IMPACT REPORT

2025

OR Asociación

Support. Research. Connect. Transform.

A PATIENT ASSOCIATION.

A NETWORK THAT CHANGES HISTIO JOURNEYS.

When a family receives a diagnosis of histiocytosis, a rare disease, they need answers. They also need to feel supported, find professionals who understand the disease, and know that someone is working to make the future different.

WE SUPPORT

Free emotional support and community.

WE RESEARCH

We fund projects with clinical potential.

WE TRAIN

Professionals connected to knowledge.

WE MOBILIZE

Partnerships transformed into resources.

“Every collaboration helps us turn solidarity into research, emotional support, training and better care.”

Contents

A report organized by areas of impact, not simply as a chronology of news.

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President's letter



Fernando Gotz Cart

President and founder

OR Asociación was founded in 2013 to support people affected by histiocytosis. Today it is also an organization that promotes research, drives medical training, connects patients with professionals and professionals with one another, supports care projects and provides emotional support to patients and families.

Throughout 2025, we continued moving forward with one very clear conviction: to improve the lives of people living with histiocytosis and help knowledge, care and opportunities continue to grow.

Every gesture matters. Every collaboration counts. Every contribution helps us turn solidarity into research, emotional support, training and better care.

Looking ahead, we want to remain a useful bridge between patients, families and leading professionals, strengthening the pediatric-to-adult transition and making more emotional support resources available to those who need them.

All the projects we carry out as an association are possible thanks to the effort of every donor, member and collaborator who has supported us throughout our 12 years of existence. Their generosity gives us the strength to achieve our goals year after year.

I hope you enjoy reading this impact report and that it helps bring visibility to all the work we do from the heart.

With my deepest thanks,
Fernando Gotz Cart
President

OR Association

An association born from a family story and transformed into a platform for support, knowledge and international collaboration.

WHY WAS OR CREATED?

OR Asociación was founded in 2013 to support families affected by histiocytosis and help improve knowledge, promote care and advance research into these rare diseases.

OR MEANS “LIGHT”

The light we seek at the end of a difficult journey: reliable information, support, new therapies and a community that leaves no one behind.

CARE — Provide emotional support to patients, families and caregivers.

ADVANCE — Fund and promote research focused on real needs.

TRAIN — Bring professionals closer to specialized knowledge in histiocytosis.

CONNECT — Build networks that accelerate learning and expand access to resources.

THE TEAM

BOARD OF DIRECTORS

Fernando Gotz Cart
President & Patient Advocacy

Daniela Sammarruco
Treasurer & Awareness Lead

Marta Formoso Iglesias
Association Secretary

MEDICAL-SCIENTIFIC ADVISORS*

MD. Jorge Braier
Pediatric Hemato-Oncologist,
Histiocyte Society member and
external advisor to Hospital Garrahan - Argentina

MD, Msc. Guido Felizzia
Pediatric Hemato-Oncologist
Hospital Garrahan - Argentina

MD. Dimitry Esveev
Pediatric Hemato Oncologyst
Kepler University Clininc, Linz, Austria

MD. Xavier Solanich
Internal Medicine, Hospital de Bellvitge
Barcelona, Spain

MD. Vicente Santamaría López
Hemato-Oncologist, Hospital
Sant Joan de Déu Barcelona

EMOTIONAL SUPPORT

Laia Ferrer Botella
Psychologist
Psychomotor Therapist

Beatriz Canales García
Health Psychologist
Psychotherapist

Andrea Torres Danés
Psychologist
Psychotherapist

TECHNICAL TEAM

Andrés Fernando Albert
Strategy and Project Evaluation

Iván Conte
Communications, IT & Web
Charity Initiatives

CAF Gestión
Administration, Legal Advisory & Accounting

***The medical scientific advisory team are not responsable for any desition taken by the board. They are volunteers that only advise on some medical and research aspects.**

Histiocytosis: a rare disease that requires specific knowledge

Histiocytosis is a rare disease characterized by the accumulation (usually organized into granulomas) of macrophages with Langerhans cell characteristics in various tissues. It can affect children and adults and cause inflammation, organ damage, or tumors.

Its rarity and complexity make rigorous information, research, specialized medical training and specific support for patients and families essential.

LCH· Langerhans Cells Histiocytosis.
ECD · Erdheim Chester Disease.
RDD · Rosai Dorfman Disease.
HLH · Haemofagocitic LinfoHistiocytosis
PLCH · Pulmonar Langerhans Cells Histiocytosis.

These are some of the most common histiocytic disorders. For the complete list and more comprehensive definitions, you can read here.

1/200.000
CHILDREN DIAGNOSED EACH YEAR

1/600.000
ADULTS AFFECTED

LCH · ECD · RDD · HLH · PLCH
HISTIOCYTIC DISORDERS INCLUDED

2025 at a glance

Figures that show the reach of a year sustained by people, partnerships and projects.

SUPPORT

106
Total individual and family interventions

22
support-group meetings for families and adult patients

15
in-person interventions with young patients

GELAH - LATIN AMERICAN STUDY GROUP ON HISTIOCYTOSIS

4
bimonthly meetings in 2025

415
registrations accumulated

35
average participants

GRANTS AND SCIENCE

9
Grants awarded to histiocytosis specialists

3
Congress participation **grants** for professionals and researchers

3
Abstracts presented at the International Histiocytosis Congress in Seattle

FUNDRAISING

16.881 €
OR Asociación & Tibu-Ron 2025 Charity Gala

112.557 €
Raised across 9 Gala editions

Behind every figure is a person supported, a professional better connected, or a research opportunity that did not exist before.

01

WE SUPPORT

Caring also means supporting. Medical care is essential; emotional support is too.

1. EMOTIONAL SUPPORT PROGRAM

1.1 Free support for patients, families and caregivers

Since 2019, OR Asociación has offered a free psychological-support program combining individual, couple and family sessions, support groups and specific support for young people. The hybrid model (in-person and online) makes it possible to support people in different locations and collaborate with partner associations.

In 2025, a continuous and flexible care model was consolidated, delivered by Laia Ferrer, Beatriz Canales and Andrea Torras. It complements medical care and helps people manage fear, uncertainty and family dynamics.

"Taking care of yourself is not optional: it helps you care better."



106	22	15
INDIVIDUAL AND FAMILY INTERVENTIONS	SUPPORT MEETINGS FOR FAMILIES AND PATIENTS	IN-PERSON INTERVENTIONS WITH YOUNG PEOPLE

Support that takes different forms

The program responds to different needs, from diagnosis through long-term follow-up. Our therapists Laia Ferrer Botella, Beatriz Canales Garcia and Andrea Torres Danes provide **continuous in-person and online support** to people affected by histiocytosis around the world. This project was partly funded by the Hard Rock Heals Foundation and Hard Rock Cafe Barcelona, which contributed funds in 2025.



Individual and family support

Free personalized therapy for pediatric and adult patients, mothers, fathers and couples, adapted to each stage of the process. Delivered by professionals employed by OR Asociación.

106 interventions in 2025



Support groups for mothers and fathers and groups for adult patients.

Online spaces for listening, support and exchange, with participants from Spain, Latin America and Spanish-speaking communities in other parts of the world. Also open to families referred by international partner associations.

22 support meetings



In-person support for young people

Specific in person support for adolescents and young adults affected by histiocytosis, provided by a specialized professional.

15 in-person interventions

Contact us If you are a patient or relative and need any kind of emotional support, contact us and we will provide information: info@orasociacion.org

Patients and families in international forums



Patient & Family Summit in Seattle, USA

OR Asociación, his president, Fernando Gotz **was invited by** Histiocytosis Association **to participate and present** to families, patients and local physicians **in the United States** the projects developed in Spain and Latin America, as well as our international alliances. It was a very emotional meeting where we met American families and patients who shared their concerns and needs. We were able to connect with them, offer emotional support and invite them to take part in our online support groups.

PLAY



Hospital de Bellvitge - Meeting for Erdheim-Chester patients and emotional support for adults

Laia Ferrer Botella, psychologist at OR Asociación, shared the work of our **emotional support program for adults with histiocytic disorders** during a meeting organized by the Erdheim-Chester Global Alliance at Hospital de Bellvitge **in Barcelona**. It was an international gathering with patients and professionals from around the world. The meeting was coordinated by **MD. Xavier Solanich**, a histiocytosis specialist at Hospital de Bellvitge.

PLAY

Supporting caregivers, also as a community

OR Asociación brings emotional support into mental-health spaces, associations and the wider community.



International Caregivers Day

We marked International Caregivers Day in **Castelldefels** together with local organizations and professionals from different associations. **Beatriz Canales**, one of our therapists, explained the work OR Asociación carries out with mothers and fathers of patients affected by histiocytosis. OR Asociación´s president, **Fernando Gotz** served as master of ceremonies and moderated the round table. Treasurer **Daniela Sammarruco** and secretary **Marta Formoso Iglesias** also attended. Participating organizations included Uszheimer, Associacio de Salut Mental del Baix Llobregat, Cordbaix and ASAF, among others.

Taula de Salut Mental

Mental Health Roundtable

OR Asociación has been part of the "Taula de Salut Mental" (Mental health round table) for two years, organized and led by **Castelldefels City Council**. There we share the knowledge we have gained and raise awareness of the emotional impact of caregiving and rare diseases.

Ajuntament de Castelldefels



Radio and community

Participation in a radio interview on Radio Madrid, 'OR Asociación, connecting patients, clinicians and histiocytosis research.'

We spoke about real lives: patients, mothers and fathers who find an organized embrace in OR Asociación, about emotional support groups and the importance of a community that understands what you are saying and living through.

We also discussed our international work to bring different patient organizations together.

PLAY

02

RESEARCH TO MOVE FORWARD

Research transforms uncertainty into new opportunities.

2.1 THIRD RESEARCH AGREEMENT IN ARGENTINA: INDOMETHACIN AND HISTIOCYTOSIS

A drug-repurposing pathway for bone involvement

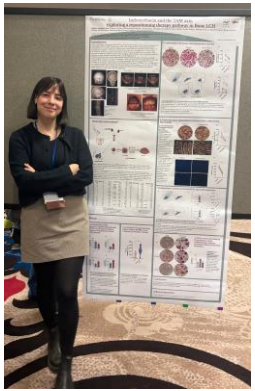
OR Asociación funds a preclinical study led by **Dr. Maria Catalina Lava** together with members of the Immunopharmacology Laboratory at the University of Buenos Aires, IMEX-CONICET and the National Academy of Medicine.

This is the third study funded by OR Asociación in Argentina, under an agreement signed with the collaboration of Fundacion Natali Dafne Flexer.

The study analyzes the **effect of indomethacin and the TAM axis on cell migration and osteoclast formation**. The research seeks a potentially safer, more accessible and less toxic alternative to chemotherapy for patients with bone involvement.

This study has received two awards in 2025. First, at the Histiocyte Society International Congress in Seattle, Washington, it was awarded **the Arceri Award for Best Scientific** Poster out of 132 papers on histiocytosis presented. Second, it received **the Best Clinical Immunology Paper Award** at the joint meeting of the Argentine Society of Immunology (SAI) and the Franco-Argentine Congress of Immunology (FAIC) in Rosario, Argentina.

This is the third study funded by OR Asociación in Argentina, thanks to an agreement in which the **Natalie Dafne Flexer Foundation** collaborates. Photos: left, Dr. Lava presenting in Seattle; right, with her team of researchers, Antonio Carrera Silva and Andrea E. Errasti, in Rosario, Argentina.





UBA
UNIVERSITY OF BUENOS AIRES

IMEX
CONICET

Seattle
SCIENTIFIC RECOGNITION

2. FOURTH RESEARCH AGREEMENT IN ARGENTINA:

Combined treatment for high-risk LCH with BRAF V600E mutation

2 Research-support agreement at J.P. Garrahan Hospital

OR Asociación and Fundacion Natali Dafne Flexer signed a fourth strategic agreement, once again supporting a study at Hospital Garrahan in Buenos Aires.

The clinical research project, led by **MD.,Msc Guido Felizzia together with MD. Paula Schaiquevich and Maria Laura Galluzzo**, studies a salvage protocol, **combining targeted therapy (BRAF pathway inhibitors) and chemotherapy. BRAF V600E** is the most common mutation in LCH. It is linked to more severe disease and may help guide targeted treatment.
The aim of this study is to improve survival, correlate response and toxicity with plasma vemurafenib levels, and reduce prolonged dependence on targeted medication.

Dr. Guido Felizzia, who leads the study, is a clinical reference in Argentina for histiocytosis treatment and regional lead for the Rare Histiocytosis Registry across South America. He is a member of the Histiocyte Society Education Committee.

This is the second study we are funding at this public hospital, which receives and treats peadiatric patients from across Argentina and Latin America.



4.º	BRAF V600E	J.P Garrahan
AGREEMENT IN ARGENTINA	HIGH-RISK POPULATION	LEADING RESEARCH CENTER IN ARGENTINA

Research, care and collaboration

Hospital Sant Joan de Déu Barcelona

2025 Associació Col·laboradora

SJD Sant Joan de Déu Barcelona · Hospital

We have maintained a continuous collaboration with this Hospital for 13 years. Its scientific work - a reference in research and care for patients with histiocytosis and childhood cancer - is complemented by care projects and hospital networks that improve patient follow-up.



PLAY

SEGUIM - Support project for cancer patients

We donate to and collaborate with the SEGUIM unit program at Hospital Sant Joan de Déu. The project provides comprehensive follow-up for childhood-cancer survivors. For the second consecutive year, we invested funds in this care project led by Mari Carmen Molero and neuropsychologist Cristina Boix Lluc (in the photo above).

€4,850

donated to the SEGUIM project in 2025



PCCB Pediatric Cancer Center Barcelona

We take part in the annual meeting of associations that support PCCB Barcelona research and care projects. As donors to different research and care initiatives, we are always motivated to listen and learn about progress. **OR Asociación is a recognized collaborating association of this Hospital**.

€125,000

donated by OR Asociación over 10 years to different projects at Hospital Sant Joan de Déu



PLAY

"Hot Chocolate" Charity campaign

OR Asociación is a founding member and ambassador of "Chocolatada Solidaria" (Charity Hot chocolate initiative) This collective movement **raised €332.765 in 2025**, funds and finances childhood-cancer research, equipment and care projects **at Hospital Sant Joan de Déu Barcelona**. This successful initiative **was created and launched in 2018** together with eight childhood-cancer associations.

€2,500,000

Raised together with Chocolatada Solidaria and donated to different projects for research across 8 editions of the Chocolatada.

03

WE TRAIN AND CONNECT SCIENCE

Knowledge grows when it is shared.

3. GELAH: LATIN AMERICAN STUDY GROUP ON HISTIOCYTOSIS

1 A group for histiocytosis professionals and specialists that has met since 2020 and operates as a 'tumor board'

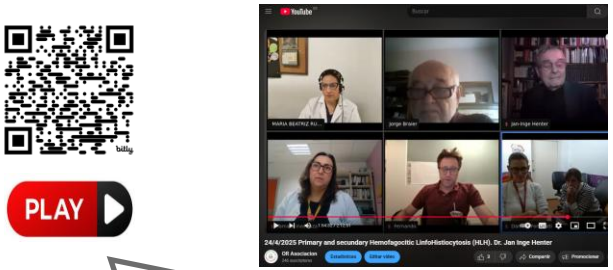
GELAH is one of the strategic projects promoted and coordinated by OR Asociación. This group brings together 400 professionals from Latin America, Spain and countries around the world **to discuss complex clinical cases, share studies, review protocols and debate therapeutic approaches in histiocytosis**.

In 2025, the group held its 19th, 20th, 21st, 22nd and 23rd meetings, strengthening a medical-scientific network that enables collective learning and improves care in regions with unequal access to specialized knowledge.

Internationally renowned physicians delivered scientific presentations, including Dr. Jan-Inge Henter, Swedish hemato-oncologist; Dr. Milen Minkov, director of the LCH-IV protocol; and Dr. Xavier Solanich, who shared the current experience of adult histiocytosis patients in Spain.
All sessions are recorded and shared on OR Asociación's channel.

The work of this collaborative group was presented as a poster at the Histiocyte Society International Congress in Seattle in October 2025, generating strong interest in the medical community because of the volume of cases reviewed collectively.

Regular participants include doctor Jorge Braier, Guido Felizzia, Diego Rosso, Blanca Diez, Maria Laura Galluzzo, Maria Catalina Lava, Magdalena Schelotto, Marcela Cordova, Romulo Reano Novoa, Vicente Santamaria Lopez, Itziar Astigarraga, Dmitry Esveev, Alejandra Cedola, Daniela Fortunatti, among many other specialists.



12	415	35	25
COMPLEX CLINICAL CASES DISCUSSED	TOTAL REGISTRATIONS IN 2025	AVERAGE PARTICIPANTS	RECORDED AND SUBTITLED SESSIONS

GELAH 2025: five meetings, a network in motion

Each session connects clinical knowledge, pathology, protocols and international collaboration.
Recorded and available sessions create a resource of high scientific and medical value for the community.

19th meeting · February 2025

Dr. Margarita Larralde and Dr. María Marta Buján
Cutaneous histiocytosis and uncommon presentations.

Clinical cases presented for discussion:
- **Adult non-Langerhans histiocytosis**
- **Juvenile xanthogranuloma and cutaneous involvement in LCH**
- **Bone-marrow failure associated with JXG**
- **Langerhans cell sarcoma**

PLAY

20th meeting · April 2025

Dr. Jan-Inge Henter
Primary and secondary HLH in pediatrics.

Clinical cases presented for discussion:
- **Complex HLH**
- **HLH + lymphoma**
- **Multisystem RDD with renal involvement**

PLAY

21st meeting · July 2025

Dr. María Laura Galluzzo Mutti
Pathology as a diagnostic and therapeutic tool in histiocytosis.

Clinical cases presented for discussion:
- **ALK+ LCH**
- **Erdheim-Chester disease**
- **Mixed histiocytosis.**

PLAY

22nd meeting · September 2025

Dr. Xavier Solanich
"Histiocytosis in Spain: lights and shadows," focused on adult patients, chronic disease and recurrences.

Clinical cases presented for discussion:
- **Follow-up of a case of sclerosing cholangitis associated with LCH.**

PLAY

23rd meeting · November 2025

Dr. Milen Minkov
LCH-IV protocol: final steps, preliminary results and protocol impact.

Clinical cases presented for discussion:
- **Histiocytosis with skin involvement and hepatic complications.**

3.2 GRANT PROGRAM

9 grants awarded for continuing education and international scientific participation

Throughout 2025, **OR Asociación awarded nine grants** to strengthen the training and integration of professionals into the international histiocytosis scientific community.
Six grants provided Histiocyte Society membership, the international society of histiocytosis specialists.Three additional grants supported travel and participation in the Histiocyte Society international congress in Seattle.

The physicians awarded grants by OR Asociación are specialists who treat with Histyiocytosis around the world:

Dr. Xavier Solanich and **Dr. Gemma Rocamora** from **Hospital de Bellvitge in Barcelona, Spain** (Internal Medicine, adult patients).
Dr. Guido Felizzia and Dr. **Daniela Fortunati (**Pediatric Hemato-Oncology), and **Maria Marta Bujan** (Dermatology) from **Hospital J.P. Garrahan** in Argentina.
Dr. Blanca Diez (Neuro-Oncology) from **FLENI** in Argentina.

This program was created four years ago to help more physicians and researchers access leading forums, connect with specialists from other countries and bring that knowledge back to their patients and teams.













9	6	3
GRANTS AWARDED	HISTIOCYTE SOCIETY MEMBERSHIPS	SEATTLE TRAVEL GRANTS

Participation and travel grants for the Histiocyte Society International Congress in Seattle







Professionals awarded grants

Dr. Guido Felizzia from Hospital Garrahan in Argentina, Dr. Maria Catalina Lava from the Immunopharmacology Laboratory at the University of Buenos Aires in Argentina, and researcher from the Dmitry Rogachev National Medical Research Center Daria Osipova of Pediatric Hematology, Oncology and Immunology all received **grants to participate in the 2025 Histiocyte Society Annual Meeting in Seattle, United States.**

The three grantees presented scientific work and studies during the congress, **and Dr. Maria Catalina Lava received the award for best scientific poster** for her basic research on indomethacin.



Sponsor of the 41st Histiocyte Society Congress

OR Association consolidated its support for the congress for the third consecutive year, further strengthening its relationship with the Histiocyte Society.

As a result of the grants awarded to support physicians and researchers, **OR Asociación was designated an official sponsor** of the 41st Annual Meeting of the Histiocyte Society in Seattle, Washington.

3. THREE ABSTRACTS PRESENTED IN SEATTLE

3 “Show me data” Turning association experience into shared knowledge

OR Asociación promoted the publication **of three abstracts, accepted for poster presentation at the 41st Annual Congress of the Histiocyte Society** in Seattle, Washington.

The papers summarized projects developed over several years: the emotional-support program, international collaboration among patient organizations and the work of the GELAH group. All three papers are published on the scientific reference platform **ResearchGate**.

- Emotional support program for Histiocytosis: A scalable, online, and person-centered model (2019-2025).
- GlobalHistio: The International Patient Advocacy Group coalition for collaboration in Histiocytosis.
- GELAH: A collaborative Latin American model for advancing research, education and patient care in Histiocytosis.

Presenting these experiences at the leading scientific forum on histiocytosis strengthens the association's role as a knowledge-transfer agent and a source of high-quality data - not only as an organization supporting patients.


OR Asociación Emotional Support Program: A Scalable Model for Psychosocial Care in Histiocytosis

Authors

Institutional Affiliations

Abstract

GlobalHistio: The International Patient Advocacy Group coalition for collaboration in Histiocytosis.

Authors

Institutional Affiliations

Abstract

GELAH: A collaborative Latin American model for advancing research, education and patient care in Histiocytosis.

Abstract Authors

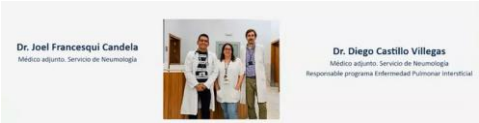
Institutional Affiliations

Abstract

3	Seattle	OR
ABSTRACTS PRESENTED	INTERNATIONAL SCIENTIFIC FORUM ON HISTIOCYTOSIS	FIRST AUTHOR / INITIATOR

Webinars, congresses and scientific updates

Activities designed to expand professional knowledge and bring specialized information closer to patients.



Pulmonary histiocytosis in adults

Dr. Diego Castillo Villegas **and Dr. Joel Francesqui**, recognized pulmonologists from Hospital Sant Pau **in Barcelona**, shared their experience in managing **PLCH (Pulmonary Langerhans Histiocytosis)**, explaining current diagnosis and treatment.

The session was aimed at affected adults, their families and treating physicians, helping them better understand the effects and impact of the disease on patients' daily lives.

This activity was organized by OR Asociación together with the Histiocytosis Association as a joint effort to bring knowledge to the histiocytosis community.

Review the talk **here**.

PLAY



Gaurav Goyal

Dr. Goyal webinar on Rosai-Dorfman disease

Dr. Gaurav Goyal of the University of Alabama at Birmingham is a leading specialist in **adult histiocytosis** (LCH, ECD, RDD & malignant histiocytoses).

In this talk, Dr. Goyal shares the actual protocols and diagnostic tests done for adult patients. This renown and charismatic doctor has published numerous scientific articles and has investyed the last years treating adult patients in the United States, while also advising and supporting physicians in Spain.

This international talk, translated into multiple languages, was organized in collaboration with the Erdheim-Chester Disease Global Alliance (ECDGA), Histiocytosis Association and Histiocytosis Association of Canada.

Review the talk **here.**

PLAY



European CAR-T Congress

OR Asociación participated in the CART25 Congress to explore personalized therapies and possible future avenues for histiocytosis.

For the second consecutive year, we participated in the CAR-T congress focused on personalized therapies for patients with cancer and ALL leukemia. Some histiocytoses share markers such as CD1a that may become treatment targets.

OR Asociación attends this congress with the goal of identifying new therapies, including gene therapies and gene editing for patients with histiocytosis. Although CAR therapies have not yet been tested in histiocytosis patients, they could represent a future option. We seek synergies with researchers and treating physicians from other cancer fields who may bring new ways of approaching the disease.

Medical participation and specialized training

OR promotes spaces to update diagnostic criteria, staging and treatments.



SEHOP - Spanish Society of Pediatric Hematology and Oncology

Presentation and recognition of GELAH's work before the Spanish Society of Pediatric Hematology and Oncology.

Dr. Itziar Astigarraga, from the Pediatric Oncology Unit at **Hospital Universitario de Cruces**, is a national and international reference in Spain for histiocytosis. At the SEHOP meeting, OR Asociación's work as coordinator of GELAH — the Latin American Study Group on Histiocytosis — was highlighted and presented.

Dr. Astigarraga is consulted by numerous medical colleagues across Spain regarding protocols for pediatric histiocytosis patients. She is also very active in **GELAH,** the **European Histiocytosis group (ECHO)**, and is an active member of the **Histiocyte Society**. She has participated in and coordinated numerous scientific publications and international multicenter studies involving histiocytosis patients.

View Dr. Astigarraga's mention of OR Asociación **here**.

PLAY



Histiocytosis meeting in Rosario

Histiocytosis Update Meeting (LCH & HLH) in Rosario, Argentina (hybrid activity).

From OR Association, we promoted, coordinated and outreached to **bring together professionals and the scientific community in Argentina** and Latin America interested in histiocytosis.

In November, healthcare professionals from Argentina met at **Hospital de Niños Víctor J. Vilela in Rosario, Argentina**, to update diagnostic criteria, staging and treatments in LCH and HLH. The event was a joint initiative with the GELAH group and the **Argentine Histiocytosis Association**. It was coordinated by **Dr. Marcelo Coirini and Miguel Galicchio**. Speakers included Dr. **Noelia Gonzalez** (Hospital Italiano de Rosario), **Dr. Miguel Galicchio** and **Dr. Daniel Solis** (Hospital Vilela), **Dr. Guido Felizzia** (LCH) and **Dr. Daniela Fortunatti** (HLH) from Hospital Garrahan.

Review the full meeting **here.**

PLAY



Histiocytosis meeting in Buenos Aires

Participation in medical-scientific forums to learn, connect and stay up to date.

In July 2025, at the invitation of **Dr. María Catalina Lava from the Immunopharmacology Laboratory at the University of Buenos Aires,** a medical-scientific meeting of the Argentine histiocytosis group was held. The meeting served to present ongoing research and brought together representatives from hospitals treating adult histiocytosis patients in Argentina. **Participants included Dr. Diego Rosso, Dr. Guido Felizzia, Dr. Blanca Díez, Dr. Jorge Braier and researchers from the Immunopharmacology Laboratory at the University of Buenos Aires.**

OR Asociación participated virtually, maintaining close relationships with the scientific and medical community and sharing experience in patient care.

04

WE GIVE VOICE AND BUILD ALLIANCES

Uniting, connecting and weaving together to go further.

4.1 ECHO - European Consortium for Histiocytosis

The patient voice before European histiocytosis experts

At its annual meeting in Florence, ECHO — the European Consortium for Histiocytosis, the medical scientific joint group of Europeans doctors and reserchers, brought together European histiocytosis experts **with the participation of patient organizations**. OR Association played an essential role in preparing and coordinating the participation of patient associations, **presenting unmet needs and proposing areas of collaboration with the medical-scientific group.**

The participation aimed to open a genuine dialogue around shared priorities, adapted content and forms of collaboration that can advance research, clinical care and person-centered support.

At this hybrid session in Florence, we were joined by **European patient organizations**: AILE spl (Italy), AIRI (Italy), Histiocytoze Hilfe (Germany), Histiocytosis Hellas (Greece), Histio UK (United Kingdom), LHF Espoir (France) and Association Histiocytose France (France).

Fernando Gotz, president of **OR Association, presented on behalf of all the organizations that make up Global Histio**, including the Histiocytosis Association (USA), ECGA (USA), Liam Lighthouse (USA), HLH Heroes (USA), Histiocytosis Association of Canada, Asociación Argentina de Histiocitosis and Família Histiocitose in Brazil.



ECHO	OR	Patient Advocacy
EUROPEAN EXPERTS	PAG COORDINATION (PATIENT ADVOCACY GROUP)	STRUCTURED PATIENT VOICE

4.2 "CHIPS" AND "GLOBAL HISTIO"

A strong and coordinated international network

CHIPS is an "International Coalition for Histiocytosis Patient Support", proposes an **international alliance of patient organizations** working with a more coordinated and effective voice in histiocytosis. Its focus is to join efforts to improve access to diagnosis, treatment, information and resources.

OR Asociación signed this global collaboration agreement together with the **Histiocytosis Association (USA), Histiocytosis Association of Canada** and **Erdheim-Chester Disease Global Alliance** (USA), promoting shared projects in advocacy, education, awareness and research.

In parallel, throughout 2025 and over the past three years, we have developed a broader international collaboration group, **Global Histio**, where we **share awareness and patient-advocacy projects** with the following patient organizations: **AILE spl** (Italy), **AIRI** (Italy), **Histiocytoze Hilfe** (Germany), **Histiocytosis Hellas** (Greece), **Histio UK** (United Kingdom), **LHF Espoir** (France), **Association Histiocytose France** (France), **Liam Lighthouse** (USA), **HLH Heroes** (USA), **Asociación Argentina de Histiocitosis** and **Família Histiocitose** in Brazil.

"Working together and supporting one another in our efforts is the only way to face a rare disease such as histiocytosis".



CHIPS members meeting during the Histiocyte Society Meeting in Seattle (Oct. 2025)

Global	Advocacy	Resources
COLLABORATION	PATIENT VOICE	SHARED ACCESS

Networks that expand OR Asociación's reach

International collaboration makes it possible to share resources, priorities and knowledge across regions.



Share4Rare

Share4Rare is a European project whose goal is to improve the quality of life of people living with rare diseases and their families.

Share4Rare is a patient-centered platform designed to carry out research initiatives that matter to patients.

OR Asociación joined this global community to connect with other patients affected by histiocytosis, raise awareness of our organization among other associations and stay up to date with research in rare diseases.

Read more about this project **here.**

Orphanet

Orphanet is a unique resource that brings together and improves knowledge about rare diseases in order to improve diagnosis, care and treatment for patients with rare diseases.

Orphanet aims to provide high-quality information about rare diseases and ensure equitable access to knowledge for all stakeholders.

OR Asociación joined this network because the scientific community is a key reference for patient registries, clinical trials and identifying patient organizations and specialists for each rare disease.

Read more about this project **here.**



Challenges in Childhood and Adolescent Cancer

We were invited to participate in the "Challenges in Childhood and Adolescent Cancer" meeting organized by **Fundacion Nuestros Hijos** in Vitacura, Santiago, Chile.

During our virtual presentation, we had the opportunity to present the work OR Asociación carries out nationally and internationally in collaboration with other patient organizations, as well as the care projects we develop to improve the quality of life of patients and families.

The event was held within the framework of the PINDA program, Chile's national initiative focused on care and access to treatment for children and adolescents with cancer.

05

WE RAISE AWARENESS AND EDUCATE

Educating for empathy also means building the future.

5. AWARENESS PROJECT IN EDUCATIONAL CENTERS

1 Inclusion, rare diseases and active citizenship

OR Asociación has been giving pedagogic talks in schools and secondary schools for years. Explaining on the reality of rare diseases from a close, educational perspective based on real experiences.

The books 'Eyal, a Little Hero', published by our association and 'Super H in the Land of the Great Owl', published by histiocytosis patient´s Super H, help bring students closer to a family's journey after a complex diagnosis, fostering empathy, inclusion and social commitment.

These activities offer to us the possibility to give back to the community and enrich the jorney of the students that encounter in this Project a way to know more about what´s happening With kids with special needs.







5	ESO	Libros
YEARS WITH LES VINYES	COMMUNITY SERVICE	EDUCATIONAL RESOURCE

Educational centers that turn empathy into action





Institut Les Vinyes

For five years, we have collaborated with **Institut Les Vinyes in Cubelles**, delivering talks on inclusion and rare diseases to 3rd-year ESO students.

The initiative began with **Cris's mother, Deysi** (in the photo up rigth), based on the experience of a student with histiocytosis and the need for the school community — tutors, teachers and classmates — to better understand his reality and the challenges associated with a rare disease such as histiocytosis.

Today, this activity is part of the **school's Community Service Project**. In addition, every Sant Jordi, students organize a charity stand to raise awareness within the educational community and raise funds in support of OR Asociación's work.





CEIP Maricel - Cubelles

For the second consecutive year, OR Asociación visited **CEIP Mar i Cel in Cubelles** to bring students closer to the reality of people affected by histiocytosis and, above all, to talk about real inclusion in the classroom.

During the activity, students learned about the work OR Asociación carries out with patients, families and reference centers such as Hospital Sant Joan de Déu Barcelona.

As part of the initiative, students took part in reading workshops, painting workshops or solidarity keyring-making activities that were later offered at a stand organized by the school itself. This action actively involved students and teachers, combining learning, creativity, awareness and social commitment.

Social awareness and community

Education also happens outside the classroom: in the media, at events and in spaces for civic participation.



PLAY

Educational talk at secondary school - Alicante

We were invited to give a talk to students at **IES Cabo de la Huerta in Alicante**, whose students take part in an Erasmus program focused on active citizenship, sport and solidarity.

During the session, we shared OR Asociación's experience as a patient organization and explained how a locally based organization can transform its environment, drive social change and generate a positive impact on the lives of patients and their families as well as on the scientific community. We carried out a practical exercise in which students proposed fundraising activities for different patient organizations.

The activity brought students closer to the reality of rare diseases and showed the value of civic participation, networking and solidarity.

Review the talk **here.**



PLAY

Radio interview

Participation in a radio interview **on Radio Libertad in Madrid** to raise awareness of OR Asociación's work in emotional support for patients and families, professional training through grants and educational awareness in schools and secondary schools.

In the interview hosted by Antonio Armas, we spoke about real lives: patients, mothers and fathers who find an organized embrace in OR Asociación. We spoke about support groups, free therapy and the Histio community. We also had the opportunity to talk about the grants we award and how we fund our association.

We also discussed the work we carry out internationally to bring different patient organizations together.

Listen to the interview **here.**

06

WE MOBILIZE RESOURCES

When a community gets involved, impact grows.

6.1 IX OR ASOCIACIÓN & TIBU-RON GROUP CHARITY GALA

The main fundraising activity of 2025

The ninth edition of the Charity Gala together with Tibu-Ron Group once again brought together patients, families, professionals, companies and donors around a common cause: sustaining support, research and specialized training in histiocytosis.

The partnership with **Tibu-Ron Group** is an example of sustained collaboration, trust and community mobilization in service of a shared mission.

This event has become the flagship of our fundraising, allowing us to finance most of our activity throughout the year.

We are very happy to continue counting on the support and solidarity of everyone who joins us year after year and fills the **Beach Club Tibu-Ron in Castelldefels.**

PLAY









€16,881	9	€112,557
RAISED IN 2025	EDITIONS	RAISED ACROSS 9 EDITIONS

One gala, many forms of impact





Donor community

The Gala is much more than a fundraising event: it is a meeting point for families, professionals, members, companies and collaborators united by the same cause.

Since OR Asociación proposed organizing **this Gala dinner with Grupo Tibu-Ron in 2015**, the Gala has grown remarkably, becoming one of the association's main solidarity events.

This growth has been possible thanks to all the people, businesses, brands and collaborating organizations that contribute products, services and support, both for the dinner itself and for the solidarity raffle enjoyed by attendees.

Together, we continue to show that unity is our greatest strength against childhood cancer.





Allocation of funds

With this edition**, we reached a cumulative total of 112,557 euros raised** since the beginning of this solidarity initiative. This collective achievement translates into more resources for research, grants, greater emotional support for patients and families and, above all, more hope for all the Histiowarriors supported by OR Asociación.

In 2025, the funds raised through the Cahrity Gala represented approximately 50% of OR Asociación's total income, demonstrating the importance of this event for the sustainability of our programs.

During the Gala, we also had the opportunity to hear from some of the professionals and people directly linked to the projects funded. Physicians, researchers, psychologists, patients and family members shared their experiences and explained how OR Asociación's programs help improve care, support and quality of life for affected people.

Solidarity actions that multiply the mission

Community activities, campaigns and socially responsible companies that help sustain OR projects.



Hard Rock Heals Foundation grant

A contribution that drives our mission.

In 2025, Hard Rock Heals Foundation awarded OR Asociación a **$5,000 grant**, strengthening a collaboration that allows us to continue developing emotional support, awareness, training and initiatives aimed at improving the lives of people affected by histiocytosis and their families. This support shows how a sustained partnership over time can become real impact.

This is the second grant we have received from the Hard Rock Heals Foundation through its international grants program. This year, we allocated those funds to organizing our emotional-support activities for patients and families.





Hard Rock Cafe Barcelona contribution

More than a decade growing together.

Since 2015, Hard Rock Cafe Barcelona has supported OR Asociación in numerous solidarity and awareness initiatives. Concerts, Solidarity Roses campaigns, markets, auctions and its participation in our Benefit Gala have turned this collaboration into a relationship based on trust and commitment.

In 2025, the Cafe staff organized a Christmas Solidarity Market and raised **€1,500** to support our projects.

Companies, organizations and community

Contributions that show human alliances are also a form of impact.



Baker Tilly and Maria Ferrer Munoz

The collaboration with Baker Tilly and the solidarity initiative led by Maria Ferrer Munoz, mother of a patient with histiocytosis, raised **€2,860** through coaching and mentoring activities offered through her company to different organizations.

This contribution was allocated to strengthening our support programs for patients and families, and represents another example of how collaboration with committed companies and professionals can become concrete resources for our community.



ATID

In January 2025, **Comunidad Atid, Barcelona's Masorti Jewish community**, which develops initiatives in community life, education, culture and solidarity, proposed supporting OR Asociación within its community-aid programs.

The donation, presented by its president Silvia Lleida, was allocated to our awareness and emotional-education programs on histiocytosis.

We are deeply grateful to the whole community, and especially to Silvia, Dominique and Paula, for thinking of OR Asociación, trusting our work and helping us continue offering this support free of charge.



Migranodearena

OR Asociación was a finalist in the migranodearena Awards, in the **"Most Active NGO"** category, thanks to the candidacy of the Benefit Gala organized together with Tibu-Ron Group and our track record in promoting solidarity challenges and campaigns.

During 2025, we raised €21,639.09 through migranodearena.org, including donations linked to our events, membership fees and contributions from companies. This was key support to continue funding our projects for support, research and assistance to patients and families.

Sport, community and solidarity

Mobilization also takes shape through tournaments, clubs and local initiatives.



PLAY

Sports tournaments - Volleyball

The Catalan Volleyball Federation invited OR Asociación to participate in the Territorial Teams Tournament held in November at the CV Gava facilities.

This collaboration stems from OR Asociación's long-standing relationship with CV Gava, an organization that has involved us in different solidarity and awareness activities throughout the year.

In addition to offering us a space to give visibility to our social project, the Federation made a generous donation during the tournament. **The check of €1.0000 was presented by its president, Maribel Zamora,** who attended the OR Asociación Charity Gala together with CV Gava president Jaume Sierra Grau.

This collaboration shows how sport can also become a tool for solidarity, awareness and support for people affected by histiocytosis**.**

Watch the check-presentation video **here.**



Club Volei Gava

A sustained relationship with sport and community

For years, **CV Gava** has maintained a close collaboration with OR Asociación, opening its doors to us and involving us in different activities organized throughout the season.

This relationship allows us to bring our social project closer to the club community, raise awareness about histiocytosis and raise funds through initiatives such as solidarity fairs during the season-closing event and the Christmas dinner.

In 2024, we also jointly held the first Solidarity Volleyball Tournament, an initiative we hope to repeat soon.

Our thanks to the club's entire Board of Directors, its president Jaume Serra Grau, and especially to the mothers and fathers who get involved in every activity with enormous generosity and always keep OR Asociación and our Histiowarriors in mind.





Members and donors

OR Asociación's social base provides stability and continuity, making it possible to sustain free projects and services for patients and families over time.

Our members, through their monthly and annual fees, allow us to turn ideas into real projects and maintain initiatives that accompany, inform and support people affected by histiocytosis.

They are joined by **our donors**, whose one-off contributions, especially during events and solidarity campaigns, strengthen our ability to keep growing and expanding the resources we place at the service of Histiowarriors and their families.

To all of them, our deepest gratitude. Their trust and generosity make it possible for OR Asociación to continue offering activities, programs and support free of charge to those who need them most.

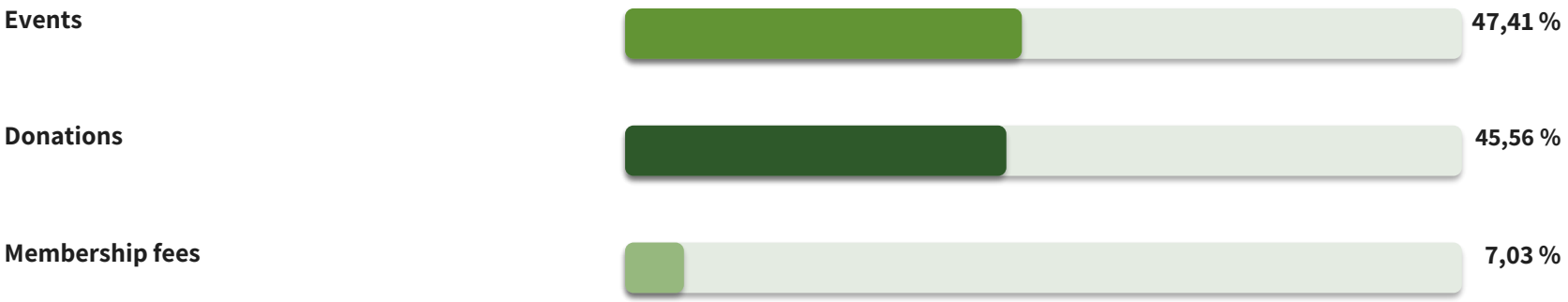
07

FINANCIAL TRANSPARENCY

Clear accounts: source, allocation and social mission.

Source of income

How resources were generated during 2025.

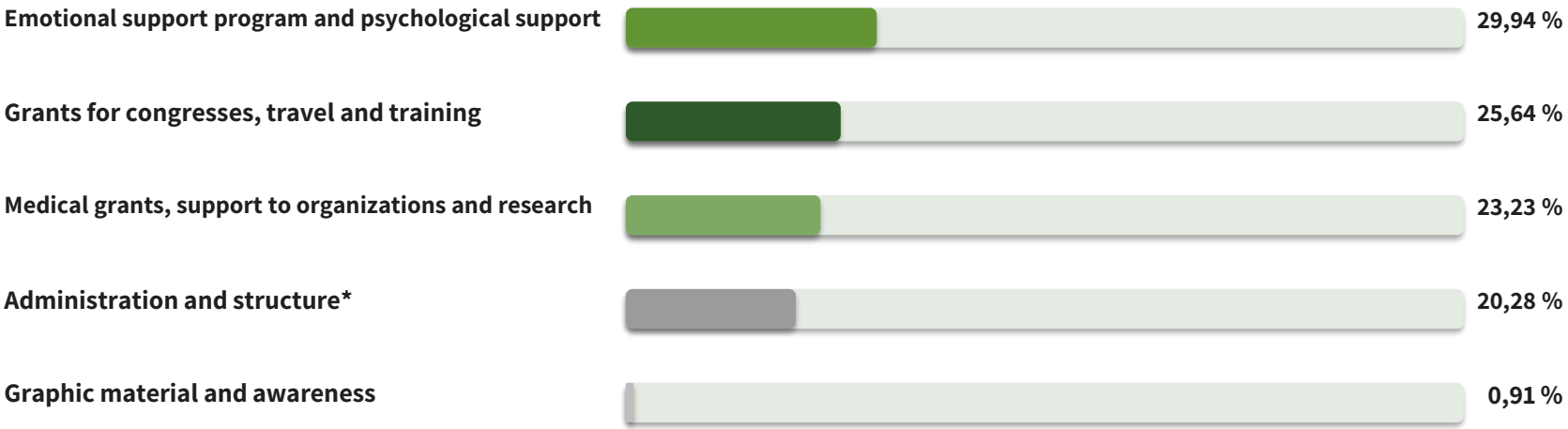


92.97% of income comes from events and donations.

This figure reflects the importance of the community, partnerships and solidarity fundraising in sustaining the programs.

Allocation of resources

How donated money was invested.



Social mission and programs: 79.72% · Administration and structure*: 20.28%
*The members of the board directors do not get compensated for their roles, they are volunteers of the association.

4 out of every 5 euros

go directly to programs and social mission

Emotional support · medical training · research · awareness · international collaboration

08

PARTNERS

A shared effort that makes every activity possible.

Hospitals, science and associations

Editable space to add logos of partner organizations.

Hospitals and research centers

Scientific societies and patient associations

International organizations for patients with histiocytosis

Companies, community and territory

Contributions of funds, products, time, knowledge and effort that made the 2025 activity possible.

Companies and foundations

TIBU-RON GROUP

Hard Rock CAFE BARCELONA

HARD ROCK HEALS

Projectes Instal·lacions Catalunya

Educational centers and sports organizations

Institut Les Vinyes

CEIP mar i cel

Club Voleibol Gavà

FCVB federació catalana de voleibol

Associations and organizations of Chocolatada Solidaria

CHOCOLATADA SOLIDARIA
Para impulsar la investigación del cáncer infantil
A beneficio de SJD

candela

Anita

Shurikan

AENAR miradas mágicas

DONA'M ALES

MUA solidaris

Nits de la LLUNA PLENA

2025 Charity Gala - OR Asociación and Tibu-Ron Group

Sponsors are the amazing collaborators who provided prizes for the Charity raffle and the **suppliers** provided products and services that made the Gala 2025 an unforgettable nigth.

Sponsors



Suppliers



To everyone,
for everything,
THANK YOU

To patients, families, members, donors, professionals, researchers, psychologists, volunteers, hospitals, educational centers, clubs, companies and allied associations.

If you want to continue supporting the work of OR ASSOCIATION...

Donate here!

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