



JULY

JUNE

2021-2022

Annual Report

Sharing the impact of the work of the Raymond A. Wood Foundation on behalf of hypothalamic-pituitary brain tumor survivors.



Raymond A. Wood
foundation

Letter from Leadership

Grateful for the use of a hospital-grade medical device to help manage a complex condition following their son's brain tumor surgery, Amy and Shawn Wood founded their son's namesake foundation to make these difficult-to-access devices available for other pediatric brain tumor survivors . Five years later, RAWF has now grown up into an adolescent of sorts; like a feisty teenager, we are pushing boundaries and boldly taking on new challenges to accomplish our mission.

Although Executive Director Amy Wood tells me she is not fearless, she behaves as if she is, and as someone who communicates with her multiple times a week, I am confident that our many accomplishments are thanks to her intrepid leadership, focused work ethic, and passion for our cause. Our year's highlights include hosting an FDA listening session for hypothalamic obesity, producing our third annual Pituitary Brain Tumor conference, and using our Chan Zuckerberg Initiative Rare As One grant to hire a Scientific Advisor (Nathalie Kayadjanian, PhD,) and Outreach Coordinator (Jamie Ping, MA).

As a board composed mostly of brain tumor families, we never lose sight of our mission. This past year, we have continued to provide blood analyzers to medically fragile patients, network and build partnerships with pharmaceutical, clinician, and researcher stakeholders, offer cutting-edge research, education, and support to patients and families, advocate for hypothalamic obesity drug development, and conduct original research on the caregiver experience.

With the support of CZI, our new hires, and the leveraging of our growing network, we are excited to tackle more projects in the upcoming year to include developing a craniopharyngioma website hub, establishing an evidence-based treatment decision-making matrix at the time of diagnosis to optimize prognosis and quality of life, innovating an app and home-use sodium meter to better manage adipsic diabetes insipidus, establishing a patient registry, supporting a biobank to expand



Eugenie Hsu, Ph.D

BOARD CHAIR

research on improving treatment options and outcomes, growing outreach to underserved communities, and increasing awareness and referrals of our services via medical providers to patients from diagnosis through long-term survivorship

From Amy and Shawn's original objective of offering pediatric patients life-saving handheld blood analyzers to our current widely expanded vision to be the leading patient advocacy organization for hypothalamic-pituitary brain tumor survivors, I am both proud and blown away by how far we have come. And like a mother watching her spirited teenager, I am also aware of how much more growth and work we have ahead of us. Indeed, our survivors' many problems are complex and daunting and demand our continued dedication and persistent efforts.

To quote Pablo Picasso, "the meaning of life is to find your gift; the purpose of life is to give it away." We thank our donors for supporting our work thus far, and every day, our survivors remind us that we have so much more to do. As a mother to a brain tumor survivor, your kindness and generosity matters deeply to me and RAWF. Thank you for making a difference in the lives of our survivors.

With gratitude,

Eugenie Hsu, PhD, Chairperson
Raymond A. Wood Foundation

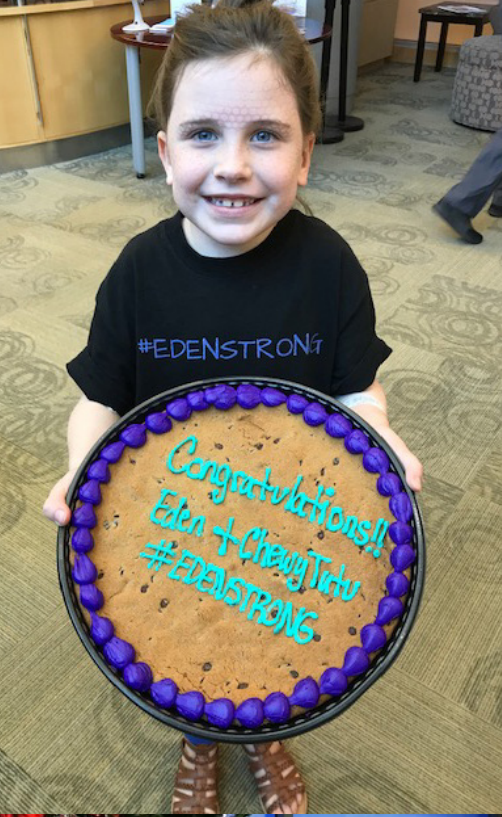


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"I live by my belief that patient-caregiver advocates can advance science and innovations to improve patients' health and quality of life."

EUGENIE HSU, PH.D, BOARD CHAIR AND CAREGIVER

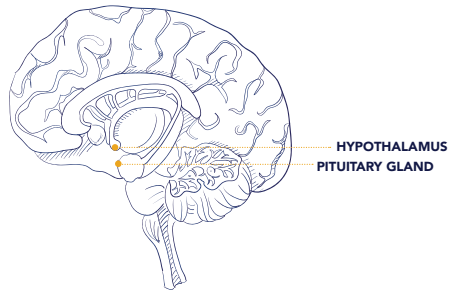
Our Why

**What Drives Us
in Our Advocacy**

Here's the Problem...

Location, Location, Location

These brain tumors occur near or on vital anatomical structures responsible for homeostasis, vision, electrolyte balance and hormone production, making their removal surgically challenging and risky.



Likely to Recur

These brain tumors grow back in 22-40% of patients. Every recurrence has the potential to cause more adverse consequences (e.g. strokes, seizures, blindness, etc.).

Affects Children and Adults

These brain tumors, specifically craniopharyngiomas, mostly develop in children aged 0 to 14 years and adults aged 50 to 74 years and occur in males and females equally.

Poor Quality of Life

These brain tumors and their treatments significantly reduce patients' quality of life and can have devastating consequences for physical and neuropsychosocial functioning.

Burden of Care

Providing adequate treatment for the multiple and chronic conditions that arise from these tumors can require hypervigilance and painstaking efforts to keep the patient medically stable.

Lacking Treatment Options

There is no standard of care for the treatment of these tumors and many of the conditions that arise in the aftermath are poorly understood and have few treatment options.

What We Believe

Vision

To be the patient voice for hypothalamic-pituitary brain tumor patients, survivors and caregivers.

Mission

The mission of the Raymond A. Wood Foundation is to empower survivors of hypothalamic-pituitary brain tumors with an improved quality of life by providing access to education, technology, and evolving treatments.

Our Core Values & Guiding Principles

Creativity & Innovation

Seeking new approaches to create solutions or improve systems to better serve the community.

Integrity & Transparency

Inspiring trust through open communication internally and externally.

Empathy, Care, & Compassion

Always operating from a place of understanding of the challenges that face all within the community.

Ethics & Confidentiality

Keeping all information pertaining to patients, survivors, caregivers, and healthcare professionals in confidence.



"I realize every family's journey is different; however, the fear and feelings of desperation that a family feels with a tumor diagnosis are the same. For this reason, I have worked to help other families who are facing uncertainty while dealing with a sick child. My goal is to offer support and provide any assistance I can."

CHRIS SELKO, BOARD MEMBER

Who We Are

**Our Staff, Board
of Directors and
Scientific Advisory Board**

Our Staff



Amy Wood

EXECUTIVE
DIRECTOR



Jamie Ping

OUTREACH
COORDINATOR



Nathalie Kayadjanian, Ph.D.

SCIENTIFIC
ADVISOR

Board of Directors



Eugenie Hsu, Ph.D.

BOARD
CHAIR



Shawn Wood

TREASURER



Caroline Coakley

SECRETARY/
FUNDRAISING CHAIR



Dean Carson, Ph.D.

RESEARCH
CHAIR



Chris Selko

MEMBERSHIP
CHAIR



Marci Serota, RDN

BOARD
MEMBER

Scientific & Clinical Advisory Board



M. Jennifer Abuzzahab, MD

McNeely Pediatric Diabetes Center and Endocrine Clinic
Children's Hospitals and Clinics of Minnesota



Lewis Blevins, MD

California Center for Pituitary Disorders
UCSF Health



Ulla Feldt-Rasmussen, MD, DMSc

Professor, Chief of Medical Endocrinology PE 2132
Rigshospitalet, Copenhagen University Hospital



Cassie Kline, MD

Director, Neuro-Oncology, for the Division of Neurology
Attending Physician, Director, Neuro-Oncology Clinical Research
Division of Oncology, The Children's Hospital of Philadelphia



Shana McCormack, MD, MTR

Scientific Director of the Neuroendocrine Center
Division of Endocrinology and Diabetes
Children's Hospital of Philadelphia



Christian Roth, MD

Endocrinology
Seattle Children's Research Institute
Seattle Children's Hospital



Ashley H. Shoemaker, MD, MSCI

Assistant Professor of Pediatrics
Ian Burr Division of Endocrinology and Diabetes
Vanderbilt University Medical Center



Fatema Malbari, MD

Director, Neuro-Oncology, for the Division of Neurology
Assistant Professor, Division of Pediatric Neurology
and Developmental Neurosciences



DELEGATION TO CHAN ZUCKERBERG INITIATIVE RARE AS ONE ANNUAL CONVENING IN SAN DIEGO, JUNE 2022 (FROM LEFT TO RIGHT): EUGENIE HSU, PH.D., BOARD CHAIR; AMY WOOD, EXECUTIVE DIRECTOR; NATHALIE KAYADJANIAN, PH.D, SCIENTIFIC ADVISOR; AND CASSIE KLINE, MD, NEUROONCOLOGIST, CHOP

“As a translational and clinical researcher, being able to partner with a strong advocacy organization like RAWF gives us much greater chances of success.”

SHANA MCCORMACK, MD, MTR

Impact by the Numbers FY 2022

\$178,567

amount raised in FY 22



4

handheld blood
analyzers provided to
families with children
with adipsic diabetes
insipidus



\$60,000

in medical devices and supplies provided

\$200,000



in grant funding awarded to RAWF for capacity building

13

educational
sessions
provided



\$3,000

awarded to Art of Surviving winners

Impact by the Numbers Since 2017

\$860,168

raised since 2017



990

donors



Direct Support to Patients

\$30,000

on research

\$10,000

on education

\$375,000

in medical devices and supplies



\$600,000

in grant funding awarded to RAWF



\$15,000

awarded to Art of Surviving winners



3

annual conferences
held

26

educational sessions provided

Milestones 2016-2018

- RAWF received 501(c)3 status
- Established board of directors

2016

- Participated in National Brain Tumor Society's Head to the Hill
- Hosted first East Coast Cranio Survivors' Picnic
- Supplied two handheld blood analyzers to pediatric patients

2017

- Hosted inaugural Art of Surviving Competition for Brain Tumor Awareness Month
- Supplied 3 handheld blood Analyzers

2018



Milestones 2019-2021

- Supplied four handheld blood analyzers
- Offered complimentary copies of Hungry for Solutions to hypothalamic obesity patients
- Co-hosted inaugural Pituitary Brain Tumor Conference with CHOP
- Named a beneficiary of the DC Dancing with the Stars Gala
- Hosted 2nd Annual Art of Surviving Competition

2019

- Supplied four handheld blood analyzers to pediatric patients
- Developed new RAWF mission statement to include support for adult survivors
- Expanded board of directors
- Hosted educational webinar series
- Hired first full-time director
- Initiated at-home sodium meter project
- Hosted 3rd Annual Art of Surviving Competition
- Hosted 2nd Annual Pituitary Brain Virtual Tumor Conference

2020

- Supplied four handheld blood analyzers to pediatric patients
- Released *TREND Research Report*
- Developed caregiver impact survey
- Hosted FDA Patient Listening Session on hypothalamic obesity
- Named as CZI Rare As One Network grantee
- Launch ROAR for RARE Campaign
- Hosted 3rd Annual Pituitary Brain Tumor Virtual Conference
- Hosted 4th Annual Art of Surviving Art Competition
- Collaborated on at-home sodium meter proof of concept
- Staff increased to include outreach coordinator and scientific advisor
- Worked with Penn Biotech Group on market analysis for diabetes insipidus

2021

"Art spills from our soul Imperfection spills from our hands Art speaks to our struggles and heals."

OLIVIA WEIDEL, ART OF SURVIVING PARTICIPANT

Programs and Events

**Awareness, Outreach
and Education**



"Fearless" by Samaya Glazier-Bae

Art of Surviving

5TH ANNUAL COMPETITION

82

art entries

8281

votes

\$3,000

cash prizes



"Brainy Days" by Angel Gregson

This year, we hosted the 5th Annual Art of Surviving online art competition in May for Brain Tumor Awareness Month to celebrate the creativity of the brain tumor community. 2021 was our biggest event to date, record-setting number of entries and participants, amount of money raised, and total value of cash prizes.

Many brain tumor survivors use art as a form of therapy. The purpose of this art exhibition is to give people in the brain tumor community an opportunity to showcase their work, share their stories, and raise awareness and much-needed resources to fund the critical programs to improve the lives of all those affected by brain tumors.

Art of Surviving Stories



“During my healing process from the surgery, I have rediscovered my love of art and music, so this painting depicts my transition into how my life was, an existence of two-dimensional color into a beautiful explosion of many colors with many depths.”

-SURVIVOR, MELANIE MONROE



“Addy was just 2 when our lives changed drastically with Sammy’s diagnosis. Yet she is always wonderfully supportive and loving towards her big sister – consistently with a kind word and incredibly understanding of how our lives can look different from those around her.”

-MOM TO ADDY AND SAMMY



“The diagnosis, although it wasn’t mine, affected my life and helped shape me into the person I am today. I developed skills such as patience, hope and independence. I have learned to appreciate small interactions, as well as how close and supporting our family is. I have learned how to look past people’s disabilities and differences, to see who they truly are. Beyond that, I am an artist, a teenager, a student, and a writer.”

-CAREGIVER, OLIVIA WEIDELLE

Sponsors



Annual Conference



PITUITARY BRAIN TUMOR VIRTUAL FAMILY CONFERENCE

NOVEMBER 14 & 15, 2020

77

global attendees

11

educational sessions

10

clinician presenters

In 2021, the Raymond A. Wood Foundation and Children's Hospital of Philadelphia hosted the 3rd Annual Virtual Pituitary Brain Tumor Conference, which allows patients and caregivers to engage with experts and hear the latest research and topics that affect them. This year, there were 10 presenters from various medical specialties who discussed:

- the latest research in hypothalamic obesity (HO) and HO nutrition
- current clinical trials and the latest research findings
- collaborative work with doctors for better patient outcomes
- optimization of thyroid replacement
- the transition of pediatric patients to adult endocrine care
- mental health and pituitary disorders

"Thank you for the great conference. The introductory sessions and the breakout sessions were very interesting. The Q&A opportunities were also valuable for attendees. You are a strong advocate for the families and individuals you represent."

PAT GILDROY
SURVIVOR & ADVOCATE

Sponsors



Partnerships and Collaborations



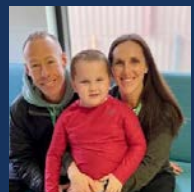
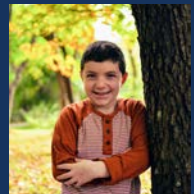
- Collaboration with Children's Hospital of Philadelphia Office of Entrepreneurship and Innovation and Archimedic for home-use sodium meter development
- Partnership with Children's Hospital of Philadelphia Neuroendocrine Clinic to host educational conference
- Collaboration with Pediatric Brain Tumor Foundation on webinar topics of survivorship and endocrine issues
- Collaboration with PNOF Foundation on webinar on craniopharyngioma
- Member of PNOF craniopharyngioma working group
- Partnership established with Giner Labs on research and development of home-use sodium meter
- Member of CZI Rare As One Network
- Founding member of Global Genes Alliance

Handheld Blood Analyzer Program

RAWF provides hospital-grade blood analyzers to pediatric patients with adipsic diabetes insipidus so caregivers can test blood sodium levels at home and be proactive in their medical care. These devices are not covered by insurance and are costly to purchase. To date, we have provided 20 handheld blood analyzers to 24 children who have faced multiple hospitalizations.

Over the course of 2021, we received numerous requests from doctors, nurses, social workers, and parents who were seeking a handheld blood analyzer to help keep their patient or child out of the hospital. RAWF was pleased to provide four devices to pediatric patients in need during 2021 including Evie, Azalea, Franklin, and Finn.

The need for handheld blood analyzers is significant, and we currently maintain a waitlist for children whose sodium levels cannot be adequately managed at home without this device.



"We will forever be grateful to those who helped give our sweet Evie this opportunity. This device is life changing for our daughter, a chance to closely monitor her sodium and prevent emergencies in the future. To all who are reading this, thank you for being the change in Evie's life, and helping her focus on her dreams and less on her fears."

EVIE'S MOM



Evie's Story

When Eve was just 15 months old, she and her family were introduced to a word that would forever change their lives: craniopharyngioma. While immediate surgery to drain the cystic portion of the tumor was performed, Evie woke up from the procedure completely blind. Not only was the family recovering from the surgery and navigating common side effects from brain tumor, they were now also adjusting to an unexpected by-product of the surgery — diabetes insipidus.

In the hospital, Evie also had her first sodium-related seizure, thus beginning the family's ongoing search to find and maintain an ideal blood sodium balance to ensure stability.

At 7, Evie faced a recurrence of the tumor and was able to have half of the tumor surgically removed, yet faced a new batch of related issues such as seizures, lack of thirst, dehydration, and an increased imbalance of blood sodium levels. Later that same year, Evie suffered a stroke due to moyamoya, a rare disease that, in her case, developed as a side effect from the radiation treatment she had undergone to fight craniopharyngioma.

Having a way to measure her blood sodium at home is literally life changing for Evie and prevents emergencies and hospital stays in the future, offering her the security she needs to feel safe at home.

Monthly Learning Series

The Raymond A. Wood Foundation hosts a virtual Monthly Learning Series with the aim of providing patients and caregivers with access to the most up-to-date research on topics of interest for our community. The topics in 2021 included:



- Understanding the Role of Oxytocin in Hypothalamic Obesity
- Focused Ultrasound Treatment of Benign Intracranial Tumors
- Breaking Through the Issues of Diabetes Insipidus Management
- Supportive Housing for Brain Tumor Survivors: Part I and Part II
- Understanding Endocrine Problems Following a Pediatric Brain Tumor Diagnosis
- All About Growth Hormone Replacement for Brain Tumor Survivors
- Review of Study Findings: Intranasal Oxytocin in Hypothalamic Obesity
- Adrenal Insufficiency and Cortisol Replacement

"I would want somebody who went through what we went through to have some kind of a guideline as to how life would be altered. I had no clue. You are just struggling to try and figure this out, but there is no playbook for us."

TANYA HAMMOND, CAREGIVER



Patient Listening Session Hypothalamic Obesity

The Raymond A. Wood Foundation (RAWF) hosted a patient listening session with the Food and Drug Administration on October 22, 2021, to increase the understanding of hypothalamic obesity (HO) and the daily challenges faced by the patients and their caregivers who live with this rare disorder. These sessions help inform medical product development, clinical trial design, and patient preferences, and shape regulatory thinking.

The session was well attended, and the panel felt positive that all key points about the challenges that come with this condition were covered. The Raymond A. Wood Foundation has prepared a summary that is currently on the FDA website. Additionally, we hosted a webinar to recap the meeting. RAWF will continue working to raise awareness about HO and to advocate for future treatments.

The session aimed to increase understanding of:

- The burden of living with the disease, especially after surviving a brain tumor
- The impact on families, including siblings
- The depth of burden on caregivers
- The social implications of HO
- The distinction between HO and typical obesity
- The challenges faced by doctors when treating patients
- The unmet needs for treatment options and other assistance

FDA reactions:

- Had never heard of this condition
- Wanted to understand more about HO and its prevalence
- Was Interested to learn more about medical devices in development
- Expressed compassion for what survivors with HO face

Finding Solutions

Management of Adipsic Diabetes Insipidus (DI)

Problem: Central DI is a condition in which the brain does not produce vasopressin, the hormone that regulates the body's fluid balance, which can result in dehydration and high blood sodium levels. Treatment for DI with synthetic forms of vasopressin can lead to excess hydration and dangerously low sodium levels. In addition, patients with hypothalamic injury from a brain tumor or brain tumor treatment may also have an absence of thirst (adipsic diabetes insipidus), making fluid management even more difficult. This condition is particularly challenging to manage in pediatric patients, both extremes (i.e., very low or very high sodium in the blood) can lead to seizures or coma and can even be fatal.

Current Program Framework

Discovered Method to Test Sodium at Home

RAWF identified a medical device that could test blood sodium in minutes with a finger prick and a few drops of blood.

Providing Devices to Patients

RAWF established a program to enlist donor support to provide devices to patients in need.

Raising Awareness in the Medical Community

RAWF is sharing case studies with clinicians showing the way the device can be used to monitor this condition proactively.

RAWF contributed experience of home testing to the "Absent Thirst and Diabetes Insipidus" chapter for *Diabetes Insipidus in Children, A Pocket Guide*.



Next Steps

Goal: Develop home-use sodium meter that can be used by any patient requiring monitoring of sodium levels. The device would be FDA approved, easy to use, require small blood volume, and be covered by insurance.



Develop Sodium Meter

RAWF has signed an agreement with Giner Lab to research and develop a home-use sodium meter

Market Analysis

RAWF commissioned the Penn Biotech Group to conduct a marketing analysis for DI, along with other conditions that would benefit from sodium testing outside of a lab.

Develop Web App

RAWF designed a web application which allows for logging daily fluid intake and output, weights, and lab results with real-time calculations.

Determine Regulatory Pathway

RAWF will engage a regulatory consultant to begin determine the best pathway for regulatory approval



ROAR for RARE

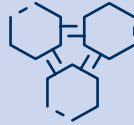
The Campaign for the Raymond A. Wood Foundation

The Raymond A. Wood Foundation (RAWF) is committed to raising \$500,000 over the next 18 months to fund five critically needed projects that will improve the quality of life for hypothalamic-pituitary brain tumor survivors and their caregivers. For more information, visit www.rawoodfoundation.org/roar.



\$200,000

**AT-HOME
SODIUM METER**



\$50,000

BIOBANK



\$100,000

**HANDHELD BLOOD
ANALYZERS**



\$100,000

**WEBSITE RESOURCE
HUB**



\$100,000

**RESEARCH
GRANTS**

Strategic Goals

In our first five years, RAWF has established a place in the brain tumor research ecosystem, provided educational opportunities for families, and increased awareness on the morbidities of these tumors and the need for treatments, all while working to develop a medical device to improve management of care.

Over the next three years, we will build research networks to improve treatment outcomes, increase outreach to underserved communities, bring a lifesaving medical device to market, and support development of treatments for the most challenging medical conditions that result from these tumor treatments.

1

Treatments & Outcomes

Facilitate the establishment of a standard of care that prioritizes the simultaneous optimization of survivorship and quality of life for patients.

Objective #1

Collaborate with the scientific community to develop an interdisciplinary standard of care to develop a treatment decision-making matrix that prioritizes improved prognostic and quality-of-life outcomes.

Objective #2

Design and build a craniopharyngioma patient registry to advance research and drug development.

Objective #3

Support and assist in growing existing craniopharyngioma biobanks to enrich data to facilitate research on tumor treatment and post-treatment management.



2

Quality of Life

Attenuate the most treatment-elusive conditions affecting hypothalamic-pituitary tumor survivors' poor quality of life.

Objective #1

Continue and grow approaches to manage diabetes insipidus from providing handheld blood analyzers and developing a fluid-logging mechanism to driving the development of a home-use sodium

Objective #2

Document the hypothalamic obesity patient experience, and gather other relevant information from patients and caregivers for an FDA-approved drug.

Objective #3

Build and coordinate a network of interdisciplinary scientific partners, biotech/pharma industry partners, and other associated-disease organizations to address such poorly understood and difficult-to-treat conditions as hypothalamic syndrome, neurocognitive deterioration, and social impairment.

3

Education and Outreach

Increase support of hypothalamic pituitary brain tumor patients and their caregivers throughout the patient journey, from diagnosis and treatment through survivorship.

Objective #1

Create and maintain a website on craniopharyngioma to provide updated information and essential resources on the tumor treatment and management of chronic conditions and other issues facing long-term survivors.

Objective #2

Provide accessible educational information and resources for all patients, including children and adults, non-English speakers, members of the African diaspora, and other underserved populations at tumor diagnosis, treatment, and post-treatment encounter points.

Objective #3

Expand membership program and community engagement that is inclusive of the diverse patient population, with resources addressing newly diagnosed patients, patients transitioning from pediatric to adulthood, and adult patients.



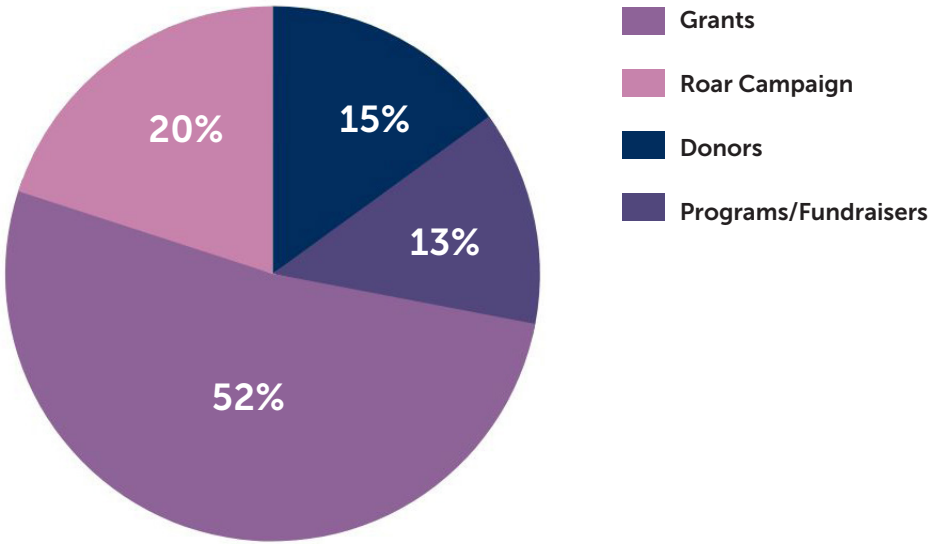
"She struggles daily with all the usual endocrine issues that come with this tumor, but we are thankful every day to have her and will continue to advocate for her and get her stronger."

KIRSTEN, MOM & CAREGIVER

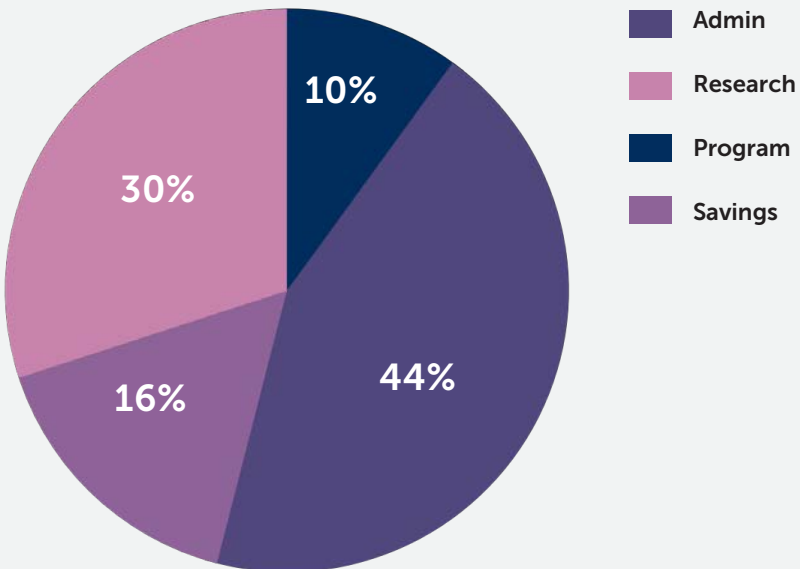
Financial Report

Detailed financial reports are available upon request.

FY 22 Income



FY 22 Expenditures



"The Raymond A. Wood Foundation has been an integral part of my son's current success at home. More than just the medical equipment, the foundation has provided us extensive training, emotional support, and hope. I do not know if my sweet Teddy would be home without this foundation."

MOLLY, MOM & CAREGIVER

Getting Involved

Ways to Support Our Work

Become a Monthly Donor

Your monthly donations provide a reliable source of funds so that we can continue the work of serving our survivors.

Roar with Us

Support the Roar for Rare campaign and choose the project you want to support.

Become a Member

Annual membership offers access to educational webinars, the members-only annual meeting, exclusive discounts and newsletters.

Share Your Story





Tell us why you are part of our community and what RAWF means to you!



12417 Ocean Gateway
Suite B11 #108
Ocean City, MD 21842

www.rawoodfoundation.org
outreach@rawoodfoundation.org

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We Want to Hear From You!



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Suite B11 #108

Ocean City, MD 21842

www.rawoodfoundation.org

outreach@rawoodfoundation.org

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