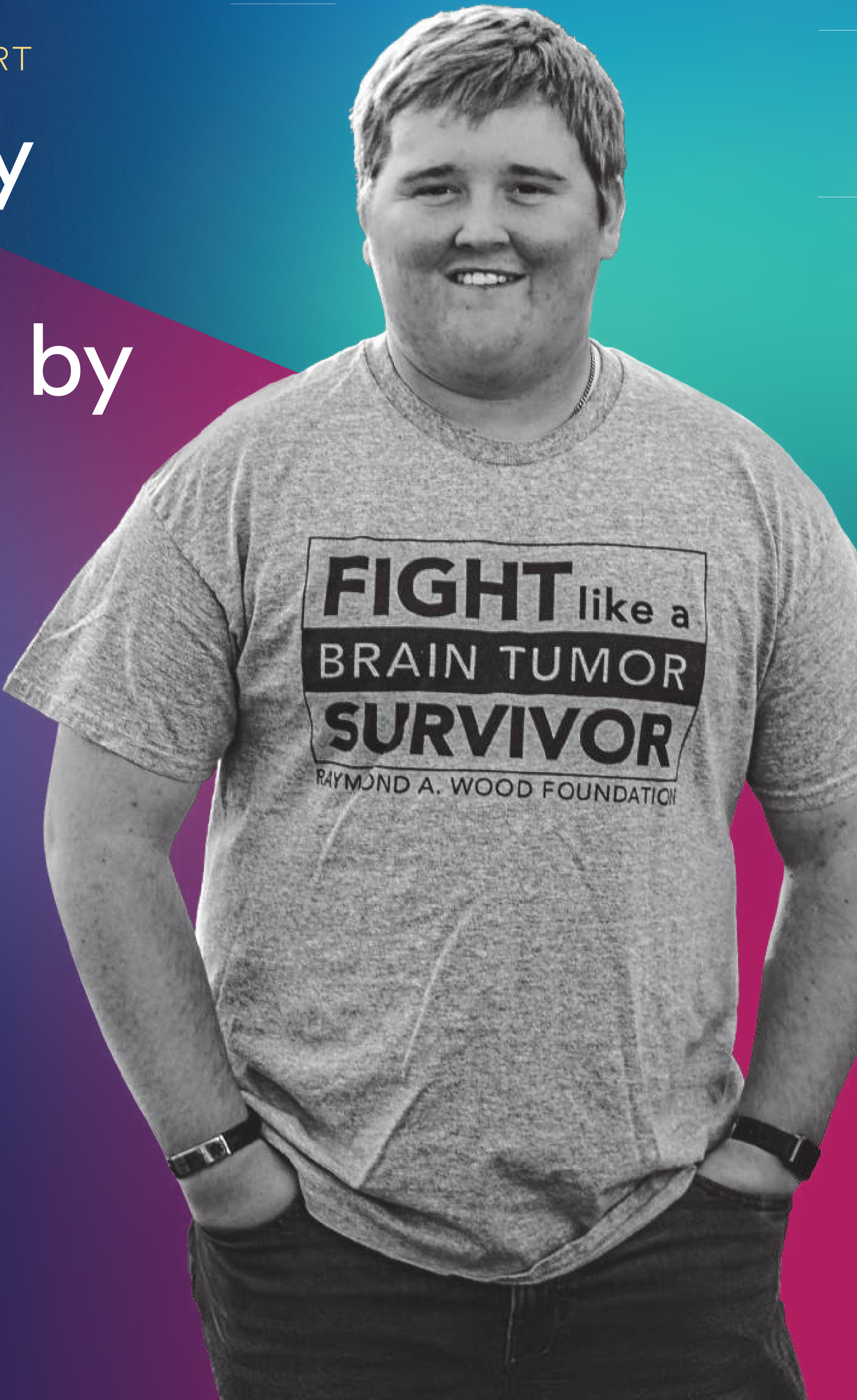
Raymond A. Wood
foundation

FY 24 | IMPACT REPORT

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.

www.**rawoodfoundation**.org

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,

As we look back on 2024, I am filled with immense gratitude and pride in the progress we have made together at the Raymond A. Wood Foundation. Over the year, we achieved significant milestones in research, advocacy, and survivor support for those affected by hypothalamic-pituitary brain tumors, thanks to our dedicated supporters, collaborators, and resilient community.

We launched the Hypothalamic-Pituitary Brain Tumors Patient Registry, an invaluable database to facilitate research on behalf of survivors and caregivers. We continued as members of the Children's Brain Tumor Network (CBTN) Executive Council, integrating patient data with craniopharyngioma tissue samples to accelerate research. Under Dr. Nathalie Kayadjanian's leadership, we have advanced the understanding of hypothalamic obesity, quality-of-life improvements, and the integration of patient-reported outcomes into treatment planning.

Our advocacy and support efforts grew stronger with educational webinars, expanded YouTube content, and a mentorship program for newly diagnosed families. The 6th Annual Art of Surviving event raised awareness during Brain Tumor Awareness Month, and monthly support groups provided essential connections for survivors and caregivers.

In observance of our original mission, we also distributed five handheld blood analyzers, improving care for pediatric patients managing diabetes insipidus. In the spirit of innovation, we continue to prioritize our development of the at-home sodium meter, with efforts focused on securing funding to enhance care for individuals managing sodium imbalances.

Our anticipation of the conclusion of the CZI Rare As One grant made us redouble our fundraising efforts and it has paid off; highlights include our partnership with the NYC Half Marathon, a successful Brain Tumor Awareness Month Matching Gift Campaign, and support from the DC Dancing Stars Gala and Shore Gives More campaign, ensuring our programs' sustainability.

Looking forward, we are motivated to face the challenges of 2025 and beyond. 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.

Thank you for your unwavering support. Your generosity empowers us to pursue groundbreaking research, provide essential resources, and advocate for meaningful change. Together, we will continue making a difference.

Eugenie Hsu, Ph.D.
RAWF Board Chairperson

Our Leadership

RAWF's dedicated board members and staff 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 2023 | **BOARD OF DIRECTORS**

Eugenie Hsu, Ph.D.
Board Chair, Caregiver

Dean Carson, Ph.D.
Research Chair

Ethan Schilling, Ph.D.
Survivor

Christine Selko
Communications Chair, Caregiver

Marci Serota, RDN
Caregiver

Josh Blumenthal
Staff

Joan Saperstein, MD
Staff

FY 2023 | **STAFF**

Amy Wood
Executive Director, Founder

Jamie Ping
Outreach & Communications Manager

Nathalie Kayadjanian, Ph.D
Scientific Advisor

Meghan A. Wood, M.Ed, MPA
Development Officer, Major Gifts

Scientific Advisory Board

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Endocrinology
Children's Hospitals and Clinics of Minnesota

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Rigshospitalet, Copenhagen University Hospital

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Neuro-oncology
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, NHI

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

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

Impact by the Numbers

$615,000

Amount raised in 2023

$1.3M

Amount raised to date

1,091

Number of donors

Grants Received in 2024

$200,000

Capacity Building (CZI)

Funding Allocation by Focus Area

$160,000

Administrative & Operating Costs

$95,000

Patient Support & Advocacy

$65,000

Fundraising & Development

$80,000

Awareness & Outreach

$155,000

Research & Innovation

FY 24 | Key Highlights

July 2023

Hosted Huk Big Fish Fundraiser in Ocean City — Ford Bronco raffle winner announced

August 2023

Launched RAWF's newly redesigned website

October 2023

Craniopharyngioma caregiver impact study published in Journal of Clinical Endocrinology & Metabolism

Attended NORD Breakthrough Summit

Presented at WAPO Global Summit on the Art of Surviving

Provided handheld blood analyzer to patient Nathan

November 2023

Hosted Pituitary Brain Tumor Family Conference at CHOP

Welcomed new board member Josh Blumenthal

Held annual in-person RAWF Board of Directors meeting

December 2023

Amy Wood presented at Rhythm Pharmaceuticals' investors meeting alongside Dr. Jennifer Miller and David Meeker

January 2024

Dan's Breakthrough T-Shirt fundraiser launched to raise awareness around AVP-D

February 2024

Amy Cairns became the first person with AVP-D to hike Mt. Kilimanjaro, raising funds and awareness for RAWF

Welcomed Meghan Wood as Major Gifts Officer

March 2024

RAWF team ran the NYC Half Marathon in support of our mission

April 2024

Traveled to Texas to connect with RAWF community members in person

May 2024

Held 6th Annual Art of Surviving during Brain Tumor Awareness Month

Launched the Hypothalamic-Pituitary Brain Tumor Patient Regustr

June 2024

Amy Wood named a 2024 RARE Champion of Hope nominee by Global Genes

Putting Our Strategy Into Action

Now in the second year of our three-year strategic plan, the Raymond A. Wood Foundation continues to make strong progress toward our long-term goals. Building on the foundational work accomplished in 2023, we spent 2024 deepening partnerships, launching new initiatives, and expanding our impact across research, support, and advocacy.

Our focus this year was on turning strategy into measurable action—driving forward projects that directly address the challenges facing survivors and caregivers of hypothalamic-pituitary brain tumors.

GOAL: ***Improve Treatment & Quality of Life***

PROGRESS ON GOAL: In 2024, RAWF took bold steps to support better outcomes for survivors through practical, data-driven solutions. We officially launched the Hypothalamic-Pituitary Brain Tumor Patient Registry, a critical tool that allows patients and caregivers to contribute directly to research. We also continued to fund the development of an at-home sodium meter and distributed handheld blood analyzers, giving families better tools to manage care safely at home. By emphasizing patient-reported outcomes, we remained focused on improving not just treatment options, but day-to-day quality of life.

GOAL: ***Address Challenging Conditions***

PROGRESS ON GOAL: We remained committed to advancing research and awareness of the most complex and under-addressed consequences of hypothalamic-pituitary brain tumors. With a continued focus on hypothalamic obesity, neuroendocrine dysfunction, and other life-altering effects, RAWF worked to ensure that these issues are recognized as research and care priorities. Our efforts throughout the year reinforced the importance of patient input in identifying and addressing these critical unmet needs.

GOAL: ***Raise Awareness & Expand Collaborative Network***

PROGRESS ON GOAL: Support for families remained at the core of our mission in 2024. We expanded our virtual support groups to better meet the needs of our community, adding dedicated sessions for teens, caregivers, and survivors. Our mentorship program continued to connect newly diagnosed families with peers who could offer insight and encouragement. We also provided ongoing educational resources and continued distributing critical medical devices to help families manage complex care at home with greater confidence and ease.

GOAL: ***Promote Sustainability to Advance Our Mission***

PROGRESS ON GOAL: With the conclusion of our Rare As One grant on the horizon, we prioritized financial and organizational sustainability. Through successful fundraising campaigns—including the NYC Half Marathon, Shore Gives More, and the DC Dancing Stars Gala—we secured critical support for our programs. At the same time, we continued strengthening internal systems and donor engagement to ensure RAWF remains a stable, independent, and impactful organization into the future.

Empowering Patients in Research & Advocacy

PITUITARY BRAIN TUMOR
FAMILY CONFERENCE

Annual Pituitary Brain Tumor Family Conference: The Power of Gathering In Person

In November 2023, the Raymond A. Wood Foundation hosted its 5th Annual Pituitary Brain Tumor Family Conference in person at the Children's Hospital of Philadelphia—our first in-person gathering since 2019. The event brought together survivors, caregivers, researchers, and clinicians for two days of education, connection, and collaboration. Sessions covered integrative medicine, hypothalamic obesity, adrenal stress dosing, social-emotional wellness, and updates on the patient registry, with opportunities for families to engage directly with experts. The conference reinforced the power of community and patient-centered research in driving progress for those affected by pituitary and hypothalamic-pituitary brain tumors.

Building Community Through Shared Experience

Over the past year, the Raymond A. Wood Foundation hosted 12 virtual sessions each for both caregivers and survivors of hypothalamic-pituitary brain tumors, offering vital spaces for connection and support. The Caregiver Support Group provided a forum for sharing experiences, asking questions, and learning from others navigating similar challenges. The Survivor Support Group created a safe space for individuals to discuss treatment effects, memory and vision changes, medications, specialists, and our patient registry. Later in the year, we launched a Teen Support Group to address the unique needs of adolescent survivors, providing age-appropriate peer connection and guidance.

Art of Surviving

RAWF's annual online art competition, held each May in honor of Brain Tumor Awareness Month, showcases the creativity and resilience of the brain tumor survivor community. Many survivors turn to art as a therapeutic outlet, using it to process their experiences, find calm during recovery, and express their journeys in a meaningful way.

In 2024, the competition saw remarkable engagement, with over 82 submissions, 493 participants casting votes, and more than 15,000 total votes. Thanks to the generosity of our community, the event successfully raised $15,385 to support brain tumor survivors and advocacy efforts.

> "The first good thing [about the survivor support group] was meeting others like me. Second was to be able to vent and see others agree." – *Sunita Gupta*

Turning Experience Into Evidence: Launch of the Patient Registry.
In 2024, the Raymond A. Wood Foundation proudly launched the Hypothalamic-Pituitary Brain Tumor Patient Registry, a groundbreaking initiative to collect real-world data directly from survivors and caregivers. This registry captures the lived experience of those navigating life after diagnosis—highlighting the challenges that often go unmeasured in traditional research. With this effort, we are building a powerful resource to inform future studies, shape treatment strategies, and advocate for the needs of our community. The registry represents a major step forward in patient-centered research, turning insights from the community into evidence that can drive meaningful change.

WINNER OF THE BEST OVERALL CATEGORY
Will Mumford — "Handbuilt Ceramic Vases"

ART OF SURVIVING

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 journey.

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 where survivors not only overcome their challenges, but thrive with a renewed sense of purpose and possibility.

Raymond A. Wood foundation

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

Chan Zuckerberg Initiative

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

www.**rawoodfoundation**.org

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