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¡Happy New Year 2018!

I am pleased to present the Spanish VHL Alliance 2017 newsletter, which includes the activities developed by our association throughout the year. As you know, we are an entity of **Public Utility**, recognition granted by the Ministry of Interior in **2012**. You can check their announcement in the BOE, by clicking [this link](#).

We continue investing in research, for which we need everyone's collaboration. Thanks to everyone, we can say that the cure for VHL disease is getting closer everyday.

Thank you for your support, a warm hug,

Susi Martínez

Spanish VHL Association President

Designation of propranolol as the first orphan drug for von Hippel-Lindau disease

As important piece of news of the year 2017 and at the presentation of this newsletter, it is necessary to highlight that, at the beginning of the year, the [European Medicines Agency \(EMA\)](#), granted **the first designation to orphan drug for the VHL disease**, worldwide, for an old and widely known drug, "**propranolol**".

This designation was based on the results obtained in **two researches financed by our association**: Firstly, the one carried out at the Center for Biological Research of the CSIC (abbreviated CIB) **with crops from surplus surgeries**, under the direction of Dr. Luisa María Botella. Secondly, the **Ophthalmology clinical trial** of the Hospital Complex of Toledo, for **the treatment of retinal**

hemangioblastomas with propranolol, under the direction of **Dr. Rosa M^a Jiménez Escribano**.

To grant the designation, the competent European health authorities (EMA), evaluate the results of the effectiveness studies (in vitro and in patients) as well as safety, and if the evaluation is positive, the designation is granted *in order to encourage the continuity of the research with said drug*.

To date, this is **the first and therefore the only designation of an orphan drug for VHL disease worldwide**. This has also been possible thanks to the collaboration of the Health Service of Castilla-La Mancha (SESCAM) to carry out the clinical trial, and the financial support of Bodegas Protos, Port Aventura, Iberdrola Foundation and all partners and anonymous people who donated to our cause.

I want to express our special thanks to those patients and their relatives who, during these four years, have collaborated in the donation of surplus tumors when they had surgeries.

Thanks to these donations, we now have a small **collection of VHL crops in the CIB 109 laboratory of the CSIC** with which we are carrying out tests with different drugs, and thanks to which we are already working on obtaining an animal **model of the disease (mouse)**.

You can find [complete information of the designation in the website of EMA](#).

What is an Orphan Drug?

According to the definition contained in **Article 3 of Regulation 141/2000 of the Parliament and the European Council**, a drug will be declared an orphan drug if its promoter can demonstrate that said product:

a) it is intended for the diagnosis, prevention or treatment of a **condition that endangers life or entails a chronic disability and that does not affect more than five people in every ten thousand** in the Community at the time of submitting the application; or it is intended for the diagnosis, prevention or treatment, in the Community, of a condition that endangers life or entails serious disability, or of a serious and chronic condition, and **that it is unlikely that, without incentives, the marketing of said medication in the Community would generate sufficient profit to justify the necessary investment**; and

b) that there is no satisfactory method authorized in the Community for diagnosis, prevention or treatment of said condition, or that, if there is one, the medicine will bring a considerable benefit to those who suffer from that condition.

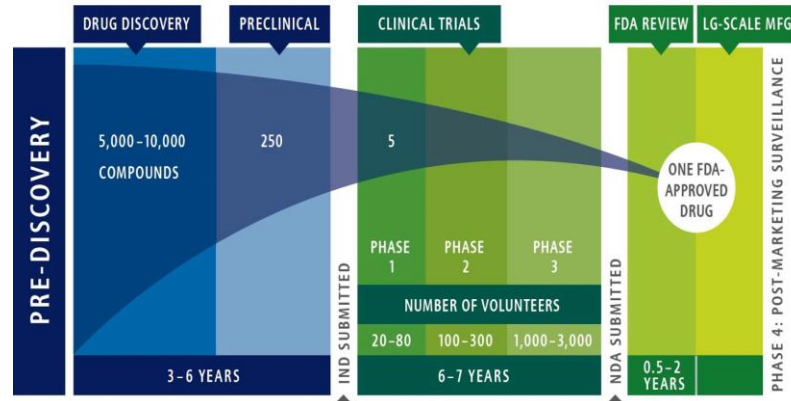
Therefore, **the orphan drug designation aims to promote the development of drugs** for "forgotten", rare, or infrequent diseases in "rich" countries, such as malaria. This is so because the future clients of the drug are few, and there is no commercial interest... it is not expected that the commercialization would generate sufficient income to justify the investment in the development of the medicine.

In EUROPE, the **orphan** designation includes a series of incentives:

1. **Commercial exclusivity for 10 years**, from its commercialization. *Another orphan drug can only be approved for the same indication if it provides a considerable clinical benefit.*
2. **Technical advice** from the European Medicines Agency (EMA) for the preparation of the clinical trial protocol.

3. Access to the **centralized marketing authorization procedure**.
4. Additional incentives, such as administrative assistance and tax benefits.
5. Funds for research and promote R+D.

Drug Discovery and Development: A LONG, RISKY ROAD



Source: Pharmaceutical Research and Manufacturers of America

What is drug repurposing?

There are **old medicines**, whose efficacy and safety have been widely demonstrated, which were **initially developed for the treatment of a frequent disease, and subsequently demonstrate effectiveness in another disease**. In this case, we are talking about **repurposing**, because the medication could be used to treat a new pathology (example: propranolol in VHL, bazedoxifene in HHT).

The *difficulties* of drugs repurposing when the **promoter is non-commercial** (as is our case, in which the association is the main stakeholder, and there is no economic interest, but health) are, above all, *economic*.

To **obtain authorization for its use in treating a different condition**, it is necessary to carry out many procedures and a clinical trial that supports it, which costs a lot of money. Most associations have a lack of infrastructure and knowledge necessary to launch a clinical trial.

The same happens with **independent researchers, those who work in public centers, universities... they also do not have the means**. Because the

pharmaceutical companies are the ones that know how to develop these tests as part of their usual work, it has been necessary to create incentive policies aimed at them, at an international level.

Our Spanish VHL Alliance is an exception in the world of clinical trials, having been the promoter of a **non-commercial, independent trial** (clinical trial identified with [EudraCT Nº: 2014-003671-30](#)). Another recent example of an association promoting its own clinical trial is [HHT association](#). In 2017 launched its own clinical trial to repurpose another drug, and they are now obtaining positive results ([EudraCT trial: 2016 -003982-24](#)).

Our research and its financing

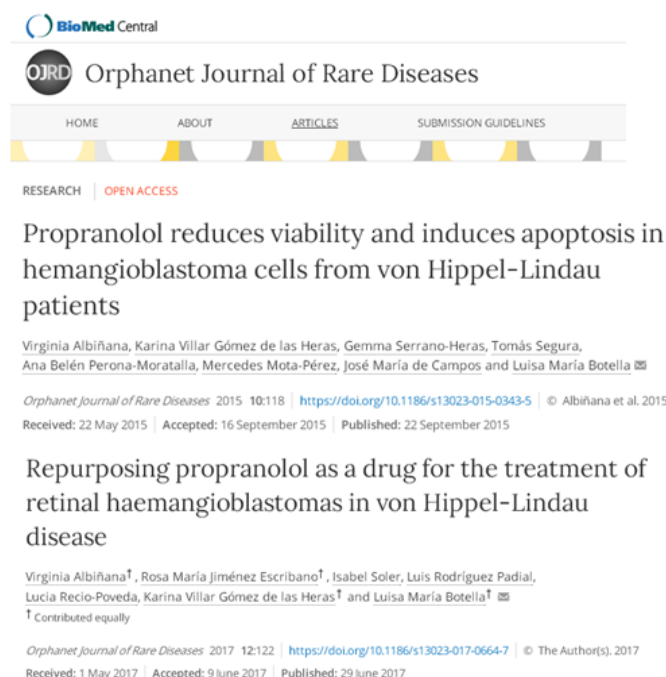
During this year we have continued financing the research projects at the **CIB-109** laboratory, **CSIC**, whose head is Dr. Luisa M^a Botella. The research team is also composed of **Drs. Virginia Albiñana and Ángel Cuesta**, and the laboratory technician **Lucía Recio**. They form the [707 CIBERER UNIT](#), dedicated to the research of two rare diseases, VHL and HHT. Both pathologies have in common the vascular component. The most notable projects that have been carried out on VHL are the following:

■ In vitro trials with VHL tumor cell crops

Since 2013 they are carrying out research with VHL tumor crops from surplus surgery. Some of the tumors that you donate generously and that the doctors do not need for diagnosis or anatomopathological study are cultivated, and **cell crops are obtained for experimentation**. In this field we can say that **we are pioneers, especially in the world of Rare Diseases**. The crops obtained are being used for two aims: **1. Testing drugs** to see the response of the crops and thus predict that of the tumors. **2. Work on obtaining a mouse model of the disease.**

The results of the research were published in two papers, in the scientific journal **Orphanet Journal of Rare Diseases**:

- [Propranolol reduces viability and induces apoptosis in hemangioblastoma cells from von Hippel-Lindau patients.](#)
- [Repurposing propranolol as a drug for the treatment of retinal haemangioblastomas in von Hippel-Lindau disease.](#)



As we have seen previously, the **drugs repurposing** consists of the use of a drug for another disease different from that for which it was originally authorized and marketed, and it is a growing trend in recent years in the world of the pharmaceutical industry and rare diseases. The advantage is the saving of years of research, with the consequent and substantial financial savings.

Recently, in **January 2018**, representatives of the Spanish VHL Alliance and CSIC researchers held a meeting at the **Spanish Agency for Medicines and Health Products (AEMPS)** to discuss the next steps for a future clinical trial with propranolol, with a larger number of patients. They also encouraged us to continue collecting evidence of the use of propranolol in isolated cases.

■ Study in pregnant women

Another study to measure plasma biomarkers **in pregnant women or those who are planning to become pregnant**, will help us to evaluate if pregnancy may be influencing the development of tumors. **Iberdrola Foundation** participates importantly in the financing of this project.

If you have VHL and you are pregnant, or are planning to become pregnant, you can help in this research, which does not represent a health risk for you or your baby. If you wish to participate, **get in touch with us or with Dr. Luisa Botella**.

■ Clinical trial with VHL patients and retinal hemangioblastomas

In the **Hospital Complex of Toledo**, steps are being taken to **create a VHL care Unit**. It was in the Virgen de la Salud Hospital of Toledo, a center dependent on this Complex, where our first clinical trial was carried out, with the aim of assessing the effectiveness of propranolol treatment in the control of growth of retinal hemangioblastomas.

Dr. Rosa María Jiménez Escribano - head of the Ophthalmology Service - is the principal investigator. This study was carried out in coordination with the CIB-109, where the study of biomarkers of disease activity was carried out.



Part of the team of the Ophthalmology Service of Toledo. Drs. Jiménez and González are the 3rd and 1st respectively, from the right of the photograph. You can read the complete news on the SESCAM Website: <http://sescam.castillalamancha.es/saladeprensa/notas-de->

[prensa/el-servicio-de-oftalmologia-del-hospital-de-toledo-participa-en-la](#)

The trial involved 7 affected people from different Spanish regions. The researchers are currently writing the manuscript with the results, to be published in a scientific journal. It seems that propranolol slows the growth of tumors, and produces **reabsorption of retinal exudates**. In addition, during the trial there were identified some biomarkers (molecules) that could be used to monitor the disease activity.

The results of this clinical trial were presented at the first **VHL Congress held by the Greek VHL Alliance** - whose president is Athina Alexandridou - **on November 4th in Athens**, and it was attended by well-known VHL specialists at an international level.



Doctors participants in the **First Greek Congress of VHL disease**, with the vice president and the president (Athina) at the left of the photograph.

Since more studies are needed to confirm the results, the researchers have proposed another clinical trial with propranolol and more patients.

■ Gene therapy

As you may remember, last year we contacted the [CIMA, Applied Medical Research Center of the University of Navarra](#). After an initial contact, this project was put off due to the need to have an animal model - preferably a mammal - to test this therapy, before going on towards a clinical trial in humans. At the moment the only VHL animal model available is the zebrafish.

Donation of blood samples, blood and surplus of tumors

As you may remember, in November 2016 we had a meeting at the CNIO with **Dr. Francisco de Luna**, coordinator of the [Biobank Platform of the CNIO](#) (National Center for Oncological Research), to discuss the possibility of creating a **biobank of VHL tumor samples**, integrated into the National Network, so that these samples are also available to other researchers who want to research on our disease.

They would study our request, to see the possibility of establishing a protocol for obtaining fresh samples and facilitate the process of donation and arrival of samples to CIB-109 laboratory, where we carried out our research. A few weeks later we were informed that for the moment it was very difficult to establish this protocol, precisely because of the current organization of the biobank network.

For this reason we were forced to continue our struggle to obtain samples, alone. The problem we have is that the samples can only leave the centers with the authorization of the Hospital Management, and it is necessary that the **Research Ethics Committee** of every center evaluates the protocol of the study and authorizes its realization.



In addition, the Law 14/2007 on Biomedical Research, requires an authorization from all the centers. Taking into account that we do not know a priori where a possible donation might come

from, and that since the protocol enters the center until it is authorized it usually takes more than a month, we conducted two consultations with two Ethics committees, the **Bioethics Committee of Spain** (<http://www.comitedebioetica.es/>), and the **Ethics Committee of the Carlos III Health Institute** (<http://www.isciii.es/ISCIII/es/contenidos/fd-investigacion/fd-evaluacion/Comite-etica-Investigacion.shtml>).

The problem is that the authorization of a center can be delayed so much, that this can mean losing the donated sample (as has already happened several times), with the consequent displeasure for all. The response obtained to the consultations indicates that there is no other legal formula to obtain a sample, regardless of whether the donor wants to donate the tumor (do not forget that **the sample is from the donor, who is the one who can, legally, decide the destination of his sample**).

Due to this bureaucratic problem, **we have begun to present the research protocol to the more than 100 Ethics Committees that exist throughout Spain**, and we have suggested to the Bioethics Committee of Spain (competent in the matter according to Law 14/2007) to propose solutions to this situation, which is particularly hard in the case of rare diseases, where there are not many patients and therefore there are not many samples, and **it is very painful to see that a sample for research is lost due to a bureaucratic issue**. The protocol does not have any legal inconvenience, and in fact we already have the favourable opinion of three centers, and we are awaiting a new approval within this month. However, the procedures with the different CEIC are complicated, since each Committee makes its comments and asks us for different modifications, which makes it very difficult to finish the approval. **Once again we can see that it is not easy to research in Spain, and even less in the case of a rare disease.**

Of the more than 80 emails sent so far, many of them are requiring us to have an investigator in their centers (whom we have to look for from the association), when this figure is not necessary

because the research will be carried out at the CIB, not at the hospital, and we do not need any personal data from the center, only the tumor surplus with the informed consent of the patient.

Thanks to the donations, we are creating a **VHL cell crop collection** to continue researching, which is located in the Center for Biological Research (CSIC).

If you are going to have a surgery, and you want to donate, get in touch with us as soon as possible, so we can organize the bureaucratic procedures. Tumor or blood samples can be sent to the research center from anywhere in Spain, without shipping costs.

The Spanish VHL Alliance donates more than € 40,000 to CIBERER for the research of von Hippel-Lindau disease

In **March** of last year, the Spanish VHL Alliance donated more than € 40,000 to hire a researcher to start working on **obtaining a VHL mouse model**. The **Irizar** bus company took part in this.

For the achievement of this project, the Direction of the Center of Biological Research proposed several alternatives, of which the donation formula was the only one that did not imply indirect costs (overheads) for our association. Due to discrepancies with the Direction of the CIB, we finally signed [the agreement with CIBERER](#), and the donation was made to start the process of **hiring a researcher with experience in cancer research and working with animals**.



The person chosen was **Dr. Ángel Cuesta Martínez, PhD in Biology, Biochemistry and Molecular Biology by UAM**, who joined the research team at the beginning of September. You can check his professional experience in this URL:

https://www.researchgate.net/profile/Angel_Cuesta2

Due to the fact that there is no genetically engineered mouse model, the research he is developing seeks to implant tumors in immunosuppressed mice in order to test **propranolol and other drugs**. With the incorporation of Angel to the CIB, there are already three researchers involved in the research of our disease.

We have to say that negotiations with the Direction of the CIB have never been easy. It has been a real problem trying to make them understand that research already costs too much money to tax it with indirect costs, as if an association of a rare disease were a company. Finally the mediation of **Juan Luque, Scientific Manager of CIBERER**, has been essential to find a solution.



Researchers of Unit 707 of CIBERER of the Center of Biological Research (CSIC), with Susi Martínez and Karina Villar, during a recent visit of our representatives to the center. From left to right, Lucía Recio, Luisa M^a Botella, Susi Martínez, Ángel Cuesta and Karina Villar.

Dr. Virginia Albiñana, who has been hired by the Spanish VHL Alliance since 2013, has become a staff of the CIB in 2017, which benefits both her career and our association.

Joyce Graff Award for the best publication on von Hippel-Lindau disease

Last year we launched the first edition of the award for the best scientific publication on the

disease. The winning work was "[Clinical case: von Hippel-Lindau syndrome, a vision from nursing](#)", and the main author - **Mónica Casero Alcázar** - attended our annual meeting to make a brief presentation of the work and collect the award, consisting in an amount of € 800 and a diploma.

The award ceremony was held on **May 20th, 2017**, in the Assembly Hall of the ONCE Foundation, Madrid, during our Annual Meeting. Mónica offered a brief presentation of the work to the attendees, highlighting the magnificent work they do in the Neurorehabilitation Unit where she works. By will of the author, the prize was donated entirely to the **Neurorehabilitation Unit of the San José Institute Foundation - Hospitaller Order of the Brothers of Saint John of God, (Madrid)**.



Mónica Casero, to the left of the photograph, picks up the diploma from **Susi Martínez**.

New call

In November 2017 we sent a letter via email to the different **Teaching Units of hospitals throughout Spain**, with an informative leaflet, calling the launch of the new call. This award **represents the recognition of the research work of Spanish healthcare professionals**, and aims to continue promoting clinical research of our disease.

The call is open to doctors, nurses, physiotherapists and other health professionals of our country. The works must have been done in public or private Spanish institutions (universities, health centers, hospitals, clinics) and have been published between January 1 and December 31,

2017, or be pending of publication at that date. You can access [the bases of the call](#) from here.

Dr. Luisa Botella receives the Award for the Best research path in rare diseases and orphan drugs, in the 1st call of the AELMHU Awards

In September, we presented the candidature of Dr. Luisa M^a Botella to the first call for AELMHU Awards (Spanish Association of Orphan and Ultra-Orphan Drug Laboratories), in the category "**Best Researching Path in Rare Diseases and Orphan Drugs**", for the search of treatments for von Hippel-Lindau disease and hereditary hemorrhagic telangiectasia (HHT). The HHT association also proposed Luisa for this category.



Photography of the AELMHU awards ceremony. Madrid, September 2017.

The ceremony was held at the Royal National Academy of Medicine in Madrid, with the assistance of Ms. Belén Crespo, Director of the Spanish Agency for Medicines and Health Products, and M^a José Calvo, Vice Principal General of Pharmacy and Health Products of the Community of Madrid, who, along with the president of AELMHU, Josep M^a Espinalt, delivered the awards **whose financial endowments of € 3,000 were donated entirely to projects linked to rare diseases and / or orphan drugs**.

AELMHU is a non-profit organization that groups together pharmaceutical and biotechnology companies.



Luisa Mª Botella (left) receives the award from Belén Crespo, Director of the Spanish Agency for Medicines and Health Products (**AEMPS**).

You can read the interview they did to Dr. Botella by clicking on [this link](#).

II International Meeting of VHL young adults

As in the previous year, the German VHL Alliance, with its president - **Gerhard Alsmeyer** - as the main responsible, organized a meeting with young adults from different European countries that took place in Berlin, from June 15 to 18.

The call to register was opened at the beginning of December 2016 and closed on the 31st of that month. Our association agreed to cover the expenses of those young Spaniards who would like to attend the meeting, through the granting of 5 grants. The **requirements to request them** were the following:

- Have von Hippel-Lindau disease, confirmed by clinical report or genetic diagnosis.
- **Be between 18 and 30 years old.**
- Be a member of the Spanish VHL Alliance and be up to date with the payment of the membership fee.

The grant included:

- Transport from Spain to Germany.
- Accommodation and meals in Berlin.

Although there was a quota of 25 participants, all places were not covered. There were a total of **17 participants from different countries, three of them Spanish**. The official language of the meeting was **English** and topics related to psychology, genetics, family planning, central nervous system, kidney and clinical aspects of the disease were discussed. The organization also planned a small tour of the city of Berlin.

It is expected that by the middle of **2019** another meeting will be organized to facilitate our young adults to share information and experiences with people of their age, from other countries, and who live similar circumstances.

From the Spanish VHL Alliance, we want to encourage you to present your request to attend this meeting. We believe that it is very enriching for all, and a unique opportunity. This is the testimony of one of the young adults attending the meeting:

““For many of us it was the first VHL meeting ever, and we were all very curious about how it would be. Gerhard started with a short VHL-Quiz and after an introduction-round we all met in a Bavarian beer garden.

There were four medical lectures, which were all very professional and interesting. Because VHL affects each of us differently, it must have been difficult to select medical topics that would interest all of us. Nevertheless, all participants felt they benefited from the four lectures.

Most important for us was getting in touch with other young adults suffering

from the same rare disease.



Meeting young warriors from other countries, exchanging VHL-related and non-VHL-related information or experiences, talking about VHL and the fears related to our disease without trying to find the perfect words or worrying about the others reaction, is an indescribable and valuable experience. It's incredible how close you can feel to people you have never met before.

Even though VHL is a difficult challenge to cope with, it is very helpful to know that none of us are alone. Such meetings allow us to share stories, talk about fears, and meet many positive thinking people. This helps us feel more confident, think more positively, and it even gives us the opportunity to enjoy small happy moments a bit more than before.

It was an unforgettable weekend: full of emotions and free of worries. We wanted

it to last longer.

All young adults suffering VHL should get the opportunity to participate.

We are looking forward to the next meeting in two years.

We are strong warriors and we can meet this challenge and win our war. “

Louisa M.

#vhlyoungwarriors”

Social Worker “Listens”

In 2017 we carried out an assessment on the **social health** of those affected, through a survey coordinated by our Social Worker, Oliver Juan Canales Sirgo.



The survey was composed of **49 questions** and the completion time was approximately **20 minutes**. Some of the participants completed it via web, and others preferred the telephone realization under Oliver's guidance.

126 people participated (affected or relatives). We are awaiting the publication of the results in a scientific journal.

We also want to remind you that you can contact Oliver Canales at tsocial@alianzavhl.org.

Grants

This year we have applied for the following:

- **Port Aventura Foundation** – January.
- **2017 Junta Castilla-La Mancha Call** for self-help associations – April.

- **Constant and vital La Sexta Award** “Biomedical research of the year” – June.
- **“II Edition of the grants for the best idea or project of patient associations of the QUAES Foundation”** – September.
- **Merck grants for research 2018** – October.

Of these, we have only been granted by the **Board of Communities of Castilla-La Mancha**, with a total amount granted of **€ 2,164**.

Events

During 2017, several events were held in different parts of Spain, with the purpose of raising funds for research and raising awareness about the disease. By date of realization:

- **Child’s Lottery 2017** – January 6th.
- **Casino Cirsa Valencia Solidary Urn** – January.
- **III Solidary Popular Race Holy Heart Slaves & Spanish VHL Alliance** – February 4th. Valencia.
- **Wizard of Oz Musical Festival. Caxton College** – March 30 and 31. Puzol, Valencia.
- **6th Golf Tournament – Scorpion Golf Club** – May 4th. Bétera, Valencia.
- **I Race BTT– Bicivoadores Val Miñor** – May 13th. A Camoesa, Pontevedra.
- **AQUA Picanya “Swim at night”** – May 20th. Picanya, Valencia.
- **Club Race Madrid 4th Charity Golf Tournament** – May 25th. San Sebastián de los Reyes.
- **4th VHL Solidary Cocktail-** May 26th. Madrid.
- **VHL Video “Our challenges for a cure”** – June.
- **I Race and Solidary March in favor of VHL** – June 25th. Paiporta, Valencia.
- **Valencia Dance “We are Art”. Hortensia Herrero Foundation** – September 30th. Palau de les Arts Reina Sofía, Valencia.
- **2017 Solidary Market** – October 1st. Madrid.
- **XVIII Tribute to Enrique Urquijo** – November 17 and 18. Galileo Galilei Theatre, Madrid.
- **2017 Christmas Lottery** – December 22th.

In our [Facebook page](#) and in the [Spanish VHL](#)

Alliance Web:

- Buy online and make a donation without cost for you.
- Mobile and tablet collection campaign.
- T-Shirts “We share effort”.
- Children’s book: “Tales to find a cure”.

You can find all the information in the ["Charitable Activities"](#) section of our website.

We want to thank all the participants for the time and effort dedicated to the organization of the events, as well as all those who collaborate in one way or another in our activities.

You can also organize an event in your environment. Contact us if you need guidance.

Solidary Celebrations

Any celebration can be a reason to collaborate in the research of our disease: a family dinner, a birthday, a wedding, a first communion...

Last year we inaugurated the section ["Solidary Celebrations"](#) on our website, with great success.

We propose several different gifts with which to give your guests, while you collaborate with us in the research of our disease. We have bracelets, running t-shirts, Japanese neck t-shirts, and children's tales. You can access by [clicking here](#).

Donations

Researching a rare disease in Spain is not easy. The help we receive from public institutions to research our disease is still scarce. Having a rare disease obliges anyone who wants to research it to seek their own funds. Therefore, individual donations are essential to finance research.

The Spanish VHL Alliance is subject to the **special tax regime regulated in Title II of Law 49/2002, of December 23rd, on the tax regime of non-profit entities and of tax incentives for patronage**. Those people who associate or make donations, can request tax relief of the amount contributed.

Become a member

We need everyone's help

Another year more, we want to encourage you to make your family and friends become members, and be part of this great family with the same goal: the research of our disease. Thanks to the membership fees we can continue with our struggle to find a cure.

The **minimum annual fee is € 36...** It is not much to achieve our goal. If you prefer split payment, you can do it from € 10 quarterly or € 10 monthly. [Online Form](#). We remind you that **the membership fees and donations can also be deferred from the Income Tax Declaration**, and this is applicable to both individuals and companies.

The year 2017 is **the fourth consecutive year that we passed an external audit**, which attests to the transparency of our accounts.

Annual meeting and board of directors

We encourage you to attend our **annual meeting**. As you know, it usually takes place in the first days

of June in Madrid, at the headquarters of the **ONCE Foundation**, C / Sebastián Herrera, 15. Currently, our board of directors is composed of President, Vice President, Secretary, Treasurer and 6 members. Any member who wishes can apply for the election of positions of the board of directors, which are renewed every two years.

You can also join us in one of the races in which the **von Hippel-Lindau Paiporta Athletics Club** participates, wearing our t-shirt and sharing effort. Or you can join us at the **Solidary Dinner** organized in Madrid during the VHL international awareness month, **May**.



In all these events you will have the opportunity to meet other affected, to meet many people who help and support us, and most importantly, **to share something unforgettable**.



Members of the von Hippel-Lindau Athletics Club, from Paiporta, Valencia.

We are waiting for you!

Federations we belong to

VHL Family Alliance

www.vhl.org



EURORDIS

European Organization for Rare Disorders

<http://www.eurordis.org>



European VHL Federation

<http://www.vhl-europa.org>

