ACTIVITY REPORT 2023

ASOCIACIÓN DE AYUDA
A LA HISTIOCITIOSIS

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STRENGTH & WILLPOWER

Dear readers of the OR Association report, **welcome:**

In 2023, we hit our 10 year anniversary, the and we are extremely happy because our projects continue to grow, and we keep connecting with “Histiowarriors” from all over the world. We are always clear that our focus must continue to be on improving the emotional well-being of the patient and thereby improving the quality of life of the patient and their closest environment.

OR Association was founded in 2013, focusing on supporting research on Langerhans Cell Histiocytosis (LCH), a rare type of cancer classified as a rare disease. Every year, one in 200,000 children and one in 600,000 adults will be diagnosed with this disease. The origin of Histiocytosis is still unknown, which is why it is considered an orphan disease. Although it is known how to treat it, there is still no definitive cure. For this reason, we created OR, to promote research on Langerhans Cell Histiocytosis. We have been funding a research grant at the Sant Joan de Déu Hospital in Barcelona for ten years, and we have added two more research projects: two basic research grants with two institutions in Argentina, in collaboration with the Garrahan Hospital, the Reference Center for all of Latin America in the care of pediatric cancer patients, and another grant to study biomarkers in adult patients. This last project is carried out by Dr. Erica Rojas at the Roffo Oncological Institute, a national reference for cancer patients in Buenos Aires.

Perhaps what we are most proud of is the positive impact that the emotional support project for patients and affected families is having. Since the end of 2019, we have been attending to hundreds of people. We carry out these support activities in person and virtually, where “Histiowarriors” from all over the world join and connect with patient support groups, as well as groups created for the parents of patients. This is truly priceless: the emotional return, the feeling of being accompanied and accompanying those who suffer the most from the diagnosis. We are increasingly closer to our mission, which makes us super proud.

In 2023, we have continued to connect internationally with more patient associations through CHIPS (International Coalition to Support Patients with Histiocytosis). We created this group along with associations from other countries. We also contacted and collaborated with more hospitals in Spain and around the world.

We are working together for better care in the present and better results in the future. We must evolve and constantly adjust treatments. We hope and work to play a relevant role in the lives of patients, connecting them to specialists, generating links, providing interesting material, and giving voice and visibility to their situation.

We will continue tirelessly supporting the Histiowarriors, wherever they need us, happy because our activity is growing, and we are very excited to continue.

Thank you very much.

Fernando Gotz Cart President OR Asociación

MISSION, VISION, AND VALUES

Vision

To achieve the definitive cure for Histiocytosis.

Mission

To accompany and improve the quality of life of patients diagnosed with Langerhans Cell Histiocytosis and their families.

To finance scientific research and prioritize medical studies to find the best therapies for patients affected by this type of childhood cancer. To provide emotional support to those affected.

To educate and raise awareness about the disease, sensitizing society to the challenges we face, increasing our social base, and gaining financial support to consolidate our work lines.

Values

Independence

Commitment

Transparency

Passion and Solidarity

Focus on Scientific Research

Comprehensive Help to Patients and Families

Honesty

Networking

LANGERHANS CELL HISTIOCYTOSIS, WHAT IS IT?

Langerhans Cell Histiocytosis (LCH) is a very rare type of cancer that primarily affects children; 1 in every 200,000 children are diagnosed each year with this disease, although it can also manifest in adults.

Histiocytosis is a congenital cellular disorder that is completely random, characterized by an abnormal and intense activation of a type of cells called histiocytes. These cells are part of the immune system and are distributed throughout many parts of the body, especially in the bone marrow, blood, skin, liver, lungs, lymph glands, and spleen. They are responsible for facilitating the destruction of foreign bodies and fighting infections.

It cannot be approached like adult cancer, and as such, studies conducted on adults, who are affected at a rate of 1 in every 600,000, are not useful in treating children. Developmental cancer is rare, with its own dynamics, thus requiring specific research to arrive at an effective treatment.

It is difficult to detect, as it is a rare disease, and specific medical training is required for early detection. It is also necessary to promote research to seek effective treatments that achieve a cure and avoid permanent sequelae.

There are multiple variants of histiocytosis disorders:

Langerhans Cell Histiocytosis (LCH)

Pulmonary Histiocytosis (PLCH)

Hemophagocytic Lymphohistiocytosis (HLH)

Rosai-Dorfman Disease (RDD)

Erdheim-Chester Disease (ECD)

Juvenile Xanthogranuloma (JXG)

ACTIVITIES EVOLUTION

2012

We started raising funds for the Hospital Sant Joan de Déu in Barcelona

2024
Asociación Colaboradora
SJD Sant Joan de Déu
Barcelona · Hospital

2013

Founded OR Association

2014

Launched a research project on LCH at the Hospital SJD for pediatric patients affected by Histiocytosis.

This grant was co-financed with the associations *La lluita d'Arnau* *SuperH* *Todos contra la Histiocitosis*

2016

Organized the first patient meeting at the Spanish level to create bonds and learn about the status of ongoing research projects. **Reorganized the meetings in 2017 and 2018**

2018

The research work on the monitoring of MAPK mutations, funded at the Hospital Sant Joan de Déu, was presented

and selected as a **finalist poster at the International Histiocytosis Congress in Lisbon**

2019

Funded a second research project at the *Garrahan Hospital* in Argentina. This study focused on immunotherapies for pediatric patients

Hospital de Pediatría
Garrahan

2020

Launched the assistance plan for patients and families of patients

Organized an international scientific talk for 400 participants

2021

Organized the International Histiocytic Days, attended by world experts, patients, and patient associations

2022

3rd Grant: to finance the attendance of two Latin American experts at the International Histiocytosis Congress

Participated in the International Histiocytosis Congress, where we met to work with Histiocytosis patient associations from around the world

2023

Emotional support project for patients and parents.

Scientific research project

SCHOLARSHIP PROGRAM for continuous professional training

Collaboration with the Hospital de Bellvitge (Barcelona)

Collaboration with the Hospital Vall d'Hebron (Barcelona)

CHIPS: Coalition of International Associations for the defense and support of patients with Histiocytosis (Barcelona)

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THE TEAM

BOARD OF DIRECTORS

Fernando Gotz Cart
President & Patient advocacy

Daniela Sammarruco
Treasurer and head of awareness

Marta Formoso Iglesias
Association Secretary

EMOTIONAL SUPPORT

Laia Ferrer Botella
Psychologist,
Psychomotor Therapist

Beatriz Canales Gacía
Health Psychologist,
Psychotherapist

MEDICAL-SCIENTIFIC ADVISORS

Dra. Veronica Celis Passini
Pediatric Hemato-Oncologist,
Hospital Sant Joan de Déu de Barcelona

Dr. Dmitry Evseev
Pediatric Hemato-Oncologist,
Independent Contractor

TECHNICAL TEAM

Andrés Fernando Albert
Strategy and project evaluation

Iván Conte
Communication, IT & Web

Susana Moreno Cordero
Solidarity initiatives,
Event organization

Ainhoa Fernández Aguin
Merchandising

MENU START

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◀ MENU START

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PROJECT ACHIEVEMENTS AND ACTIVITIES 2023

1 **Emotional support projects for patients and parents of patients affected by Histiocytosis** ▶

2 **Scientific research projects funded by OR Association in 2023** ▶

3 **Support for scientific research and training and collaboration among professionals and experts in Histiocytosis** ▶

4 **Scholarship program for continuous training of professionals specialized in Histiocytosis** ▶

5 **Collaboration on adult patients affected by Histiocytosis at Bellvitge Hospital** ▶

6 **Collaboration with the Hospital Vall d'Hebron in Barcelona: Care for Histiocytosis patients and monitoring of the BRAFV600E mutation** ▶

7 **CHIPS: Coalition of International Associations for the defense and support of Histiocytosis patients** ▶

8 **Awareness project in schools and institutes** ▶

9 **Network activity with cancer associations** ▶

EMOTIONAL SUPPORT PROJECT, SUMMARY IN NUMBERS ▶

RESEARCH PROJECTS, SUMMARY IN NUMBERS ▶

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1 EMOTIONAL SUPPORT PROJECT

For patients and parents of patients affected by Histiocytosis

This project involves providing emotional support to patients and caring for their immediate environment. To achieve this, we have two therapists on our team, Laia Ferrer and Beatriz Canales, who have been working with our association and supporting patients and families since late 2019.

All these services are FREE for users as OR Association raises funds through donations and membership fees to finance this work. We have also received contributions from companies that helped cover these costs.

SERVICES WE OFFER TO PATIENTS AND PARENTS OF PATIENTS

1.1 **Emotional support groups for adult patients** ▶

1.2 **Emotional support group for parents of children affected by Histiocytosis** ▶

1.3 **Consultations for parents about parenting** ▶

1.4 **Consultations on psychomotricity** ▶

1.5 **Couples therapy** ▶

1.6 **Individual therapy** ▶

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1.1

EMOTIONAL SUPPORT GROUPS FOR ADULT PATIENTS

The emotional support group is composed of adult patients affected by Histiocytosis. The aim is for **patients to get to know each other, build connections, and share lived experiences**.

This group meets every two months and has been consolidating since 2020. All group activities are conducted ONLINE and are moderated by our therapists.

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1.2

GROUP FOR PARENTS WITH CHILDREN AFFECTED BY HISTIOCYTOSIS

This group consists of parents from around the world who meet to share experiences, emotions, and the treatments their children undergo. **Bonds are created, and much information is shared**. Initially, this group met in person, but due to the pandemic, we discovered that we could meet ONLINE, allowing families from Latin America to join.

Families from Spain, Argentina, Guatemala, and Haiti have participated.

1.3 CONSULTATIONS FOR PARENTS ABOUT PARENTING

We provide support to parents with young children **who often have concerns about their and their children’s emotional well-being**. In private consultations with therapist Laia Ferrer, topics such as fear, living with uncertainty about relapses, and how to avoid overprotecting a child with a long-term illness are addressed.

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1.4

CONSULTATIONS ON PSYCHOMOTRICITY

One of the most common concerns among parents of children affected by Histiocytosis is how the disease will impact their child and what side effects it may cause. Laia Ferrer, a psychomotrician, assists in treating any symptoms and provides support to the children.

Laia typically sees patients in her Barcelona office, where much of the treatment is linked to play and mobility. However, she also successfully sees patients ONLINE.

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1.5 COUPLES THERAPY

In these sessions, **we focus on helping couples manage their relationship and how it is impacted by their child's illness**, in this case, Histiocytosis. We recognize that dealing with a rare disease can place significant strain on a relationship. Our goal is to provide support and tools to navigate this challenge together.

Therapist Beatriz Canales works with couples to explore different aspects of their relationship, identify areas of conflict, and develop communication and problem-solving strategies. Complex emotions such as fear, anxiety, sadness, and frustration are addressed, and support is provided to process these feelings healthily.

1.6 INDIVIDUAL THERAPY

Beatriz and Laia are the talented psychologists responsible for conducting individual therapies at our association. Their work focuses on **providing emotional and psychological support to those facing the challenges associated with the disease**. These therapies offer an invaluable opportunity to explore and understand the internal conflicts arising from the illness, whether emotional, cognitive, or relational.

Bea and Laia are committed to helping patients develop effective strategies for managing stress, anxiety, and other challenges. Their compassionate, patient-centered approach ensures a safe and trusting environment where individuals can feel heard and understood while working towards emotional and mental well-being. With their dedication and expertise, Bea and Laia are fundamental pillars in the path to recovery and personal growth for our patients.

EMOTIONAL SUPPORT

SUMMARY OF 2023 IN NUMBERS

240

INTERVENTIONS/
PARTICIPANTS

16

SUPPORT GROUP
MEETINGS

25

PARENTING AND
PSYCHOMOTRICITY
CONSULTATIONS

20

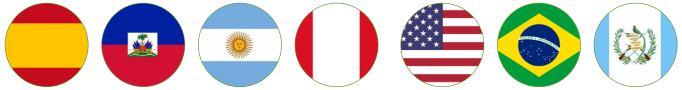
COUPLES
THERAPY
SESSIONS

90%

ONLINE
ATTENTION

7

COUNTRIES SERVED



2 SCIENTIFIC RESEARCH PROJECTS

funded by OR Association during 2023

2.1 **Research grant** for the follow-up of patients with neurodegenerative involvement at *Hospital Sant Joan de Déu*, Barcelona ▶

2.2 **Scientific research grant** for the project "Pathology of Systemic Histiocytic Disorders. Evaluation of Biomarkers, Prognostic and Predictive Factors," at *Instituto Oncológico Roffo*, Buenos Aires ▶

2.3 **Research grant on Histiocytosis** "OR Association SEED PROJECT" *Dr. Dmitry Esveev* ▶

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2.1 RESEARCH GRANT for the follow-up of patients with neurodegenerative involvement

This grant is the first research project we have funded, and we have been doing so for ten consecutive years.

The research is led by *Dr. Vicente Santamaría López*, supported by *Dr. Jaume Mora Graupera*, scientific director of Oncology and Hematology at *Sant Joan de Déu* in Barcelona.

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2.1

RESEARCH GRANT for the follow-up of patients with neurodegenerative involvement

Thanks to the support of OR Asociación in the initial phase of the research project, it has been possible to better understand the disease and implement a new, less aggressive, and less toxic treatment. The project is currently advancing to determine the best way to identify patients at higher risk of developing the neurodegenerative version of histiocytosis and to prevent it.

The ongoing study focuses on monitoring patients with neurodegenerative involvement, tracking lesions, and trying to avoid any sequelae left by the disease in affected patients.

- This grant has made Hospital **Sant Joan de Déu a national and European reference** for treating Histiocytosis patients.
- **OR Asociación is an official collaborating association of Hospital Sant Joan de Déu in Barcelona.**

2023
Asociación
Colaboradora

SJD Sant Joan de Déu
Barcelona · Hospital

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2.2 RESEARCH GRANT FOR THE PROJECT “Pathology of systemic histiocytic disorders, evaluation of biomarkers, prognostic and predictive factors”

Instituto Oncológico Roffo, Buenos Aires

The research focuses on detecting new biomarkers that could be targets for possible new treatments.

This research is part of the doctoral studies of Erica Roja Bilbao, director of Pathology at Instituto Oncológico Angel H. Roffo, University of Buenos Aires. This research group has been involved and generating knowledge about the morphology of Histiocytosis for many years.

The study is conducted in collaboration with *Dr. Diego Rosso*, an expert in Histiocytosis, who refers patients to Instituto Roffo and provides patient samples from the Oncohematology services of the Pediatric Oncology Service at *Hospital de Clínicas José de San Martin-UBA*. The study population (N) comprises adult patients and occasionally pediatric patients.

Our association thoroughly studies projects requiring funding, which are previously reviewed by expert researchers we collaborate with. Thanks to these evaluations, we receive information and can assess the feasibility and impact these studies may have. For the implementation of this collaboration agreement with *Instituto Roffo*, we have had the support of Fundación Natalí Dafne Flexer, an Argentine organization with 25 years of experience in the world of pediatric cancer, whose mission is to improve the quality of life of children and young people with cancer. It is through such synergies that we can materialize this type of international collaboration.

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2.3 RESEARCH GRANT ON HISTIOCYTOSIS

“Or Asociación Seed Project

Purpose of this grant: The goal is to create a scientific research project unique to OR Asociación. This study will be conducted in collaboration with treating physicians, renowned national and international researchers, and reference hospitals in Histiocytosis. The project will be scalable, replicable in various countries, and innovative.

Study object: Study the real probabilities of curing Histiocytosis through the long-term use of BRAF mutation inhibitors.”

Project justification: Currently, BRAF mutation inhibitors are mainly used to treat patients with multiple relapses or the most aggressive forms. This study proposes to explore methods for safely discontinuing these inhibitors. It aims to measure the extent to which patients receiving this medication are cured.

Grant recipient: Dr. Dmitry Esveev, a member of the Histiocyte Society, is a doctor and clinical researcher trained in Russia. He has conducted various studies and published numerous papers on Histiocytosis in prestigious international scientific journals.

Dr. Esveev enjoys a high reputation worldwide and is regarded by his colleagues as the doctor with the greatest potential within the scientific community of Histiocytosis. He is the author of the publication: “Vemurafenib combined with cladribine and cytarabine results in durable remission of pediatric BRAF V600E-positive LCH” - https://pubmed.ncbi.nlm.nih.gov/37216396/ Published in the journal Blood Advance in May 2023, he is referenced by all his colleagues as one of the doctors and researchers with the greatest global projection.

3

SUPPORT FOR SCIENTIFIC RESEARCH

Ongoing collaboration between professionals and experts in Histiocytosis - GELAH

GELAH GROUP: Latin American study group on Histiocytosis

The aim of this group is to unite Histiocytosis professionals from Latin America has been promoted by OR Association and has been meeting since the end of 2021.

The group is convened bimonthly and on average 50 doctors and researchers participate per session. They also attend professional meetings in Europe. At these scientific meetings Treatment protocols, complex medical cases are presented, scientific discussions about publications are carried out. Links are generated and cooperation is sought at an international level.

This group was born from the impulse of OR Asociación together with *doctors Jorge Braeir, Guido Felizzia, Diego Rosso* and with the support of *Dr. Guillermo Chantada*.

Notable milestone: we have created a joint SCIENTIFIC POSTER that was presented during the Internal Congress of the Histiocyte Society, in Athens, Greece, in October 2023.

DEVELOPING A LATIN AMERICAN STUDY GROUP OF HISTIOCYTOSIS DURING AND AFTER COVID-19-PANDEMIA

Jorge Braier[1], Guido Felizzia[1], Diego Rosso[2], Guillermo Chantada[3], Fernando Gotz[4].

[1]Hospital de Pediatría Garrahan, [2]Hospital de Clínicas San Martin. Buenos Aires, Argentina. [3]Hospital Sant Joan de Déu, Barcelona, Spain, [3]Fundación Scremini, Montevideo, Uruguay. [4]OR Asociacion, Barcelona, Spain and [5]Grupo de Estudios Latino Americano de Histiocitosis (GELA-H).

Goals

To connect Latin American study groups on Langerhans cell histiocytosis (LCH).
To debate in subjects related with all the histiocytic diseases.
To collaborate in the discussion of complex clinical patients, and to start clinical research studies.

The annual incidence of Langerhans cell histiocytosis (LCH) has been estimated to be between two and ten cases per 1 million children aged 15 years or younger. There is a population of 188,000,000 pediatrician in LATAM (UNICEF, 2022). Although there is no clear data, **the number of estimated Latinoamerican LCH patients is 940 cases per year.**

Countries with representatives in GELA-H group

- Argentina
- Uruguay
- Chile
- Colombia
- Mexico
- Panama
- Haiti
- Dominicana Rep.
- Costa Rica
- Brazil
- Guatemala
- Peru
- Bolivia
- Paraguay
- Honduras
- Venezuela
- Spain
- Ecuador

Methods

From October 2021
to May 2023

- Participants from **eighteen countries** met online by zoom every two months.
- We used the tool Customer Relationship Management System (CiviCRM,USA) to notify and register participants from all countries, including Spain.
- We shared protocols using the Resonance system (Resonance Inc., USA).
- We recorded and edited meetings for publication on the OR association YouTube Channel.

Milestones

Participants	Bimonthly meetings	Medical presentations	Complex clinical cases
334	9	14	8

Results

The mean of participants per meeting was 41, with a range of 20 to 68.

Presenters and audience included experts in the LCH field (including hemophagocytic lymphohistiocytosis) and in organ involvement (including neurology, neumonology, hepatology, dermatology and other related specialties).

- The first discussed topic was the guidelines for therapy and follow-up of LCH patients. Specifically, we presented and discussed **two proposals of LCH chemotherapy guidelines** related to vinblastine-indomethacin or cytarabine-indomethacin and **discussion was around modifying or combining those therapies.**
- Second, we debated oral and poster **presentations of Latin American studies at 2020, 2021 and 2022 Histiocyte Society meetings,** with emphasis on the studies regarding (i) the new score based in blood levels of CD1a/207 cells, (ii) international registry of rare histiocytic disorders, and (iii) Erdheim Chester disease with CNS involvement and neurodegenerative involvement in LCH.
- Third, we discussed multiple complex **patients with LCH and other histiocytic disorders of different countries in Latin America**. We performed additional unscheduled meetings due to the severity of some cases.

Conclusions

The developed network, with participation of parental and medical groups, helped to build a more efficient and participative Latin American Histiocytosis Study Group. We optimized the clinical debate of complex patients and promoted educational activities. Our group enhances the possibility of future research on these rare orphan diseases in countries with limited resources.

Watch all recorded and subtitled GELA-H talks here, SCAN NOW.

Organizers: GELA-H & OR Association www.orasociacion.org

Histiocyte Society 39th Annual Meeting, Greece, Oct. 2023

3 SUPPORT FOR SCIENTIFIC RESEARCH - GELAH

SUMMARY IN NUMBERS 2023

310

PARTICIPANTS

in all meetings between doctors and specialists in Histiocytosis

5

BIMONTHLY MEETINGS

Presentations of protocols, basic research and forum for the resolution of complex clinical cases

34

PARTICIPATING COUNTRIES

Argentina (146 specialists), Austria (1), Bolivia (16), Brazil (11), Canada (1), Chile (9), Colombia (21), Costa Rica (2), Cuba (2), Denmark (1), Ecuador (4), Egypt (1), Spain (38), United States (5), Guatemala , (21), Haiti (2), Netherlands (1), Honduras (1), India (1), Italy (1), Jordan (1), Mexico (29), Nicaragua (3) Panama (1), Paraguay (3), Peru (15), Poland (1), Dominican Republic (6), Sweden (1), Switzerland (2), Ukraine (1), Uruguay (13), Venezuela (7), Vietnam (1)

4 SCHOLARSHIP PROGRAM

for continuous collaboration of professionals specialized in Histiocytosis

Purpose of these scholarships

These scholarships consist of financing the cost of memberships to belong to the International Scientific Society “Histiocyte Society”. And we also provide scholarships for doctors and researchers so that they can attend virtually or in person the *Annual Congress organized by the Histiocyte Society.*

These scholarships created by OR Association are intended to encourage the participation and training of treating physicians and researchers. Promote international collaboration, update yourself and work alongside professionals from around the world. Connect all these professionals under the umbrella of activities that the Histiocyte Society offers to its members.

The scholarships are designed for doctors, as well as specialists and researchers in Histiocytosis. Interested in taking part and participating in the annual congress of the Histiocyte Society.

Reasons why these scholarships are awarded:

The Histiocyte Society is a professional medical association created in 1989, made up of more than 250 doctors and scientists from around the world. Members of the organization are considered leaders in the understanding and treatment of histiocytic disorders. The Society is committed to advancing knowledge about histiocytic disorders and improving patient outcomes through the planning, development, sponsorship and supervision of clinical research.

4.1 OR Association Scholarships to be part of the Histiocyte Society Medical Society ▶

4.2 OR Association scholarships to attend the Annual Congresses of the Histiocyte Society ▶

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4.1 SCHOLARSHIPS TO BE PART OF THE MEDICAL SOCIETY “HISTIOCYTE SOCIETY

Receiving doctors of these scholarships:

Phd. Gemma Rocamora Blanche

Researcher at Bellvitge Hospital Barcelona, Spain

Dr. Xavier Solanich

Internal medicine at Bellvitge Hospital Barcelona, Spain

Dra. Blanca Diez

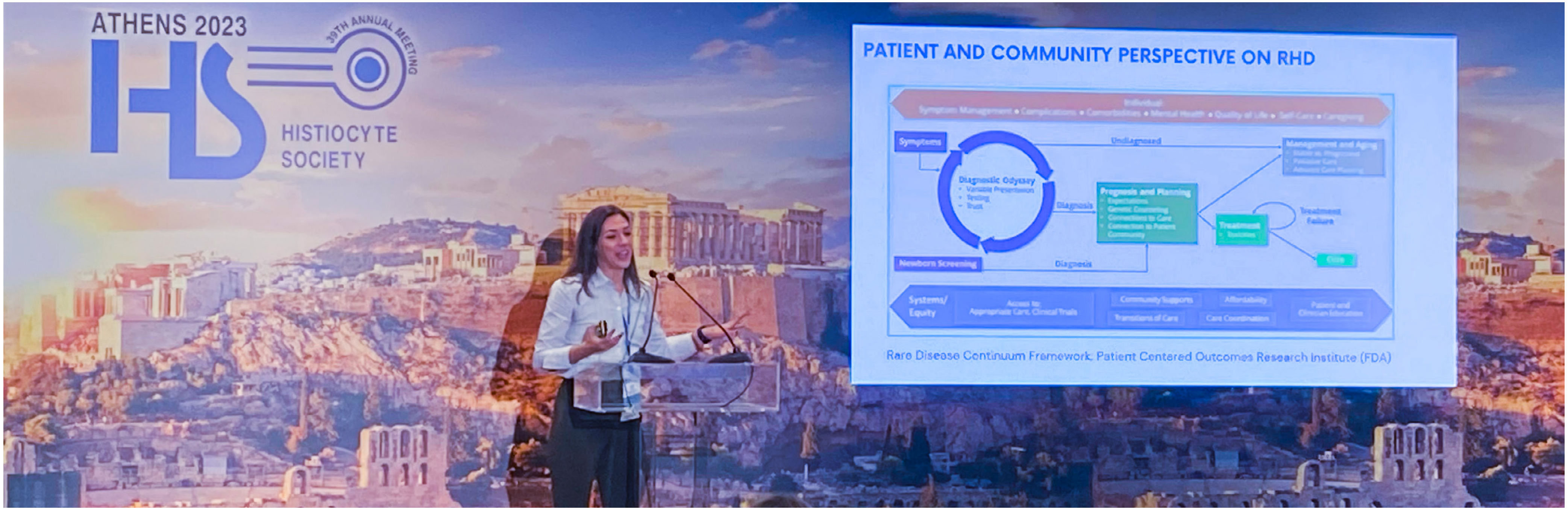
Pediatric oncologist at the Fleni Institute Buenos Aires, Argentina

Dr. Martin Hornos

Internal Medicine, Hospital de Clínicas Jose Sant Martín - Buenos Aires, Argentina

Dra. Lorena Valero Arrese

Pediatric Oncology and Hematology Physician, Vall d’Hebron University Hospital, Barcelona,



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4.2 SCHOLARSHIPS TO ATTEND CONGRESSES

We award these scholarships to physically or virtually participate in the ***Histiocyte Society Congress***, which is organized annually in a different location every year. Members of the Society from all over the world participate in this congress. Hundreds of research works on Histiocytosis are presented and debated there and it is part of the collaborations that OR Asociación is interested to promote.

The doctors receiving these scholarships have been:

Gemma Rocamora Blanche
Intern medicin at Bellvitge Hospital
Barcelona, Spain

Dr. Xavier Solanich
Internal medicine at Bellvitge Hospital
Barcelona, Spain

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COLLABORATION WITH BELLVITGE HOSPITAL

a reference center for adult patients in Barcelona

Bellvitge Hospital has been treating and assisting adult patients with Histiocytosis of all types for many years. This Hospital has extensive experience in various types of histiocytosis, including Langerhans Cell Histiocytosis, Erdheim Chester, Rosai Dorfman in Pulmonary Histiocytosis. We met Dr. Solanich and Gemma Rocamora, both are members of internal medicine who are leading **a registry of patients with Histiocytosis, a pioneer in Spain.** This registry is crucial to categorize and characterize the different types of histiocytic disorders.

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COLLABORATION WITH THE BELLVITGE HOSPITAL

At OR Association we seek to connect reference hospitals that care for adult patients with centers for pediatric patients to reach agreements. **Our idea is to help make a smooth transition of the pediatric patients to adult centers with experience in Histiocytosis.**

The surprising thing about this contact is that we learned of its existence thanks to a talk we had in Sweden, during the International ***Congress of the Histiocyte Society*** with the president of the Global Erdheim Chester, *Kathy Brewer*. She put us on the track of this Hospital to further collaborate. This is the proof that attending these conferences has definitely paid off.

We have helped these doctors from the Bellvitge Hospital get in touch with other International specialists who are part of the ***Histiocyte Society***. Also, we have financed their membership fees so that they can be part of the Histiocyte Society and we also financed their virtual participation in the annual congress of the ***Histiocyte Society***, at Athens 2023.

6

COLLABORATION WITH VALL D'HEBRON HOSPITAL (BCN, SPAIN)

This institution takes care of patients with Histiocytosis and they have in place a follow-up study of the BRAFV600e mutation as a marker for relapses.The VHIR Cancer and Childhood Hematological Diseases group **investigates to explore the use of liquid biopsy for predicting the evolution of patients with Histiocytosis**.

The project led by *Dr. Josep Roma*, principal investigator of the VHIR Childhood Cancer and Hematological Diseases group, will investigate the use of liquid biopsy (obtained from blood or cerebrospinal fluid) to improve the prediction of the evolution of the patients.

"The potential of biopsy liquid in the follow-up of histiocytosis is enormous and its clinical potential is just beginning to emerge. However, comprehensive clinical implementation will only be possible if validation studies such as those proposed in this project are completed", says Dr. Roma.

OR Asociación learned about this project thanks to the relationship we have maintained since 2019 with the Association *"La Sonrisa de Daniela"* (Daniela´s smile) , another Histio patient´s association, founded by a family from Badalona and led by Rosi, Daniela's mother, an Histiocytosis patient with bone lesions.

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COLLABORATION WITH VALL D'HEBRON HOSPITAL

We have been collaborating with the association “Daniela’s Smile” in different campaigns. They are the ones who finance this research study at VHIR. The role of OR Asociación is to finance the participation of the Pediatric Oncologist Dr. Lorena Valero in the Histiocyte Society. We disseminate this project and look for synergies with those interested in this research whose objective is: to better understand the behavior of the BRAFV600e mutation. as a marker of Histiocytic activity in patients.

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SCIENTIFIC PROJECTS

SUMMARY IN NUMBERS

€150.000

INVESTED IN 10 YEARS
FOR RESEARCH SCHOLARSHIPS
ON HISTIOCYTOSIS

€11.200

INVESTED DURING 2023 IN
5 SCHOLARSHIP - GRANTS
FOR RESEARCH ACTIVITIES

7

CHIPS:

Coalition of International Associations for the defense and support of patients with Histiocytosis

For years we have been working globally, connecting and weaving ties with the international community of associations and with international patients. This year 2023 we have had the opportunity to meet again during the International Congress we attended in Athens, Greece. There we were able to set activities and prioritize specific actions that we will work on throughout the year.

The goals we set are:

- **Promote international collaboration** and exchange of ideas.
- **Better access** to diagnostics
- Seek **more care and more treatments** equitable for all patients regardless of the limits geographical or governmental.
- **Lobby** to advocate for better treatments
- **Greater support** to the patient/family through visibility of global efforts
- **Greater knowledge** about the disease of Histio through research and collaboration.
- **Enhance the patient's voice!**
- **Promote actions and pool resources** to provide emotional support to patients and your families.

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7 CHIPS: Defense and support for International

OR Asociación is part of this coalition together with ***Histiocytosis Association of the United States***, the ***Hitiocytosis Association of Canada***, ***AILE*** in Italy, ***LHF Espoir*** of France/Switzerland, ***Histiocytosis Hellas Association*** of Greece and with the ***Erdheim Chester Global Alliance***, with which we share information and co knowledge.

We meet every two months ONLINE with the aim of sharing information and finding a way to patients in less favored regions to access the best treatments and diagnoses.

7.1 **Participation in Scientific Conferences** ▶

7.2 **Attendance and presentation scientific poster** ▶

7.3 **Organization of medical-scientific webinars** ▶

7.1 ATTENDING SCIENTIFIC CONFERENCES

Organized by the Histiocytosis Association in New York

At *Memorial Sloan Kettering Cancer Center* in New York we have had an incredible experience with American patients and relatives of patients affected by various forms of Histiocytosis. The Histiocytosis Association organized these conferences and invited us to take part. These talks were intended for family members and patients with Histiocytosis, both pediatric and adult patients, with LCH, ECD, JXG, RDD and HLH.

Sharing with more families and adult patients was an exciting experience. **We were able to confirm that, in all parts of the world, we all experience this disease in a very similar way: with a lot of uncertainty and fear, but also with a lot of hope.**

We attend medical presentations on Histiocytosis given by prestigious doctors and researchers, for both pediatric and adult patients. Among them, stood out Dr. Eli Diamond (adults), Dr. Michael Jordan (HLH) and Dr. Ira Dunkel (pediatric patients).

Additionally, we had the opportunity to participate in an intimate workshop, where we helped moderate a chat with parents about the emotional resources that we have developed and made available to patients through associations.

The transition from pediatric patients to adults and the goals that we set in common at the international level were also discussed. We greatly appreciate the trust of Deanna Fournier, CEO of the Histiocytosis Association, and all of her staff in the organization. They have opened the doors wide to OR Asociación, allowing us to moderate a workshop. With the Histiocytosis Association we share vision, mission and values, and we have been working side by side for several years, with both present and future projects.

7.2 ASSISTANCE AND SCIENTIFIC POSTER PRESENTATION

OR at the International Congress of the Histiocyte Society

We have been part of and participated in the 39th edition of the Histiocyte Society Congress, which was held in Athens, Greece, from October 22 to 24.

In Greece, more than 350 specialist doctors and researchers in the different types and fields of Histiocytosis gathered. We have participated in all the medical talks to inform ourselves about the latest studies and treatments carried out.

We are proud to announce that we present a scientific poster together with the doctors of the Latin American Group of Studies on Histiocytosis (GELA-H).

It was an honor and a pleasure to be able to participate in the Poster sessions and to be able to share with all the participants the work that we have been doing from the association together with so many doctors and researchers. Also during the congress we were able to talk with the board of directors of the Medical Society (Histiocyte Socitery BOARD), along with more patient associations about the objectives and goals that we set in common and about the collaboration that is becoming more common every day. narrow.

For several years now we have been collaborating internationally and this type of meeting helps us connect, generate synergies and advance in the cure of the disease.

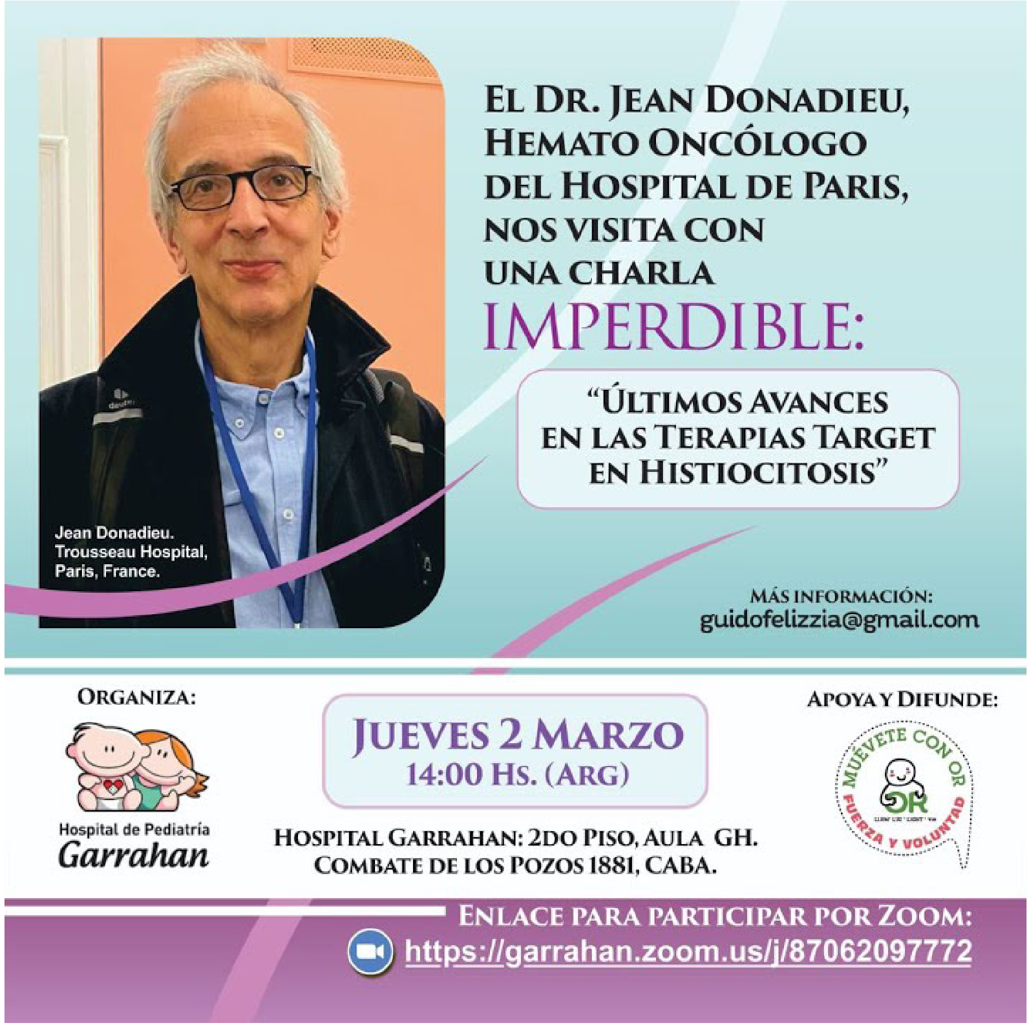
Dr. Kim Nichols, oncologist and current president of the Histiocyte Society; Mr. Paul Kontoyannis, host of the congress in 2023 and president of the Hellenic Histiocytosis Association "Histiocytosis Hellas". Along with them is Dr. Carlos Rodriguez-Galindo, expert in Histiocytosis, renowned oncologist and director of St Jude Global. Photo from the Histiocyte Society Congress Athens 2023.

CHIPS NEXT

7.3 ORGANIZATION OF MEDICAL-SCIENTIFIC WEBINARS

for professionals

In February we co-organized, together with the Garrahan Hospital of Buenos Aires, a conference by *Dr. Jean Donadieu*, French expert in Histiocytosis sis. Dr. Donadieu is conducting a very important, ` *Latest advances in target therapies*', on the impact of mutation inhibitors BRAFV600e. Taking advantage of the visit to Buenos Aires, organized this talk coordinated by *Dr. Guido Feli zzia* and *Dr. Jorge Braier*, leading oncologists in the Garrahan Hospital. This talk was organized in a hybrid way so that other international experts have been able to participate nals, from Spain *Dr. Itziar Astigarraga*, from the BIOBruces Hospital in the Basque Country and *Dr. Dimitry Esveev*, from Russia.



Jean Donadieu.
Trousseau Hospital,
Paris, France.

**EL DR. JEAN DONADIEU,
HEMATO ONCÓLOGO
DEL HOSPITAL DE PARIS,
NOS VISITA CON
UNA CHARLA
IMPERDIBLE:**

**"ÚLTIMOS AVANCES
EN LAS TERAPIAS TARGET
EN HISTIOCITOSIS"**

MÁS INFORMACIÓN:
guidofelizzia@gmail.com

ORGANIZA:
Hospital de Pediatría
Garrahan

JUEVES 2 MARZO
14:00 HS. (ARG)

HOSPITAL GARRAHAN: 2DO PISO, AULA GH.
COMBATE DE LOS POZOS 1881, CABA.

APOYA Y DIFUNDE:
MUÉVETE CON OR
FUERZA Y VOLUNTAD

ENLACE PARA PARTICIPAR POR ZOOM:
https://garrahan.zoom.us/j/87062097772

8 AWARENESS PROJECT IN SCHOOLS AND INSTITUTES

Social project “INCLUSION AND AWARENESS”

We love to transmit the social project of OR Asociación in schools and institutes. This is the third consecutive year that we carried out this activity at the Institut Les Vinyes de Cubelles, as part of the 3rd ESO subject, “Community Service”.

The relationship with the institute arose thanks to the mother of Cristian, a child with Histiocytosis, who asked us He gave a talk a few years ago to raise awareness among students and teachers about this disease and about the problems his son was facing.

Using the book “*Eyal, a little hero*” as a resource we are able to explain in an accessible way what children (and their families) with rare diseases experience when receiving a complex diagnosis. The activity has an informative part, in which we talk about the patient´s inclusion at schools. We talk about the importance

8

AWARENESS PROJECT IN SCHOOLS AND INSTITUTES

of properly treating children who live between chronic treatments and medical controls, and the need to recognize, accept and support those who are "different".

The students, with the support of the school, organize some activities to raise funds. We greatly appreciate the students who were involved in the activit. **Big thanks to the teachers and our recognition to the institute for continuing to support this solidarity initiative**. The comments, the expressions we get and the emotions that these young people transmit are intense, generous, positive and rewarding. This is, without a doubt, a beautiful and enriching educational experience.

NEXT

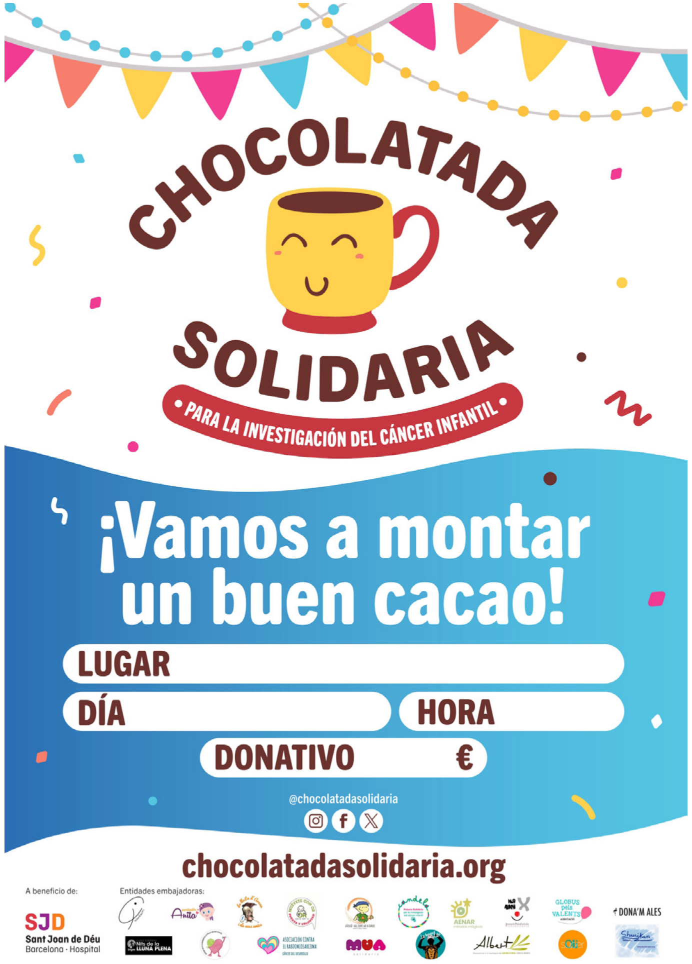
9 ACTIVITY DONE IN NETWORK TOGETHER WITH OTHER PEDIATRIC CANCER ASSOCIATIONS

Charity Hot Chocolate

In 2023 this solidarity activity designed and promoted by patient associations, among them OR Asociación completed its sixth edition and managed to raise €317,350 in the 2023 edition. directly Hospital Sant Joan de Déu in Barcelona who decide what type of lines of research they finance. Thanks to the funds raised in This edition of the “Chocolatada Solidaria” has been able to finance seven research scholarships and for the purchase of equipment for the laboratory of the Sant Joan de Déu Hospital in Barcelona. The great value of this solidarity movement is that, behind it, there is the strength and tenacity of many families who have experienced first-hand the cruelty of childhood cancer and through associations promote fundraising for the Sant Joan de Déu Hospital in Barcelona. In the total of six editions,there were more than 3,700 solidarity “hot chocolates”, €1,800,000 have been raised and more than 18 different projects have been financed.

A great demonstration that united cancer associations can organize activities of high impact on society.

We will continue!!!



PREVIOUS

NEXT

HOW WE ARE FUNDED?

HOW WE ARE FUNDED?

1 **OR ASSOCIATION**
7th Gala Charity Dinner
with TIBU-RON GROUP ▶

2 **Raising funds thanks to initiatives of patients and families** ▶

3 **Raising funds thanks to tournaments and sports clubs** ▶

4 **Tribute to a being beloved “In memoriam”** ▶

5 **OR Association Membership plan** ▶

6 **Economical data** ▶

7 **Partners and collaborators** ▶

7th CHARITY DINNER

OR ASSOCIATION & TIBU-RON GROUP

It is the seventh consecutive year that OR Asociación and Tibu-ron Group organize a charity dinner whose funds are entirely destined to our association.

This gala with a solidarity purpose reaches its seventh edition (it could not be held in 2020 and 2021 only due to the COVID pandemic). We highlight and thank the Tibu-Ron group who assume all expenses related to all, food, drinks, space, production and human resources of the event.

Like every year, the evening took place at the Solraig restaurant, in Castelldefels, and welcomed OR members and donors, as well as those affected by the disease, family members and health professionals. Everyone comes year after year to contribute to promoting research, which is currently the only way to improve current diagnoses and treatments.

7th CHARITY DINNER OR ASSOCIATION & TIBU-RON GROUP

To the amount raised with the price of the cover, is added the amount that was entered through the numerous raffles that were held throughout the night, which distributed among the attendees numerous gifts donated selflessly by various collaborating companies and businesses in Castelldefels . The traditional charity dinner, which this year broke its attendance record, with a total of 167 people, was a magical and effervescent night, in which a total of 16,157.50 euros were raised.

The directors of Tibu-Ron Group went in person to the Sant Joan de Déu Hospital in Barcelona to handle the donation to Emma Perrier, responsible for donor care at this children's health institution. Also Fernando Gotz, president of OR Associtaion. At Sant Joan de Déu PCCB Hospital.

167

DINERS

€16.157

RAISED IN 2023

€81.139

RAISED IN TOTAL

2 ACTIONS CREATED

by adult patients and families with histiocytosis

A Beautiful Story: Liam's Family in Úbeda and their Great Contribution to Our Association.

Through Liam's Histiofigther´s family, and especially his brave mother Mayly, we have received invaluable support during all this year. For some time now, they have contacted us with the desire to participate and organize events in their community to help our common cause.

With great effort and dedication, Liam's family and the local community organized a solidarity Zum-ba Masterclass in Úbeda. Thanks to this initiative, we managed to raise 1,000 euros for our association. We want to express our most sincere gratitude to the organizers of this event: La Cofradía Carmelitan of Silence Christ of the no Mayor Juan Ángel Gómez Quesada, Member of Charity Inma Arance Villar, Board of Directors of the Brotherhood of the Good Death of Úbeda, to the monitors who participated altruistically in this event, to the face painter and all those who contributed gifts .

A special thank you from OR Association to adult Histio patients: Ainoha Fernández and Susana Moreno, from Galicia and Valencia, respectively. They have been coordinating these activities and are also in charge of creating the merchandising, along with the support of Mercedes Rio Miranda. And the support of more patients who contribute in various ways. Thank you all for your commitment and generosity. Together, we continue to advance our fight against histiocytosis.

3 RAISING FUNDS

in tournaments and with sports clubs

1 VI Charity Tournament

“Let’s score a goal to fight pediatric cancer”

The VI Charity Tournament “Let’s Score a Goal to Childhood Cancer” has been carried out in the city of Sant Boi de Llobregat, organized entirely by CF Vinyets Moli Vell in favor of OR Association. Year after year for 8 years this Charity tournament is already part of the DNA of our association and combines sport with dissemination of our social project.

We want to express our deep gratitude to the club and its president, Francisco Cervera (“Paco”), as well as to David Barragan, football coordinator and its board of directors: Pepi, Moi, Leo, Miguel, Timo and Pili, for their exemplary organization, dedication and absolute delivery. Thanks to the siblings and relatives of the participating players for their enormous contribution to the cause. Thanks to their efforts, we have received numerous donations, including the creations of patients who have been making their own merchandising.

We also thank the mayor of Sant Boi de Llobregat, Lluïsa Moret, and the sports councilor, María Antonia, for their presence and collaboration through Sant Boi Esports.

A special thank you to Helios and his family, for the enormous love they always give us and for how they take care of us. We thank the volunteers who help us each year, Mari Estévez, and the Barragán brothers, including Juan and Quim Barragán Rodríguez for their tireless encouragement and help. Quim, as speaker of the event, encouraged those present to make important contributions. It is the union of everyone that truly makes the difference.

3 FUNDRAISING

2 Gavá Volleyball Club

Communication, awareness and solidarity activities of this magnificent Volleyball club

We are so proud of our relationship with the Volley Club Gava. **The club proposed that our LOGO and the social work of OR Asociación should be published on its T-shirts as "sponsors".**

Throughout the entire Spanish national volleyball league they carried out our branding logo. During the closing events ("cloenda") of the 2022/23 season, **the Gavà Volleyball Club organized a solidarity raffle in order to raise funds for OR Association.**

Both the president of the club, Jaime Sierra Grau, and the Board of Directors are fully committed, generating activities to spread our association and always inviting us to participate in their activities.

RIFA BENÈFICA AMB
OR ASOCIACIÓN
JUNTAMENT AMB LA COL·LABORACIÓ
DELS NOSTRES SPONSORS

NEXT

4

TRIBUTE TO A LOVED ONE "IN MEMORIAM"

So significant to receive the funds in memory of a deceased relative

We are proud to be recipients of the love of families who lost a loved one and want to make a donation. "In memoriam". Our dear and beloved Carlo Sammaruco passed away, and his family wanted to give us the value of the funeral flower arrangements. The family of the deceased requested friends and family who make donations in favor of our association instead of flowers. By this enormous and generous gesture we raised €1,500. **Thanks to the family and friends for thinking on us.**

5

MEMBERSHIP PLAN at OR Asociación

We offer the possibility of joining, both to patients, relatives of patients, and any person who wants to contribute funds on a regular basis.

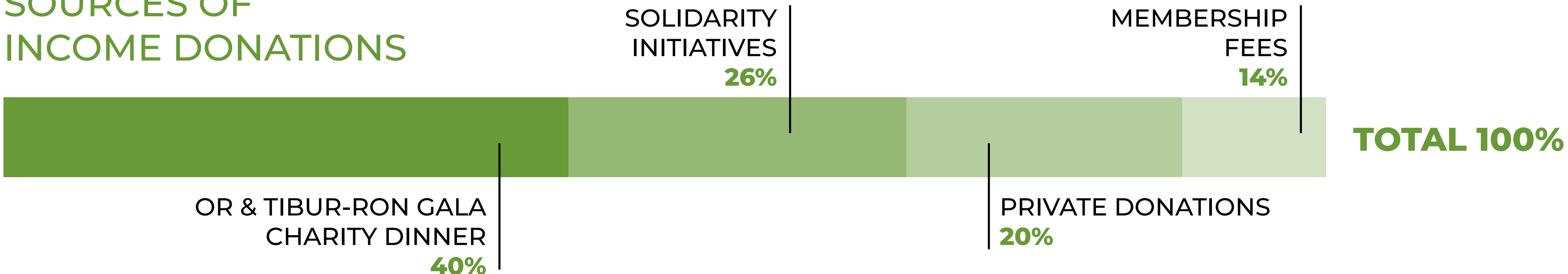
This fixed income offers us the possibility of having funds on an ongoing basis and reinforces morale and spirit to continue with all activities and the projects of our association.

6 ECONOMIC DATA

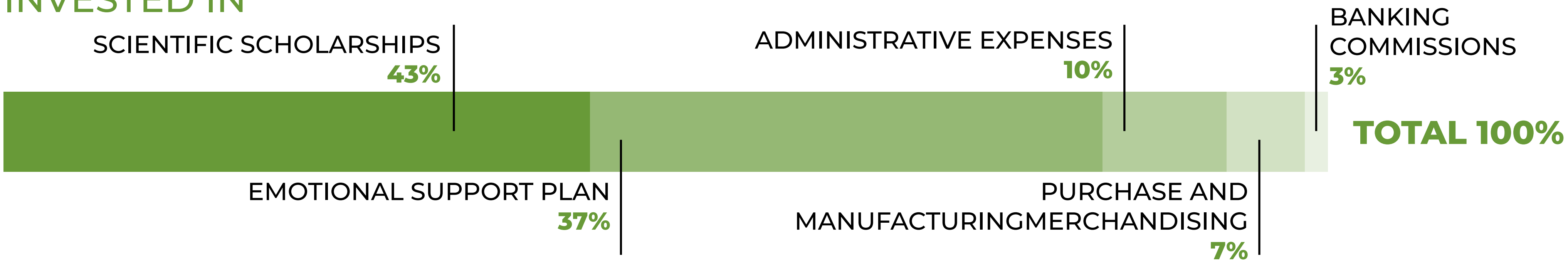
clear accounting

DESTINATION OF THE FUNDS OBTAINED

SOURCES OF INCOME DONATIONS



INVESTED IN



7 COLLABORATORS

MAIN CONTRIBUTORS

TIBURÓN GROUP

HARD ROCK CAFÉ BARCELONA

PROINCAT S.L.

CLUB VOLEI GAVÁ

CF VINYETS MOLI VELL

THE COTT CASTELLDEFELS

GALA CHARITY DINNER 2023 COLLABORATORS

DISALVI ALVAREZ CASA PEÑAFIEL SENTITS DEL BORN QUERALT SELFRIENDS GRUPO LIDER EL NOSTRE FCH CHAVES CÁRNICAS ABARROTES PERET I OLIVE ASSOLIM MAX PREMIUM MEA ANJOEVENTS SAAVEDRA

GALA CHARITY DINNER 2023 TIBU-RON SUPPLIERS

OLAFUR ANANDA BEACH HOUSE MARAE SANTA GAROTA CELLER VALLES HARD ROCK CAFÉ BARCELONA PROINCAT 9 REINAS CENTRE DENTAL MONTMAR DENTAL PUGACH BODEGAS ENATE CAROL CLUB GRANVÍA MAR RESTAURANTE MOMENTS CASA ESCALA VINALLIUM CASTELLDEFELS HOLYBOARD MARÍA PINTADO IDA NAILS CV GAVÁ LA CASA DE GIULIA CHIRINGUITO CHALITO CHIRINGUITO PLAYEROS CHIRINGUITO COCODY RESTAURANTE LLORET ALFAPARF THE COTT CASTELLDEFELS EVA BERMÚDEZ

7 COLABORATORS

HOSPITALS, ASSOCIATIONS AND FRIENDLY ENTITIES WITH THOSE WE COLLABORATE

HOSPITALS

HOSPITAL SANT JOAN DE DÉU DE BARCELONA   HOSPITAL DE BELLVITGE   HOSPITAL VALL D'HEBRON
HOSPITAL GARRAHAN (BUENOS AIRES, ARGENTINA)   ST JUDE CHILDREN'S RESEARCH HOSPITAL   MEMPHIS USA

HISTIOCYTOSIS ASSOCIATIONS AND FOUNDATIONS

HISTIOCYTE SOCIETY   HISTIOCYTOSIS ASSOCIATION (ESTADOS UNIDOS)   HISTIOCYTOSIS ASSOCIATION OF CANADA
ASOCIACIÓN ARGENTINA DE HISTIOCITOSIS   A.I.L.E ONLUS (ITALIA)   AIRI ONLUS (ITALIA)   LHF ESPOIR (FRANCIA Y SUIZA)
HISTIOCYTOSIS HELLAS ASSOCIATION (GRECIA)   ERDHEIM CHESTER DISEASE GLOBAL ALLIANCE (ESTADOS UNIDOS)
HISTIO UK (GRAN BRETAÑA)   LIAM LIGTHHOUSE FOUNDATION (ESTADOS UNIDOS)   FAMILIA HISTIOCITOSE (BRAZIL)
LA LLUITA DE ARNAU (ESPAÑA)   SUPER H (ESPAÑA)   TODOS CONTRA LA HISTIOCITOSIS (ESPAÑA)   LA SONRISA DE DANIELA (ESPAÑA)

PADIATRIC CANCER ASSOCIATIONS

FUNDACIÓN NATALÍ FLEXER (ARGENTINA)   ASOCIACIÓN PULSERAS CANDELA (ESPAÑA)   ASOCIACIÓN BENÉFICA ANITA (ESPAÑA)
ASOCIACIÓN CONTRA EL RABDOMIOSARCOMA (ESPAÑA)   MUA SOLIDARIS (ESPAÑA)   ASSOCIACIÓ ANIOL (ESPAÑA)
AENAR: MIRADAS MÁGICAS (ESPAÑA)   DONA'M ALES (ESPAÑA)   ASSOCIACIÓ SHURIKAN BLAU (ESPAÑA)
ASSOCIACIÓ GLOBUS PELS VALENTS (ESPAÑA)   NITS DE LA LLUNA PLENA (ESPAÑA)

OTHER ENTITIES

AYUNTAMIENTO DE CASTELLDEFELS   INSTITUT LES VINEYS

PREVIOUS

NEXT

7 PARTNERS

MAIN CONTRIBUTORS

TIBU-RON GROUP

Hard Rock CAFE BARCELONA

Club Voleibol Gavà

SANT BOI C.F. VINYETS MOLI-VELL

Projectes Instal·lacions Catalunya

the colt

SUPPLIERS AND PARTNERS AT 2023 GALA CHARITY DINNER WITH TIBU-RON GROUP

TIBU-RON GROUP

Hard Rock CAFE BARCELONA

vinalium

ANJOEVENTS

9R

moments restaurante & cafe

Saavedra profesionales del jamón

Projectes Instal·lacions Catalunya

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7 PARTNERS

HOSPITALS

Bellvitge Hospital Universitari

SJD Sant Joan de Déu Barcelona · Hospital

St. Jude Children's® Research Hospital

Vall d'Hebron

Hospital de Pediatría Garrahan

ASSOCIATIONS AND FOUNDATIONS WE PARTNER WITH

A.I.L.E.

AAH Asociación Argentina de Histiocitosis

ECD Erdheim-Chester Disease Global Alliance

HISTIOCYTOSIS™ ASSOCIATION A Rare Community

Histiocytosis Association of Canada

FAMÍLIA HISTIOCITOSE

La lluita d'Arnau i els seus amics

HISTIOCYTOSIS HELLAS Together we will find a cure

LHF ESPOIR

AIRI ETS AIRI Associazione Italiana per la Ricerca sulle Istiocitosi

LIAM'S LIGHTHOUSE FOUNDATION

Super h

Ma Alei X Asociación Todos Contra la Histiocitosis

HISTIO UK No-one should die of Histiocytosis

La sonrisa de Daniela

asociación Anita

FNDF Fundación Natali Dafne Flexer Ayudamos a niños y jóvenes con cáncer

Candela Polsera Solidària per la investigació del càncer infantil

ASOCIACIÓN CONTRA EL RABDOMIOSARCOMA CÁNCER DEL DESARROLLO

AENAR miradas mágicas

ASSOCIACIÓ ANIOL, SEMPRE AMB UN SOMRIURE contra el càncer infantil

DONA'M ALES

GLOBUS pels VALENTS ASSOCIACIÓ

MUA solidaris

cursa solidaria Nits de la LLUNA PLENA Sitges

Shurikan Blau www.shurikanstar.com

OTHER ENTITIES

Ajuntament de Castelldefels

Institut Les Vinyes

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NEXT ▶

10 YEARS IN IMAGES

◀ MENU START

THANK YOU ▶

Help us keep going on with all our activities, make a donation NOW!

I WANT TO DONATE

We need your help in order to continue with our work.

Thank you so much

◀ START

To everyone, for everything,

THANK YOU

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