continued to invest in the development of an at-home sodium meter.

GOAL: Address Challenging Conditions

PROGRESS ON GOAL: We continued to prioritize complex, under-researched consequences of hypothalamic-pituitary brain tumors, such as hypothalamic obesity, neuroendocrine dysfunction, and neurocognitive challenges. In FY2025, we strengthened our collaborations with pharmaceutical partners to support clinical trial awareness and recruitment, ensuring that the lived experiences of survivors are better represented in therapeutic development. These partnerships are helping to shape research that reflects the unique needs of our community, with a continued emphasis on patient-centered outcomes.

GOAL: Raise Awareness & Expand Our Collaborative Network

PROGRESS ON GOAL: In FY2025, RAWF expanded its visibility and influence through active participation in scientific conferences, collaborative meetings, and community events. These efforts strengthened partnerships, increased recognition of hypothalamic-pituitary brain

tumors within the broader rare disease and research communities, and reinforced our role as a trusted patient-led organization. Through outreach, education, and advocacy, we continued to connect with new allies and elevate the voices of survivors and caregivers.

GOAL: Promote Sustainability to Advance Our Mission

PROGRESS ON GOAL: With the planned conclusion of our participation in the Rare As One initiative, RAWF focused FY2025 on building long-term sustainability. Exiting the CZI grant prompted a strategic shift toward diversified fundraising and organizational resilience. Through successful campaigns like Shore Gives More and the NYC Half Marathon, we secured essential funding for our programs and innovations.

We also had significant internal growth, including the expansion of our Board of Directors. New members brought expertise in science, outreach, and nonprofit leadership, enhancing our capacity to govern, grow, and sustain our mission. These efforts ensure that RAWF remains strong, independent, and impact-driven well into the future.

FY 2025 Key Highlights

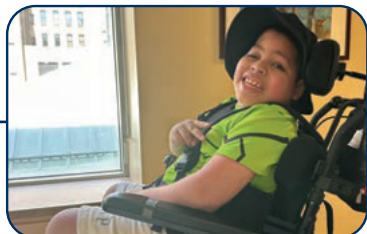
July 2024 – June 2025

July 2024



Amy Wood attended International Symposium on Pediatric Neuro- Oncology in Philadelphia

September 2024



• RAWF welcomed Dr. Scott Coven and Othman Ouenes to the Board

• A handheld blood analyzer was provided to Elder Garcia

October 2024



• Amy Wood attended Children's Brain Tumor Network Summit at Amazon HQ in Arlington, VA

• Jamie Ping participated in NORD Registry Meeting and Breakthrough Summit in Washington, DC



• Amy Wood and Nathalie Kayadjanian attended CZI Science in Society Meeting in San Jose, CA

• A handheld blood analyzer was provided to Peter Wieland

November 2024



• Marcia, RAWF's celebrity dancer, takes home mirror ball trophy in the 2024 DC Dancing Stars Gala

• Over \$95K was raised from Shore Gives More / Giving Tuesday



• Handheld blood analyzers were provided to Lennox Murphy and Grace Banks

• Erin Centofani and Yasmine Asaad were welcomed to the RAWF Board

January 2025

The teen support group and one-on-one grief sessions for bereaved families were launched

February 2025



- A handheld blood analyzer was provided to Sabrina Studor
- RAWF hosted "Research Starts with You" webinar with Dr. Jennifer Miller for Rare Disease Week
- Amy Wood attended the EveryLife Foundation's Rare Artist reception in Washington, DC, for Rare Disease Week in support of Eugenie Hsu, a finalist in the competition

March 2025



- Nurse volunteer Michele Blacksberg join the team to support handheld blood analyzer families
- TEAM RAWF raced to the finish in NYC Half Marathon

April 2025



- Staci and Abby Memmesheimer hosts Musical Bingo fundraiser in NYC
- Giner, Inc. begins final work of phase one development of the sodium meter with funding support from RAWF

May 2025



- RAWF hosted 7th Annual Art of Surviving art exhibition for Brain Tumor Awareness Month
- Dr. Nathalie Kayadjanian met with the French Craniopharyngioma Association in Sommieres, France
- A handheld blood analyzer was provided to Trenton Lins
- Jamie Ping and Amy Wood attended CZI Science in Society / Rare As One Meeting in Las Vegas, NV
- RAWF celebrated the one-year anniversary of the Hypothalamic-Pituitary Brain Tumor Patient Registry

June 2025

- Dr. Nathalie Kayadjanian presented at the 8th Postgrad Course on Childhood Craniopharyngioma in Denver, CO
- Welcomed Malukah Kelly as new Outreach Coordinator
- Amy Wood met with FDA with Rhythm Pharmaceuticals to reinforce the need for a treatment for hypothalamic obesity

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
Division Chief,
Neuro-oncology Vice Chair,
Neurology Professor
UNC School of Medicine



Christian Roth, MD
Endocrinology
Seattle Children's Research
Institute



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



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



Sadhana Jackson, MD
Investigator, NINDS, NIH



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



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



Jeffrey H. Wisoff, MD
Clinical Professor,
Department of Neurosurgery,
Clinical Professor,
Department of Pediatrics
NYU Lagone Health

Advancing Patient-Led Research: FY 2024–2025 Highlights

RAWF continues to make significant strides in our mission to drive patient-centered research that improves the lives of hypothalamic-pituitary brain tumor survivors. FY 2025 marked a year of critical progress across multiple research initiatives, reflecting our commitment to scientific discovery, clinical collaboration while amplifying the voices of our community.

Launch and Growth of the Global Patient Registry

In May 2024, RAWF officially launched the Hypothalamic-Pituitary Brain Tumor Patient Registry, an ambitious initiative to gather robust, patient-driven data that will inform research, treatment development, and care practices. Over the course of the year, three key studies were initiated through the registry:

Hyperphagia Study: The first study implemented in the registry explored hyperphagia—compulsive hunger and eating behavior—in craniopharyngioma (CP) survivors. Building on RAWF's previous findings published in the *Journal of Clinical Endocrinology and Metabolism*, this follow-up effort developed a new questionnaire to quantify and characterize hyperphagia. Preliminary analysis confirms that hyperphagia is particularly pronounced in patients with hypothalamic obesity (HO) and shows similarities to Prader-Willi syndrome. The data reinforce the urgency of developing targeted treatments for this critical unmet need.

Treatment Priorities Study: Launched in January 2025, this study seeks to better understand which symptoms and outcomes matter most to CP survivors

and caregivers. Data analysis is currently underway. The findings will guide future research priorities, inform industry partnerships, and support regulatory advocacy that centers the lived experience.

Fatigue Survey (in collaboration with Rhythm Pharmaceuticals): This joint study aimed to explore fatigue, a debilitating yet understudied symptom among CP survivors. Analysis is ongoing, with early results expected to shed light on its underlying causes and potential therapeutic strategies.

Expert Collaboration Through the Registry Advisory Board

In February 2025, the Registry Advisory Board convened with leading clinicians, researchers, and patient advocates to review registry progress and discuss future directions. The meeting emphasized the registry's potential to deepen our understanding of disease presentation and elevate community perspectives in scientific discourse.

We also welcomed Kirsten Schreuders, an experienced clinical professional from the pharmaceutical sector, as our new registry coordinator. Her leadership is already enhancing the coordination and impact of registry studies.

Scientific Advisory Board: Guiding Our Research Vision

January 2025 marked the third meeting of our Scientific Advisory Board, where expert advisors reviewed RAWF's entire research portfolio and provided strategic guidance. These touchpoints ensure our scientific efforts remain rigorous, relevant, and aligned with patient needs.

Expanding External Collaborations

RAWF has continued to expand its collaborations with partners in industry, academia, and the patient community. We engaged with pharmaceutical companies, including Rhythm Pharmaceuticals, Soleno, and Aardvark Therapeutics, to ensure that the patient voice is embedded in treatment development for hypothalamic obesity and related conditions. In academic research, we partnered with Dr. Shana McCormack's team on a study aimed at identifying barriers to exercise among CP survivors and designing patient-centered solutions. On the global front, we connected with the French craniopharyngioma community and participated in its annual meeting, initiating efforts to translate our patient registry into French to support broader international participation. We also deepened our involvement in national collaborative research through our Executive Council membership in the Children's Brain Tumor Network, a multi-institutional international clinical research consortium created to advance therapeutic development through the collection and rapid distribution of biospecimens and data via open-science research platforms for real-time access and use by the global research community.

Bringing Our Community's Voice to Scientific Forums

RAWF participated in the Childhood Craniopharyngioma Conference led by Dr. Todd Hankinson, sharing insights from our registry and joining a broader dialogue on advancing research and clinical care for HO and CP.

Looking Ahead: Building on Momentum

Through every survey launched, partnership built, and dataset analyzed, RAWF is reshaping how hypothalamic-pituitary brain tumor research is

conducted, placing survivors and caregivers at the center of every question asked and every solution sought.

Advancing Innovation: Sodium Meter Development

This fiscal year, RAWF made critical progress in the development of a home-use sodium meter—a tool envisioned to empower families managing chronic sodium imbalances following hypothalamic-pituitary brain tumor treatment. Building on our early-stage feasibility efforts, we continued advancing the technical development and refinement of the device with support from expert partners in medical technology and patient-centered design. With generous funding committed for the next development phase, we focused on laying the groundwork for Phase 1 feasibility validation and stakeholder engagement. While the device is rooted in the needs of the hypothalamic-pituitary tumor community, it has the potential to benefit a broader range of patients managing conditions for which hydration and blood sodium levels are critical, including those with diabetes insipidus, heart failure, or kidney disease.

The sodium meter project represents a cornerstone of our innovation agenda and exemplifies our commitment to solutions that directly improve day-to-day quality of life for survivors and caregivers.

As we prepare for the next stage, including regulatory planning and expanded user testing, we remain dedicated to ensuring that the final product is not only scientifically sound but accessible, affordable, and responsive to the needs of our community.



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
Philadelphia | USA



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



Soma Sengupta, MD, Ph.D., FRCP
Chair, Department of Neurology
Tufts University | USA



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

Patient Support

Empowering Families Through At-Home Care

RAWF's very first direct support initiative, the Handheld Blood Analyzer Program, remains a cornerstone of our mission to empower families with tools that make a tangible difference in day-to-day care. Designed to address the urgent need for home sodium monitoring in patients with central arginine vasopressin deficiency and other related conditions, this program continues to meet families where they are with life saving technology and compassion.

This year, six handheld blood analyzers were distributed to families across the United States. These devices are already making a meaningful impact by reducing emergency room visits and preventing avoidable hospitalizations—something many of these patients have experienced repeatedly due to sodium instability. Caregivers now have real-time insights to support safer, more confident at-home care.

"I cannot put into words how much of a help you guys are with the handheld blood analyzer. Trent at this time is bedridden, so without the machine, I really am not sure how we could be getting his sodium checked."

- Justin Lins



Art of Surviving

Art That Heals, Stories That Inspire – RAWF's annual online art competition, held each May in honor of Brain Tumor Awareness Month, continues to spotlight the creativity, resilience, and voices of the brain tumor survivor community. Many participants turn to art as a therapeutic outlet—using it to process their experiences, find calm during recovery, and express their journeys in deeply personal ways.

In 2025, the event welcomed 53 artists and 74 submissions from around the world. Two hundred eighty-one supporters cast a total of 22,839 votes, reflecting incredible



engagement and community support. We were proud to bring back our judging panel this year to celebrate artistic expression across categories. Thanks to the generosity of our supporters, the event raised \$15,272 to fund RAWF's programs for survivors and advocacy efforts.

"After significant hardships following radiation in 2012, I started leaning into the arts as a source of strength, including music, writing, and photography. What I have learned is that no one will ever know the complete darkness or light of the life I live, but at a minimum, perhaps they can draw inspiration from me or what I am able to share with this world."

- Lindsay K. Robinson, 2025
Art of Surviving Participant

Support Groups

Building Community Through Shared Experience – Over the past year, RAWF expanded its peer support offerings to meet the evolving emotional and practical needs of our community.

Through a range of virtual groups and one-on-one connections, survivors, caregivers, and families found safe spaces for support, shared understanding, and healing.

In FY 2025, we hosted 12 Caregiver Support Groups and 12 Survivor Support Groups, each providing ongoing connection and guidance. The Caregiver Support Group continued to serve as a trusted forum for sharing experiences, asking questions, and learning from others navigating similar challenges.

The Survivor Support Group offered a welcoming environment for participants to discuss treatment effects, memory and vision

changes, medications, access to specialists, and our patient registry.

Recognizing the distinct challenges faced by younger patients, we introduced a Teen Support Group and held six virtual sessions tailored to adolescent survivors, providing age-appropriate peer connection and support.

We also responded to growing community needs with the addition of one-on-one grief sessions with Holly Gainsboro, a grief support specialist that works specifically with those in the brain tumor community. These offerings provide compassionate spaces for those coping with loss and seeking personal support.

RAWF remains committed to fostering a strong, inclusive support network that validates lived experiences and builds lasting community.

Fueling Our Mission Together

From gala dance floors to marathon routes, from classrooms to community foundations, our supporters made FY 2025 a turning point for growth. Every dollar raised this year helped accelerate research, expand access to care, and uplift families living with the lasting effects of hypothalamic-pituitary brain tumors.

Community Giving, Fundraising, and Partnerships

The Raymond A. Wood Foundation reached an exciting financial milestone this year, raising over \$760,000, a powerful show of support during our first full fiscal year following the conclusion of the CZI Rare As One grant. Thanks to the generosity of individuals, families, event participants, and corporate partners, we continue to expand life-changing programs and patient-driven research that meets the real needs of survivors and caregivers.



The Return of DC's Dancing Stars Gala

After a three-year hiatus, the DC's Dancing Stars Gala returned with flair, and RAWF was honored to be among the 2025 beneficiary organizations. Dancing for RAWF, Dan Gradishar and Marcia Davis brought heart and energy to the floor—culminating in a Mirror Ball Trophy win for Marcia and an incredible \$93,000 raised to support our work.



Shore Gives More: Giving Tuesday, Amplified

As part of Shore Gives More, the 24-hour local giving day hosted by the Community Foundation of the Eastern Shore, RAWF raised nearly \$96,000, which was a remarkable show of community-based support. This annual event coincides with the global Giving Tuesday movement and is enhanced by local matching funds and sponsorships that make every gift go further. We're grateful to our local Maryland supporters who continue to show up for our mission in powerful ways.



Team RAWF Runs the NYC Half Marathon

In March, a team of dedicated runners took on the NYC Half Marathon for RAWF. Ross Martin and Cecilia Scimia of Rhythm Pharmaceuticals and David Johnson, a caregiver to a craniopharyngioma survivor, each crossed the finish line with purpose—raising close to \$15,000 for the foundation. Their commitment helped elevate awareness and support for our work on a national stage.



Grassroots Generosity: Music Bingo for a Mission

In April, survivor Abby Memmensheimer and her mother, Staci, hosted a Music Bingo Night to raise funds for RAWF bringing in a powerful \$20,000 while also raising awareness of the daily challenges survivors face. Abby, a recipient of a handheld blood analyzer through RAWF's support programs, brought her personal story full circle by giving back to a cause that has helped her family directly.

Growing Major Donor Support

This year marked significant growth in our major donor community. With increased outreach, stewardship, and personal engagement, we've seen more donors investing in RAWF's long-term vision. Their commitment ensures that as our programs and partnerships expand, we have the resources to sustain and scale what's working.

Together, we are not just funding a mission—we are building a movement.

About Raymond A. Wood Foundation

The Raymond A. Wood Foundation is a parent- and patient-led rare disease patient advocacy organization, dedicated to empowering survivors of craniopharyngioma and hypothalamic- pituitary brain tumors.

Advocating for a Brighter Future

Founded in 2017 by parents who personally experienced the challenges of craniopharyngioma, the Raymond A. Wood Foundation is driven by a deep commitment to making a difference. Witnessing their child's resilience in the face of this rare condition, they established the foundation to be a beacon of hope and support for others facing similar battles.

A Voice for the Patient Community

We serve as a powerful advocate for the craniopharyngioma and hypothalamic-pituitary brain tumor patient community in the realm of research and healthcare. Through our advocacy efforts, we strive to amplify the voices of survivors and caregivers, ensuring that their perspectives are heard and valued.

Empowering Survivors and Caregivers

At the heart of our mission is the belief that survivors and caregivers possess the power to be their own best advocates. We are committed to providing them with the

knowledge, resources, and tools needed to navigate the complexities of these conditions. Through education and support, we empower individuals to take an active role in their healthcare journeys.

Pioneering Solutions for Complex Challenges

Craniopharyngioma and hypothalamic-pituitary brain tumors present multifaceted challenges that significantly impact quality of life. The Raymond A. Wood Foundation is dedicated to advancing treatment outcomes and seeking innovative solutions. Through strategic partnerships and funding, we drive research initiatives aimed at improving the lives of those affected by these conditions.

Together, We Thrive

The Raymond A. Wood Foundation stands as a beacon of hope, unity, and resilience for the craniopharyngioma and hypothalamic-pituitary brain tumor community. Together, we work toward a future in which survivors not only overcome their challenges, but thrive with a renewed sense of purpose and possibility.



A proud grantee of the
Chan Zuckerberg Initiative
Rare As One Project

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

www.rawoodfoundation.org

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