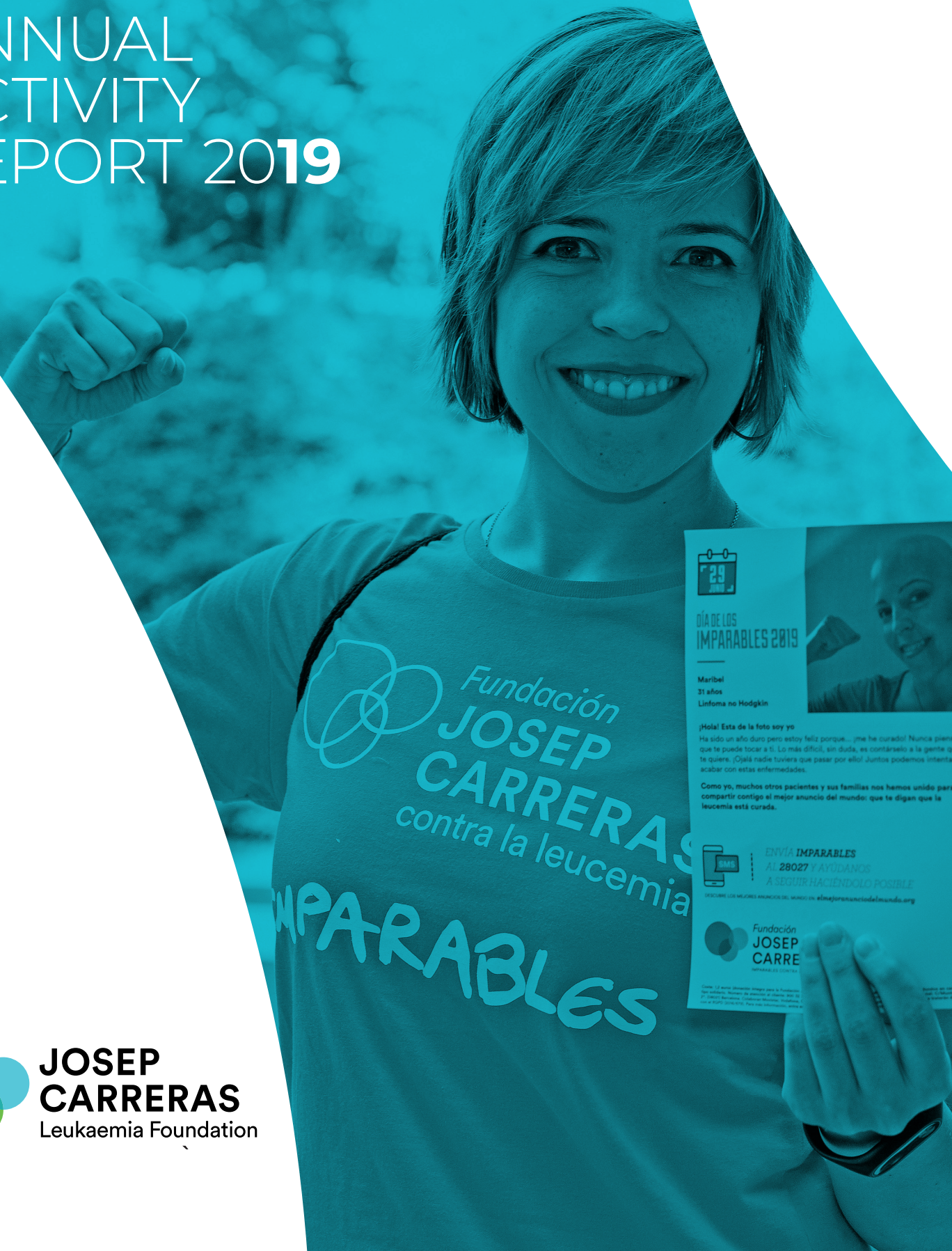


ANNUAL ACTIVITY REPORT 2019



DÍA DE LOS IMPARABLES 2019

Maribel
31 años
Linfoma no Hodgkin

¡Hola! Esta de la foto soy yo
Ha sido un año duro pero estoy feliz porque... ¡me he curado! Nunca pienso que te puede tocar a ti. Lo más difícil, sin duda, es contárselo a la gente que te quiere. ¡Ojalá nadie tuviera que pasar por ello! Juntos podemos intentar acabar con estas enfermedades.

Como yo, muchos otros pacientes y sus familias nos hemos unido para compartir contigo el mejor anuncio del mundo: que te digan que la leucemia está curada.

ENVÍA IMPARABLES AL 28027 Y AYUDANOS A SEGUIR HACIÉNDOLO POSIBLE

RECORDE LOS MEJORES ANUNCIOS DEL MUNDO EN elmejoranunciodelmundo.org

Fundación JOSEP CARRE



**JOSEP
CARRERAS**
Leukaemia Foundation

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The report can also be downloaded from:
www.fcarreras.org

Publisher:
Fundació Josep Carreras contra la Leucèmia

Design and typesetting:
aliamc@grafika.help / www.aliamccarry.com

Photography:
Photographic archives of the Josep Carreras Leukaemia Foundation

Printing:
Serafí

**OUR AIM IS
TO MAKE
LEUKAEMIA
100%
CURABLE**



Institut de Recerca
CENTRA LA LEUCÈMIA i L'EMFISSEMA
COP Carreras

Dear friends,

2019 was a very important year for us because it marked **two historic milestones**.

Firstly, the achievement, over the last 28 years, of more than **10,000 bone marrow transplants** throughout the world, thanks to an anonymous donor located by the Josep Carreras Foundation's Bone Marrow Donor Registry (REDMO).

And secondly, because we achieved a figure of **100,000 partners** whose generosity and support accompany us in our work and make it possible for us to continue to grow and broaden the scope of our projects.

The Josep Carreras Leukaemia Foundation was founded in 1988 with the aim of contributing to finding a definitive cure for this disease. The Foundation's efforts are concentrated on four basic areas: scientific research, which is carried out at the Josep Carreras Leukaemia Research Institute; administering REDMO in Spain; guidance for patients, and the reception apartments programme.

In this report you can read about the 10 new research groups that joined us in 2019 at the Josep Carreras Leukaemia Research Institute's ICO-Germans Trias i Pujol Campus in Badalona. The Institute already has two other campuses (Hospital Clínic and Sant Pau) and at the present time has more than **30 scientific research groups**.

Our REDMO programme has also continued with its laudable work. There is a 90% probability of finding a donor within two months, the average time taken **being 28 days**, and this too is an achievement that deserves special

recognition, for it demonstrates the perseverance applied to the work carried out every day.

This 2019 Activities Report also contains information about our reception apartments and patient guidance programmes. Amongst other things, the Foundation has attended to **1,567** online medical consultations, as well as **3,123** requests for information of a more general nature. Furthermore, **31** families have been accommodated in one of our reception apartments.

Finally, I would like to make a very special mention of our community of Unstoppables against leukaemia.

That is to say, all the patients and former patients who go out onto the streets to raise awareness about the disease on 'Unstoppables Day', our partners and supporters, the companies that have joined ranks with our cause, and all those who have decided to leave us a legacy or inheritance, as well as all those who have organised fundraising events to assist us.

Each and every one of these people constitute the motor that drives the Foundation along. I thank them for their support with all my heart.

Thank you for making us UNSTOPPABLE.

With my kindest regards,



Josep Carreras, president

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**ABOUT
US**

01

JOSEP CARRERAS FOUNDATION



Thousands of people around the world fall ill with leukaemia every year. The Josep Carreras Leukaemia Foundation was founded in 1988 with the aim of finding a definitive cure for this disease and of improving the lives of patients.

Having recovered from his disease, Josep Carreras created the Foundation to mark his gratitude to science and for the many kindnesses he received.

The Foundation concentrates its efforts on the following basic spheres:



**SCIENTIFIC
RESEARCH**



REDMO



**RECEPTION
APARTMENTS**



**PATIENT
GUIDANCE**

MISSION, VISION & VALUES



Mission

To work constantly to increase our social base, prioritise efforts into scientific research, and consolidate current lines of research.

Vision

To make leukaemia, one day, a disease that is 100% curable, for everyone and in every case.

Values



Independence



Rigour and transparency



Commitment



Upholding scientific research



Constant association with our founder and president, Mr. Josep Carreras



To give a friendly and personalised response to the consultations received

TRANSPARENCY AND LEGAL COMPLIANCE



Corporate governance

Our mission and vision have been defined, as well as our values, which are reinforced by closely following the *Codes of good governance and ethics*, the code of conduct and of financial investments, approved by the Board of Trustees.

We monitor compliance with our commitments through reports, controls and the monitoring of indicators to **give a clear, detailed and transparent account of the way the funds entrusted to us by our supporters are used.**

Of note in 2019:



Report on corporate governance, detailing all the activities performed: meetings of the Board of trustees, meetings of the Delegate Committee, Trustee members' meetings with the management team, institutional relations with the Generalitat de Catalunya (Government of Catalonia), the Ministry of Health, and with universities, participation in national organisations (National Transplant Organisation) and international working groups (World Marrow Association, WMDA), to mention the most prominent.



Agreement with the Government of Andorra and the Ministry of Health to promote donation in the principality and to administer the data through REDMO.



For the third year running **we have been placed in first position for transparency in the classification of the foundations of notable personages** in the report, *Building Confidence 2018*, issued by the Commitment and Transparency Foundation.

Legal compliance

The Josep Carreras Foundation **and the Bone Marrow Donor Registry (REDMO)** have the necessary manuals, processes and resources to demonstrate compliance with the laws and regulations governing our activities. Amongst them are those concerning the prevention of money laundering, the prevention of penal risk, and data protection.

The Legal Compliance officer, together with the members of the Legal Compliance Committee, the Data Protection delegate and the members of the Operations Unit, are responsible for promoting and verifying the strictest compliance with the regulations, and for making them known to all the Foundation's members and their associates.

In 2019 the following accreditations and documents remained in force and were renewed:



Framework agreement with the Ministry of Health for the administration of REDMO.



Authorisation of REDMO by the Generalitat de Catalunya as a tissue centre, in accordance with State legislation.



Data protection audit, conducted by Faura-Casas.



Annual accounts audit, conducted by the Acordia ACR firm.



Revision of the *Penal Risk Manual*.



Revision of the *Security Document*.



Revision of the *Prevention of Money Laundering Manual*.



Website accredited by the Official College of Physicians of Barcelona and by Health on the Net (HONcode).



REDMO qualification from the World Marrow Donor Association (WMDA).

Quality control systems

We follow the requirements defined in a quality control system based on ISO 9001:2015, the aim of which is to constantly improve our work and achieve an impact in the results.

In 2019:



Quality control
system audit finds no incongruities.



Revision and updating
of documentation for the quality system manuals, processes map, procedures, protocols...



Implementation
of a new administrative (A3ERP).



Implementation
of Power BI.



Updating of the Contingency Plan.



Updating of the Strategic Plan.



Updating of the *Indicator Dossier* for system processes that reflect our activities and their impact.

GOVERNING BODIES



The Board of Trustees is the administrative organ and its role is to accomplish the foundational aims, as well as ensuring that the Foundation's assets are correctly administered.

(*) Members of the Delegate Committee

Board of Trustees

President

Mr. Josep Carreras Coll*

Vice-president

Prof. Evarist Feliu*

Treasurer

Mr. Albert Carreras Coll*

Dr. Rainer Storb

Mr. Marcel Pascual*

Mr. Arcadi Calzada

Mr. Albert Carreras Pérez*

Dr. Jordi Sierra*

Dr. Álvaro Urbano*

Mr. Lluís Bassat

Mr. Joan Uriach

Mr. Joaquim Folch

-

Secretary

Mr. Calixto Mut

Permanent invitees to the Board of Trustees and Delegate Committee

Administrator

Mr. Antoni Garcia Prat

REDMO Director

Dr. Enric Carreras

Delegate Committee Minutes Secretary

Mrs. Virginia Ensesa

Legal Compliance Officer

Prof. Rafael Jiménez de Parga

Legal Compliance Committee

Prof. Evarist Feliu

Mr. Albert Carreras Coll

Mr. Antoni Garcia Prat

Dr. Enric Carreras

Secretary

Mrs. Anna Giner

Data Protection Officer

Mrs. Iris Bargalló

Prevention of Money Laundering Operational Unit

Mr. Antoni Garcia Prat

Mrs. Albertina Grau

Mrs. Anna Giner

Board of Honour Former Vice-president and co-founder

Prof. Ciril Rozman Borstnar

During the last meeting on 25 April 2019, the Board of Trustees accepted with great sorrow the resignation on health grounds of the founding trustee, **Dr. Clarence Dean Buckner**, whose loyalty and devotion since the creation of the Foundation were noted by the Trustees, as was his inestimable support for the Foundation's growth in the fields of science and health care. On 24 November 2019 the Trustee, **Mr. Ramiro Giménez Labrador** departed our company. Mr. Giménez joined the Foundation almost as soon as it was founded, and throughout these years he sat on the Foundation's Delegate Committee and made numerous contributions in both the scientific field, as chemist, as well as in the organisational field, given his extensive experience in the field of business. His loss is a great one for the institution.

OUR TEAM



Administration

Mr. Antoni Garcia Prat

Scientific director

Prof. Evarist Feliu

General secretariat

Adriana Bararu

Bone Marrow Donor Registry (REDMO)

Director

Dr. Enric Carreras

Assistant director

Dra. Juliana Villa

Institutional Coordination

Núria Marieges

Technical Coordination

Cristina Fusté

Accounts

Carolina Salillas

Raissa Dardet

Donor Dept.

Cristina Bueno

Núria Giménez

Serrat Marieges

Work Ups Dept.

Cecilia Montesinos

Mariam Pérez

Isabel Montegudo

Jordi Martínez

Patient Dept.

Ana Montesinos

Clara Rosés

Mavi Díaz

Ana Pertusa

UCB Dept.*

Montse Rebagliato

Marketing

Partners, Fundraising Events and Inheritances

Albertina Grau

Partner and Donations Administration

Anna Grau

Benefit Events

Regina Díez

Clàudia Nogués

Loyalty and Campaigns

Mireia Bel

Corporate Alliances

Sira Franquero

Quality and Legal Compliance

Anna Giner

Community Manager

Inés Martí Fabra

E-Marketing and Patient Experience

Alexandra Carpentier de Changy

Institutional Communication

Marta Fernández

Others

Attention to the Public

Maite Santiago

Computing

Mario Gran

Reception

Apartments and Partner

Administration

Esther Soto

Legal Compliance Officer

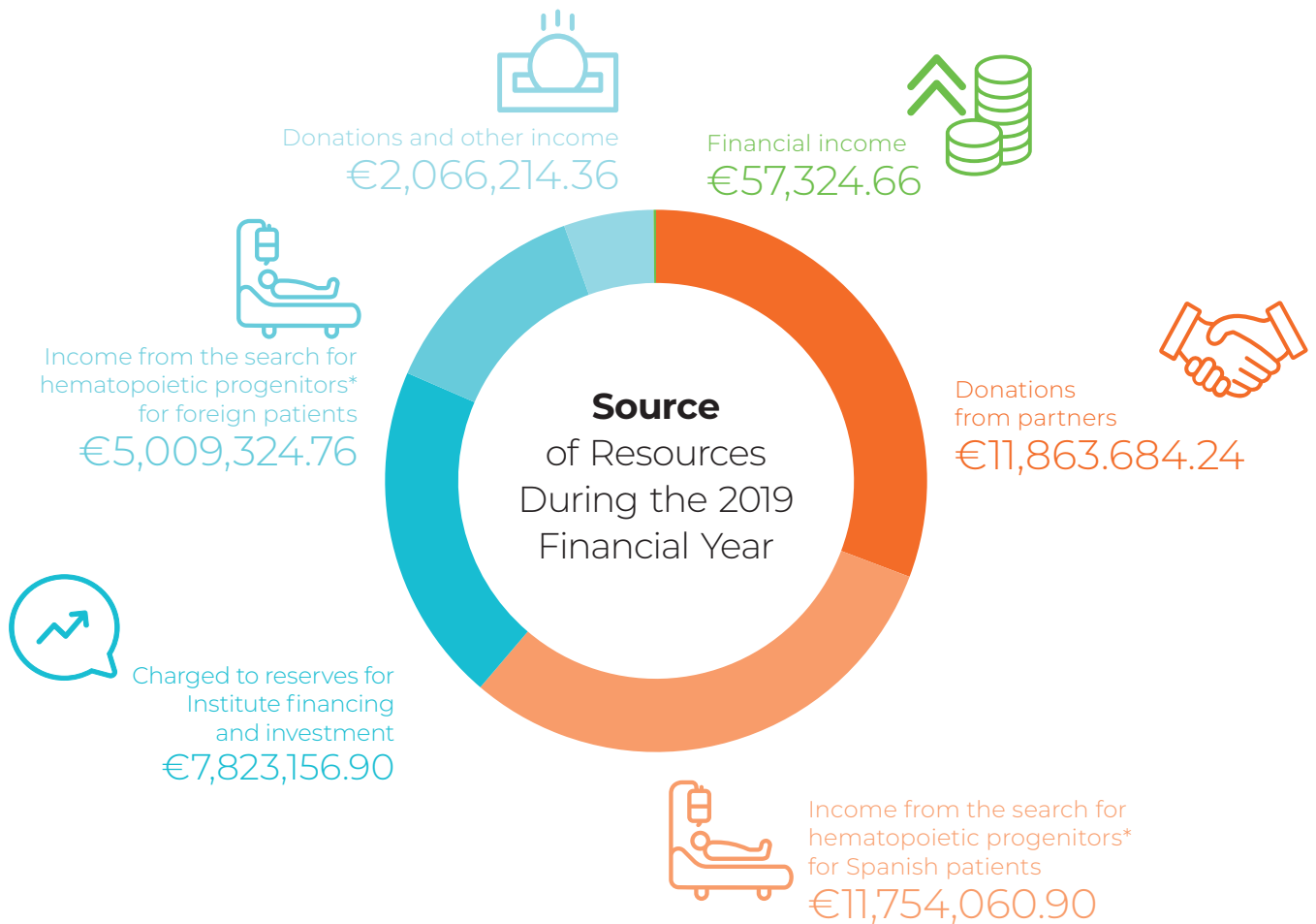
Mr. Rafael Jiménez
de Parga

Data Protection Delegate

Iris Bargalló

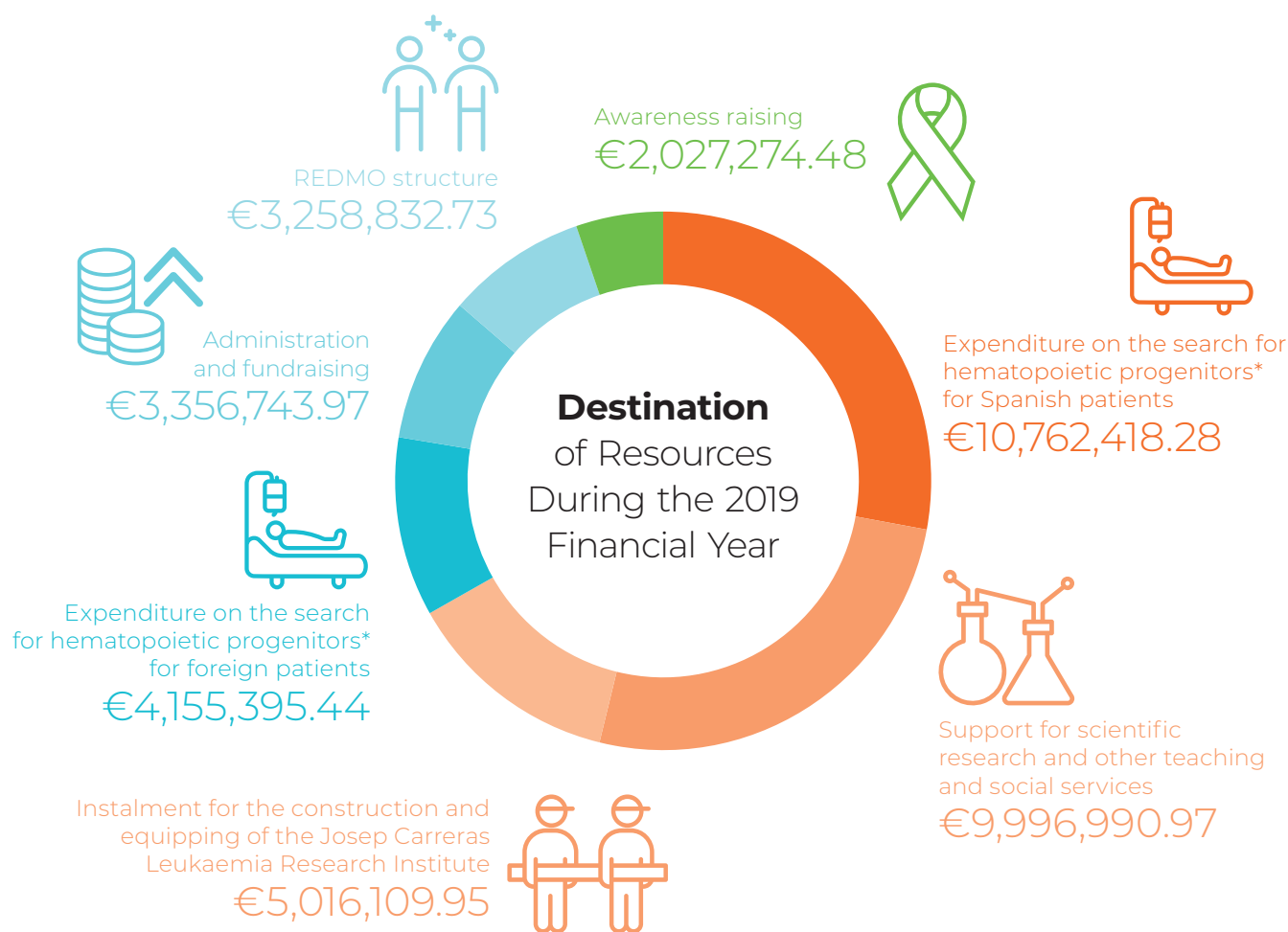
(*) Umbilical cord blood.

FINANCIAL INFORMATION



Total

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€38,573,765.82

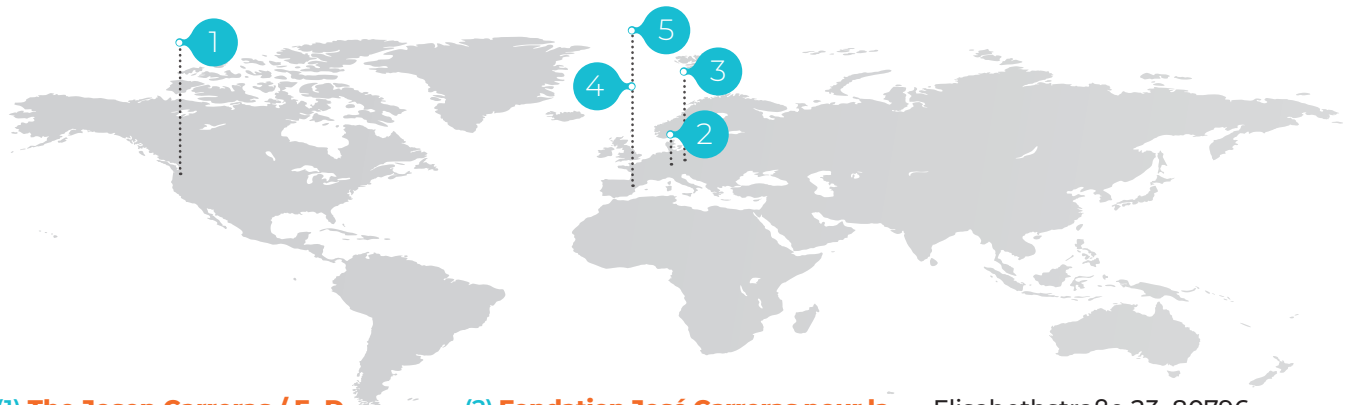


Total

.....
€38,573,765.82

(*) Bone marrow, peripheral blood and umbilical cord blood.

INTERNATIONAL PRESENCE



(1) The Josep Carreras / E. D. Thomas Endowed Chair for Cancer Research

The Friends of Josep Carreras International Leukaemia Foundation agreed its liquidation and to apply the funds, more than a million dollars, to a professorship amongst the members of the clinical research division of the Fred Hutchinson Cancer Research Center (Hutch) in Seattle for five-year periods of tenure.

In 2018 this professorship was awarded to Dr. Geoffrey Hill, a world-renowned hematologist from Brisbane, Australia. Dr. Hill is also the director of the Hutch's Hematopoietic Cell Transplant Programme.

(2) Fondation José Carreras pour la lutte contre la leucémie, Genève

The Josep Carreras Foundation runs a high-resolution characterisation programme for umbilical cord blood units in Switzerland, collated by the Swiss registry and available to any patient in the world.

**1 Case Postale 85, CH
1217 Meyrin 2 - Switzerland**

(3) Deutsche José Carreras Leukämie Stiftung e.V.

Thanks to the more than 220 million euros raised in the course of 25 editions of the televised Gala against leukemia and the generosity of German donors, the Josep Carreras Foundation in Germany has funded 1,300 projects, 789 of them for grants and support for research, 65 for the creation and enlargement of health-care and research, 123 for smaller projects, and 334 for social matters and help for associations of patients and their relatives.

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Munich - Germany
Telephone: (+49) 89 272 9040
Fax: (+49) 89 272 9044
www.carreras-stiftung.de

(4) Josep Carreras Leukaemia Foundation

Muntaner, 383, 2n
08021 Barcelona - Spain
Telephone: (+34) 93 414 55 66
Fax: (+34) 93 201 05 88
www.fcarreras.org

(5) Josep Carreras Leukaemia Research Institute

THE DIFFERENT LINES OF WORK

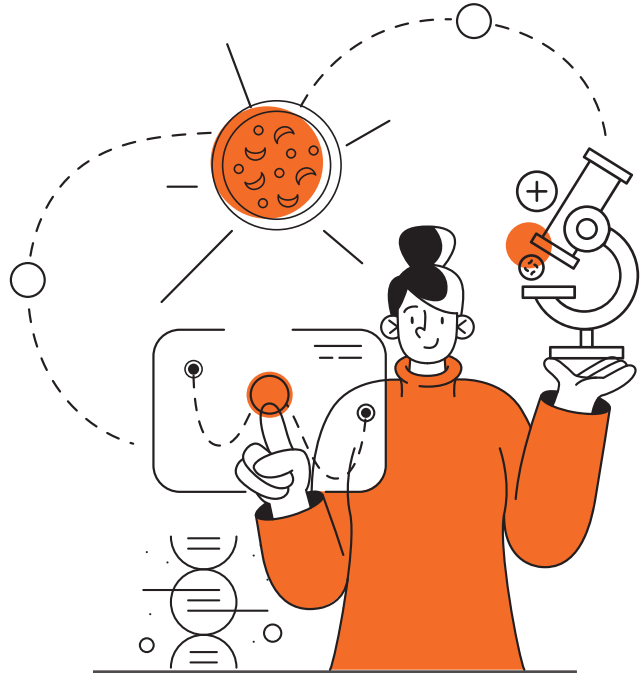


THE DIFFERENT LINES OF WORK

02

SCIENTIFIC RESEARCH

THE JOSEP CARRERAS LEUKAEMIA RESEARCH INSTITUTE




The Josep Carreras Leukaemia Research Institute, a Government of Catalonia (Generalitat de Catalunya) CERCA research centre, was founded in 2010 by the Catalan Government and the Josep Carreras Leukaemia Foundation with the aim of strengthening biomedical research and personalised medicine in the field of malignant blood diseases.

It is a centre without precedent, and benefits from the endeavours and professional rigour of world-class basic and clinical researchers. It employs the most innovative technologies, participates in many multi-centre projects, and competes successfully both at the national and international level. Its scientific production is already voluminous and of great relevance and has been published in the best international journals.

The Josep Carreras Institute has **three independent but coordinated scientific campuses**: the University of Barcelona **Hospital Clínic Campus**, located at the research facilities of Hospital Clínic, Barcelona,

and its University of Barcelona Faculty of Medicine August Pi i Sunyer Institute for Biomedical Research (IDIBAPS); the Catalan Institute of Oncology/**Germans Trias i Pujol Campus** (ICO-GTiP Campus), located near the Germans Trias i Pujol University Hospital in Badalona and its Research Foundation, and at the Autonomous University of Barcelona (UAB) Germans Trias i Pujol Teaching Department, and the **Sant Pau Campus**, located in the health-care complex of the Hospital de la Santa Creu i Sant Pau and the UAB Sant Pau Teaching Unit and its IIB Sant Pau Research Institute.

More information about the Josep Carreras Institute and its teams is available here

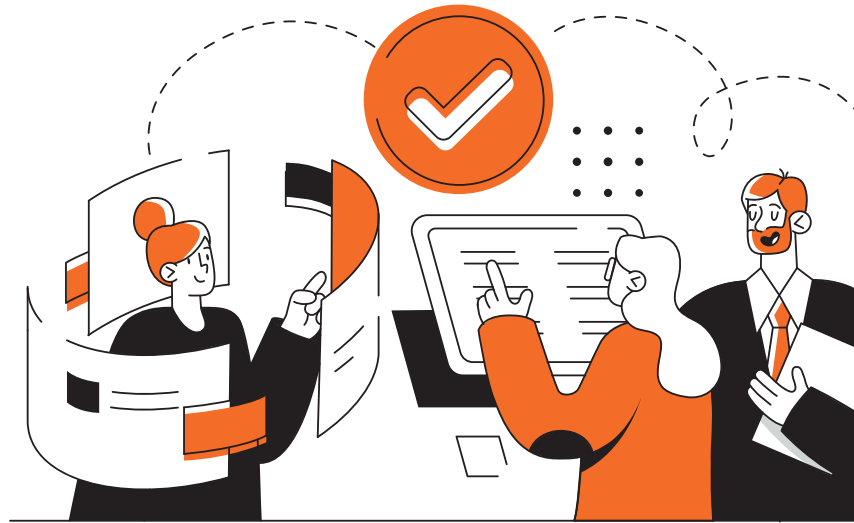
www.carrerasresearch.org/en 



Josep Carreras
LEUKAEMIA
Research Institute

SCIENTIFIC RESEARCH

THE INSTITUTE IN NUMBERS



Publications in 2019:



The team in 2019:



SCIENTIFIC RESEARCH

THE FOUNDATION'S CONTRIBUTIONS TO THE INSTITUTE

In 2019 the Josep Carreras Foundation provided **€9,734,048.59 to the Josep Carreras Leukaemia Research Institute.**

The contributions were of various kinds:



Contributions to running costs:

A contribution for the funding of the operational costs of the buildings at the various campuses:

€1,625,463.50



Funding and investments:

A contribution the Foundation uses to fund works, and the acquisition of equipment and technology that remains the property of the Institute:

€2,925,810.23



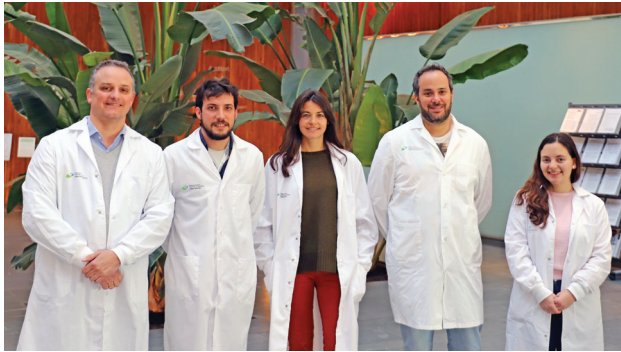
Support for research:

A contribution to fund specific projects. Funds are provided to the various research teams in accordance with their proposals and the criteria of the Institute's management:

€5,182,774.86

SCIENTIFIC RESEARCH

RESEARCH TEAMS JOINING IN 2019



Lymphoma Translational Group

This group works with very innovative preclinical models, from the identification of possible therapeutic targets to the development of molecules.

They work with 3D models in order to, not only recreate in vitro everything that happens in the organism, but also to recreate the structure that may be found there, for example, a lymphatic ganglion. The idea is to reproduce what happens in the organism as closely as possible. This 3D model enables what is happening with the patient to be almost perfectly reproduced, and the drugs that may be effective, and those that are not, to be identified. Furthermore, it enables the kind of cells that may respond to drugs to be seen, and helps identify which patients would most benefit from a drug.

This is already being done with other kinds of solid tumour, but with lymphoma (in hematology) it is very novel. The group works mainly with B lymphocytes and specialises, above all, on the most aggressive lymphomas, such as diffuse large B-cell lymphoma and mantle cell lymphoma.



Lead researcher

.....

Dr. Gaël Roué



Cancer genetics

Cancer is a disease produced by the accumulation of alterations in certain genes.

These genetic abnormalities causes uncontrolled cell behaviour whereby cells grow more than they should, leading to cancer. Some of the genes that are involved in the development of cancer are known, but others are yet to be discovered.

The group's work is focussed on identifying these unknown genes, and on biological studies in order to understand the way they work. The identification of all the altered genes and the clarification of the mechanisms involved in the development of cancer will help to diagnose cancer earlier and to design new anti-tumour therapies.



Lead researcher

.....

Dr. Montse Sánchez-Céspedes



Regulatory RNA and chromatin

This group studies the non-coding regions of RNA, or ncRNA. ncRNA is derived from DNA but does not incorporate the code to produce a protein. It is therefore distinguished from most traditional genes whose main function is to transcribe into RNA, which provides the instructions for producing proteins, which in turn fulfil multiple functions in cells and living organisms. In the case of ncRNA, this failure to translate into a protein has led to it, until recently, being devalued, with regard to its biological function, and the corresponding DNA has even been referred to as "junk DNA". However, it has been discovered that these regions are extremely important for controlling the expression of the rest of the genes and can have essential regulating functions for correct cell function.

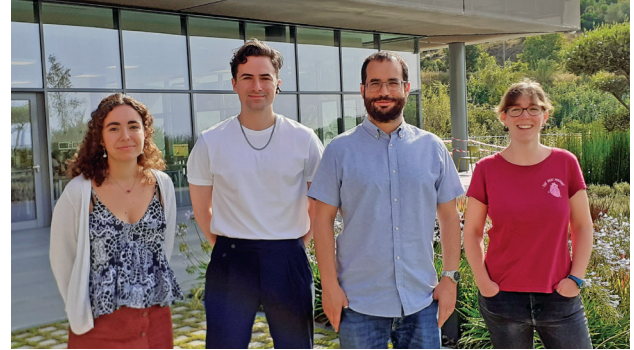
What is the purpose of non-coding RNA? Is there any relation between non-coding RNA and the development or prevention of leukaemia and other cancer processes?

Dr. Guil's group's research focusses on studying the emerging roles of ncARN as key regulators of gene expression in physiological cell programmes, and also at the beginning, or progression of, human diseases, with great interest focussed on the formation of tumours.



Lead researcher

.....
Dr. Sonia Guil



Epigenetic control of hematopoiesis

The aim of this research group is to understand how to reversibly change a specific kind of DNA modification so that any silenced gene reverts and re-expresses to, for example, repress the advance of a leukaemia or avoid relapse.

It is a question of knowing where these DNA modifications that cause cells to become leukaemic have occurred, and attempt to fix them.

Dr. José Luis Sardina is especially focussed on explaining these questions with regard to acute myeloid leukaemia and myelodysplastic syndromes, diseases for which there has hardly been any progress over the last 20 years. The gene he and his team use to 'modify' the DNA to encourage re-expression is gene TET2, which in turn is altered, as a consequence of mutation, in 10% of patients with acute myeloid leukaemia, and in 20% of patients with myelodysplastic syndromes.



Lead researcher

.....
Dr. José Luis Sardina



Cancer epigenetics

Epigenetics is genetic regulation. Genetics is like the alphabet and epigenetics like the handwriting of that alphabet, and is consequently a way of regulating genetics.

Epigenetics studies the correct function of genes whereby they are expressed correctly in the tissue corresponding to them. In many diseases these cells lose their memory and cease their assigned function to adopt others. They do this by altering their genetics, and also their epigenetics. All leukaemias and lymphomas have different epigenetic alterations, depending on the kind of disease. The first epigenetic drugs in cancer were approved precisely for their use with leukaemias and lymphomas, since it is possible in these cells to induce cell differentiation, that is to say, cells that do not 'remember' what they were (undifferentiated) then differentiate and 'remember' what their function is.



Lead researcher

.....
Dr. Manel Esteller



Lymphocyte development and disease

This group carries out research into the molecular mechanisms implicated in the formation of B lymphocytes and the processes that make them transform in an abnormal way leading to leukaemia or lymphoma.

These researchers have identified a protein that is essential for the formation of B lymphocytes and have observed that their expression is very low or almost inexistent in B-cell lymphocytic leukaemia, in both adults and children, and in some kinds of lymphoma.

They consider, therefore, that this protein could be a new prognostic marker and a therapeutic target.

In parallel with this, the group, led by Maribel Parra, aims to establish 3D cultures of cells derived from patients with diffuse large B-cell lymphoma, and carry out screening with a large number of compounds. The aim is to identify new compounds that could be used in combination with current therapies in a personalised manner for each patient.



Lead researcher

.....
Dr. Maribel Parra



Chromatin biology

Cells are exposed to aggression from the environment surrounding them. Such aggression is what we know as cell stress, to which the cells must adapt in order to survive. Dr. Vaquero's team is studying the mechanisms of response in cell stress.

Epigenetic regulation enables a specific enzyme to be modified, a gene to be turned on or off, or for its expression to be adjusted or modified. Epigenetics is therefore crucial for an effective response to cell stress.

This group focusses its research on a family of proteins, called sirtuins, which are determinant in communication between the environment and the genome, as well as in the organisation of cell response. These proteins therefore play a key role in the development of many kinds of disease, such as leukaemia and lymphoma.



Lead researcher

.....
Dr. Alex Vaquero



Epigenetics and immune disease

This team studies the epigenetics of blood cells with the aim of understanding how these mechanisms determine the identity of these cells and their correct functioning. When there are defects in the epigenetic mechanisms the blood cells can give rise to leukaemias and lymphomas, autoimmune or immunodeficient diseases in which the immune system overreacts or, on the contrary, is insufficient to respond to the infectious agents.

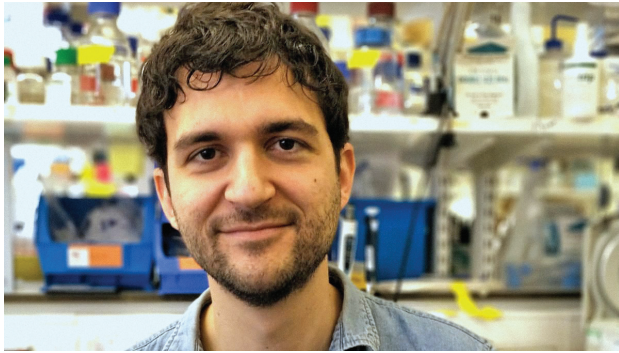
The group studies the cells of both the lymphoid and myeloid branches, which are the cause of the various kinds of blood cancers.

As part of their research, the group is carrying out a project that focusses on multiple myeloma, and is also working in the field of primary immunodeficiency, a group of diseases caused by the quantitative or functional deficiency of the different mechanisms implicated in immunological response.



Lead researcher

.....
Dr. Esteban Ballestar



Transcriptional dynamics in leukaemia

This group studies the mechanisms that regulate gene transcription, or their 'activation', to become proteins during hematopoiesis, or the generation of blood cells. Studying transcription in the formation of healthy and malignant cells could lead to the detection of gene regulation mechanisms in the development of leukaemias, and reveal the vulnerabilities of malignant blood diseases thereby opening up new therapeutic opportunities.

Hematopoietic differentiation is a very rigorous process that maintains the production of blood cells throughout life. The transcriptional changes the cells undergo as they grow and differentiate into different types of cells, such as white and red blood cells, platelets, etc., is controlled at many levels, and these control mechanisms are key for understanding the development of malignant blood diseases.

Most cases of acute myeloid leukaemia present mutations in the transcriptional regulators and chromatin modifiers. These mutations alter the transcription dynamics and can adversely affect the normal formation of cells. To understand how this happens, the mechanisms that regulate transcription during blood cell differentiation is being studied, as well as the leukogenetic potential of the mutations in these proteins.



Lead researcher

.....
Dr. Sergi Cuartero



Epigenetic Therapies

Dr. Berdasco's team aims to take a step further in knowledge about epigenetics, studying the potential of epigenetic discoveries for their application in clinical practice. Based on this, the group has three fundamental pillars:

- To establish which epigenetic mutations are really important for a tumour to develop and progress, in other words, to identify the target to be inhibited.
- To direct the therapies better by stratifying the patients who might receive them. This project is specifically focussed on acute myeloid leukaemia and uses the genetic profile of the tumour to determine its sensibility to the drug.
- To progress towards personalised medicine. When applying immunotherapy to patients suffering from blood diseases, some respond and others do not. This group aims to determine whether epigenetic profiles, specifically of DNA methylation, are different amongst patients who respond and those that do not, and whether these profiles could be used as response markers.



Lead researcher

.....
Dr. María Berdasco

There is more information about all the Josep Carreras Institute's research groups on the website: www.carrerasresearch.org



BONE MARROW DONORS REGISTER

WHAT IS REDMO?

Often the only chance of a cure for many patients with leukaemia and other malignant blood diseases entails a bone marrow transplant, or a transplant of peripheral or umbilical cord blood (hematopoietic progenitors). **But 3 of every 4 patients do not have a compatible related donor.**

It was on account of this that, in 1991, the Josep Carreras Foundation established the Bone Marrow Donor Registry (REDMO), with the aim of enabling patients without a compatible family member to have access to a bone marrow donation from a voluntary unrelated donor.

Its full development was reached in 1994 when it was incorporated into the public health system with the signing of the first framework agreement between the Josep Carreras Leukaemia Foundation and the Ministry of Health, through the National Transplant Organisation (ONT).



REDMO is the only official programme in Spain to be entrusted with administering the donor data base for voluntary Spanish donors, with data being received directly from the Autonomous Communities, the search for compatible donors for Spanish patients, and the coordination of the transport of bone marrow, peripheral blood and umbilical cord blood from the place of donation to the transplant centre.

Furthermore, REDMO receives requests from foreign registries in other countries to conduct searches for Spanish donors that are compatible with their foreign patients.

BONE MARROW DONORS REGISTER REDMO'S GLOBAL ACTIVITIES



Over the last 28 years it has been possible to perform **10,332 transplants** throughout the world thanks to an anonymous donor located by the Josep Carreras Foundation's Bone Marrow Donor Registry.

You can consult REDMO's full report here: www.fcarreras.org/en/memorias 

TRASPLANTS	DONORS BM/PB/UCB/LYM*		
	Spanish donors	Foreign donors	Total
Spanish patients	1,465	5,595	7,060
Foreign patients	3,272		3,272
Total	4,737	5,595	10,332

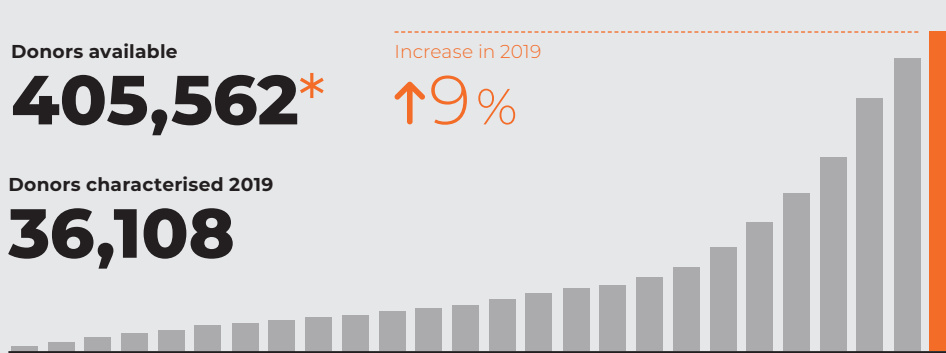
(*) BM: bone marrow; PB: peripheral blood; UCB: umbilical cord blood ; LYM: lymphocytes.



REDMO'S ACTIVITIES IN 2019

Bone marrow donors

Evolution of the number of bone marrow donors available in Spain (1994-2019)

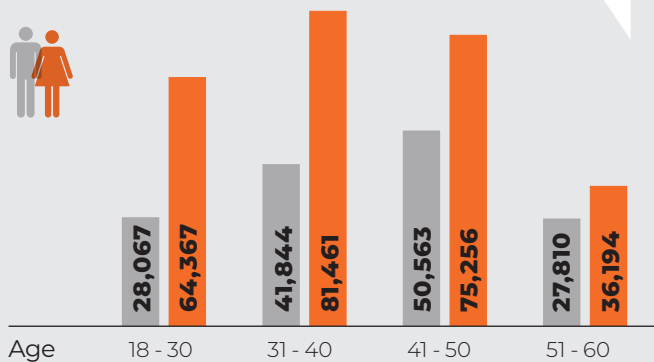


(*) As can be seen, the increase in the number of registered donors has been very marked over the last few years. Nevertheless, it should be borne in mind that the number of donors registered with REDMO does not always coincide with the number of registered donors offered by the ONT or the Autonomous Communities. That is because, although donors may be registered, they can not be included in REDMO and the international network of donors until their HLA study has been received, as well as their signed informed consent form together with the minimum data established in the National Bone Marrow Plan (PNDMO).

Profile of donors available by age group and sex

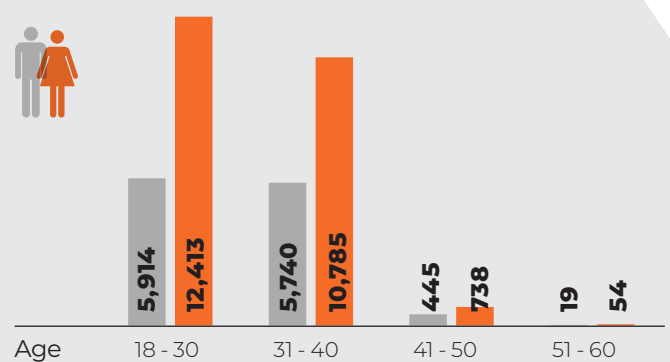
Available (n = 405 562)

The average age of available donors is 34 (standard deviation ±10,06) and the median age is 40.

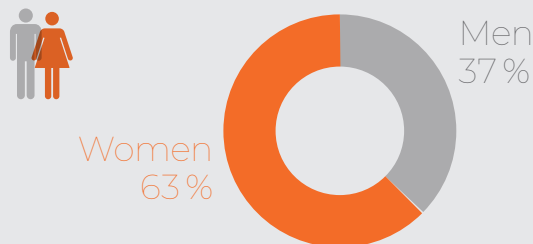


Incorporated in 2019 (n = 36.108)

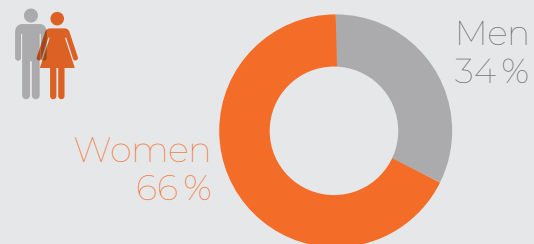
The average age of incorporated donors is 30 (standard deviation ±6,86) and the median age is 30.



53% of available donors are less than 40.

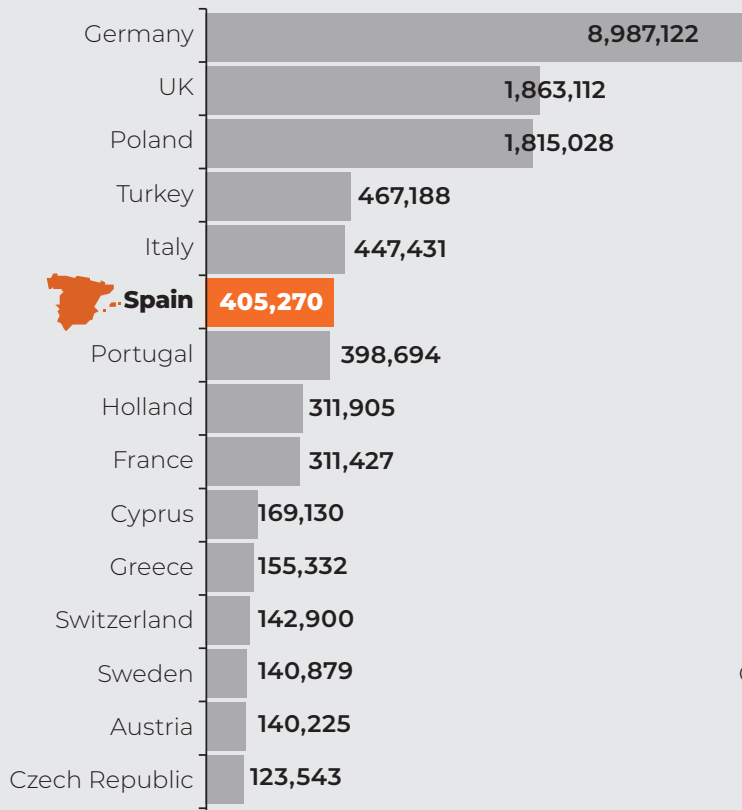


96% of new donors are less than 40.

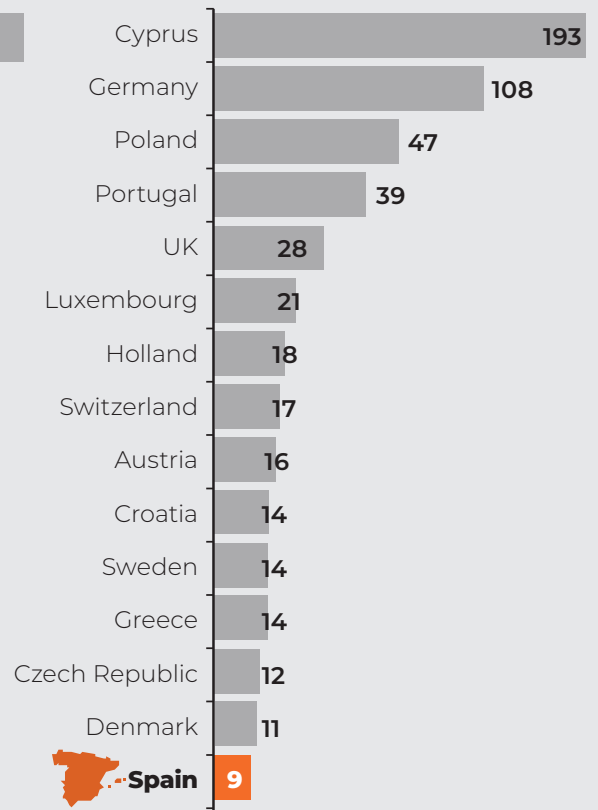


Distribution of donors in Europe

By country



For every 1,000 inhabitants



You can consult REDMO's full report here: www.fcarreras.org/en/memorias



Requests for collection of hematopoietic progenitors

350*

Requests received
(51% national;
49% international)

221

Collections made
(24 requests in 2018)

130

Cancelled before extraction
(includes postponed processes
and 10 requests in 2018)

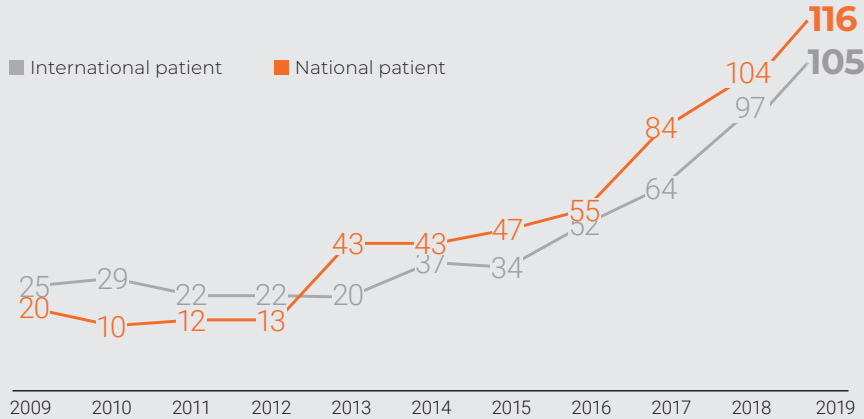
33

Collections underway

(*) These 350 requests correspond to 288 patients.

Requests for collection of hematopoietic progenitors have **increased by 15% with respect to 2018** (and 614% since the launch of the National Bone Marrow Donation Plan in 2012).

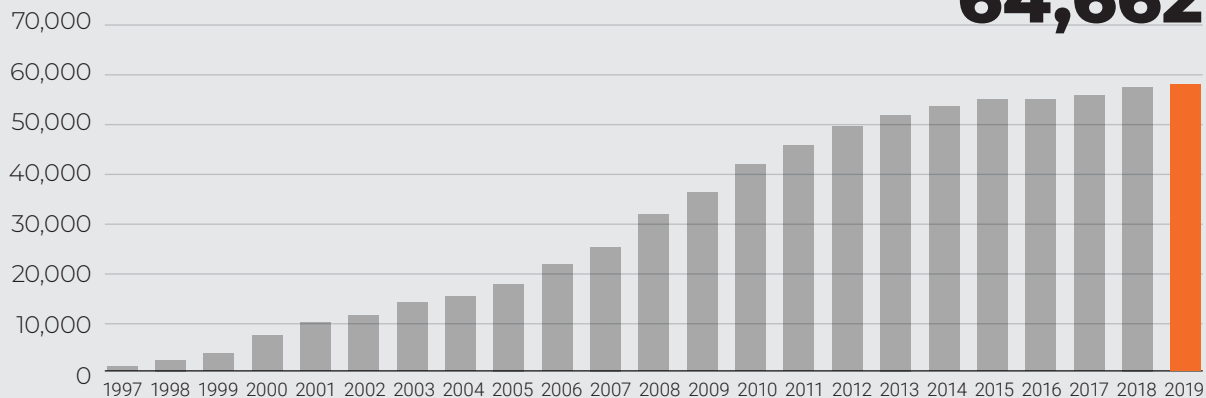
Evolution of collections carried out by destination



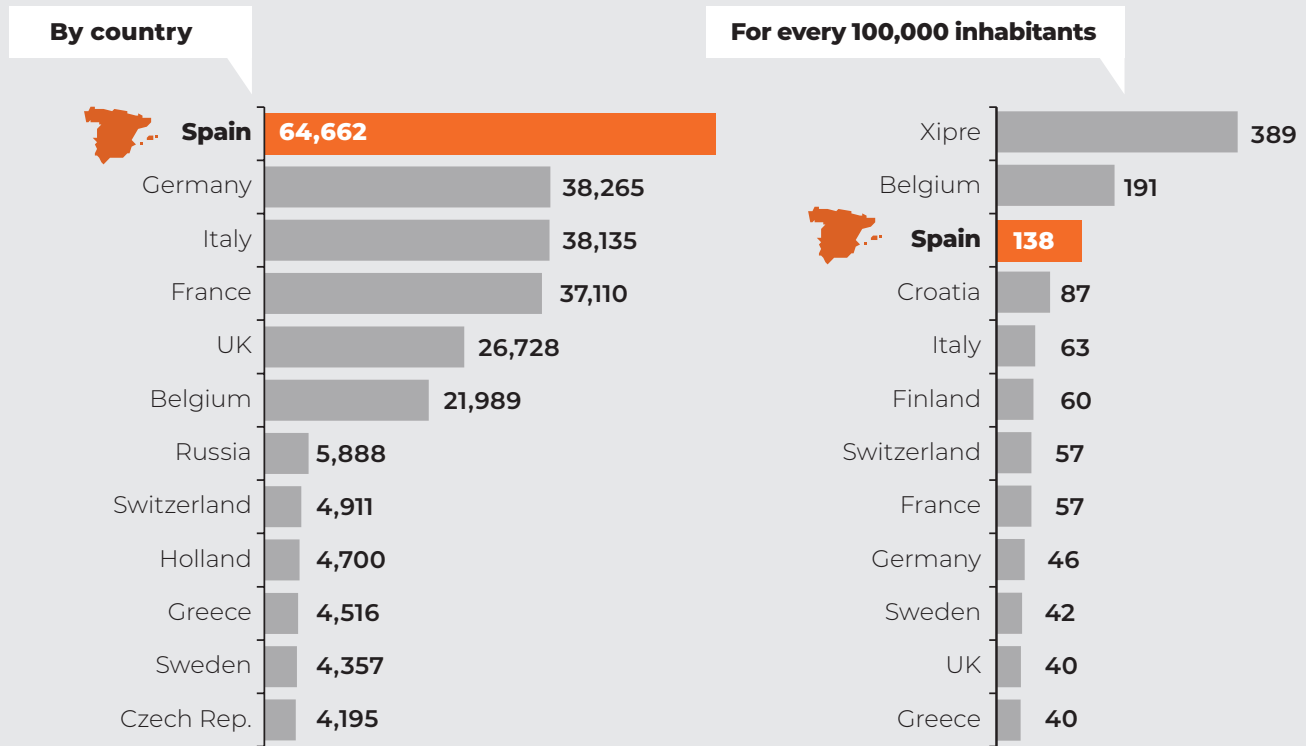
Evolution of the number of umbilical cord units available in Spain

Umbilical cord units available

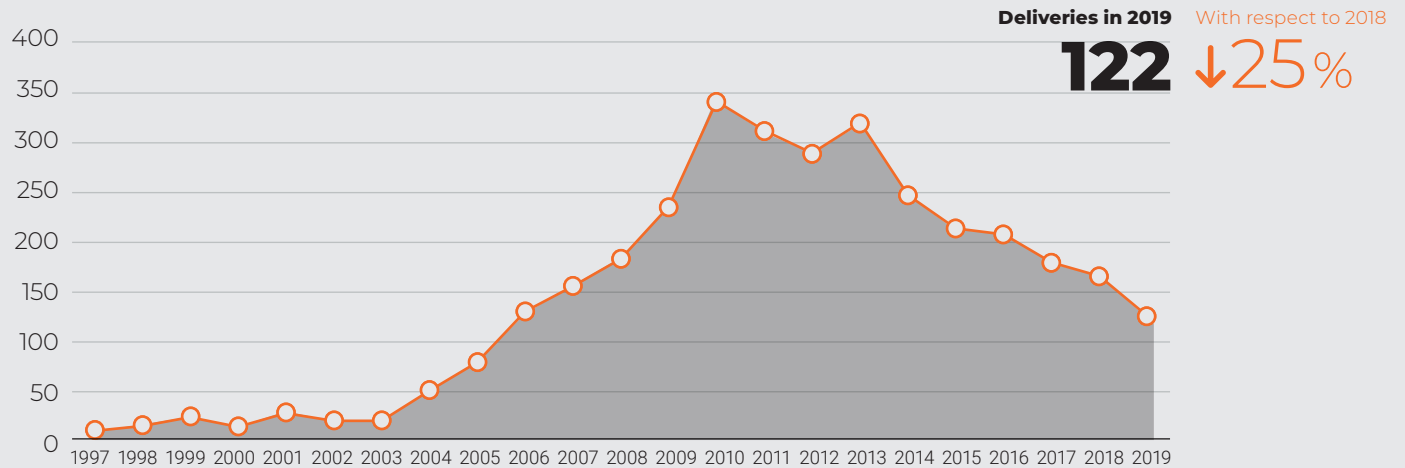
64,662



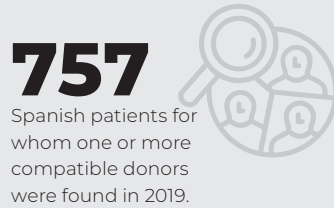
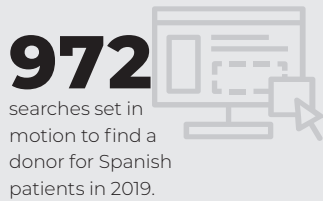
Distribution of umbilical cord units in Europe



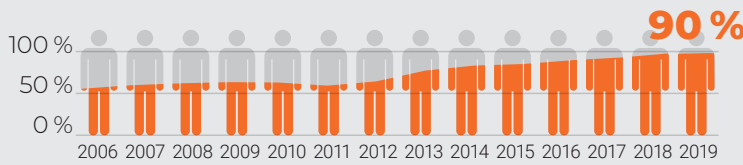
Evolution of deliveries of umbilical cord blood



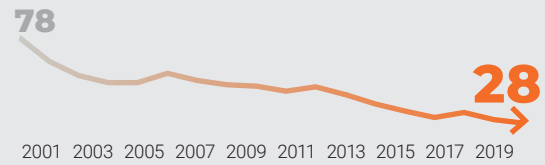
Searches for a compatible donor



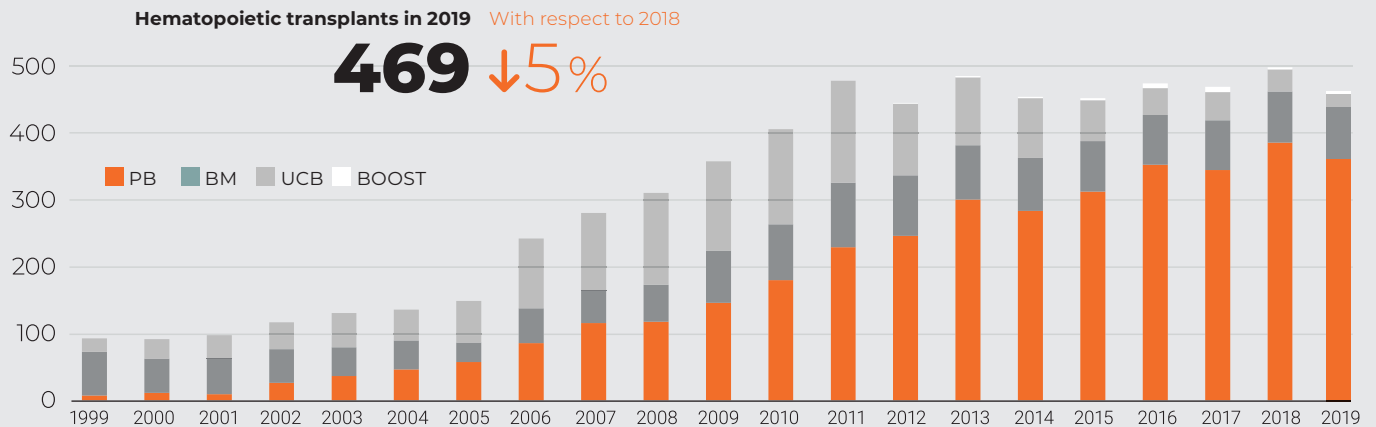
Percentage of hematopoietic progenitor donors found within two months



Average number of days taken to search for bone marrow or peripheral blood



Transplants for Spanish patients in 2019



By type of product



* Includes 3 Boost CD34+.

You can consult REDMO's full report here: www.fcarreras.org/en/memorias



PATIENT GUIDANCE

In 2019 **1,567 online medical consultations** were attended to as well as another **3,123 requests for general information**.

The Josep Carreras Foundation provides an online medical consultation service to resolve people's doubts about blood diseases. This service is directed by Dr. Enric Carreras, a renowned hematologist, the Foundation's medical director and the director of the Bone Marrow Donor Registry.

Similarly, many people, above all on account of our presence in social media, approach our Foundation seeking more information about blood diseases, and about bone marrow donation, as well as other questions.

To raise awareness of our work and answer these requests for information, the Foundation, has staff dedicated to attending to, and following up, the requests received through these channels and by telephone.



Hello, my name is Azahar and in March 2019 I celebrated my 29th birthday. For my birthday I was alone in isolation in a hospital room on a blood cancer ward in Madrid.

Everything started a few days before my birthday. I went to the hospital to give blood only to be diagnosed with leukaemia. What's more, it was **Philadelphia + acute lymphoblastic leukaemia**, a sub-type of the disease that has a complicated prognosis and requires a bone marrow transplant to find a cure. Lucky, hey? I'd gone to give blood for someone else!

I spent a long time in isolation and receiving strong doses of chemotherapy. In September I had a bone marrow transplant from an anonymous donor found by the Josep Carreras Foundation. I am so very grateful to the Foundation's Bone Marrow Donor Registry for finding my kindred spirit and to that anonymous person for returning the possibility of life to me and of being with my son Jesús.

Jesús is 7 years old, and while I was hospitalised we could hardly see each other. For transplants you are all alone in an isolation chamber. I couldn't have visits or company because my family lived far away. The only smile I saw was through the hospital window was that of my little one who always said, with a VITAL SMILE, "You're getting better mummy". And it was true. It doesn't seem like it, but even though support comes via the telephone, it counts for a lot.

You forget the time you spent inside. You forget half of all the bad things. You have to give life a chance. Thank you, Josep Carreras Foundation; thank you bone marrow donors; thank you to everyone supporting research.

Together we are unstoppable.

RECEPTION APARTMENTS

In 2019 we welcomed **31 families**, who have stayed for a total of **1,426 days in our apartments.**

The creation of a network of reception apartments sprang from the Josep Carreras Foundation's special concern for the wellbeing of patients and their families during treatment. Since 1994 we have provided six reception apartments to patients and their families with limited economic resources.

It is often the case that a patient undergoing treatment must spend a long time away from home. Our apartments are located very close to the main hospitals in Barcelona that provide treatment for leukaemia and other malignant blood diseases.

Since 1994, 389 families have been accommodated in one of our apartments.

Furthermore, since 2012, the Foundation has also had a room available for patients and their families in the Hotel NH Porta in Barcelona, thanks to a collaboration agreement signed between the Hospital Infantil Sant Joan de Déu in Barcelona and the NH Hotels chain.



My name is Vanesa and I am 43 years old.

I have been ill since the age of 37. I started with **follicular lymphoma** and was treated with chemotherapy, but I suffered many side effects. In 2018 I was diagnosed with secondary myeloid leukaemia, but because the chemotherapy didn't produce much of a response, I suffered a relapse and a search for a compatible donor started immediately. I was given a transplant from a non-related donor located by the Josep Carreras Foundation.

I am 200 kilometres from home, and I would like to thank the Foundation for also offering me a reception apartment so that I could stay there with my husband and recover, while being close to the hospital and receiving visits.

It's a tough road to follow, but I feel full of optimism and hope that everything will work out well so I can enjoy life. This time, it seems like an epoch, is teaching me the fundamental values in life, which are sometimes lost along the way, and with those values, when all this is over, I will be able to fly again.

**THE
COMMUNITY
OF
UNSTOPPABLES**

03

OUR ONLINE COMMUNITY



f+239,432

people who like our Facebook page www.facebook.com/fundacioncarreras

Instagram+58,181

followers on Instagram [@imparablescontralaleucemia](https://www.instagram.com/imparablescontralaleucemia)

Twitter+14,155

followers on official Twitter www.twitter.com/fcarreras

YouTube+3,560

subscribers to our channel www.youtube.com/fundacionjcarreras

Our website in 2019
www.fcarreras.org

2,500,000
sessions

1,900,000
users

Our media presence in 2019

563
mentions in the press

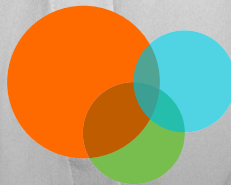
2,217
mentions in digital media

CAMPAIGNS

EL MEJOR ANUNCIO DEL MUNDO

ES PODER DECIR A UNOS PADRES QUE SU HIJO ESTÁ CURADO.

ENVÍA IMPARABLES AL 28027.



Fundación
JOSEP CARRERAS
IMPÁRABLES CONTRA LA LEUCEMIA

GRACIAS

Chopard

NOVARTIS

Allianz

WÜRTH

Coste: 1,2 euros (donación íntegra para la Fundación Josep Carreras). Servicio de SMS para la recaudación de fondos en campaña de tipo solidario. Número de atención al cliente: 900 32 33 34. Correo electrónico: info@fcarreras.es. Dirección postal: c/ Muntaner, 383, 2.º 08021 Barcelona. Colaboran Movistar, Vodafone, Orange, Yoigo y Euskaltel. Los datos personales facilitados se tratarán de acuerdo con el RGPD (2016/679). Para más información, entre en <http://www.fcarreras.org/es/privacidad>.

"The best announcement in the world"

The Josep Carreras Foundation launched a new campaign to coincide with Leukaemia Week (21 to 28 June).

The funds raised are already being applied to research being carried out at the Josep Carreras Leukaemia Research Institute.



Patients, former patients and families: Unstoppables Day

This is the most anticipated day of the year. A day in which patients and former patients, accompanied by their families and friends, go out onto the streets to raise awareness about the disease.

It marks the start of a very special week: Leukaemia Week, which is held every year from 21 to 28 June.

The Josep Carreras Foundation has organised this great gathering of patients and former patients for the last eight years.



In 2019, **more than 3,000 people** went out onto the streets in **63 Spanish cities.**

"A match 4 a life"

The National Transplant Organisation (ONT) and the Josep Carreras Foundation, together with the various Autonomous Communities, launched the "A match 4 a life" campaign with the aim of acknowledging the generosity of bone marrow donors, improving information, and promoting this kind of donation, principally amongst the young.

The campaign was launched on 21 September 2019 to coincide with World Bone Marrow Donor Day, which is held every third Saturday in September, and it came to a close in January 2020.

The campaign was launched digitally with a video:



The video showed the abusive use of dating apps as a starting point for inviting people to think about the time spent looking for the person of their dreams without realising that, with much less effort, it would be possible to save someone's life.

The campaign was not restricted to the digital world and there were street marketing events in the 17 Autonomous Communities to provide information about bone marrow donation.

The "A match 4 a life" campaign reached thousands of people:

- The video was watched more than 50,000 times.
- The campaign's social networks registered 4,000 new followers and we achieved more than a million visits.
- There was considerable media impact with more than 170 mentions in all media.
- Furthermore, there were more than 1,000 requests for information about bone marrow donation.

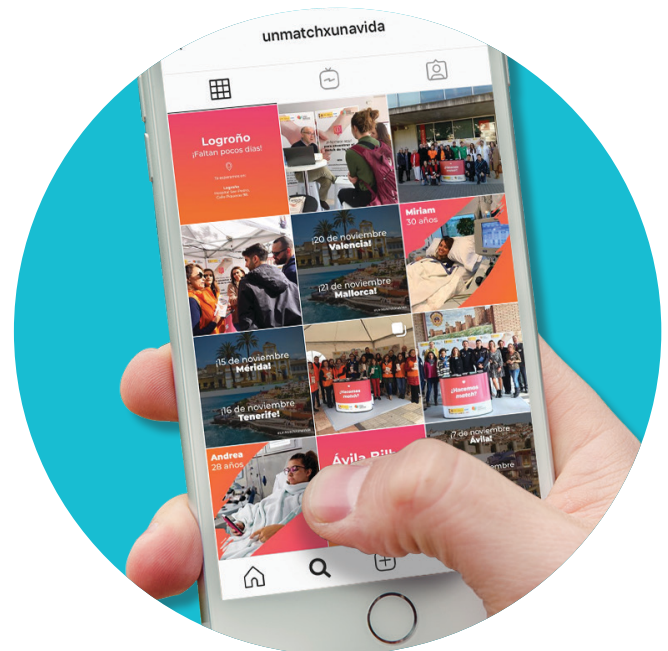
You can see the results of the campaign in the summarising video hosted at:

www.unmatchxunavida.com 

 www.instagram.com/unmatchxunavida/

 www.facebook.com/unmatchxunavida

 twitter.com/unmatchxunavida



Our thanks go to everyone who actively participated in the campaign, making it a great success!



We were in all these cities!

15.10 SANTANDER
17.10 VIGO
23.10 TOLEDO
30.10 ZARAGOZA
01.11 PAMPLONA
05.11 MÁLAGA
07.11 ÁVILA
09.11 OVIEDO

15.11 MÉRIDA
16.11 LA LAGUNA
20.11 VALENCIA
21.11 MALLORCA
27.11 LOGROÑO
10.12 MURCIA
11.12 BILBAO
17.12 BARCELONA
10.01 MADRID

OUR PARTNERS & FRIENDS




In 2019 we welcomed...

 **22,049**
new partners and...

 **2.241**
friends.

We are...

 **107,035**
partners and...

 **13.928**
friends.

And thanks to them we have raised...

 **€11,131,880.00**
from our partners and...

 **€257,810.94**
from our friends.

In 2019 we reached **100,000!**

In 1988, when Josep Carreras was recovering from leukaemia, he established a Foundation named for him, and with an aim: to enable people in a similar situation to himself to one day have greater opportunities.

Since then the family of Unstoppable partners who support us in this cause has not ceased to grow, and in 2019 we were able to celebrate reaching 100,000!

100,000 people united in the same battle: to make leukaemia and all malignant blood diseases 100% curable for everyone, and in every case.

100,000 thanks!

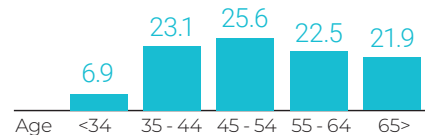
WHO IS BEHIND THE NUMBERS?

These are our partners:*

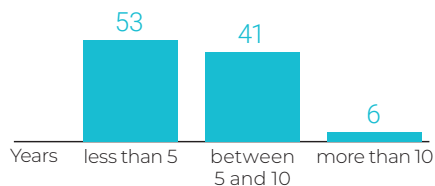
Distribution by sex



Distribution by age (%)



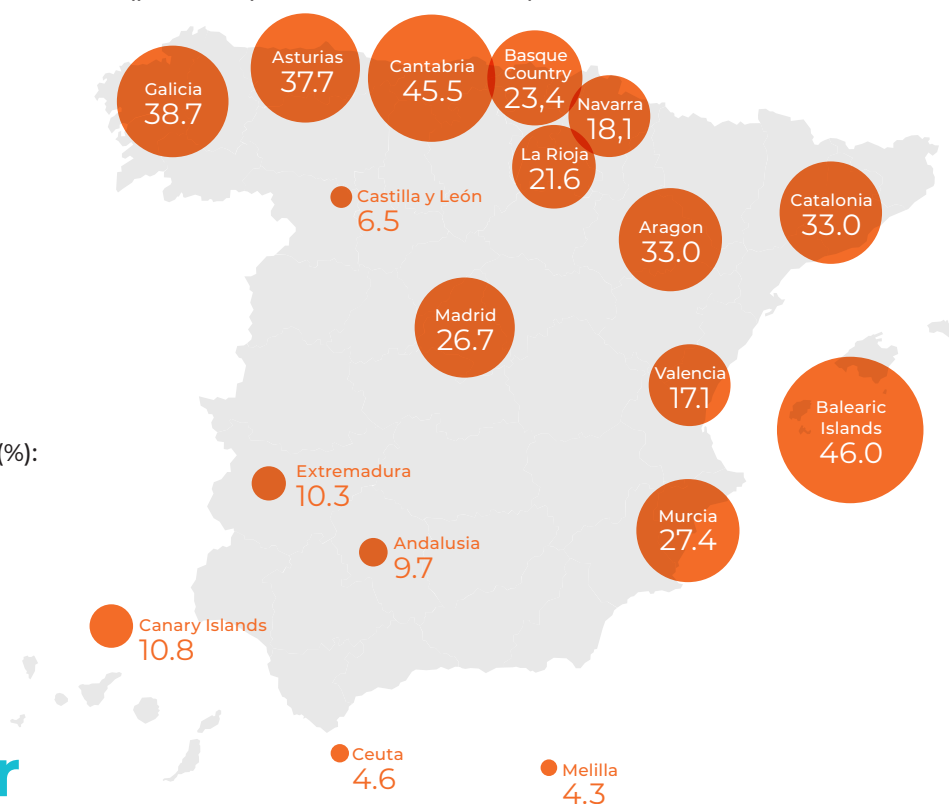
Distribution by years of affiliation (%)



The most usual contribution

€120 per year

Index of penetration by Autonomous Community (partners per 10,000 inhabitants)



Would you like to adjust your contribution? Call us free on 900 32 33 34

With **€180 per year**, you can help our experimentation unit, which is dedicated to a rare kind of childhood leukaemia with a very poor prognosis.

With **€240 per year**, you can help us carry out research into the complications that arise with bone marrow transplants. You can consult the tax benefits of your contribution here: fcarreras.org/calculadora-fiscal



(*) Profiles based on available partner information.

The Josep Carreras Foundation was established in 1988. Marta and Victoria became our partners more than 10 years ago. They tell us why they are Unstoppable.



Marta Andrés, Barcelona.
Partner since 2009



"As children we don't know about illness, unless we are suffering from one. We only complain about things that hurt us or about things that are bad. Until, that is, at the age of eight, I really discovered what illness was when my best friend, Clàudia, died of leukaemia.

My parents tried to explain things to me, but I was not convinced because I was with her throughout the whole process, from her diagnosis, to her hospitalisation, when her hair fell out, and finally when she said goodbye.

For me there was a before and after. I didn't want to see more cases like Clàudia's. And that's what inspired me, when I received my first pay cheque, to help with the cause. For Clàudia. For everyone. Unstoppables!"



Victoria Rigual, Guadalajara.
Partner since 2010



"I became a partner of the Josep Carreras Foundation by chance. For years I had been involved with various voluntary social activities and, one day, as I was leaving my class at university, one of the volunteers approached me at the Metro station and told me about the Foundation.

I think what made me sign up at that moment was the Foundation's research work in the battle against leukaemia.

Quite a few years have passed since that day and the results the Foundation continues to show just make me proud to contribute my little bit to this enormous task. Thank you so much for everything."

THE TEAM OF PARTNERS FROM WITHIN



Anna Grau

is the person responsible for answering the questions and doubts of our partners and friends. For eleven years she has been the person who responds when one of our supporters gets in touch with us.

"What I most like about working with the partner team is the relationships you have with people. I love talking to our partners and friends on the telephone, receiving their grateful emails..., although it is us who are really grateful, for their financial contributions and for all the lovely messages we receive. We like to keep them because every time we read them we are encouraged to carry on the fight.

Without their help we would not be able to carry out research or do all the things we do for leukaemia patients and their families. Without their help, without their messages, our work would not be so special.

Thanks to them many lives are saved, and neither we nor the patients will ever be able to thank them enough for everything they do."

FUNDRAISING INITIATIVES



1,740

activities organised

75.9 %

increase in activities

€591,544

raised in total

20.8 %

increase in funds raised

Fundraising events have been held in all the provinces. The ones which have organised **more than 10** are:



Most frequent initiatives:

- Celebrations.
- Artistic events.
- Fundraising challenges via virtual micro-donation platforms.
- Sporting events.

Contact channels:

- Email.
- Telephone.
- Websites (*Foundation, wedding portals*).

Other kinds of initiative:

- Weddings.
- Dinners.
- Schools.
- Companies.
- Sales.
- Memorials.



136

Repeated initiatives



176

Initiatives by juridical persons



297

Initiatives by patients and their families



1,132

Initiatives by private individuals

Thank you to everyone who has made it possible!

Master Youth Badminton
Memorial Guadalupe Burgos

€1,000



Masia Can Companyà
Restaurant

€4,850



Mayordomos de
Lobres Paella

€3,200



Thomas Rating's
birthday

€1,351



Orientados hasta la médula

€15,955

JAN

FEB

MAR

APR

MAY

JUN

Magic BDN Running

€6,000



Jaume Balmes School

€1,838



Thank you
to everyone
who has
raised funds
by organising
events in 2019!



Fundraising barbecue
in Tarancón
€4,243

Fundraising walk by
Sahagún Town Council
€2,013



Acaye Asociation
concert
€8,000



JUL AUG SEP OCT NOV DEC

Unstoppable paddle tournament
€10,152



School football fiesta
€7,500



«No hay penas con rumba» concert
€12,338

Gomet Day - Siena Memorial
€2,905

INHERITANCES AND LEGACIES



We have inherited

€2,183,722

We have administered

23
**inheritances
and legacies**



Everyone would like to leave a better world to their loved ones, one without injustices, pain or illness and there is a growing number of people who choose to leave inheritances and legacies to good causes, and this has become an important source of income for Foundations and NGOs.

What can I leave as an inheritance or legacy?

A particular item can be left, or the entire estate.



Personal property

Jewellery, furniture, etc.



Immovable property

Apartments, houses, land, etc.



Financial securities

Shares, investment funds, etc.



A sum in cash, or funds in a financial institution

A percentage of the value,
or a specific sum.



Life insurance

By naming our institution
as the beneficiary.

What can the Josep Carreras Foundation do with an inheritance or legacy?



Turn a flat into a reception apartment for patients suffering from leukaemia and their families during treatment.



Turn a jewellery collection into a new research machine.



Convert an investment fund into improved techniques for finding compatible bone marrow donors for patients needing a transplant.

PURCHASERS OF OUR FUNDRAISING ITEMS



The Foundation has a virtual shop where items with an added value can be purchased. The funds raised go towards our research projects



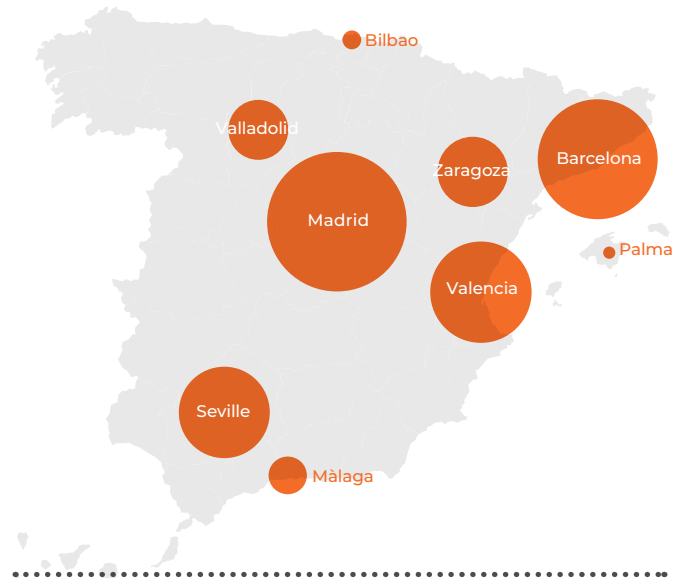
We provide:

- Return guarantee.
- Delivery tracking.
- Payment on delivery or by bank card.
- Personalised customer care.
- Despatch in 24-48 hours.



Customer profile

80.4% are women. 43% are between 25 and 34 years of age and 57% are between 35 and 44 years of age.



Places with the most frequent customers



Devices used to visit us



Items sold



Cash purchase

Thank you to everyone who has purchased from our shop!

SUPPORTING COMPANIES

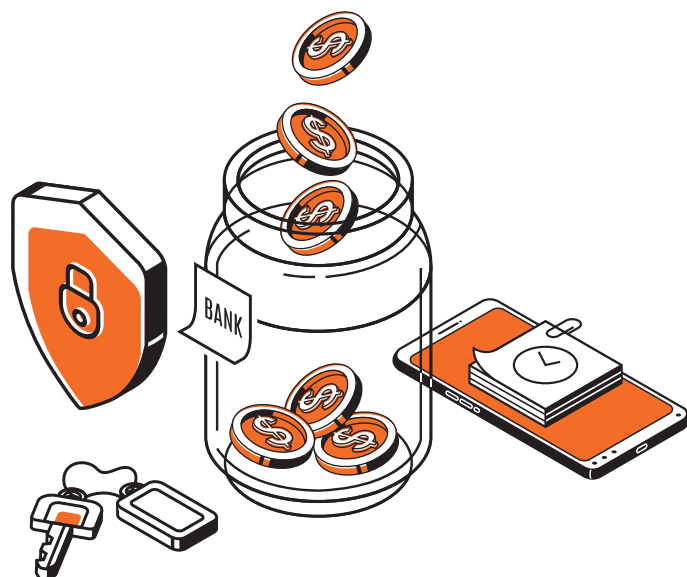
In 2019 **150 companies and organisations** supported the Josep Carreras Foundation in its fight against leukaemia. They are companies and organisations that are committed, not only to the Foundation, but also to research into treatments for these kinds of disease, to the benefit of patients.

All of them have contributed, be it through regular contributions, a one-off contribution, or by organising an event for the Foundation's benefit.

Thanks to all of them we have raised

€780,580.25

to continue our fight against leukaemia.



There are many ways for your company to offer support:



.....
Fund a project



.....
Become a partner company



.....
Make a present of solidarity



.....
Involve your team



.....
Social marketing



In 2019 we remained Unstoppable

Alliance with Fedefarma to increase the number of information points for bone marrow donation

Since September the pharmacies belonging to the Fedefarma cooperative have had the opportunity to become information and sample collection points for potential bone marrow donor. To this end, the pharmacies belonging to the pharmaceutical distribution cooperative undertake a course to obtain accreditation granted by the Foundation through the Bone Marrow Donor Registry (REDMO), enabling them to provide information about donation, and to collect samples from people between the ages of 18 and 40 who wish to become donors.



The Leo Messi Foundation joins forces against childhood leukaemia

With the signing of an agreement in March, the Leo Messi Foundation started collaborating with the Foundation to support the line of research focussed on childhood leukaemia, led by the laboratory of Dr. Pablo Menéndez, the scientific director of the Josep Carreras Leukaemia Research Institute at the Hospital Clínic-UB Campus, with a team that is internationally renowned for its work in the field of acute childhood leukaemia, with an emphasis on infant leukaemia (under the age of 12 months).



Banco Santander

The Josep Carreras Foundation has, since 2019, been one of the 12 winners of the Banco Santander 11th Call for Social Projects, for which there were 327 candidate projects from not-for-profit organisations. The bank's staff in Spain voted on the projects. The Foundation's winning project, on acute infant lymphoblastic leukaemia, will be the recipient of €40,367,68 which the Banco Santander allocates to each project.





Satocan Júnguel Sanjuán Foundation

The Satocan Júnguel Sanjuán Foundation, belonging to the Satocan Group, has been supporting the Foundation since 2013, and in 2019 it wanted to support the "Unstoppable Cell Factory" project, and to involve its employees, who also joined forces with the cause. The Satocan Foundation donated €22,233 to the project. Thanks to this contribution, and to the efforts of all those who participated in the campaign, the "Unstoppable Cell Factory" is now a reality.

Il Caffè di Francesco, the fundraising coffee

For the second year running, Il Caffè di Francesco has run the "fundraising coffee" initiative whereby a percentage of the cost of every coffee served is donated to the fight against leukaemia via our Foundation. €12,047 were raised and applied entirely to the fight against the disease.



We would like to give our thanks to the companies and organisations who have supported us in 2019. Both those that have just joined us, as well as those who have remained constant in their support in the fight against leukaemia. Their support is an alliance of shared values, affirms solidarity and enables us to carry out our work. To all of them, THANK YOU!

Companies that have supported our awareness-raising campaign:

Chopard

Allianz 

Janssen 

 NOVARTIS

 WÜRTH

Partner companies

Forming part of the Foundation as a partner company implies a long-term commitment to combat the disease with the values and aims of the Foundation and with an annual contribution of a minimum of €1,500 per annum. We would like to express our most sincere thanks to all of them.



ABET S.L.
ENAGÁS S.A.
FUNDACIÓN CANARIA SATOCAN
JÚNGUEL SANJUÁN
KERN PHARMA S.L.



ALIMENTACIÓN Y FARMACIA S.A.
AUXADI CONTABLES & CONSULTORES S.A.
AYUDAS TECNODINÁMICAS S.L.
COMMON MANAGEMENT SOLUTIONS S.L.
DRONAS 2002 S.L.
SCHULLER S.L.



ALUMINIOS CORTIZO S.A.
ALUMINIOS SECADES S.L.
ALZAMORA PACKAGING S.A.
ASOCIACIÓN GAIA COMMERCIIUM CAFF S.L.
CENTRAL DE CATERING SERVICATERING S.L.
CONSUM S. COOP. VALENCIANA

ERRA TECNI RAM S.L.
EV. SANT JUST S.L.
FRUTOS SECOS IBIZA S.L.
FUNDICIONES Y SISTEMAS AVANZADOS S.L.
GEDESCO S.A.
HARRY BROKERS S.L.
HOUSE STANDING S.L.
INGECAL S.L.
INGENIEROS EMETRES S.L.P.
JOSÉ SALCEDO SORIAS.L.
LAMBERTS ESPAÑOLA S.L.
LERRASA HIDRÁULICA S.A.
MÓN-PIRINEU SL
ONTECNIA MEDIA NETWORKS S.L.
PAVIMARSA,S.A.
PILGRIM REST PROJECT S.L.
PINOS DEL RASO S.L.
UNASI
URBINIUM S.L.
VELLERINO SDI S.L.
VILASECA S.A.
VITOGAS ESPAÑA S.A.
VIVE ENERGÍA ELÉCTRICA S.A.
VOE S.A.

For more information, please contact our Corporate Alliance Department: **93 414 55 66**

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