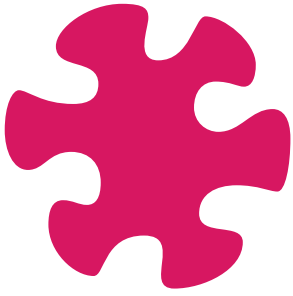




**Barcelona
PID
Foundation**

2019 Annual Report





**Barcelona
PID
Foundation**

2019 Annual Report

**FUNDACIÓ BARCELONA PER A LES
IMMUNODEFICIÈNCIES PRIMÀRIES A PEDIATRIA**

Registre de Fundacions de Catalunya nº 2.859

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An abstract graphic design featuring a vibrant red background. A large, semi-transparent pink circle is positioned in the center-left. A thick, dark blue diagonal band runs from the top right towards the bottom right. In the top right corner, a white circle is partially cut off by the blue band. The text 'Letter from the president' is written in a bold, white, sans-serif font at the bottom of the page.

Letter from the president

Dear all,

I am once again writing you this letter as President of the Foundation to present this year's annual report.

It is time, again, to sit down and look back over everything we accomplished together in 2019. And it is important to do so away from the stress of our daily lives. We are helping improve quality of life for patients with primary immunodeficiencies and their families.

Of course, it is very hard to sum up everything we've done in this letter and highlight just a few activities. So, I encourage you to watch the video "You are the missing piece", in which we explain who we are and reflect on our main goals, featuring patients and professionals.

This report also shows how the *Bufa la bombolla!* (Blow the Bubble) campaign has taken shape and how our sponsors have been working to make possible the new Health Care Park for children with PID at the Vall d'Hebron Children's Hospital.

The Foundation is more committed than ever to helping patients and families,

and raising awareness of the disease among healthcare professionals and the general public, in line with our founding aims. It is clear that none of this would be possible without collaboration from many people and organizations, as well as effective, transparent management of resources, as shown by the Foundation's yearly internal and external audits.

Nor would it be possible without the friends of the Foundation and all of you who have blown bubbles to help us raise awareness of PID!

We invite you all to join us and our campaigns, and to be "the missing piece".

Our social media is on fire, with more followers all the time. Follow us to stay up-to-date on everything we're doing.

Thanks to all of you for making it happen.

A handwritten signature in blue ink, consisting of a series of loops and a long horizontal stroke at the bottom.

Pere Soler Palacín
BCN PID Foundation President





About us

BCN PID FOUNDATION

WE ARE THE FIRST FOUNDATION IN SPAIN TO PROMOTE RESEARCH AND COMPREHENSIVE CARE FOR PATIENTS WITH PRIMARY IMMUNODEFICIENCIES.

What are PID?

Primary immunodeficiencies (PID) are a group of more than 430 genetic diseases caused by quantitative and/or functional defects in the immune response that occur predominantly in childhood. They are considered to be rare diseases because they affect 1 in 2,000 live births. Boys and girls with a PID are more susceptible to severe infections, autoimmune disorders, childhood cancer (leukaemia, lymphoma) and serious allergies. The most severe form is Severe Combined Immunodeficiency (SCID), also known as bubble baby disease.

The most severe forms of PID mainly affect children.

Who are we?

The Barcelona PID Foundation (BCN PID Foundation) is a non-profit organization established in 2014 as an initiative to improve paediatric care for PID patients and associated complications. It is made up of healthcare professionals and patients' family members. It is registered in the Government of Catalonia Registry of Foundations, entry number 2,859. The Foundation performs its functions mainly in Catalonia, although it can act in the rest of Spain, as well as on an international level.

FOUNDATION BOARD

HEALTHCARE PROFESSIONALS AND PATIENTS
JOIN FORCES FOR PID.

Foundation board

The board has 5 members, whose function is to accomplish the Foundation's goal and ensure proper management of the Foundation's assets.



Dr. Pere Soler Palacín
President



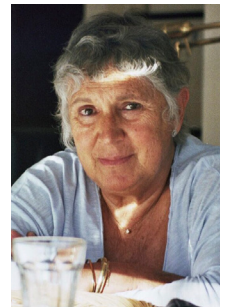
Ms. Carlota Villar Amer
Vice president



Dr. Andrea Martín Nalda
Secretary



Ms. Aurora Fernández Polo
Treasurer



Dr. Concepció Figueras Nadal
Member

The Foundation also receives support from:



Laura López Seguer
Psychological support
and activity coordinator

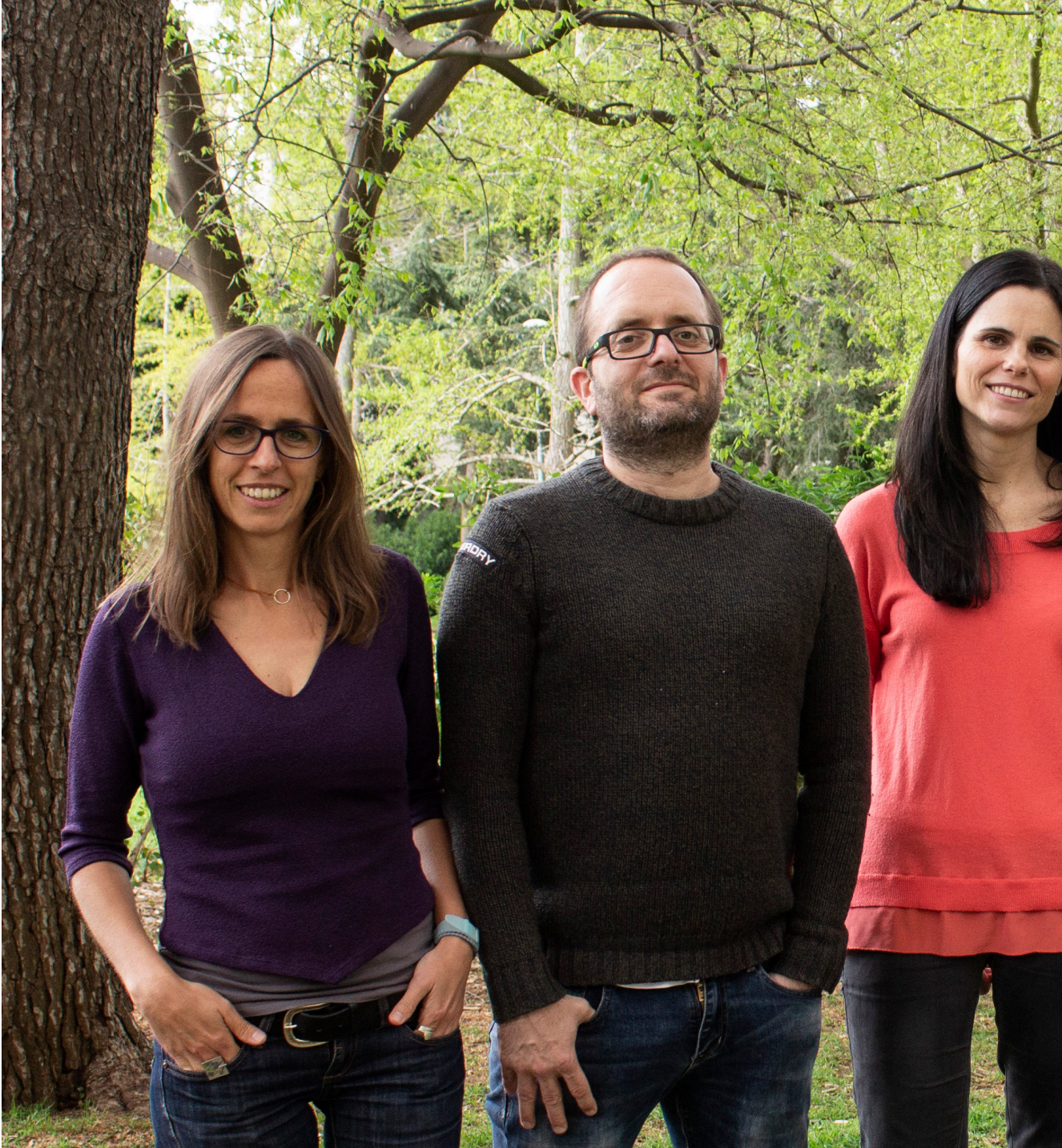


Gloria Nuñez Rueda
Coordinator of research
activities



Marina García Prat
Communication and Social
media management

FOUNDATION BOARD
BCN PID FOUNDATION TEAM





OUR VALUES

RESEARCH, TRAINING AND COMPREHENSIVE CARE ARE THE PILLARS OF OUR WORK.

Mission

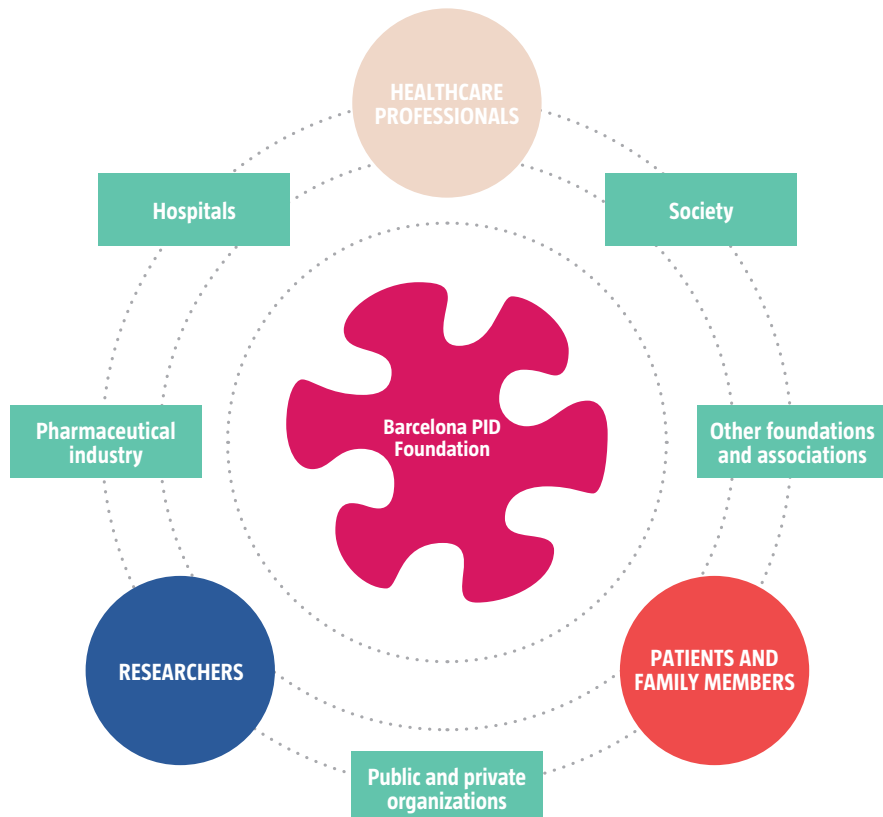
The mission of the BCN PID Foundation is to provide support for PID in order to raise awareness, promote research and care for patients and their families.

Vision

The vision pursued by the BCN PID Foundation is for children with this disease to have better quality of life during the progression of the disease and to foster all sorts of social support to achieve this.

Goals

- 1 To promote excellence in PID knowledge, study, research and awareness with regard to paediatric patients.
- 2 To promote excellence in comprehensive healthcare for PID patients to improve their quality of life through advanced actions in clinical advisory services, research, education, awareness and social care for patients and their families.
- 3 To enable and facilitate interdisciplinary connections among healthcare professionals, research groups and patient and family associations.





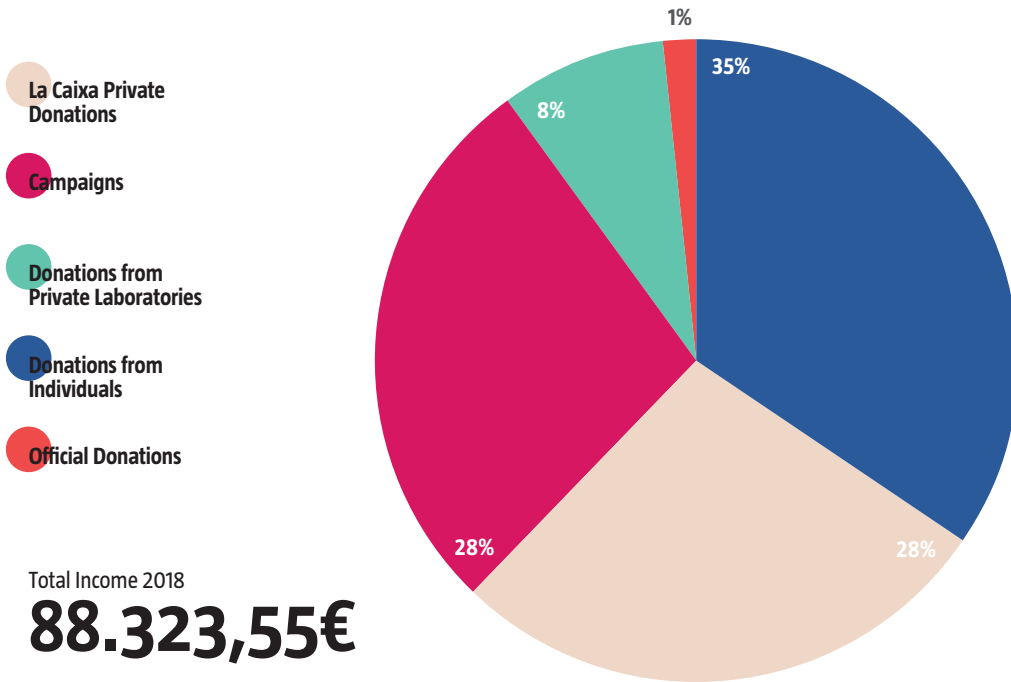
FINANCIAL INFORMATION

BCN PID FOUNDATION IS COMMITTED TO RESPONSIBILITY, EFFICIENCY AND TRANSPARENCY REGARDING ITS INCOME.

Source of income 2019

WHO HAS SUPPORTED US FINANCIALLY?

In 2019, the majority of our income came from individual donations, active campaigns and private donations from laboratories. A significant percentage comes from private donations from "la Caixa".



We are firmly committed to transparency and good governance of the Foundation. Therefore, in 2019 we submitted our accounts to GM Auditors for an accounting audit. Likewise, the financial

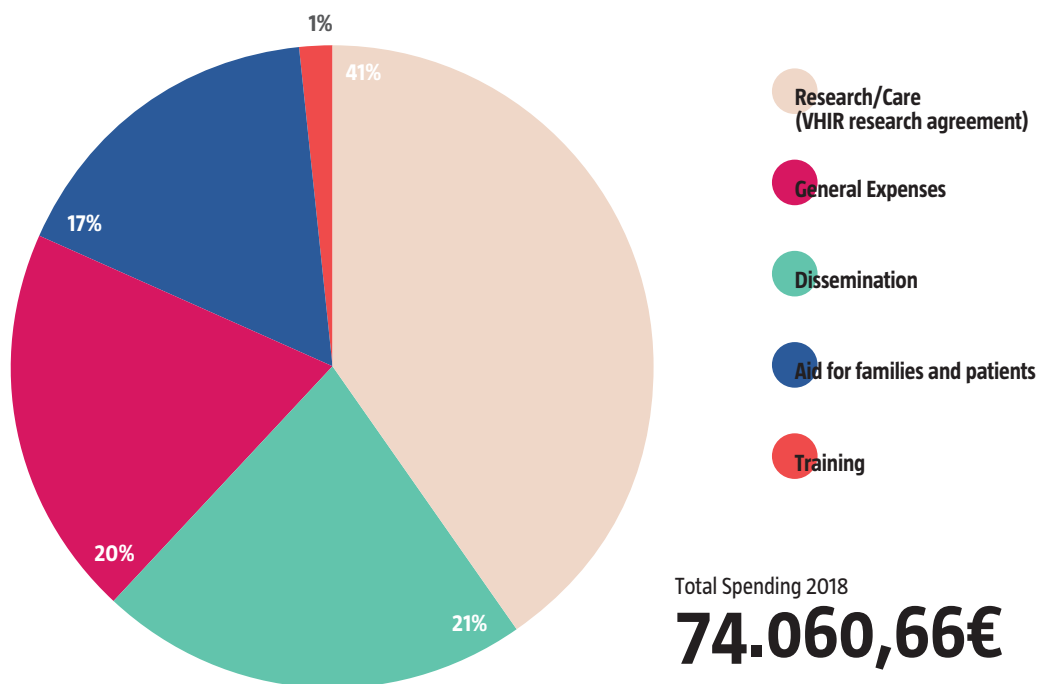
report on aid granted by the "la Caixa" Foundation to the *I have PID. I am not alone.* project was audited by KPMG. Both audits returned a positive report on our accounts.

Expenses 2019

HOW DID WE USE THE 2019 BUDGET??

In 2019, the majority of our resources went to research and dissemination. We remain committed to caring for patients and their families by providing direct aid to cover basic needs, transport and bio-psycho-social support. Plus, in 2019

the Foundation gave Marina Garcia a Jana Esteve grant for €500 so she could attend the “ESID Summer School 2019” and the “5th Workshop on Diagnostics of Immunodeficiencies”, as well as 3 grants of €500 each to attend the “ESID Juniors Retreat” held 5 to 8 April in Cambrils.



Goals 2020

For 2020, the Foundation’s main goals are:

- In comprehensive care for patients and their families, to continue the *I have PID. I am not alone.* programme.
- In research, to support the creation and optimization of a new PID laboratory at the Vall d’Hebron Research Institute.
- In healthcare, to make possible the new Health Care Park at the Vall d’Hebron Children’s Hospital, with the first JMF infusion centre in Europe.

- To continue with our campaigns to raise awareness, especially *Blow the Bubble* in collaboration with Mago Pop, Abacus and the Vall d’Hebron Campus.
 - In training, to offer more grants in collaboration with other organizations.
- Plus, we hope to encourage our partners to continue supporting us with a new campaign to attract new members.





Lines of work

INTERNAL TASKS OF THE BCN PID FOUNDATION

Research

We work to support research activities to improve scientific advances and knowledge of PID and newborn diagnosis of the most severe forms of PID.

PROJECTS

Support for newborn screening and early diagnosis of PID (PIDCAP project).

Optimization of immunoglobulin replacement treatment.

Genetic studies with mass sequencing (exoma).

Setting up PID research labs in Catalonia.

Patient care

We work to improve comprehensive healthcare for PID patients and we offer support programmes and expert medical advice for patients and PID patients' and family associations.

PROJECTS

Social support: per diems and transport.

Psychological support for patients and family members.

Adapting spaces for patient healthcare.

School projects.

Training and education

We promote PID training for doctors, students and researchers. We prepare programmes for health education and clinical counselling in PID and related infectious complications, for the national and international healthcare community.

PROJECTS

National and international training grants.

Research grants.

Educational talks.

Management

A variety of Foundation projects and functions are coordinated by our staff to improve operations and help achieve our goals.

Awareness

We design information and communication advertising strategies to raise awareness of PID and the associated infectious complications.

PROJECTS

Support for World Primary Immunodeficiency Week (WPIW).

Social, awareness and fundraising events.







Activities 2019

INSTITUTIONAL RELATIONSHIPS

NATIONAL AND INTERNATIONAL TEAMWORK
FURTHERS OUR TASK.

Vall d'Hebron Barcelona Hospital Campus

For World Rare Disease Day, the Vall d'Hebron Barcelona Hospital Campus hosted an event on 26 February at the Vall d'Hebron General Hospital, with healthcare professionals from the hospital and patients who explained their personal experiences. In the same line, on 13 June, Vall d'Hebron Barcelona Hospital Campus hosted a conference titled *"Fem un pas més? Posant el pacient al centre de la recerca de Vall d'Hebron"* (Let's take it one step further. Putting patients first at the Vall d'Hebron Research Centre), with Dr Pere Soler and Ms Carlota Villar speaking about the Foundation's role as a mediator between patients and the research centre. ¹

Also on 13 June, we made another donation to the Infection in Immunosuppressed Paediatric Patients research group at the Vall d'Hebron Research Institute (VHIR), contributing €30,000 to help them continue their research in PID. ²

On 10 December, the Vall d'Hebron Barcelona Hospital Campus hosted its Volunteer Acknowledgement Day with the slogan *"El meu temps és per a tu"* (My time is for you). This event aimed to pay tribute to all the charity groups, volunteers and foundations that are working to humanize and boost the quality of the hospital. BCN PID Foundation was there and collected the certificates for all our volunteers. ³



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Josep Carreras Foundation – Redmo

The Josep Carreras Leukaemia Foundation has updated its section on PID with extensive information like: What are PID? How are they classified? Are they common? How are they diagnosed? ...and many other aspects. This updated information was made possible by Dr Pere Soler, Dr Andrea Martin and Dr Jacques Rivière.

You can find it here: <https://www.fcarreras.org/es/cancerdelasangre/inmunodeficiencias-primarias>

¿Qué es una inmunodeficiencia primaria?



Las **Inmunodeficiencias Primarias (IDP)** son un grupo de enfermedades causadas por la alteración cuantitativa y/o funcional de distintos mecanismos implicados en la respuesta inmunológica. Las diferencias en sus manifestaciones clínico-inmunológicas, especialmente el tipo de infecciones que presentan, están relacionadas con la alteración molecular en cada caso.

Los pacientes con IDP son susceptibles a **Infecciones** de gravedad variable y que, de no ser tratadas en forma adecuada, pueden ser fatales o dejar secuelas que empeoran la calidad de vida de los pacientes. Además, actualmente aparecen cada día, más ejemplos de estas enfermedades en los cuales existe una susceptibilidad selectiva a ciertos microorganismos lo que nos lleva a estar cada día más alerta de la existencia de estas entidades.

Es muy importante tener presente que **las IDP se asocian frecuentemente a cuadros de autoinmunidad y neoplasias** (especialmente del tejido linfoide), con una frecuencia mucho mayor a la población general.

¿Cómo se clasifican?



En la actualidad se han descrito más de 350 IDP, de las cuales en más de 250 se conoce el defecto genético.

La clasificación actual fue realizada por un comité internacional de expertos, **International Union of Immunology Societies (IUIS)**, que en su última reunión bienal (2017) agrupó las IDP en los siguientes 9 grupos:

1. Inmunodeficiencias combinadas de células T y B
2. Deficiencias predominantemente de anticuerpos
3. Otros síndromes de inmunodeficiencias bien definidos
4. Enfermedades de disregulación inmune
5. Defectos del número y/o función fagocítica
6. Defectos en la inmunidad innata
7. Deficiencias del complemento
8. Trastornos autoinflamatorios
9. Fenocopias de IDP

¿Son frecuentes las IDP? ¿Cómo se diagnostican? Signos de alarma



Las IDP ocurren en más de 1/2.000 recién nacidos vivos con una gran variabilidad entre las diferentes entidades. Así, mientras el déficit selectivo de IgA es muy frecuente afectando a 1/500 personas (población caucásica), el grupo de las **inmunodeficiencias combinadas graves (IDCG)** aparecen en alrededor de 1/500.000 recién nacidos vivos.

Jeffrey Modell Foundation

Thanks to a Win grant from the prestigious “Jeffrey Modell Foundation” (JMF) based in the United States, we were able to bring its new documentary “Do Something. The Jeffrey Modell story” to Cinemes Verdi in Barcelona. The documentary chronicles the Modell family’s story of overcoming pain and their tireless fight to find answers to the premature death of their son, Jeffrey, and raise awareness of primary immunodeficiencies. After the film, the audience took part in a group discussion, blew bubbles and enjoyed some snacks by Jovent catering at Café Salambó.



Plus...

Ms Carlota Villar Amer, vice-president of BCN PID Foundation, attended a work session for PID associations hosted by AEDIP. Representatives of ABADIP, ANADIP, AEDIP and ACADIP met on 12 and 13 July to debate the scarcity of plasma, importance of benchmark centres and need for multidisciplinary teams to treat PID patients.

In September, the Carlos III Health Institute, Spanish Society for Immunology (SEI), Spanish Association of Paediatrics (AEP) and the Spanish Society of Pulmonology and Thoracic Surgery (Separ Respira) signed an agreement to carry out activities related to the Spanish registry of primary immunodeficiencies (REDIP).

We attended a work session for PID associations to debate the scarcity of plasma, importance of benchmark centres and need for multidisciplinary teams to treat PID patients.



SOCIAL, AWARENESS AND FUNDRAISING ACTIVITIES

World PI Week (WPIW)

On 21 March, World Primary Immunodeficiencies Week (WPIW) kicked off with a seminar titled “Inborn errors of central nervous system intrinsic immunity in childhood viral encephalitis” by Dr Shen-Ying Zhang, assistant professor of Clinical Investigation at Rockefeller University (USA). ¹

On 25 April, *Blow the Bubble* was in the hall at the Vall d’Hebron Children’s Hospital, bringing together friends, acquaintances and new faces to blow and buy bubbles. Thanks to all of them, our bubbles have spread even further, raising awareness of these rare diseases. ^{2 3}

As we do each year, BCN PID Foundation co-sponsored two PID training courses for residents and nursing staff, coordinated by the PID group at the Catalan Society of Paediatrics and the Catalan Immunology Society:

- 9th annual PID training course for residents.
- 5th PID course for nursing staff. ⁴



Bufa la bombolla

On 12 March, we presented the *Bufa la bombolla!* (Blow the Bubble) campaign at the Abacus shop on Carrer Còrsega, Barcelona. The event was led by Aurora Fernández, representing the BCN PID Foundation; Dr Pere Soler, head of the Paediatric Infectious Diseases and Immunodeficiencies Unit (UPIIP) at the Vall d'Hebron Barcelona Hospital Campus; Núria Tomàs, mother of Martina and founder of the Blow the Bubble project; and Ramon Pérez, head of Marketing for Abacus. ¹

The event raised awareness of primary immunodeficiencies (PID), the Foundation's goals, and gave participants a first-hand look at how the #BufaLaBombolla campaign got started, with its patron Antonio Díaz – El Mago Pop. The event finished with everyone blowing bubbles. ²

Year-11 students at Escoles Fonlladosa, in Malgrat de Mar, took part in two solidarity activities with the *Blow the Bubble* campaign at the centre. On 5 May, Malgrat residents took part in a charity walk, a 10k scavenger hunt and a craft and cake sale, with items made by the students. On the run up to the day, the year-11 students spoke to the other classes at the school to raise awareness of this disease and help them understand that, together, we can make a big difference. The activities held raised a total of €1,015. These funds will go to fund PID research projects through the Foundation. ^{3 4 5 6}

Blow the Bubble was at several events in 2019, including Festivalot in Girona, the Taral·la fair in Granollers,

and various charity events in Malgrat de Mar and all over Catalonia. Plus, Abril and Ot celebrated their birthdays with bubbles from *Blow the Bubble* to raise money for primary immunodeficiencies (PID) research at the Vall d'Hebron Barcelona Hospital Campus.

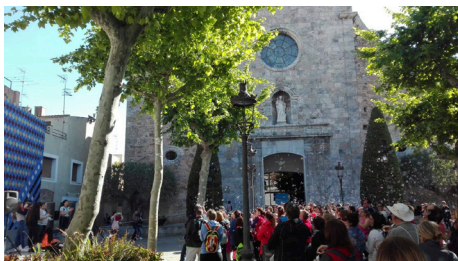
The campaign featuring Antonio Díaz – El Mago Pop receives support from Abacus, which sells the bubbles at its shops for €2.50. These funds go towards PID research at the Vall d'Hebron Barcelona Hospital Campus. As of late 2019, more than 15,000 pots of bubbles had been sold and the campaign had raised over €23,000 total. Want to join the campaign? Purchase your pot of bubbles and share pictures or videos of you blowing bubbles wherever you go on social media with the hashtag #BufaLaBombolla. ⁷



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Dinner at TIBU-RON beach club

On 8 August, our friends at the TIBU-RON Beach Club in Castelldefels presented us with a cheque for €4,500 raised at the 2018 dinner. These funds will go to projects to improve quality of life for PID patients, and to advance research into these rare diseases. As is now traditional, in 2019 we held our beachside dinner on 1 September with over 175 people enjoying a

charity dinner at the Tibu-Ron beach club, raising a total of €4,000.

The charity dinner at the Tibu-Ron was first held in 2016 and has become a not-to-be-missed event for the BCN PID Foundation. The four Tibu-Ron dinners held have raised a total of €13,000 for the Foundation, which goes to primary immunodeficiencies research.



Solidarity Christmas Fair 2019

New this year, to kick off the Christmas Solidarity Fair, we hosted a charity cooking class on 18 November, thanks to support from Fondo de nevera and Gastroshows. This event gave 20 participants the chance to enjoy a masterclass and then have lunch. 1



The Christmas Solidarity Fair took place from 28 November to 5 December at the shop Merc&Cia and, new this year, participants could enter a charity raffle on the first day of the fair. Everyone who attended got sparkling wine and could enter a draw to win exclusive products, dinners and wines. Once again this year, the Christmas Solidarity Fair was a resounding success thanks to all our partners, volunteers and everyone who came out to do their part. We are very excited to announce that we hit a new record in terms of funds raised, all of which will go towards promoting PID research projects at the Vall d'Hebron Barcelona Hospital Campus.



Plus...

On 6 February this year, we received a visit from Mariona and Candela Costea, who presented us with the €210 they had raised by selling charity bracelets. ¹

On 25 May, HP invited us to attend HP Barcelona Charity Day, where we explained who we are, what we do and raised awareness of the *Blow the Bubble* campaign making huge soap bubbles! At the end of the event, HP presented us with a €13,400 cheque. These funds will go towards humanizing the new Health Care Park at the Vall d'Hebron Children's Hospital. ^{2 3}

Former students at Jesuïtes Casp Sagrat Cor de Jesús school chose the BCN PID Foundation for their annual charity dinner, organized by the AMPA CASP parents' association. On 6 June, 200 people filled the school courtyard with bubbles at the school's 4th annual charity dinner. The event was hosted by journalist Lluís Payarols and Dani Alegret of the band "Els Amics de les Arts". ^{4 5}

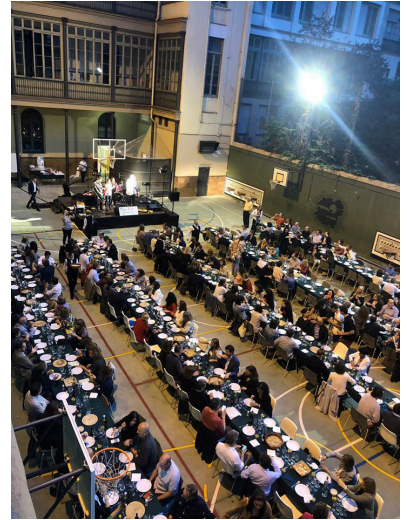
On 6 July, BCN Shopping&Shooting, an initiative of the BCN Comerç Foundation, raised €8,620 for the new Health Care Park at the Vall d'Hebron Children's Hospital, which will improve the wellbeing of children and their families. Dr Pere Soler, president of the Foundation, was presented with a symbolic cheque representing the donation. The new Health Care Park will boost patients' quality of life and safety by creating a separate area for PID patients and individual rooms for patients with contagious diseases and for administering medications without having to be hospitalized. Plus, everything is being designed and decorated in order to make the children and their families more comfortable. ⁶



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TRAINING AND EDUCATION

WE ARE COMMITTED TO TRAINING THE PROFESSIONALS WHO CARE FOR PID PATIENTS IN ALL AREAS TO FACILITATE EARLY DIAGNOSIS.



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Courses, congresses and conferences

Thursday 7 February, at the Paradigm Forum promoted by Takeda in Madrid, Dr Pere Soler, head of the Paediatric Infectious Diseases and Immunodeficiencies Unit (UPIIP) at the Vall d'Hebron Barcelona Hospital Campus and president of the Foundation, moderated a panel discussion that featured all the associations of patients with PID in Spain, including Ms Carlota Villar, vice-president of the Barcelona PID Foundation. This forum focused on newborn SCID screening, the Spanish PID registry, research and training. From the panel, a document was created to collect requests from patients in Spain for professionals and institutions. ¹

On 21 March, World Primary Immunodeficiencies Week (WPIW) kicked off with a seminar titled “Inborn errors of central nervous system intrinsic immunity in childhood viral encephalitis” by Dr Shen-Ying Zhang, assistant professor of Clinical Investigation at Rockefeller University (USA). ²

From 5 to 8 April, the ESID Juniors’ retreat was held in Cambrils, Tarragona. This event aimed to strengthen the Juniors PID network by sharing educational and social activities with the youngest members of the European Society for Immunodeficiencies (ESID) who attended the latest summer schools. With the philosophy of a “Junior 4 Junior” meeting, participants took part in an exciting programme that got everyone involved. The Barcelona PID Foundation collaborated with the ESID Juniors’ retreat, providing 3 travel grants in collaboration with ESID. ³

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From 22 to 24 May, the 1st Argentine Congress of Allergy and Immunology in Paediatrics was held in Buenos Aires. Dr Pere Soler, head of the UPIIP and president of the Barcelona PID Foundation, was invited to speak at the event, with presentations on genetic studies conducted with CVID patients, deregulation and Hyper IgE syndromes, and diagnostic protocols for PID. The congress was part of a week of congresses and conferences hosted by the Argentine Paediatric Society that brought together more than 4,000 paediatricians and paediatric residents in Argentina with national and international speakers. ⁴



On 28 November, at the Vall d'Hebron Barcelona Hospital Campus, we had the opportunity to hear Dr Yenan Bryceson of the Karolinska Institutet in Stockholm, Sweden, give a conference titled "Hemophagocytic Lymphohistiocytosis: signalling processes and activation of cytotoxic lymphocytes and NK". ⁵

VHIR SEMINAR AND CONFERENCES

Nov 19
28

Hemophagocytic Lymphohistiocytosis: signaling processes and activation of cytotoxic lymphocytes and NK

Dr. Yenan Bryceson

Center for Hematology and Regenerative Medicine. Department of Medicine, Karolinska Institutet. Karolinska University Hospital - Stockholm - Sweden

DATE: 28/11/2019

STARTING TIME: 15:30 h

END TIME: 17:00 h

LOCATION: Auditorium 10th floor, General Area



5

Course for residents and nurses

As we do each year, the BCN PID Foundation co-sponsored two PID training courses for residents and nursing staff, coordinated by the PID group at the Catalan Society of Paediatrics and the Catalan Immunology Society:

- 9th annual PID training course for residents. ⁶
- 5th PID course for nursing staff.

6



SOCIAL SUPPORT (*I HAVE PID. I AM NOT ALONE.*)

I have PID. I am not alone.

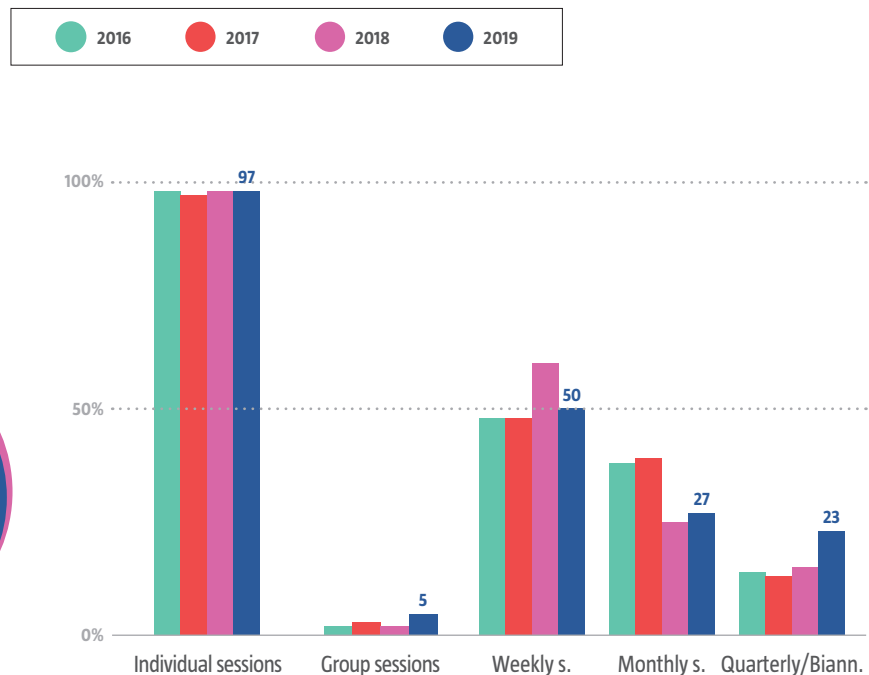
The *I have PID. I'm not alone.* project was developed to focus on the emotional wellbeing and quality of life of children with PID. In 2019, 87 patients and 151 family members took part in this project. A total of 510 visits were made to help them adjust to living with a chronic illness and to cover various needs of immunocompromised children and their families. ¹

We also hosted group activities, including a visit to a laboratory and a self-care workshop. Under the *PID in schools* programme, we carried out activities at 3 educational centres where some of our patients study. The programme is coordinated by Ms Laura Lopez Seguer, a psychologist who has recently joined the UPIIP. Laura provides psycho-social

support for PID patients and their families at the Vall d'Hebron Barcelona Hospital Campus and coordinates all the activities in this project. ²

She has provided psycho-social support to 20 children on long hospital stays, with weekly (or more frequent) visits, adapting to the severity of their health and emotional suffering. Additional support for the child and their family is provided in cases of serious clinical complications and palliative care.

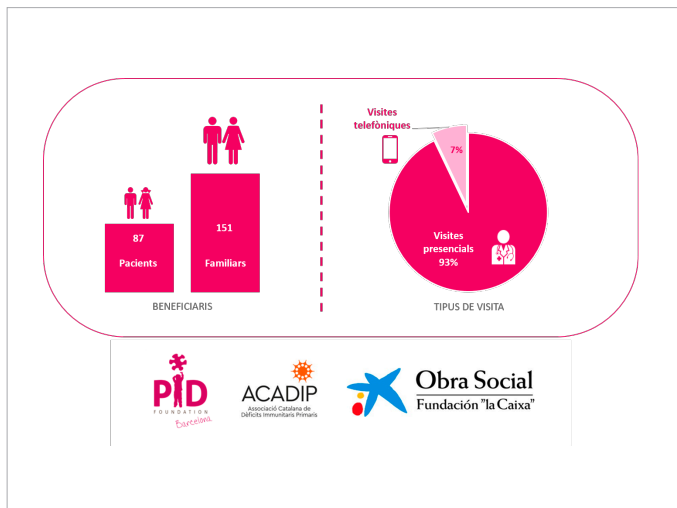
The project has been carried out using a comprehensive support model and coordinated with the multidisciplinary team and the two organizations involved: ACADIP and Barcelona



PID Foundation. It was made possible thanks to collaboration from the "la Caixa" Foundation and support from the Government of Catalonia and the Barcelona Regional Council.

Overall feedback has been very positive from all participants. Being able to focus on patients' and families' psychological and personal wellbeing has led to better acceptance of diagnosis, improved treatment adherence and, therefore, improved quality of life for the children.

In 2019, 107 quality of life questionnaires were analysed (PEDS QL 4.0), 53 from paediatric patients and 54 from family members (all part of the *I have PID. I am not alone.* project), who rated their perception of quality of life and fatigue taking into account the PID diagnosed. The data was included in a research project that will be published in the Journal of Clinical Immunology in 2020. ³



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Health-Related Quality of Life and Multidimensional Fatigue Scale in Children with Primary Immunodeficiencies

Saida Ridao-Manonellas¹ · Anna Fàbregas-Bofill¹ · Gloria Núñez-Rueda¹ · Míriam González-Amores¹ · Marina García-Prat¹ · Laura López-Seguer¹ · Jacques G. Rivière¹ · Andrea Martín-Nalda¹ · Natalia Mendoza-Palomar¹ · Susana Melendo-Pérez¹ · Pere Soler-Palacín^{1,2}



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PID in schools

Thanks to the "la Caixa" grant for the *I have PID. I am not alone.* project, the Foundation is able to carry out the *PID in schools* activity. This activity was created to share the experience of children with PID with their schoolmates and teachers. The goal is to raise awareness of these chronic rare diseases in schools, to make the whole school community aware, while also helping the children develop values of cooperation and solidarity through actions to help spread the word about PID.

In 2019, the Barcelona PID Foundation visited 3 schools in Catalonia that have PID patients, between the ages of 10 and 12.

– On 28 March, we led an activity with 75 year-5 students at CEIP Quatre Vents de Blanes, where Xavi, who has PID, is a student. ¹

– On 13 May, we led an activity with 50 year-5 students at Escola La Palmera in Barcelona, where Lola, who has PID, goes to school. ²

– On 11 November, we led an activity with 110 year-6 students at Escola Pia de Terrassa, where Pol, who has PID, studies. ³

Patient workshops

Through the *I have PID. I am not alone.* project, on 7 January we hosted a new workshop for children with PID to work on self care and learn how to take care of their physical and emotional wellbeing. Our goal was also for the group activity to be a fun way for them to share with other children with PID. ⁴

On 16 April, we held a workshop with children with PID at the pharmaceutical laboratory at the Vall d'Hebron Barcelona Hospital Campus. We hosted two activities to learn how they make creams and syrups. During the workshop, participants got the chance to visit the pharmaceutical laboratory and see some of the instruments, materials and techniques used to make medicines. The children got to be assistant pharmacists and had loads of fun. ⁵

On 23 July, we hosted another group activity for children with PID and their siblings and friends: a Summer Karaoke session! The activity aimed to give the children a fun experience together, strengthen their bonds and let them enjoy singing their favourite songs. ⁶



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Collaborations/donations

In 2019, Father Christmas came early thanks to Ona Gràfica. The little, and not so little, ones got a chance to enjoy this toy machine throughout January. All the money raised with this toy machine went to primary immunodeficiencies research at the Vall d'Hebron Barcelona Hospital Campus. ^{1 2}

Mercedes-Benz Autoliga Barcelona and the Barcelona PID Foundation delivered two electric Mercedes-AMG GT Roadsters to the Vall d'Hebron Barcelona Hospital Campus to make the ride to get tests done at the hospital more fun for the youngest hospitalized patients. ³

Colleagues at Éditions Larousse made two donations of children's books in 2019: the first for the toy machine and the second for the Welcome Kits given to hospitalized PID patients at the Vall d'Hebron Barcelona Hospital Campus. ⁴

Cavall Fort, a pioneer and benchmark in publishing children's magazines in Catalonia, wanted to once again take part in the *I have PID. I am not alone.* project promoted by the Barcelona PID Foundation and ACADIP. Since August, patients in hospital, who have frequent appointments or have to undergo treatment at the Vall d'Hebron Barcelona Hospital Campus outpatient clinic can read stories and articles in Tatano and Cavall Fort magazines, making the hours or days in hospital go by a bit faster. The publishing house also gave us stories and books for the children in hospital. This educational material is part of the Welcome Kits

our hospitalized patients receive to make their stay more pleasant. ⁵

The Barcelona PID Foundation received a €9,500 grant from the Montbau branch of "la Caixa" (CaixaBank). The collaboration between these two entities has been ongoing in recent years, focusing on the project to support hospitalization of children with PID. With this grant, immunocompromised patients and their families have access to food vouchers while the children are in hospital and transport grants to cover travel to hospital. Plus, to make their stay more pleasant and entertaining, we offer all hospitalized patients a rucksack with stories, toys and educational materials to distract them, as well as a service to loan out tablets and cover other basic needs. Helping cover these basic needs makes a big difference in quality of life for the families. Little things can make their stay more bearable and humanize their care. ⁶

Once again this year, the "la Caixa" Foundation has awarded ACADIP and the Barcelona PID Foundation €60,000 for the *I have PID. I am not alone.* project.



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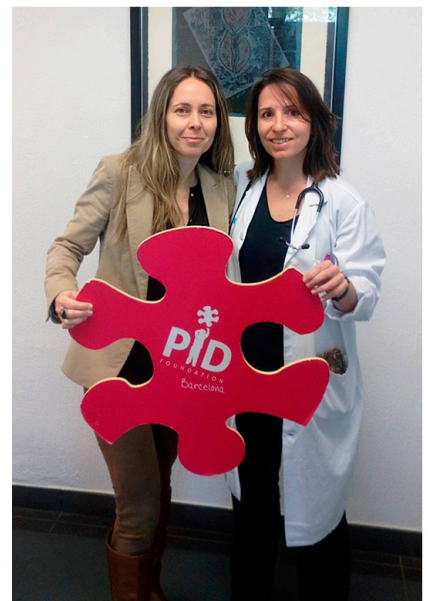


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RESEARCH

WE SUPPORT RESEARCH TO IMPROVE DIAGNOSIS AND TREATMENT OF PID PATIENTS.

Newborn screening for SCID

Derek, the first baby with Severe Combined Immunodeficiency (SCID) to be detected through newborn screening, successfully received a stem cell transplant at the Vall d’Hebron Barcelona Hospital Campus and is now healthy. Catalonia was the first public health system in Europe to incorporate newborn SCID screening into the blood tests done on newborns, in 2017. ¹ At the press conference held at Vall d’Hebron Barcelona Hospital, Catalan Minister of Health Alba Vergés highlighted the importance of newborn screening for Severe Combined

Immunodeficiencies: “Experts said bubble baby cases were being caught too late, when they had already had infections, their vital organs had been affected and they were very weak. The survival rate in these cases is between 40% and 60%. So, early diagnosis is key to survival. The earlier the diagnosis, the better the chances of surviving. That’s why newborn screening is so important.” ²

The news got lots of support from the press. We’ve included some examples on page 51.



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PIDCAP

The project submitted by the Paediatric Infectious Diseases and Immunodeficiencies Unit (UPIIP) at the Vall d'Hebron Barcelona Hospital Campus with Azienda Ospedaliera Ordine Mauriziano di Torino in Italy, and Ghent University Hospital in Belgium, won the 2019 VBHC Dragons Endorsement. This VBHC award recognizes inspiring initiatives that take a fundamentally new approach to create excellent value for patients in terms of real results, real connections and a shared language. Each year, an excellent initiative is awarded the

prestigious VBHC prize, chosen by a panel of world-renowned judges and announced by honorary doctor Michael Porter, president of Harvard University. We continue working to promote early diagnosis of PID.



Biobank

The PID biobank now has 300 samples from paediatric patients with Primary Immunodeficiencies. This biobank, the first of its kind in Catalonia, has a collection of samples from PID patients, which means these samples are available at any time for functional and/or genetic studies on these diseases, in Spain or in collaboration with international centres. This project of the Vall d'Hebron Research Institute (VHIR) has received support from several organizations, including our Foundation, ACADIP and the ALL WITH DÍDAC (fundraising campaign led by the Gauxax-Fuenllana family that launched and disseminated the project).



SUPPORT FOR ACTIVE CAMPAIGNS

Bufa la bombolla! **(Blow the Bubble!)**

The *Blow the Bubble!* campaign was created by Martina's parents, a 7-year-old girl with primary immunodeficiency (PID). Based on their daughter's illness and in order to raise general awareness of these little-known conditions, they launched the *Blow the Bubble!* campaign, which seeks to raise funds for PID research by selling bubbles. As of the end of 2019, this initiative had raised over €23,000 for PID research and made donations to our Foundation and to VHIR.



+ Info! www.bufalabombolla.org

Help children like Jana - Teaming

Would you like to help children with a PID, like Jana? You can with just €1 a month! With this mini-donation, you will be helping improve quality of life for children with PID.

The *Help children like Jana teaming*, which was started by the Esteve Cols family in 2014, donated €951 to our Foundation in 2019. With these donations, we give out the "Jana Esteve" grants to attend meetings and training courses on PID.



+ Info! www.teaming.net/ayudadaninoscomojana

All with Dídac

The *All with Dídac* campaign was created 5 years ago by the parents of Dídac Gauxax, a child diagnosed with Severe Combined Immunodeficiency (SCID). The purpose of this campaign is to raise funds to raise awareness of primary immunodeficiencies (PID).

In the last two years, *All with Dídac* has raised more than €9,000, which went to award the first Juan Gauxax grant in 2016 (in honour of Dídac's older brother, who died of SCID 7 years ago) to Dr Jacques Rivière at CHU Sainte-Justine Hospital in Montreal, Canada. This annual grant is intended for training in a hospital or PID specialized centre, in Spain or abroad, for a minimum of 2 months and a maximum award of €1,500.

In 2019, the campaign raised €800 for the Foundation through events like the Christmas concert of the Assumpció de Vinaròs Children's Choir and selling crafts throughout the year.

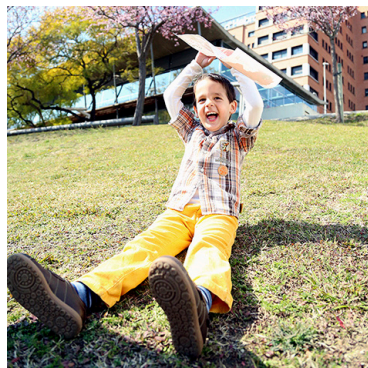


CASTELLANO

Pots contactar amb nosaltres

ivanjanenc@gmail.com

Tots amb Dídac!



+ Info!

www.totsambdidac.com

PRESS, SOCIAL MEDIA

La Marató de TV3, with rare diseases

In 2019, La Marató de TV3 focused on Rare Diseases. A group of 7,000 diseases, including PID, that affect patients in a wide variety of ways, including mobility, the nervous or immune systems, metabolism, hormone balance, among others. As they are

rare, they need more dissemination, education, funding and research. Marc, a patient with Chronic Granulomatous Disease who had a stem cell transplant at the Vall d'Hebron Barcelona Hospital Campus, had the opportunity to share his experiences on the programme.



News in the media or interviews

On Saturday 30 March, La Sexta helped raise awareness of rare diseases and the specific hospital units to treat them, which are essential in diagnosing them and making sure they aren't forgotten. The news story featured Nil, a UPIIP patient with PID, and Dr Andrea Martín-Nalda, who works at the UPIIP and is secretary of the Foundation. ①

Also in the press, the news of the first bubble baby detected through newborn screening who successfully received a stem cell transplant at the Vall d'Hebron Barcelona Hospital Campus and is now healthy. Here are some examples. ②

“Now I look at my son and it seems like he was never even sick” - First ‘bubble baby’ saved thanks to newborn blood tests spends his first Christmas at home. Article in ARA newspaper. ③

①



Andrea Martín

■ Unidad Inmunología pediátrica Hospital Vall d'Hebron

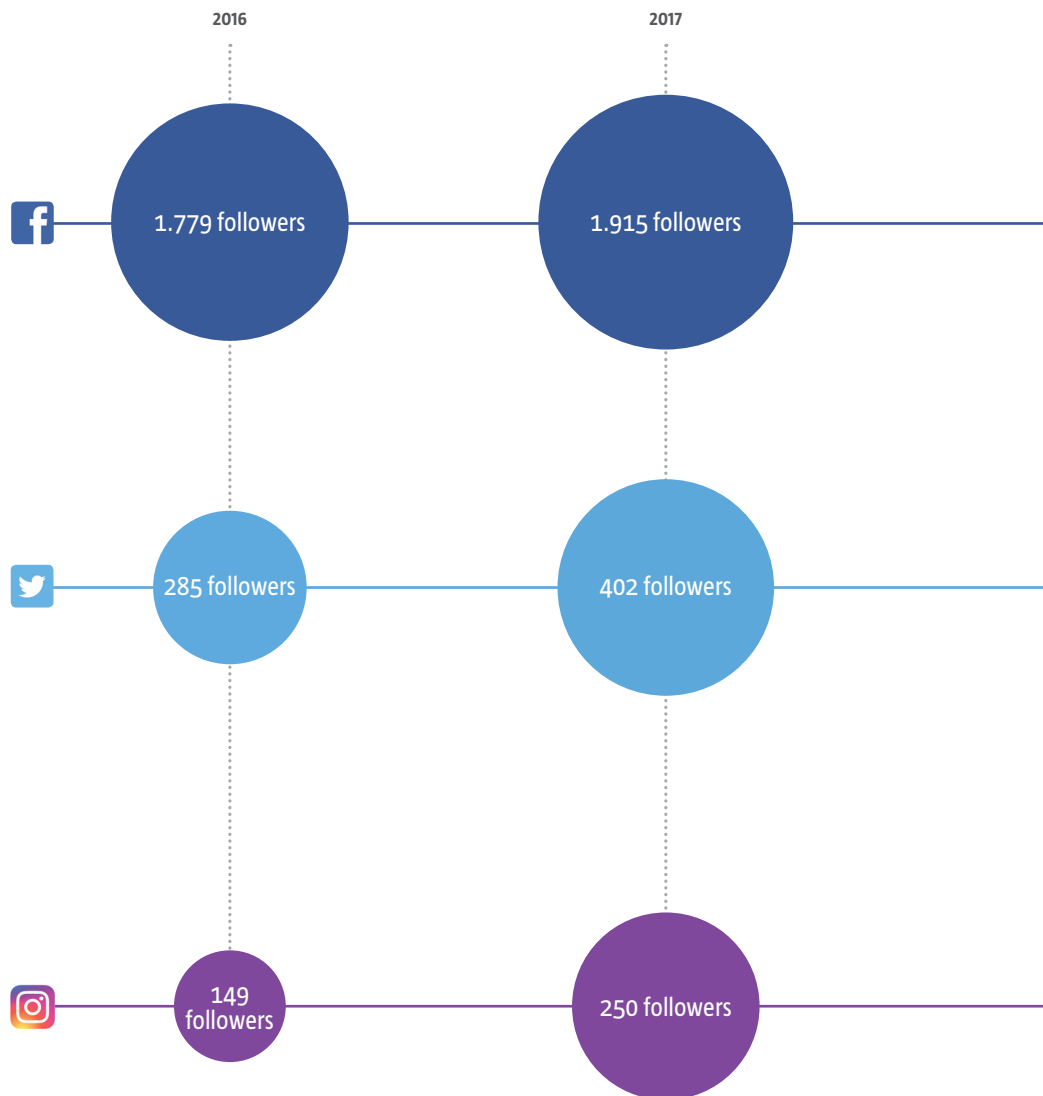
③



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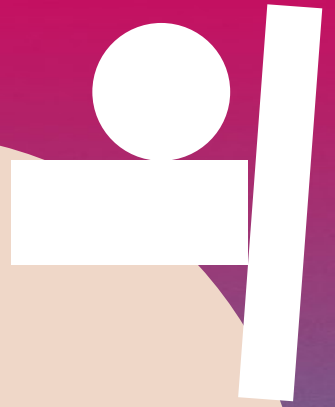
Followers on social media

On social media, we have seen a great increase in followers on Twitter and Instagram over the past year.









Friends of Barcelona PID Foundation

BECOME A FRIEND OF PID. YOU ARE THE MISSING PIECE!

To raise awareness of PID, we've kicked off the campaign *Fes-te amic de les IDP. Ets la peça que falta* (Become a friend of PID. You are the missing piece) featuring well-known athletes, entertainers, journalists, etc. who take a picture with a puzzle piece in support of our Foundation and children with PID. This year, we've added 7 new "pieces" to our puzzle, which now includes more than 100 "Friends of the BCN PID Foundation" who support us



Carlos Sadness - Singer/songwriter and illustrator



Jordi Martínez Vendrell - Actor and clown



Núria Mendoza Miralles - Member of the first team at Real Sociedad de Fútbol



Dr. Shen-Ying Zhang - Laboratory of Human Genetics of Infectious Diseases The Rockefeller University, USA



Immunology Service - Vall d'Hebron Barcelona Hospital Campus

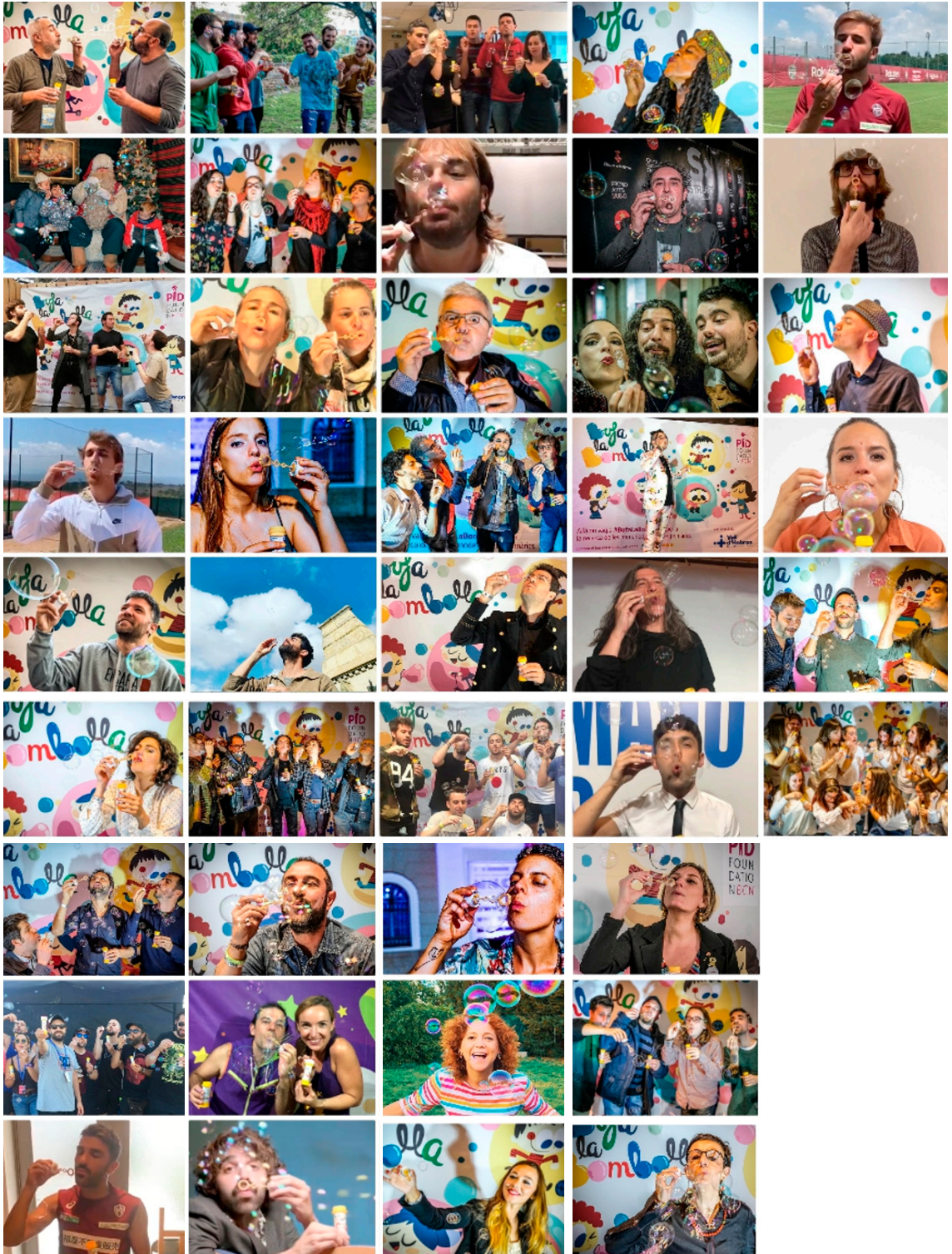


Melchior, Gaspar and Balthazar - The three Magi



Ms. Alba Vergés - Catalan Minister of Health

Many people and organizations have already joined the *Blow the Bubble* initiative organized by Martina's parents. This initiative works to raise awareness and promote research on these diseases at the Vall d'Hebron Barcelona Hospital Campus and improve quality of life for many children. All the proceeds from the charity campaign go to the Barcelona PID Foundation. You can find our bubbles at any Abacus shop or in their online store. Will you join us?



From left to right starting in back: Xuriguera i Faixedas, Txarango, Tot es mou (TV3), The Sey Sisters, Sergi Samper, Santa Claus, Roba Estesa, Quim Masferrer, Pemi Fortuny, Óscar Dalmau, Obeses, Núria Picas, Màrius Serra, Marina Paje-Israel Fernandez-Victor Rosell, Marc Parrot, Marc Muniesa, Magalí Saré, l'Últim Indi, Lildami, Judit Nedermann, Joan Rovira, Joan Dausà, Guillem Roma, Gerard Quintana, Els Catarres, Elena Gadel, Elèctrica Dharma, Doctor Prats, El Mago Pop, Cor Geriona, Els Amics de les Arts, Eloi Vila, Clara Peya, Alba Vergés, El Senyor Peix, El Pot Petit, Dàmaris Gelabert, Buhos, David Villa, David Verdaguier, Beth Rodergas, Carme Ruscallada.





Partners and acknowl- edgments



PARTNERS

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Institutions, Hospitals and Research Institutes



Vall d'Hebron Campus Hospitalari



Ministry of Health.
Government of Catalonia



Barcelona Regional Council

Societies, Foundations and Patients' Associations



Jeffrey Modell Foundation



ACADIP



ESID

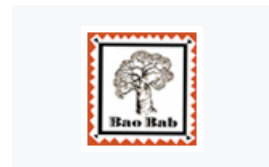
Companies and other private entities



"la Caixa" Foundation



Cuckoo Fruits



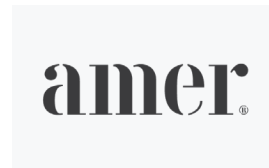
Bao Bab



Elias Mora



Cava Colet



Amer Gourmet



SSS Xarcuteria Subirats



Bramona



Pago de los Capellanes



Tibu-Ron



RCD Espanyol



Som-hi!



Chocolates Solé



Fundació Vallformosa



Zabriskie



Ona Gràfica



Larousse



UE Castelldefels



CTAG Castelldefels



Cines Verdi

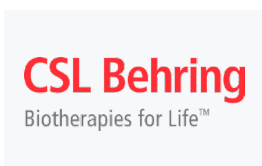


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Grifols



Takeda



Binding Site

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Jordina Molas – Jordi Masso – Alba Parra.

You are the missing piece!

Collaborate with the project!

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Tel: 934 893 140, from 9 to 18, Mon - Thu

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