

# NEWSLETTER

**MAY 2020**



**Social Action**  
**Training and Research**  
**Aliances and solidarity**  
**Networks**  
**Visibility**  
**Advocacy**  
**Association Management**

MEMBER OF



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Translations for non-profit **AGIT**

## 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.



## *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](mailto: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](http://www.aliber.org)

@inforaliber aliber org



@infoaliber

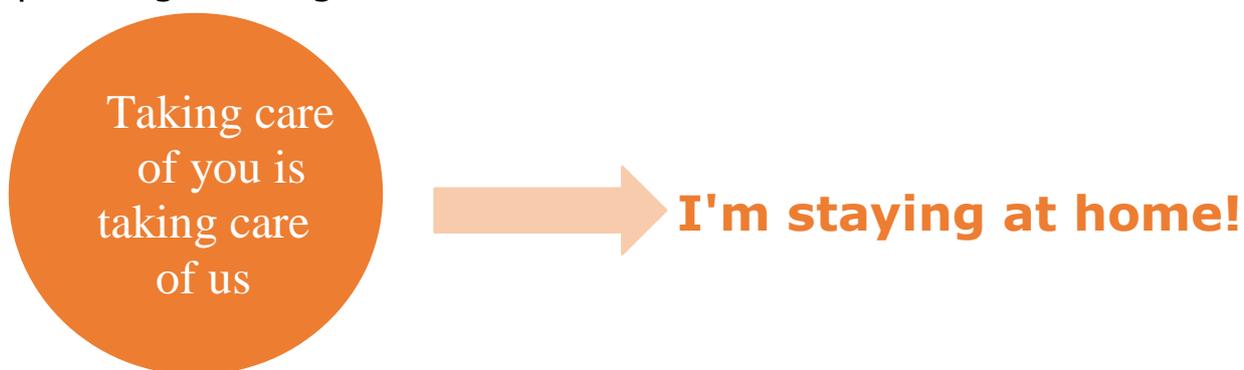


YouTube

## *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:



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/>

# MEMBER ENTITIES IN MAY 2020



MEMBER OF



RARE DISEASES INTERNATIONAL



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