

*Asociación Costarricense
de Hipertensión Pulmonar*

**COSTARICAN ASSOCIATION OF
PULMONARY HYPERTENSION**





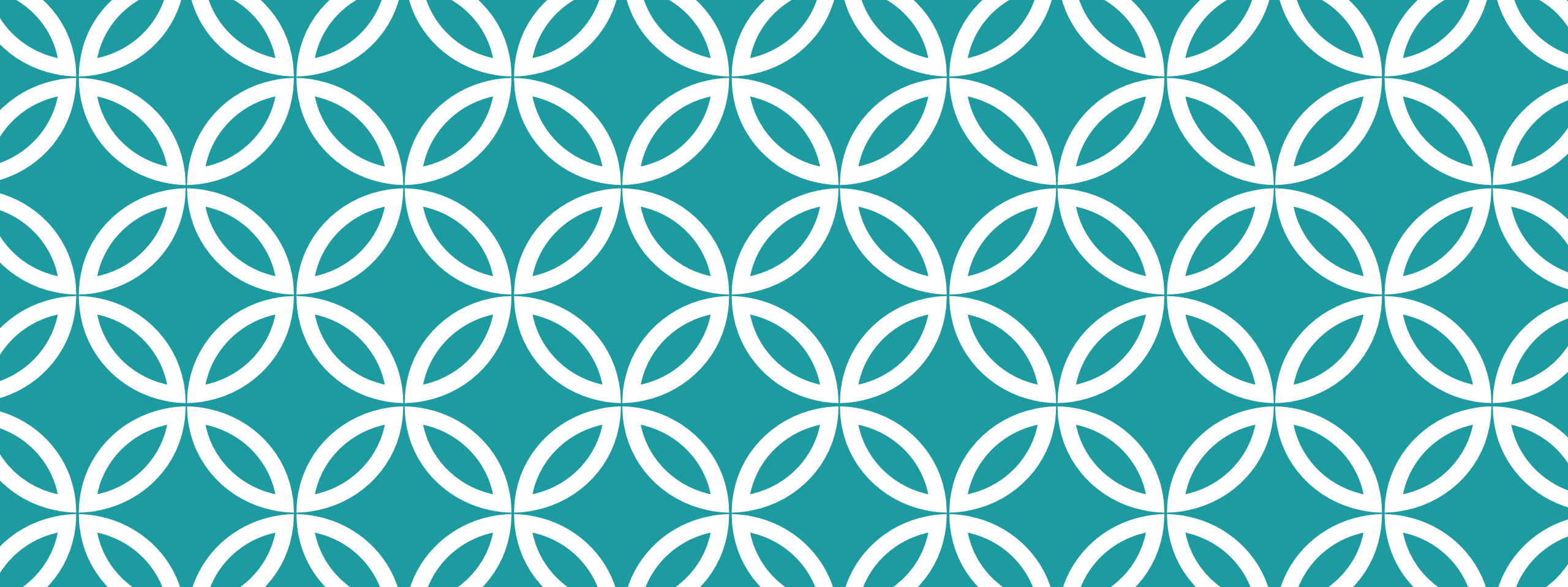
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NANCY RIVAS ELIZONDO

I am Hackeem's mother. He is a patient diagnosed with Pulmonary Hypertension associated to chronic thromboembolism

**I am also the Vice president of the
Costarican Association of Pulmonary
Hypertension**





OUR OBJECTIVE

Porque estamos en
tus zapatos!



From Patient to Patient

**WE WANT TO EDUCATE, TO SUPPORT AND
TO IMPROVE THE QUALITY OF LIFE OF THE
PATIENT WITH PULMONARY HYPERTENSION**



OUR OBJECTIVES

- Increase disease awareness
- Educate patients and their relatives about the disease, stages, treatments
- Support other associations that have similar purposes.
- Promote and participate in activities to support patients
- Advise and help patients to obtain specific medications to treat their disease.



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STATUS OF EXISTING LEGISLATION AND POLICIES IN YOUR COUNTRY

- In our country there is no legislation that contemplates rare diseases
- In the case of Pulmonary Hypertension we have achieved some awareness by making the disease visible through social media campaigns and facebook lives



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CURRENT NATIONAL ACTIVITIES AND AREAS OF EMPHASIS

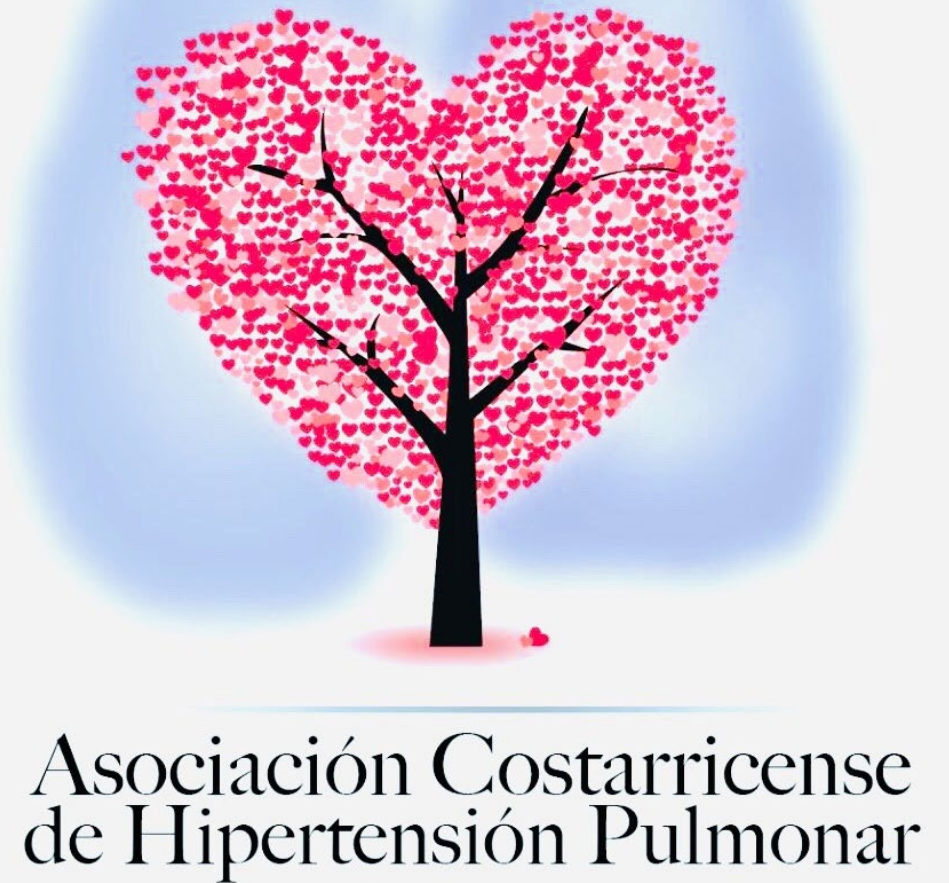
- Make disease visible and increase disease awareness during the **World Rare Diseases Day**, **World Pulmonary Hypertension Day** and **Latino American Pulmonary Hypertension Day**, leveraging the fact that patients need support from key areas: government, medical & pharmacological



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CHALLENGES, BARRIERS OR OBSTACLES TO NEEDS IN RARE DISEASE COMMUNITY

- In our country there is no legislation that contemplates rare diseases
- We have many barriers but the most important for us is access to high-cost drugs.
- The drugs our patients need to have better quality and life expectancy are rejected based on the lack of symptoms improvement, and the fact that they will not cure the disease and that the cost benefit is very high.
- The Association support patients who have had a treatment request rejected to raise a case through the Constitutional Court.



LEGISLATIVE OR POLICY NEEDS
IN RESEARCH, REGULATORY
OR HEALTHCARE SERVICE

- A public policy that recognizes rare diseases as diseases that require specialized and faster care and an earlier diagnosis
- Accelerate regulatory approval of new treatments
- Inclusion of treatments at social security level (public hospitals level)



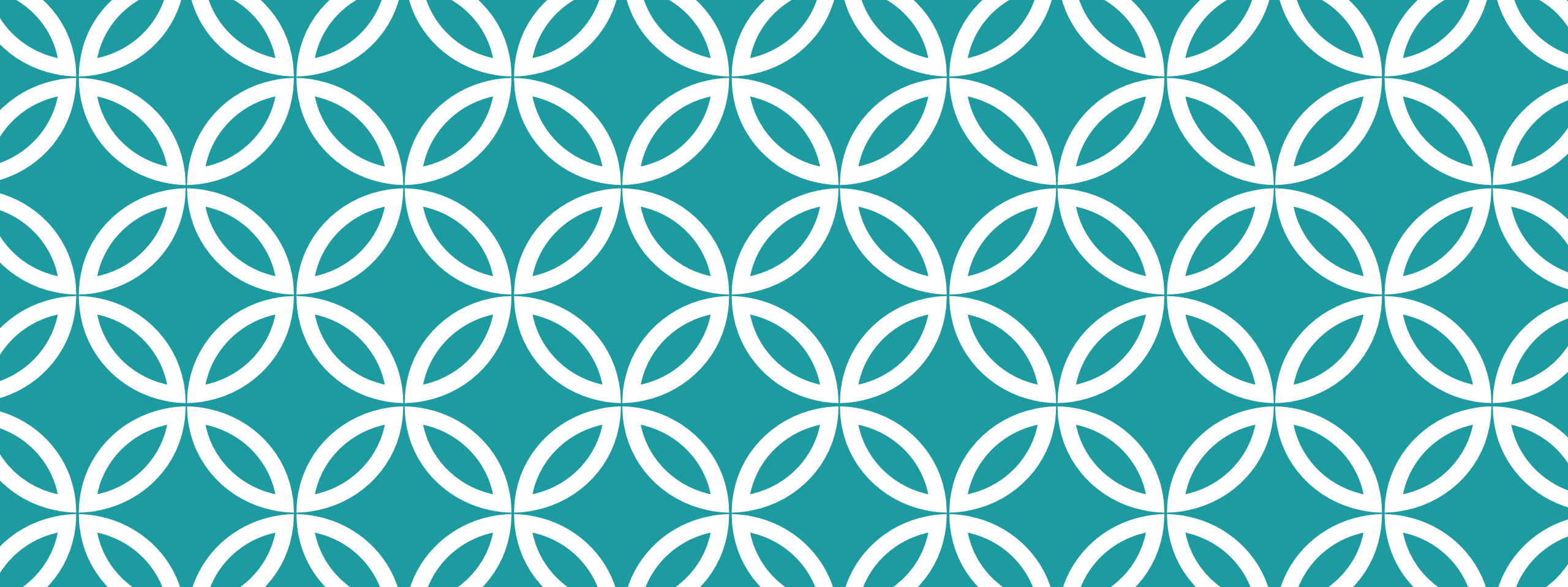
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SUGGESTED ACTIVITIES FOR THE COUNTRY AND THE REGION FOR A SUSTAINABLE ERCAL

- Maximize efforts in order to improve the quality of life of patients by working together in:
 - Creation of work tables
 - Training of local physicians in other countries with advanced surgical techniques and equipment, such as thromboendarterectomy surgery in Mexico, Argentina and Brazil.ç
 - Develop international events to call the attention of decision makers, pharmaceutical companies and researchers in order to have more therapies drugs for orphan disease patients.



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MUCHAS GRACIAS |