

FY 23 | IMPACT REPORT

Empowering patients, advancing research.



Our Progress and Vision

I am thrilled to report that 2023 has been yet another year of rapid growth for RAWF. I am proud of our many accomplishments to date, but more importantly, I am gratified that our work is making a real difference in the lives of our brain tumor survivors.

In our second year as Chan Zuckerberg Initiative Rare As One grantee, we put our resources to work by focusing our energies on scientific research. Leading the way, RAWF Scientific Advisor Nathalie Kayadjanian, Ph.D., developed a scientific research plan and now its projects are well underway.

With the goal of collecting data from patients and caregivers about living with hypothalamic-pituitary tumor syndromes, we are using a National Organization for Rare Disorders (NORD) platform to develop an international patient registry. This patient registry aims to improve the understanding of patients' unmet needs to facilitate research and improve patient care. We are excited to launch our registry soon.

To better address unmet needs for patients with arginine vasopressin deficiency (also known as

diabetes insipidus), we are in our fourth year of developing an at-home-use sodium meter, which has successfully concluded phase one development. I

am certain that Amy and Shawn Wood did not plan to be in the business of medical device development when they founded RAWF, but necessity is the mother of invention, so here we are!

Thanks to the participation of our caregivers, we were able to conduct new and important research on the impact of disease on craniopharyngioma caregivers. We are pleased to announce that "Caregiver Burden and Its Relationship to Health-Related Quality of Life in Craniopharyngioma Survivors" was recently published in the prestigious *Journal of Clinical Endocrinology and Metabolism*. We believe that our survivor-caregiver voice deserves to have a seat at the table in the research and clinical world, and this publication gives RAWF a strong start as a research champion for our survivors and families. We already have

plans to conduct more studies in the near future, so stay tuned.

Although I never wished to have my child diagnosed with a brain tumor, our work at RAWF makes me believe that there is help and hope. If you are new to RAWF, I invite you all to learn more about the important work we are doing and to join our cause to make a difference.

Thank you to our generous sponsors and donors. We could not do this work without you!

Eugenie Hsu, Ph.D.
RAWF Board Chairperson



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 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. RAWF is dedicated to advancing treatment outcomes and seeking innovative solutions. Through strategic partnerships, 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.



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.



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Our Strategic Goals

01

IMPROVE TREATMENTS AND QUALITY OF LIFE

Collaborating with the scientific community to create an interdisciplinary care standard and treatment matrix. This lays the foundation for optimizing survivorship and quality-of-life outcomes. Establishing a patient registry and supporting biobank expansion advances research and drug development.

02

ADDRESS CHALLENGING CONDITIONS

Developing innovative solutions for conditions like diabetes insipidus and hypothalamic obesity, aiming for FDA approval. Focusing on poorly understood conditions, such as hypothalamic syndrome, neurocognitive symptoms, and social impairment, through a network of scientific partners and industry alliances.

03

SUPPORT PATIENTS AND CAREGIVERS

Our commitment led to development of a comprehensive website with patient resources in multiple languages while providing accessible educational resources for diverse patient populations, including underserved communities, to ensure that everyone facing this diagnosis receives necessary information and support.

04

RAISE AWARENESS AND EXPAND COLLABORATIVE NETWORK

We have built a strong scientific advisory board and patient registry advisory board made up of researchers, clinicians, industry representatives, patients, and caregivers. In addition, we are actively sharing resources with healthcare providers, developing communication plans for global awareness, expanding our board, and building an ambassador program to represent diverse patient communities.

05

PROMOTE SUSTAINABILITY TO ADVANCE OUR MISSION

We have been focused on investing in resources and capabilities to expand revenues, diversifying funding sources, implementing a stewardship program to engage and retain donors, and building relationships with corporate, organizational, and industry partners to grow sponsorships for research and patient programs.

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.

Eugenie Hsu, Ph.D. & Amy Wood attend the Chan Zuckerberg Initiative Science in Society 2023 Annual Meeting →



FY 2023 BOARD OF DIRECTORS



Eugenie Hsu, Ph.D.
Board Chair, Caregiver



Dean Carson, Ph.D.
Research Chair



Caroline Coakley
Secretary



Ethan Schilling, Ph.D.
Survivor



Marci Serota, RDN
Caregiver



Christine Selko
Communications Chair, Caregiver



Shawn Wood
Founder, Treasurer Caregiver

FY 2023 STAFF



Amy Wood
Executive Director, Founder



Jamie Ping
Outreach & Communications Manager



Nathalie Kayadjanian, Ph.D.
Scientific Advisor

Impact by the Numbers



\$423,839

Amount raised
in 2023



\$1.2M

Amount raised
to date



3,554

Number
of donors



Grants Received in FY2023



\$200,000

Capacity Building (CZI)



\$14,000

Spanish Language
Educational Materials
(Global Genes)

Funds distributed to support hypothalamic-pituitary brain tumor patients and families:



\$140,000

Research



\$20,000

Education



\$50,000

Support



Financial Accountability



RESEARCH & PROGRAMS

Advancing scientific knowledge and providing support to our patient and caregiver community affected by H-P brain tumors.



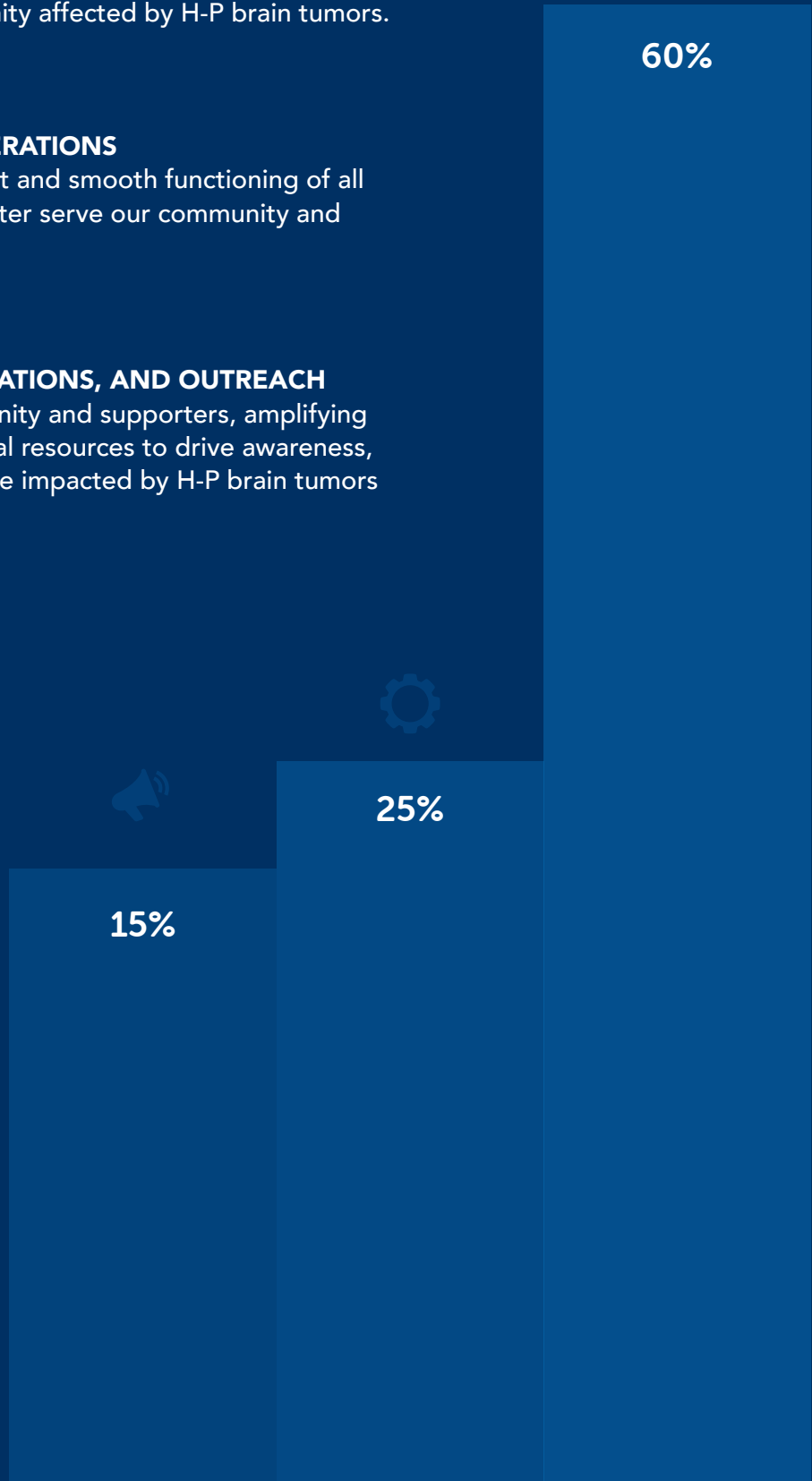
ADMINISTRATION AND OPERATIONS

Ensuring efficient management and smooth functioning of all organizational activities to better serve our community and advance our mission.



FUNDRAISING, COMMUNICATIONS, AND OUTREACH

Engaging with patient community and supporters, amplifying our message, and securing vital resources to drive awareness, research, and support for those impacted by H-P brain tumors worldwide.



FY 23 Key Highlights



July 2022

Launched a new 3-year strategic plan

September 2022

Unveiled research road map

October 2022

Joined CBTN Executive Council

November 2022

Hosted 4th Annual Pituitary Brain Tumor Virtual Conference

January 2023

Initiated Hypothalamic-Pituitary Brain Tumor Patient Registry

January 2023

Commissioned MSquared as regulatory consultant on sodium meter project

March 2023

Hosted first Registry Advisory Board meeting; participated in Mission in Action panel at Komodo Week in Las Vegas

April 2023

Hosted second Scientific Advisory Board Meeting

May 2023

Hosted 5th Annual Art of Surviving Virtual Art Exhibition

May 2023

Hosted first Art of Surviving Reception and Art Auction (in person)

June 2023

Presented "Novel Approaches to Supporting Young Hypothalamic-Pituitary Brain Tumor Patients" at IBTA Summit in Vienna, Austria



Advancing Research

The patient's voice is invaluable in research, as it provides real-world insights, personal experiences, and unique perspectives that can shape more patient-centered and effective healthcare solutions, ultimately improving outcomes and quality of life.



Research Priorities & Goals

In 2022, RAWF developed a patient-centered research plan, defining priorities and structuring long-term activities. In 2023, we built on this foundation, making significant progress in implementing initiatives, forging partnerships, and advancing research to improve outcomes for hypothalamic-pituitary brain tumor patients.

GOAL: *Develop a patient registry to facilitate research, inform medical decision-making, identify patterns, and improve patient care and outcomes through a deeper understanding of diseases and their treatments.*

PROGRESS ON GOAL: In 2023, the Raymond A. Wood Foundation began developing the Hypothalamic-Pituitary Brain Tumor Patient registry on the National Organization for Rare Disorders' I Am Rare platform. This registry collects vital patient data, fostering community and advancing research and advocacy for rare diseases. By offering valuable insights and aiding in treatment development, such registries play a crucial role in improving patient outcomes and quality of life.

GOAL: *Gather evidence-based data on the viewpoints of patients and caregivers on symptoms of importance, treatment priorities, and benefit/risk evaluation.*

PROGRESS ON GOAL: The Raymond A. Wood Foundation's inaugural study, "Caregiver Burden and Its Relationship to Health-Related Quality of Life in Craniopharyngioma Survivors," published in the *Journal of Clinical Endocrinology & Metabolism*, sheds light on the challenges faced by caregivers of craniopharyngioma survivors and the significant socioeconomic impact. Caregivers reported an average of 13 out of 29 health issues in survivors post-treatment, with hyperphagia being a notable factor, surpassing caregiver burden levels for other conditions. This study emphasizes the urgent need for comprehensive support for caregivers and survivors, reaffirming RAWF's dedication to advancing research and advocacy in this field.

GOAL: *Develop an international network of craniopharyngioma experts, including clinicians, researchers, surgeons, and patients and caregivers.*

PROGRESS ON GOAL: Our commitment to advancing hypothalamic-pituitary brain tumor research involves establishing an international network of experts, including a Registry Advisory Board and a Scientific Advisory Board. The Registry Advisory Board, consisting of clinicians, researchers, caregivers, patients, and industry professionals, oversees the development and maintenance of our patient registry. Meanwhile, the Scientific Advisory Board provides invaluable guidance, enabling us to connect and mobilize a global community of craniopharyngioma experts to drive research, advocacy, and support worldwide.

Scientific Advisory Board

The scientific advisory board (SAB) provides valuable guidance and expertise, offering insights on the latest advancements in research, treatment options, and emerging technologies. The SAB helps ensure that RAWF's strategies and initiatives are grounded in the most current and credible scientific knowledge, ultimately benefiting our brain tumor community through informed decision-making and advocacy efforts.



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



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



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



Sadhana Jackson, MD
Investigator, NINDS, NHI



Soma Sengupta, MD, Ph.D., FRCP, FAAN, FANA Neuro-oncology
UNC School of Medicine



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



Christian Roth, MD Endocrinology
Seattle Children's Research Institute



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



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



Fatema Malbari, MD Neuro-oncology
Texas Children's Hospital

2023 Highlights

- Welcomed two new distinguished members to further enrich the diverse knowledge base
- Successfully convened the annual meeting, providing a platform for strategic discussions and collaborations.
- Played a pivotal role in reviewing and endorsing the comprehensive research strategic plan.
- Received a detailed briefing on the progress and potential impact of the sodium meter development, were apprised of the ongoing Caregiver Impact Study, emphasizing its significance in understanding and supporting caregivers, and reviewed and discussed strategic plans for the forthcoming establishment of the patient registry.

Driving Innovation

Advancing Arginine Vasopressin Deficiency (AVP-D) Management: The Raymond A. Wood Foundation’s Collaborative Breakthrough

The Raymond A. Wood Foundation, in partnership with Giner, Inc., and the Children’s Hospital of Philadelphia, is revolutionizing arginine vasopressin deficiency (AVP-D) management through groundbreaking innovation. Together, they are pioneering the development of an at-home sodium meter, promising a transformative shift in blood sodium level monitoring.

The Science Behind the Innovation

Giner, Inc.’s solid contact ion selective electrode (SC-ISE) technology has achieved remarkable milestones during the NIH/NIDDK Phase I SBIR program. Notable achievements include precise calibration curves, long-term stability, and impressive accuracy, all of which position the technology as a frontrunner in blood sodium testing.

Innovations Leading the Way

Giner’s introduction of a 3D printed ion-selective electrode further enhances sensitivity

and stability, propelling the technology toward new horizons in arginine vasopressin deficiency (AVP-D) management.

Next Steps: A Glimpse into the Future

As Giner progresses to the NIH Phase II program, focus shifts to creating a prototype testing system ensuring rapid, precise, and highly sensitive measurement of blood sodium levels. Crucial support from the Raymond A. Wood Foundation facilitates further testing and enhances sensor chip development.

A Leap Toward Publication and Prototyping

Giner’s commitment to transparency and scientific rigor is evident in its pursuit of additional data for anticipated peer-reviewed journal publication. Simultaneously, Giner has embarked on prototyping crucial components of the at-home analyzer, advancing real-world application.

Conclusion: Pioneering Progress in Blood Sodium Testing

The collaborative efforts of the Raymond A. Wood Foundation, Giner, Inc., and their partners signify a significant leap forward in arginine vasopressin deficiency (AVP-D) management.

The development of the at-home sodium meter holds immense promise for those living with this condition, offering them a more

convenient and accurate way to monitor their health. As Giner looks ahead to Phase II, the future of this technology appears brighter than ever, with the potential to transform lives and shape the future of healthcare.



Accelerating Tumor Treatment Research

RAWF’s support of the Children’s Brain Tumor Network aims to accelerate research on craniopharyngioma tumor treatment and post-treatment management. This partnership enhances data collection for the biobank, furthering research opportunities and advancing discoveries in pediatric brain tumor care.

Empowering Patients

Annual Pituitary Brain Tumor Family Conference

At our patient and family virtual conference in November 2022, we highlighted the current clinical trials in craniopharyngioma and led informative sessions on educating patients about clinical trial involvement. Additionally, we delved into crucial topics, including neuropsychology and endocrine concerns for survivors of hypothalamic brain tumors. With an impressive global turnout of about 80 participants, we also introduced translations in over 50 languages through Wordly, ensuring accessibility for a diverse audience.



**PITUITARY
BRAIN TUMOR**
FAMILY CONFERENCE

Caregiver Support Group

This group is a place for caregivers of hypothalamic-pituitary brain tumor survivors to ask questions, share their experience, and learn from other caregivers at various stages of their journey. Over the past year, we have provided support for 54 caregivers.

Survivor Support Group

This group allows hypothalamic-pituitary brain tumor survivors to come together and share their journeys and experience with others. Over the past year, we have provided support for 32 survivors. The topics covered include treatment options, effects of treatment, memory issues, care team, specialists, medication options, and clinical trials.



Educational Webinars

- An Overview of Rhythm Pharmaceuticals Phase 3 Study in Hypothalamic Obesity
- Creating Meaningful Online Communities for Brain Tumor Survivors

Mentorship

Board Member Chris Selko mentored 14 newly diagnosed families.



Art of Surviving

This annual event held in May is an online art competition celebrating Brain Tumor Awareness Month and recognizing the creativity of the brain tumor survivor community. Many brain tumor survivors use art as a way to cope with the challenges that come with treatment, a means to calm and focus on a healing brain, and an opportunity to express their experiences.

In 2023 we had 85 entries, 463 voters and over 10,000 votes. A total of \$10,276 was raised for the



 ART OF SURVIVING

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

Handheld Blood Analyzer Program

Recipient Story: Gadiel

Gadiel is described as a loving and strong 6-year-old boy. On 3/6/2020, he endured a 10-hour surgery that almost cost him his life. In the operating room, the doctor was ready to remove a mass that was on top of the pituitary gland, but, upon attempting the surgery, it was discovered that the mass was latched on to the pituitary, making it difficult to remove. During the surgery, Gadiel started to hemorrhage and flatlined for 15 minutes. The doctors were successful in reviving Gadiel and sealing the hemorrhage but less than 24 hours after surgery, Gadiel contracted meningitis and pneumonia and endured 25 days of pain and immobility.

"Our journey took us to four code blues and many scary moments and a complete six-month hospital stay," said Gadiel's mom, Heyde.

Gadiel was diagnosed with arginine vasopressin deficiency (AVP-D, also known as diabetes insipidus), the brain's inability to manage the body's fluid balance, which can cause abnormally high or low blood sodium levels, which can result in seizures, coma or fatality. Because of the rarity of this condition, there is no home-use device to test blood sodium, making management of this condition very challenging. Often, the patient is required to get labwork in the form of venous blood draws almost daily. For children with small veins, low pain tolerance, and fear of needles, this is especially challenging.

Heyde says Gadiel is a "hard stick" when it comes to drawing blood. He has to be placed inpatient for every lab draw because it takes about two hours to collect a blood sample for testing. She said out of all the diagnoses and

challenges, blood draws are the worst for him.

Raymond A. Wood Foundation provided Gadiel with a handheld blood analyzer in December to help with management of this condition and eliminate the difficult and painful venous blood draws.

"This gives me as a parent peace of mind to know my son's exact levels of sodium. Also, since it's a finger stick, it allows my son to comply in getting this collection and avoiding going to the emergency room to get a reading when I sense a difference in my child."

– Heyde, Gadiel's mom

Lorem ips



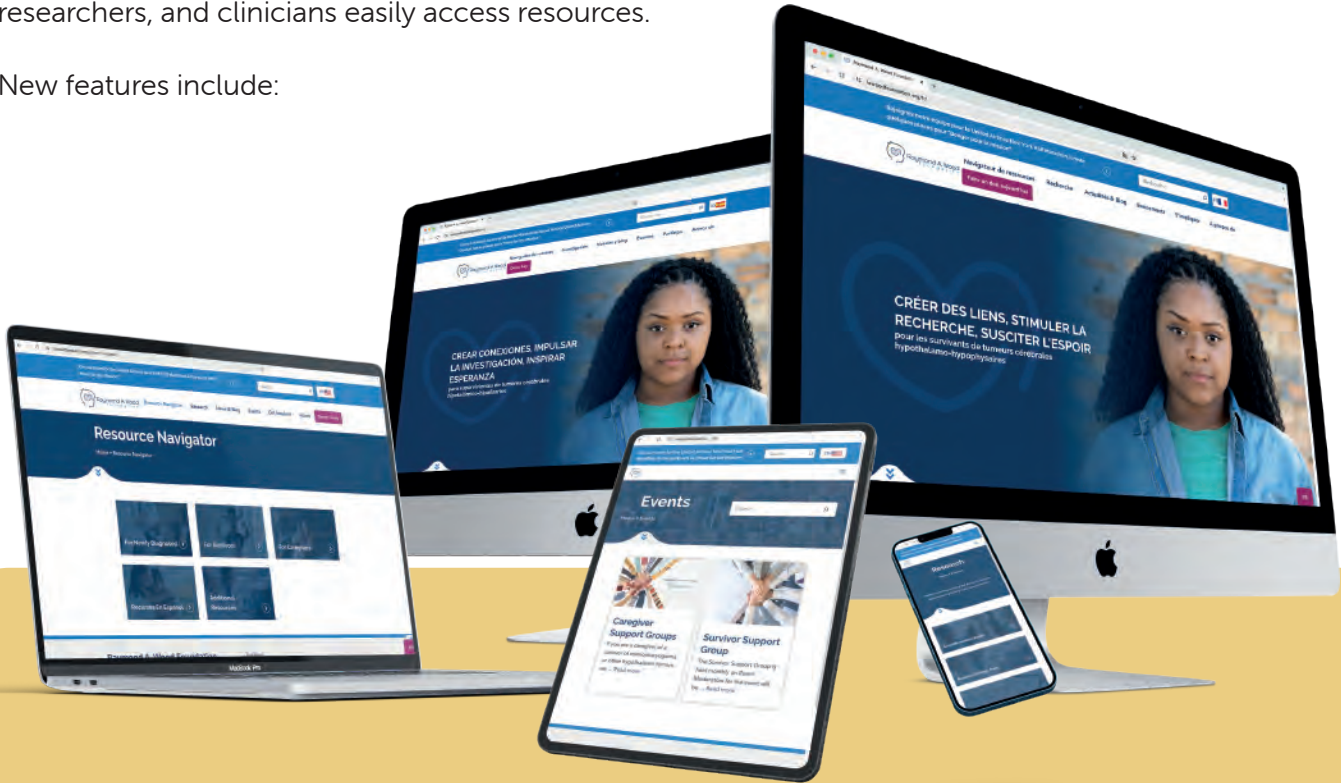
In FY 2023, Raymond A. Wood Foundation provided five handheld blood analyzers to patients with adipsic arginine vasopressin deficiency. Since RAWF's inception, we have provided 30 handheld blood analyzers to patients in need.



New Website

RAWF launched a new website to help patients, caregivers, researchers, and clinicians easily access resources.

New features include:



Community Map

Features include an interactive map so patients and families can connect.

Accessibility

In order to reach our global patient community, the website content is translated into multiple languages.

Resource Pages

Information on tumors and associated conditions, including physician finders, is now easily accessible.

Events and Blog

Visitors can easily access support groups and educational events and get the latest news from our blog.

Research Updates

Visitors can get up-to-date information on clinical trials and research activities focused on tumor treatment and the conditions that affect patients.

Enhanced Search

The new website features a site search to get visitors to the information they are looking for quickly.

www.rawoodfoundation.org

12417 Ocean Gateway, Suite B11 #108
Ocean City, MD 21842
Tax ID # 81-4548646



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