NEWSLETTER

MAY 2020

Social Action
Training and Research
Aliances and solidatity
Networks
Visibility
Advocacy
Association Manegement

MEMBER OF

RARE DISEASES INTERNATIONAL

IRDiRC INTERNATIONAL RARE DISEASES RESEARCH CONSORTIUM

This English translation has been possible thanks to the PerMondo project: Free translation of website and documents for non-profit organisations. A project managed by Mondo Agit. Translator: Emma Dewick

PERMONDO Translations for non-profit

MONDO AGIT

SOCIAL ACCION

Information and Advisory Service on Rare Diseases

At ALIBER, we are continuously working towards creating an Information and Advisory Service for families with rare diseases in Ibero-America. As we all know, responding to the doubts that arise when a rare disease is diagnosed or when the search for an explanation to certain symptoms has not yet resulted in a diagnosis is essential for all families with uncommon diseases. Many issues can be overcome with access to quality information, such as confronting the psychological challenges brought on by life with a rare disease, feeling isolated from doctors and researchers, as well as from other patients with the same pathology, and overcoming difficulties in accessing education, employment and social inclusion.

SERVICIO DE INFORMACIÓN Y ORIENTACIÓN DE ALIBER

The needs of people with rare diseases and their families are linked to common issues:

- *Lack of knowledge of the origin of the disease.*
- *Confusion at the time of diagnosis.*
- *Lack of protocols for the disease*
- *Lack of specific medications to treat the disease*
- *Social rejection and loss of self-esteem*
- *Feeling of being alone, of being isolated.*
- *Lack of information on care and technical assistance that help make life easier*
- *Lack of financial aid*
- *Lack of legal coverage to promote research*
- *Lack of visibility and recognition that hinders social acceptance.*

SOCIAL ACTION

For this reason, since we began our journey as an ALLIANCE we have aimed to answer all queries that we receive from patients, as well as from professionals and researchers. We rely on the Information and Advisory Service of the Spanish Federation of Rare Diseases (FEDER), as well as on data that we are gradually compiling from various information sources, which include the different member entities of ALIBER.

We are pleased to present the data relating to the **number of queries that have been received by both the FEDER Information and Advisory Service and the Ibero-American Information and Advisory Service during the first 6 years of the ALLIANCE:**

During the period **2003-2019, we have responded to 2,673 queries from Ibero-America**. The main queries were related to:

- *Sending more specific information on the disease and/or on patient management: 518*
- *Provision of Reference Association data: 749*
- *Sending information on practitioners: 77*
- *Provision of Reference Association data (FEDER): 545*
- *Providing information on medications: 77*
- *Providing contact information of other people affected by the same disease: 22.*

We will continue to work towards creating our own database, which we hope to launch in the near future. This will contain our own resources for different diseases and countries, so that our responses are tailored to the needs of patients, families and professionals. To do this:

We need your help

Remember, this is a free service. If you have any questions, contact us

and we will try our best to help you.

Email: sio.aliber.org

SOCIAL ACTION

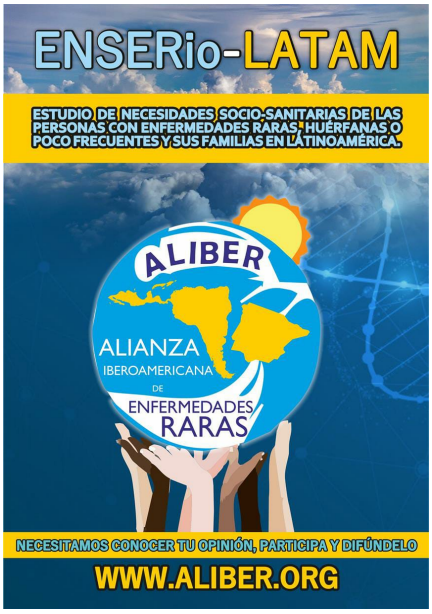
ENSERio-LATAM. Social and health health needs study of people with rare diseases and their families in Latin America.

It is well known that the majority of rare, orphan or uncommon diseases are genetic, chronic and degenerative and more than half of them are serious, highly debilitating illnesses.

We also know that all these characteristics create numerous **social and health needs** in the affected people and their families. Among these requirements, the following stand out:

- *those relating to the diagnosis,*
- *those relating to treatment,*
- *the perceived impact of the disease on the affected person and their family*
- *and the financial costs of the disease.*

Our ability to plan actions to meet these needs depends on the knowledge that we have about the patients' situation. For this reason, the Ibero-American Alliance for Rare, Orphan and Uncommon Diseases, with the support of its partners and of universities in Argentina, Brazil, Spain, Mexico and Venezuela, focused their efforts some time ago on collecting data through a survey that will reveal the reality of people living with a rare disease and their families in Latin America. The survey also allows us to collect information on health centres and professionals that treat various illnesses. We can use this information to build a map of specific and unique resources from around the world for the Latin American population.



SOCIAL ACTION

We have not yet received enough questionnaires for each country in order to achieve a representative population sample. However, we are on the right track and want to continue with this spirit of hope and united effort, since it is with your cooperation that we will succeed in:

compiling the necessary information, which we will use to carry out health and social welfare analyses on each country in the area of Rare, Orphan and Uncommon Diseases.

so that:

The Policies, Plans and Strategies are designed and developed to meet and to respond appropriately to our needs.

As a reminder, **anyone who is affected by a rare, orphan or uncommon disease and is living in Latin America can participate in the study.**

It is important that, where possible, the person affected by a rare disease is the one who answers the questionnaire. However, if the person who answers the survey is a relative or a caregiver (informant), they should respond according to the data of the affected person, unless otherwise specified.

ALIBER relies on YOUR support to share the survey with friends and contacts who are affected by a rare disease, as well as with other rare disease patient organisations in Latin America.

CAN YOU HELP US?

Questionnaire in Spanish:
http://formularios.aliber.org/index.php/918226?lang=es
Questionnaire in Portuguese:
http://formularios.aliber.org/index.php/918226?lang=pt
Questionnaire in Portuguese (Brazilian):
http://formularios.aliber.org/index.php/918226?lang=pt-BR

7th Ibero-American Rare Diseases Meeting

Last November we held the 7th Ibero-American Rare Diseases Meeting in the beautiful city of Murcia, Spain. 15 Ibero-American countries took part in the meeting, held over two days, during which participants evaluated the current situation of rare, orphan and uncommon diseases in the various countries in which the ALLIANCE has representation.

The president of the Ibero-American Alliance for Rare Diseases (ALIBER), Juan Carrión Tudela, highlighted the exchange of knowledge, experiences and best practices that took place at the meeting. Participants had the opportunity to visit the Pilar Bernal Giménez Multidisciplinary Centre for people with Fragile X Syndrome and other Rare Diseases in Murcia.

Participants also visited the Virgen de la Arrixaca University Hospital and the Biomedical Research Institute of Murcia (IMIB), where interesting discussions were held on the rare disease patient care at this health centre.

Other topics discussed during the meeting included the current situation regarding access to orphan drugs and the situation of people with rare diseases in several Latin American countries.

The closing presentation was attended by the president of the autonomous community of Murcia, Fernando López Miras, who thanked all attendees and professionals for participating and for their excellent work on behalf of people and families living with a rare disease in Ibero-America.

Presenting the Sibling Study by D´genes and the Fundación Poco Frecuentes

Two ALIBER organisations, the D'Genes Association and the Fundación Poco Frecuente, have come together to carry out a wonderful study. The two foundations are jointly involved in a research project on a group that is of special interest to those with rare or undiagnosed diseases: brothers and sisters of children/adults with rare or uncommon diseases.

Siblings of children with Rare Diseases. Communication and Quality of Life.

This study seeks to investigate the quality of family life based on the diagnosis of a rare or undiagnosed illness, the needs of patients and their families due to the lack of knowledge about these diseases, the delay in diagnosis, and the lack of drug and treatment coverage to treat these diseases by government agencies, among other topics.

The **main goal** of this project is to **gather specific data on this population group**, which will give us a fundamental base for the development of care proposals for families who are in this situation. This information will allow us to create work protocols on their health and the management undertaken regarding their direct or indirect care responsibilities for the affected siblings.

The focus of the study is on the families' perspective of the situation, as in the Study on Social and Health Needs of people with Rare Diseases 1, with regards to **caregiver support to people with rare diseases**, it was already indicated that **"among the relatives who provide this support**, responsibility falls mainly on the parents (41.12% of the total number of people who provide the support). However, **siblings also provide care (17.75%),** as do spouses (14.26%) and grandparents (10.62%), among others".

TRAINING AND RESEARCH

A very significant additional piece of information that appears in this same document (ENSERIO I) is that sisters provide care more often than brothers (1.71 sisters for each brother). This once again confirms that gender is a factor is determining who will be the caregiver of people with chronic diseases.

Research on families with uncommon diseases as an analysis unit is still scarce on an international level, and so are those that are developed from a multidisciplinary point of view, giving deserved prominence to Psychology, Education, Social Sciences and Humanities.

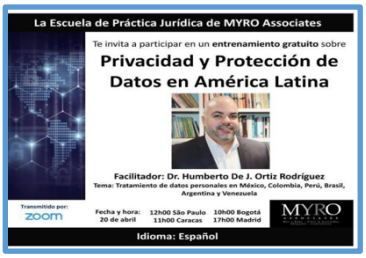
The scientific literature on uncommon diseases and the technical reports on the subject do not provide specific data on the siblings of people with rare diseases within the family context. It could therefore be described as a silent protagonist.

The purpose of the study is to give a voice to this group and understand their needs, in order to make specific proposals in the social, family or educational field, among others.

The D'Genes Association and the Fundación Poco Frecuente invite you to complete the questionnaire at the following link:

https://docs.google.com/forms/d/1Hx5RVN7L19hZ9vWC1G1TMmbM7XoGi7dJ1B cWFFbs/viewform?edit_requested=true

ALIBER takes part in a privacy and data protection workshop in Latin America.



Dr. Humberto Ortiz Rodríguez, a former university professor in Venezuela and the current Data Protection Manager at Mercedes Benz, provided a free training course open to the general public on Privacy and Data Protection in Latin America.

At ALIBER we wanted to make the most of this opportunity to continue learning and to keep informed of the most relevant aspects of this topic, which in our case is data protection in the health sector. This workshop contributed to our continued development on such a valid, practical topic for organisations such as ours.

The agenda included:

- *General aspects of privacy and data protection*
- *The processing of personal data in Latin America:*
  - Mexico
  - Colombia
  - Peru
  - Brazil
  - Argentina
  - Venezuela

- *Regulation and self-regulation. The challenge for governments and companies.*
- *Comparison of Regulatory Frameworks regarding the treatment of personal data in Latin America*
- *Treatment of personal data in the health sector.*

For ALIBER, this type of event is an invaluable source of information and a very useful resource when it comes to approaching and understanding the different situations in Latin America, which require a different approach depending on the regulations of each country. We extend our gratitude to Dr. Ortiz for providing us with this opportunity for continued education and joint learning.

ALIBER joins the IRDIRC

ALIBER has joined the IRDIRC as the sole representative of rare diseases in Ibero-America, and will also be represented in the PACC (Patient Advocates Constituent Committee).

The International Rare Diseases Research Consortium (IRDiRC) is formed of funding agencies, public and private institutions and scientists who commit to investing a minimum of $10 million over a 5-year period in rare disease research programs, as well as umbrella organisations representing patient interests for all rare diseases in at least one country or a large area.

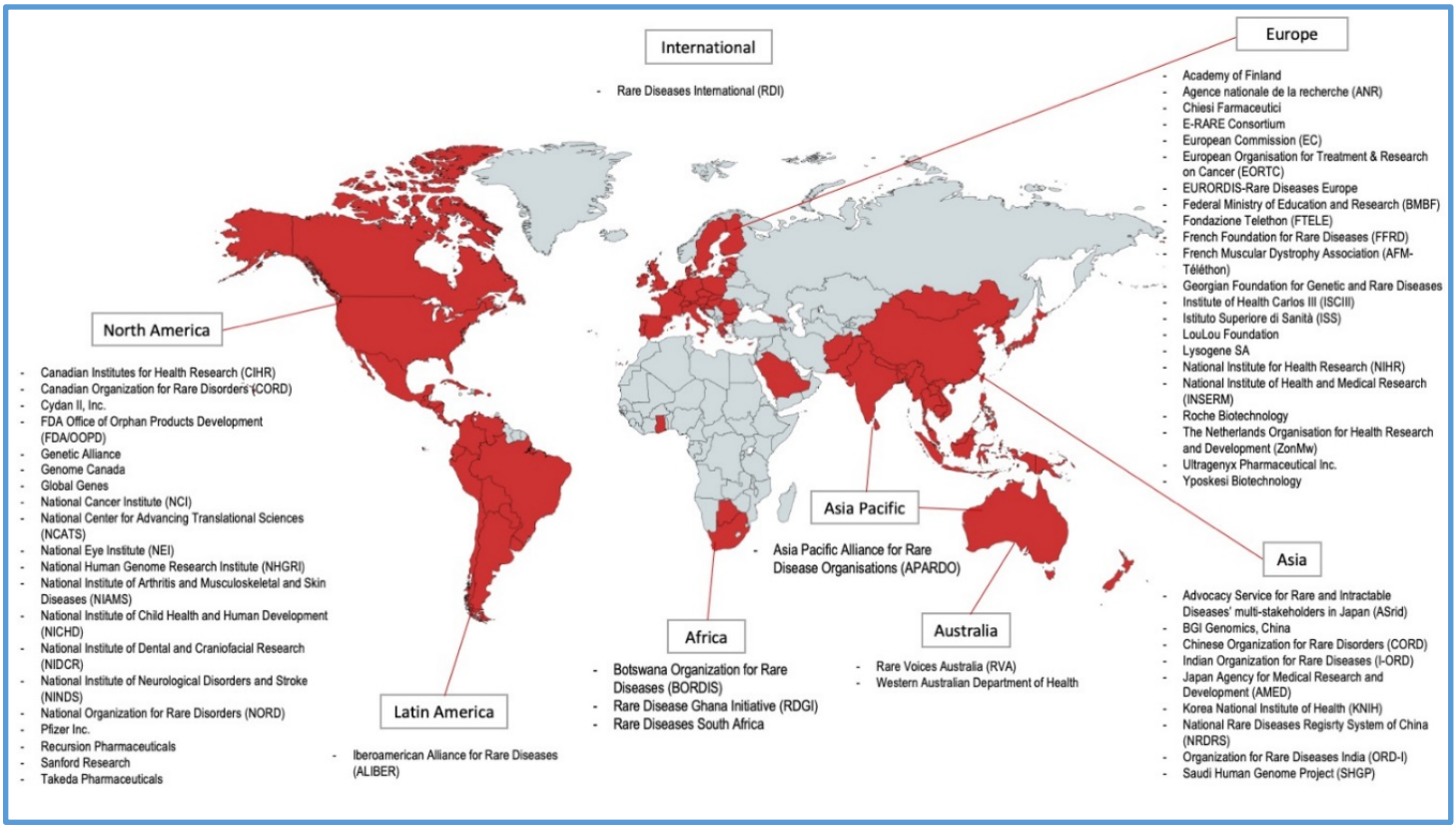
The IRDiRC was launched in April 2011 as an initiative of the European Commission and the National Institutes of Health (USA) to foster international collaboration in rare disease research.

Its initial aim was to develop 200 new therapies and methods to diagnose most rare diseases by the year 2020. Today these goals have almost all been achieved. As the result of a yearlong collaboration process between all the relevant agents, the Consortium has now announced its objectives for the period 2017-2027, with the ultimate aim that:

All rare disease patients will receive an accurate diagnosis, care and therapy within one year of seeking medical attention. Furthermore, 1,000 new treatments for rare diseases will be approved and methodologies will be developed to assess the impact of diagnoses and therapies applied to rare disease patients.

Since the beginning of this year, ALIBER has represented Latin America in the consortium, being the first and only organisation that provides information on the situation and research needs of rare diseases in the ALIBER member countries.

ALLIANCES AND SOLIDARITY NETWORKS



Representatives of the IRDiRC Patient Advocates Constituent Committee (PACC)

The IRDiRC Patient Advocates Constituent Committee (PACC) is formed of patient umbrella organisations representing a large region or country and whose interests include promoting research on rare diseases. Alba Ancochea will represent ALIBER on the committee, supported by the various alliance members.

The role of the PACC and, therefore, of each of its members, is to actively contribute to the vision, objectives and the set of global actions of the IRDiRC, in order to promote the development of the diagnostic and therapeutic process of rare diseases.

The PACC tackles crosscutting problems applicable to all members and all rare diseases, and coordinates the presence of patients in areas of the diagnostic and therapeutic process where their participation is crucial. It also measures the impact of diagnostic and therapeutic advances on the quality of family life.

Access to Treatment Group in lower-middle income countries

The ALIBER's first action as part of the IRDiRC will be participating in this working group, which aims to address the problems presented by the vast majority of patients with rare diseases in accessing treatments for their disease. The main reasons for this are lack of funding and legislative difficulties for drug approval. Other barriers include lack of reimbursement, administrative infrastructure, and poor knowledge on diagnosis and use of treatments.

The working group will initially create a list of basic products needed for the treatment of rare diseases, with the aim of making these available to countries around the world. At the same time, the working group will begin to identify the barriers to accessing medicines for rare diseases, particularly amongst lower-middle income populations. The working group will be composed of 15-20 members from academia, the pharmaceutical industry and patient organisations. The group will be lead by William A. Gahl (NIH), Durhane Wong-Rieger (chair of the Patient Advocates Constituent Committee) and Susanne Weissbaecker (Global Director, Access to Medicines, Takeda).

VISIBILITY

29 February 2020: WORLD RARE DISEASE DAY

To commemorate World Rare Disease Day, ALIBER took part in various activities and shared details on its website and social media platforms, as well as sharing the campaigns carried out by some of its member entities in Latin America. In February and March of this year, the associative movement's strength enabled ALIBER to replicate initiatives from associations in Colombia, Panama, Argentina, Guatemala and Mexico, among other countries. The aim of this celebration is to increase the visibility of rare diseases in society, the government and the scientific community using the pillars of social action, training, alliances, solidarity networks and advocacy.

A multitude of events and activities were held, with the aim of showing the world the reality of families living with rare diseases and their needs, which are caused by the lack of knowledge of these diseases, the delay in diagnosis, and the lack of coverage for treatments and medications to treat diseases by government bodies, among other issues.

In a meeting held in Mexico, the Ibero-American Alliance for Rare Diseases (ALIBER) together with the Mexican Organisation for Rare Diseases (OMER), which brings together patients, organisations, doctors, politicians and members of the Latin American community, highlighted the vital role of patient organisations. During the meeting, the various stakeholder groups were able to discuss the possibility of working in synchrony, using the latest technologies to provide solutions that could change the lives of patients with rare diseases and their families. The meeting allowed everyone to work together to build a social structure invested in improving of the current conditions of the group with rare diseases worldwide.

VISIBILITY

Additionally, the President and Vice President of the Alliance, Juan Carrión and Inés Castellano, gave two talks during the International Week of Orphan Diseases, which was promoted by the Ministry of Health of Santiago de Cali in Colombia. The event was aimed at professionals and students from the health sector, as well as patients, families and the wider community, with the goal of hosting a public administration event to inform, educate and raise awareness.

ALIBER also attended the First International Congress on Rare Diseases, held by the Peruvian Federation of Rare Diseases (FEPER), which highlighted the need to raise awareness amongst policy makers and to create a network to provide Latin America with a unique regulatory framework that enables better care. This would guarantee fairness and equality in access to diagnoses and treatments, safeguarding the rights of the 47 million people who suffer from these diseases.

The commemoration of the World Rare Disease Day 2020 was a forum to promote the continued implementation of strategies that strengthen ALIBER as a network of hope in Ibero-America.

VISIBILITY

ALIBER: keeping up to date on social media

ALIBER is currently updating its website and social media platforms with news on recent events that are of common interest to members. This is an opportunity to invite members to share the information that they want to be made visible on these channels.

By communicating the initiatives undertaken in each association, we are spreading the word on our current actions and activities around the world. In this regard, ALIBER invites everyone to make use of this resource, along with our publications, in order to give it a boost and to increase its impact. The aim is to strengthen our online social fabric, thus allowing each news item to be seen and shared more often and positioning the Alliance as a reference platform in rare diseases throughout Ibero-America.

To share any news that needs to be copied from another association, please send it to: **management@aliber.org**

We are delighted to share our achievements in Ibero-America with the world.

We would like to remind you of where you can access information from ALIBER and its member entities:

www.aliber.org

@infoaliber

@inforaliber aliber org

YouTube

VISIBILITY

I'm staying at home!

Our Alliance has not been immune to COVID-19 and in line with the recommendations given in all the affected countries, ALIBER calls on the importance and the need to stay at home to prevent the spread of COVID-19.

For this reason, members of the Alliance have participated in an awareness video aimed at the general population, showing the realities of patients and expressing messages such as:

Taking care of you is taking care of us

→ **I'm staying at home!**

Several member entities of ALIBER participate in the video. The goal is to raise awareness among the general population of the importance of following quarantine rules, given that the most vulnerable groups are at greater risk of catching the disease. This risk increases if those people with no previous health problems ignore the calls for personal responsibility.

The aim of the phrases "Cuidarte es cuidarnos" (Taking care of yourself is taking care of us") and "Yo me quedo en casa" ("I'm staying at home") is to raise awareness among the Spanish-speaking population of the importance of small gestures of solidarity for people with rare, orphan or uncommon diseases.

You can watch the video at the following link:

https://aliber.org/web/2020/04/07/yo-me-quedo-en-casa/

Organisations joining forces to purchase medicines: An appeal from Paraguay

The creation of ALIBER is a demonstration of the strength of a united associative movement. The individual organisations on their own can struggle to make their voice heard and to get governments and administrations to consider the rights and interests of families and people with rare, orphan or uncommon diseases.

Many of the developing Latin American countries find it very difficult and expensive to buy medicines and health products to meet the needs of people with rare diseases. Sometimes orders are cancelled or they are not able to buy all the necessary medicines, which leaves countries forced to make decisions on generic or alternative drugs on the market. Patients are therefore not able to access the medicines prescribed to them by doctors, which for those affected causes damage to their health and/or reduces the chance of their symptoms improving.

Faced with this situation, our friend Deolinda Acosta, president of the Paraguayan Association of Scleroderma and Autoimmune Diseases, has sent us a proposal from the Government of Paraguay through the Minister of Health, Dr. Julio Daniel Mazzoleni Insfrán. The proposal calls for a centralised purchasing system between governments in the same region, which would offer greater guarantees of access to medicines and lower costs.

Following on from this proposal from the Paraguayan Ministry of Health, ALIBER is offering to serve as an umbrella entity, with the aim of developing a recommendation paper to the governments of the countries that wish to collaborate in this initiative. In order to do this, countries wishing to participate need to provide us with the necessary information to be able to prepare this document. The ALLIANCE firmly believes that this initiative is possible through the union of larger and more developed countries plus smaller and/or less developed countries, such as Paraguay or Guatemala. This would offer supportive alternatives, guaranteeing the well-being of a specific population, who should not suffer negative consequences due to their place of birth and/or residence.

If you are interested in joining this proposal and providing us with the necessary information, please contact: advocacy@aliber.org or projects@aliber.org

ADVOCACY

ALIBER's stance on COVID-19

COVID-19 has inundated the media and government activity around the world. Facing a situation such as this, unprecedented in modern times and where the most vulnerable people suffer the consequences, ALIBER is taking action. Together with a group of voluntary bodies belonging to the ALLIANCE, ALIBER is taking a stance to defend the vulnerable social and health conditions of all people with rare diseases in Ibero-America during this pandemic.

We strongly believe that action can be undertaken without the state of alert or lockdown seriously damaging the health and social circumstances of families living with a rare disease. Therefore, we want to remind all administrations and organisations, both public and private, who are at the forefront of decision-making, to establish priorities for our community such as:

- ***The early identification of cases affected by COVID-19 within the community we represent*** *and* ***the rapid and effective action by the public health systems****, responding to the needs that arise and creating measures that can contain the exacerbation of other symptoms. For this,* ***each government will need to provide support and resources to health professionals*** *who are on the front line of action.*

- ***The vital solidarity between countries with the early establishment of intervention protocols and their dissemination*** *so that they can be replicated in other countries, by other administrations, and in other policy areas.*

- ***Maintaining treatments by coordinating procurement processes*** *that do not cause delays and prioritising adequate hygiene and infection prevention measures.*

- ***Using on-line clinical consultations to provide care*** *or through specific processes, incorporating the necessary digital means, which speeds up the resolution of doubts on changes in their pathology, symptoms, treatment, etc.*

ADVOCACY

- *The coordination of specific advice for **continuing therapy at home** whenever possible.*

- ***Close monitoring** of the **consequences of lockdown** caused by COVID-19, both on a health and psychosocial level, considering the possible need for support.*

- ***The provision of protective equipment for our community** (masks and gloves as a minimum) in order to meet basic needs or in the case of needing to go to establishments where there's a risk of contagion.*

- ***Prioritisation of people with rare, orphan or uncommon diseases in access to diagnostic tests**, along with other high-risk groups.*

- ***The establishment of exceptional measures that allow access to social and health resources** to people on a low income.*

- *Coordinating agile, reliable and clear **information campaigns regarding the social and health resources available to the rare disease communit**y in each Ibero-American country.*

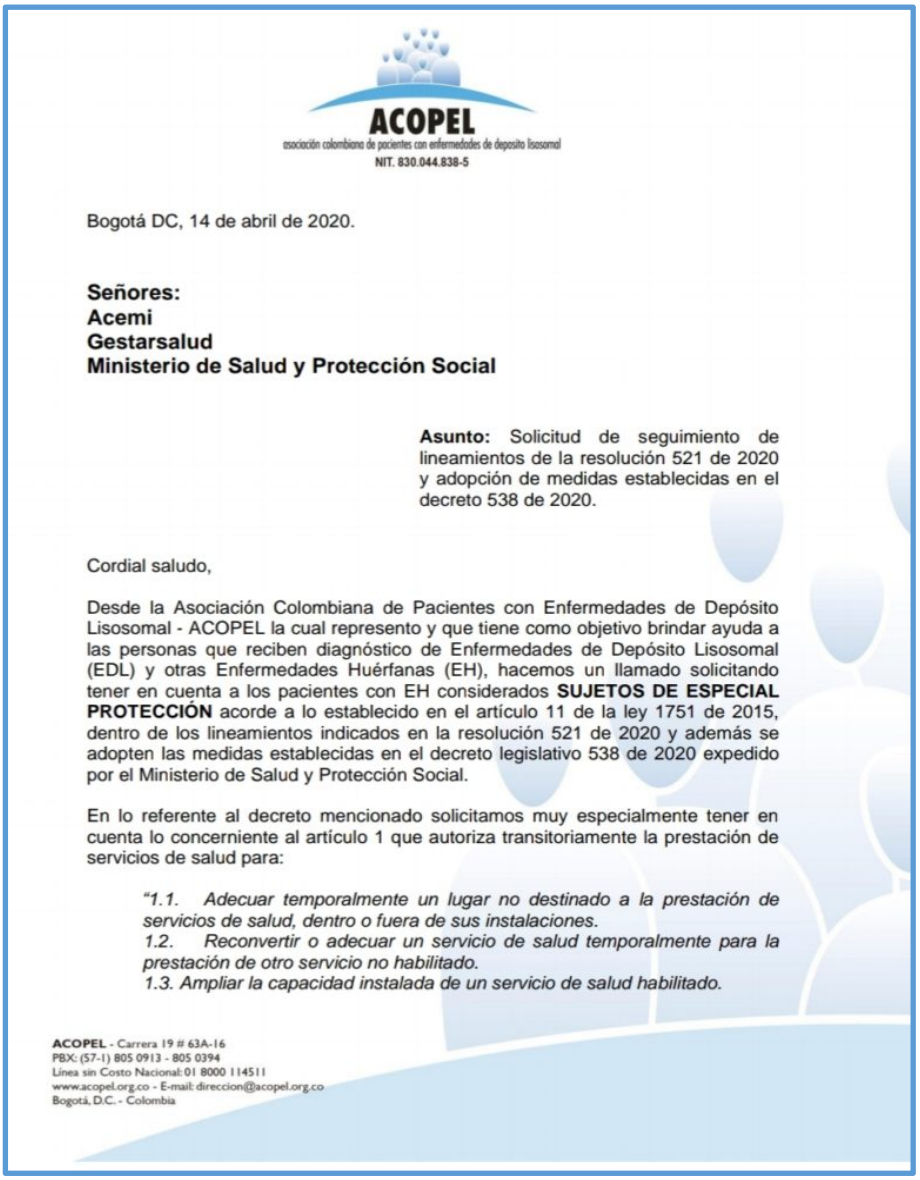
We must take action in line with this stance in every Ibero-American country in which there is a violation of the rights of people with rare diseases, threatening the health of patients.

If you want to learn more, click on the following link:

https://aliber.org/web/2020/03/24/posicionamiento-de-aliber-frente-al-coronavirus-covid-19/

Request from ACOPEL to the Colombian Ministry of Health and Social Protection

The Colombian Association of Patients with Lysosomal Storage Diseases (ACOPEL) made a follow-up request on the guidelines of resolution 521 of 2020 and adoption of measures established in the decree 538 of 2020. ACOPEL requested special attention since the necessary conditions are not in place to guarantee that patients with orphan diseases can access their medicines through home infusions or have access to IPS (Healthcare Institutions), which ensure biosafety conditions in the places where treatments are provided and that are outside hospitals, which poses a significant risk for this group.



ACOPEL
asociación colombiana de pacientes con enfermedades de depósito lisosomal
NIT. 830.044.838-5

Bogotá DC, 14 de abril de 2020.

Señores:
Acemi
Gestarsalud
Ministerio de Salud y Protección Social

Asunto: Solicitud de seguimiento de lineamientos de la resolución 521 de 2020 y adopción de medidas establecidas en el decreto 538 de 2020.

Cordial saludo,

Desde la Asociación Colombiana de Pacientes con Enfermedades de Depósito Lisosomal - ACOPEL la cual represento y que tiene como objetivo brindar ayuda a las personas que reciben diagnóstico de Enfermedades de Depósito Lisosomal (EDL) y otras Enfermedades Huérfanas (EH), hacemos un llamado solicitando tener en cuenta a los pacientes con EH considerados **SUJETOS DE ESPECIAL PROTECCIÓN** acorde a lo establecido en el artículo 11 de la ley 1751 de 2015, dentro de los lineamientos indicados en la resolución 521 de 2020 y además se adopten las medidas establecidas en el decreto legislativo 538 de 2020 expedido por el Ministerio de Salud y Protección Social.

En lo referente al decreto mencionado solicitamos muy especialmente tener en cuenta lo concerniente al artículo 1 que autoriza transitoriamente la prestación de servicios de salud para:

"1.1. Adecuar temporalmente un lugar no destinado a la prestación de servicios de salud, dentro o fuera de sus instalaciones.
1.2. Reconvertir o adecuar un servicio de salud temporalmente para la prestación de otro servicio no habilitado.
1.3. Ampliar la capacidad instalada de un servicio de salud habilitado.

ACOPEL - Carrera 19 # 63A-16
PBX: (57-1) 805 0913 - 805 0394
Línea sin Costo Nacional: 01 8000 114511
www.acopel.org.co - E-mail: direccion@acopel.org.co
Bogotá, D.C. - Colombia

Appeal from the Latin Society of Pulmonary Hypertension in the face of COVID-19

The Latin Society of Pulmonary Hypertension (SLHP) appeals to Latin American health authorities in the face of the COVID-19 pandemic, which has so far led to the deaths of more than 100,000 people worldwide.

Abril 14, 2020

COMUNICADO OFICIAL

Llamamiento de la SLHP en el marco de la pandemia por COVID19

La **Sociedad Latina de Hipertensión Pulmonar (SLHP)** hace un llamamiento a las **autoridades de salud de Latinoamérica** ante la situación de **pandemia por COVID-19** que ya ha llevado a la muerte a más de cien mil personas[1] a nivel mundial.

Como organización que representa a pacientes cardiorrespiratorios de alto riesgo y pertenecientes a un grupo ya vulnerable por la baja prevalencia de sus condiciones (Hipertensión Arterial Pulmonar -**HAP**- e Hipertensión Pulmonar Tromboembólica Crónica -**HPTC**-), deseamos recordar que **las normas de bioética son aplicables en todo momento** y, muy especialmente, deben ser difundidas y reforzadas en tiempos de crisis de emergencia sanitaria como la que estamos viviendo.

CONSCIENTES de que los sistemas de salud de América Latina no están suficientemente dotados y capacitados para enfrentar una pandemia como la actual,

RESALTAMOS que la recuperación económica y social solo será posible preservando el mayor número de vidas, para lo cual es imprescindible disponer la mayor cantidad de recursos materiales y económicos **aprovechables para garantizar el derecho a la salud de todos los ciudadanos. Por este motivo, los presupuestos ya asignados dentro del sistema de salud para los pacientes de enfermedades raras y, especialmente, los pacientes de HAP y HPTC deben ser respetados y mantenidos sin ser derivados a la respuesta a la pandemia.**

RECORDAMOS que los **criterios de priorización** de acceso a los cuidados sanitarios deben emanar únicamente de **criterios clínicos objetivos** atendiendo a las expectativas de supervivencia.

SOLICITAMOS que las autoridades de salud y el personal sanitario sean informados que **los pacientes de HAP y HPTC pueden sobrevivir a la infección por COVID-19** por lo que **la evaluación de su estado clínico y su acceso a los cuidados deben ser llevados a cabo sin prejuicios derivados de su diagnóstico preexistente**.

La SLHP se pone a disposición para colaborar en la medida de sus posibilidades para respaldar las acciones necesarias en la respuesta a la pandemia. Nuestras redes sociales, nuestros contactos con destacados médicos especialistas en enfermedades cardiopulmonares a nivel mundial y nuestra capacidad de concienciación de la población en general están destinadas a promover la responsabilidad individual en frenar la expansión del contagio.

Adjuntamos el documento de la Sociedad Española de Medicina Intensiva, Crítica y Unidades Coronarias, titulado **RECOMENDACIONES ÉTICAS PARA LA TOMA DE DECISIONES EN LA SITUACIÓN EXCEPCIONAL DE CRISIS POR PANDEMIA COVID-19 EN LAS UNIDADES DE CUIDADOS INTENSIVOS.**

https://semicyuc.org/wp-content/uploads/2020/03/Ética_SEMICYUC-COVID-19.pdf

[1] https://www.worldometers.info/coronavirus/?utm_campaign=homeAdUOA?

ALIBER entities react to COVID-19

Ecuador reminds us of the importance of staying at home

In Ecuador, rare disease patients call for people to stay at home in solidarity with vulnerable people with these illnesses.

Click on the following link to watch the video:

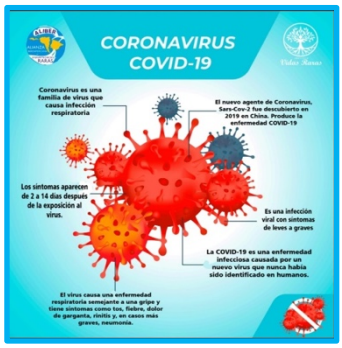
https://aliber.org/web/2020/04/21/el-colectivo-de-enfermedades-raras-ecuador-nos-recuerda-la-importancia-de-quedarse-en-casa/

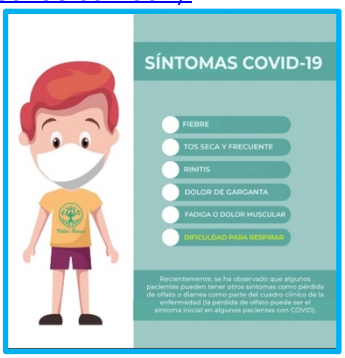
The Rare Lives Institute shares an excellent document on COVID-19 for people with rare disease

In order to raise awareness on the measures that we must take in the face of the current global situation, the Rare Lives Institute of Brazil has shared a very useful booklet with key aspects to bear in mind about COVID-19.

If you would like to read the full document, please click here:

https://aliber.org/web/2020/04/19/el-instituto-vidas-raras-comparte-excelente-documento-sobre-covid-19-para-personas-con-eerr/





Mundo Marfan Latino against COVID-19

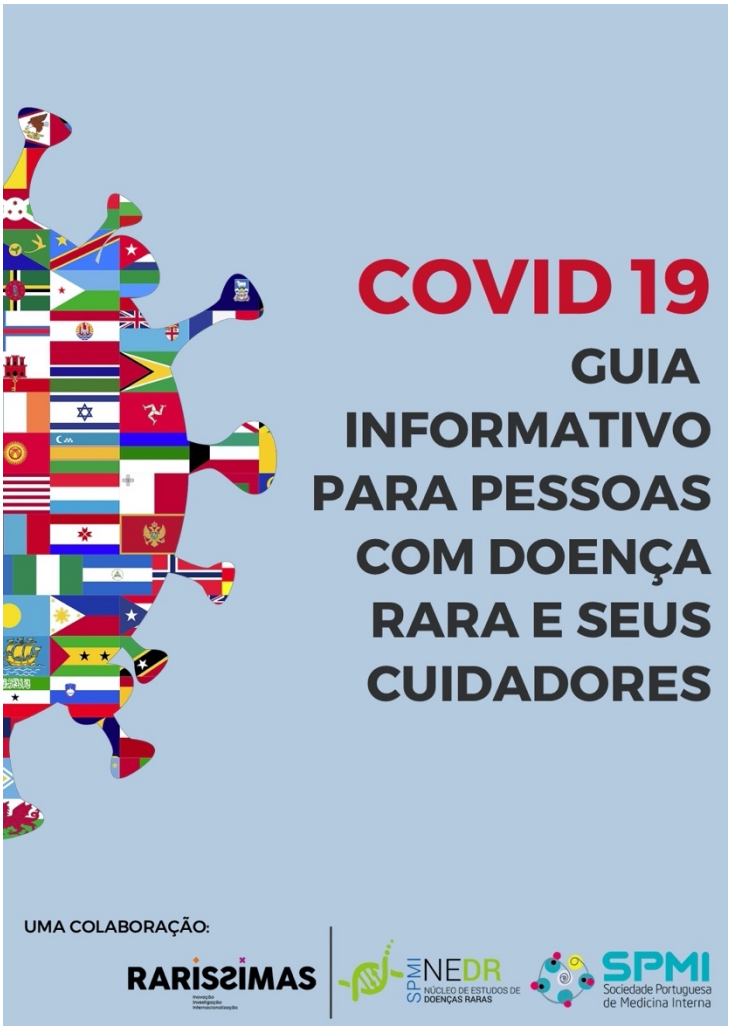
Mundo Marfan Latino coordinated the creation of an informative document on COVID-19 and Marfan syndrome, along with various Marfan associations and Latin American groups. They thereby created a webpage with verified and revised information that is updated regularly.

Visit the webpage at the following link at:

https://mundomarfan.org/coronavirus/

Both the content and the page itself are available under a free license, which means it can be reused elsewhere by indicating the source. Therefore they are offering assistance in adapting the content if it is of interest to other pathologies or associations.

Rarissimas shares Information Guide on COVID-19 for people with Rare Diseases and their Caregivers



In light of the rapid development of the global COVID-19 pandemic, Rarissimas Portugal is aware of the concern of rare diseases patients, their relatives and caregivers on their disease and the state of their health. Therefore, the organisation has created an informative guide, which has been prepared using information from validated national and international sources.

The main objective of this guide is to inform and support people with rare diseases and their caregivers who want to learn more about SARS-Cov-2 and COVID-19. It also aims to prevent, combat, and eliminate behaviours that are likely to cause the spread of this pandemic, which can only be achieved with the commitment and participation from the whole of society.

Click on the following link to read the full guide:

https://www.spmi.pt/wp-content/uploads/2020/04/COVID-19-Guia-informativo-para-Pessoas-com-Doenca-Rara-e-seus-Cuidadores.pdf

AELIP celebrates World Lipodystrophy Day

31 March 2020 was celebrated as World Lipodystrophy Day and AELIP, a member of ALIBER, wanted to participate in the events held on this day with various initiatives.

In spite of the current pandemic and not being able to go out, 20 countries commemorated the day with visibility and awareness-raising campaigns using social media. The aim was to raise awareness in society that the daily lives of people and families living with lipodystrophy around the world is just as exceptional, bewildering and uncertain as the situation that we are experiencing at the moment. Therefore, the World Lipodystrophy Day 2020 campaign was developed under a single message "**TOD@S NOS NECESITAMOS SUMANDO"** ("WE NEED TO BE UNITED").

AELIP encouraged people to create their own drawings and upload them to social media with the World Lipodystrophy Day official hashtags:

#WorkingForLipodystrophies
#TrabajandoParaLasLipodistrofias (WorkingForLipodystrophies)
#InvestigandoLipodistrofias2020 (ResearchingLipodystrophies2020)

Following the launch, drawings were received from people in over 20 different countries, including Spain, Portugal, Chile, Argentina, Venezuela, Peru and Colombia, among others.

AELIP also encouraged people to share the manifesto of people and families living with Lipodystrophy around the world, which also had a huge impact.

ASSOCIATION MANAGEMENT

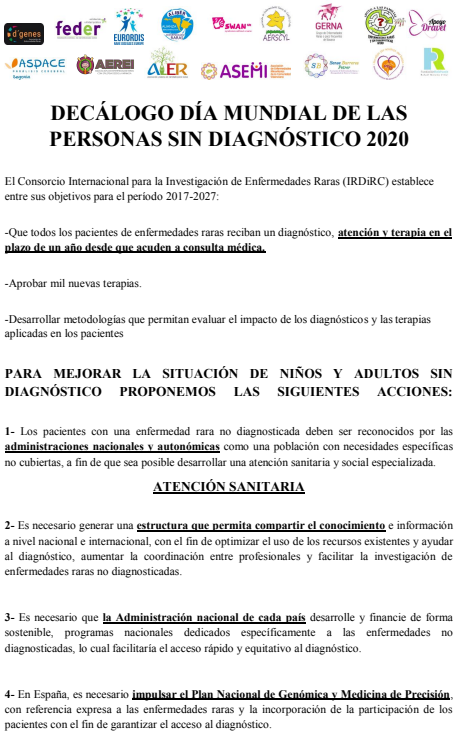
24 April: World Undiagnosed Day

To celebrate World Undiagnosed Day on 24 April, ALIBER invited all its member entities and the general population to show their support on social media to all families living with an undiagnosed illness.

As part of the initiative **"No tenemos diagnóstico pero sí necesidades" ("We don't have a diagnosis but we do have needs"),** ALIBER joined other associations and patient organisations to raise awareness of the feelings and realities of people who are not able to put a name to the disease that they suffer from.

To do this, a manifesto of the needs of undiagnosed people was shared and videos of support for the community were uploaded on social media with the hashtags:

#DiaMundialSindiagnístico
[WorldUndiagnosedDay]
#Syndiagnosis [Undiagnosed]



DECÁLOGO DÍA MUNDIAL DE LAS PERSONAS SIN DIAGNÓSTICO 2020

El Consorcio Internacional para la Investigación de Enfermedades Raras (IRDiRC) establece entre sus objetivos para el período 2017-2027:

-Que todos los pacientes de enfermedades raras reciban un diagnóstico, **atención y terapia en el plazo de un año desde que acuden a consulta médica.**

-Aprobar mil nuevas terapias.

-Desarrollar metodologías que permitan evaluar el impacto de los diagnósticos y las terapias aplicadas en los pacientes

PARA MEJORAR LA SITUACIÓN DE NIÑOS Y ADULTOS SIN DIAGNÓSTICO PROPONEMOS LAS SIGUIENTES ACCIONES:

1- Los pacientes con una enfermedad rara no diagnosticada deben ser reconocidos por las **administraciones nacionales y autonómicas** como una población con necesidades específicas no cubiertas, a fin de que sea posible desarrollar una atención sanitaria y social especializada.

ATENCIÓN SANITARIA

2- Es necesario generar una **estructura que permita compartir el conocimiento** e información a nivel nacional e internacional, con el fin de optimizar el uso de los recursos existentes y ayudar al diagnóstico, aumentar la coordinación entre profesionales y facilitar la investigación de enfermedades raras no diagnosticadas.

3- Es necesario que **la Administración nacional de cada país** desarrolle y financie de forma sostenible, programas nacionales dedicados específicamente a las enfermedades no diagnosticadas, lo cual facilitaría el acceso rápido y equitativo al diagnóstico.

4- En España, es necesario **impulsar el Plan Nacional de Genómica y Medicina de Precisión**, con referencia expresa a las enfermedades raras y la incorporación de la participación de los pacientes con el fin de garantizar el acceso al diagnóstico.

Click here to read the full manifesto:
https://aliber.org/web/2020/04/24/en-el-dia-mundial-de-personas-sin-diagnostico-aliber-lanza-decalogo-de-necesidades/

ASSOCIATION MANAGEMENT

Our family continues to grow: 59 ENTITIES, 532 ORGANISATIONS AND 16 COUNTRIES.

On 18 October 2013, a new organisation was born in the city of Totana, Murcia, driven by various non-governmental organisations dedicated to sending hope and optimism to thousands of families with rare diseases. This was how ALIBER, the Ibero-American Alliance for Rare, Orphan and Uncommon Diseases, bridged the gap between the European and American continents (South and Central America) with the purpose of bringing attention to and increasing the strength of the associative movement in rare diseases.

The main action plans are:

- Promoting the recognition of Rare, Orphan and Uncommon Diseases as a social, health, educational and labour priority
- Safeguarding the rights of people with a rare disease and their families,
- Encouraging the participation of those affected and the member entities,
- Knowledge development in the field of Rare, Orphan and Uncommon Diseases and
- The involvement of professionals in the social and health fields and institutions concerning the care of rare, orphan and uncommon diseases.

Almost 7 years later, the enthusiasm of a group of people committed to rare diseases has united **59 entities that encompass 532 organisations from 16 different countries.**

ASSOCIATION MANAGEMENT

We would like to introduce and give a special welcome in this newsletter to the most recent 8 entities to have joined our ALIBER family:

- *Instituto Contemplo Brasil*
- *Hereditary Angioedema Patient Association of Peru.*
- *Association of Inherited Rickets and Osteomalacia of Peru.*
- *Spanish Association of Inherited Rickets and Osteomalacia.*
- *Fundación Poco Frecuentes España*
- *Primary Immunodeficiencies Foundation. Bolivia.*
- *Spanish Association of Porphyria.*
- *GENES Foundation Latin America. Mexico*

We remember the mission, vision and values that underpin this Alliance.

Our mission

Our mission is to create a network of entities that represent people with rare, orphan and uncommon diseases and their families, coordinating actions to strengthen the community and give visibility to rare diseases. We also aim to represent people with rare diseases in Ibero-America at local, regional, national and international organisations, creating a space for joint and permanent collaboration to share knowledge, experiences and best practices in the social, health, educational and employment fields.

Our vision

Our vision is to be a coalition that integrates and empowers the various rare disease patient associations in Ibero-America, safeguarding the rights of those affected and their families.

Our values

Our core values are: Commitment, Solidarity, Inclusion, Responsibility, Quality and Equity.

ASSOCIATION MANAGEMENT

Thank you to all the organisations that work every day to make the world a better place

ALIBER has a volunteer technical team: TRAINED PROFESSIONALS AT THE SERVICE OF IBERO-AMERICA

The Ibero-American Alliance for Rare Diseases has a team of volunteers, who are trained professionals in the social and psychological fields. The team's voluntary contribution helps the Alliance to provide its portfolio of services available to all members. Their commitment, help and professionalism will certainly enable the Alliance to continue growing and reinforcing its role as a reference network for orphan diseases in Ibero-America.

The team's responsibilities include attending to the issues raised by ALIBER partners in which the Alliance can offer help, such as with orientations, statements of support, representation, guarantees, among others.
Let's meet the members of ALIBER's Technical Team:

Estrella Guerrero Solana - projects@aliber.org

Estrella holds a Master's Degree in Social Intervention in Knowledge Societies from the International University of La Rioja, as well as a Bachelor's Degree in Social Work from the Pablo de Olavide University of Seville.

Estrella has worked in the public health field and with the processes of rare and complex chronic diseases for over 11 years, occupying roles such as Head of the Andalusian Delegation at the Spanish Federation of Rare Diseases and Head of Policy at the Spanish Association of Epidermolysis Bullosa. Estrella formed part of the team at the New Health Foundation, where she held the position of Head of Integrated Care Projects.

ASSOCIATION MANAGEMENT

Estrella has promoted and carried out research projects related to the complexity of rare diseases. She is a collaborating member of the EUROPLAN working groups, whose main purpose is to promote the harmonised creation of plans and strategies for rare diseases in the European Union.

Role at ALIBER:

- Managing the project area
- Fundraising
- Membership supervision and quota control
- Promoting partner activities
- Support from the ALIBER Information and Advisory Service in collaboration with FEDER
- Monitoring the WhatsApp of Members and Friends of ALIBER
- Reviewing and updating content and documentation hosted in the cloud.

Alicia María Males - management@aliber.org

Alicia is a trained social worker specialising in family counselling and leadership and management training. Alicia has 15 years' experience providing support to patients and families during the processes of adapting to a diagnosis and treatment of chronic and orphan diseases in Colombia. She also has experience in psycho-social counselling with the families of patients hospitalised in neonatal and paediatric intensive care units, general hospitalisation and paediatrics at the Fundación Clínica Valle del Lili. Alicia has extensive experience as a director of a non-profit foundation on an international scale, dedicated to strengthening education and empowerment actions for the management and treatment of low-prevalence diseases. Thanks to Alicia's management, the entity that she led became a founding member of ALIBER.

Her contribution at ALIBER includes:

- *Revival of the ALIBER Information and Advisory Service*
- *Helping to manage the social media accounts*
- *Updating the content on the ALIBER website*
- *Supporting the coordination of projects*
- *Fundraising*
- *Managing documentation and content hosted in the cloud.*

ASSOCIATION MANAGEMENT

Alba Ancochea - advocacy@aliber.org

Alba holds an Undergraduate and Master's Degree in Psychology and Special Needs Teaching, a Master's in Brief Psychotherapy and a Master's in NGO Management. Alba has 10 year's experience and commitment in implementing and planning public health policies, programs and projects in the area of rare diseases. She also has further training in advocacy and treatment access and has organised and spoken at many conferences and specialised workshops.

Since 2009, Alba has actively participated in the Spanish Federation of Rare Diseases (FEDER) and its foundation. She represents the community of people with rare diseases and their families in different committees and working groups. At an international level, her professional highlights include being a member of the Patient Advocacy Group at Rare Diseases International, her role within the EURORDIS Board of Directors and a representative of ALIBER in the IRDIRC PACC.

Alba defines herself as an agent of change and social transformation, highlighting the responsibility, commitment and positivity that she brings to all of her the work.

Role at ALIBER:

- *Policies on advocacy and defence of rights*
- *Execution of the ENSERio-LATAM Study*
- *Institutional relations*
- *Supporting Rare Diseases International (RDI)*
- *Participating in International Rare Diseases Research Consortium (IRDiRC)*
- *Collaborating with APEC*
- *Fundraising, movement control in banks and through Paypal*
- *Managing documentation and content hosted in the cloud.*

Our team is here to help Ibero-America!

ALIBER newsletter:

Original idea:
- Juan Carrión - President of ALIBER

Design and Development:
- Estrella Guerrero Solana - Project Manager at ALIBER
- José Jerez Ruíz-ALIBER Collaborator

Editorial Committee:
- Alba Ancochea - advocacy@aliber.org
- Juan Carrión - presidencia@aliber.org
- Estrella Guerrero Solana - projects@aliber.org
- Alicia María Males - management@aliber.org

MEMBER ENTITIES IN MAY 2020

MEMBER OF

IRDiRC
INTERNATIONAL RARE DISEASES RESEARCH CONSORTIUM

RARE DISEASES INTERNATIONAL