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fibrosi
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1. Cystic fibrosis (CF)



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Cystic fibrosis

Questions and Answers

What is Cystic Fibrosis (CF)?

It is a chronic and hereditary disease that represents a serious health problem. It is a degenerative disease that mainly affects the lungs and digestive tract. It affects one in 4000/5000 newborn babies each year. Around 180 people in the Basque Country have the disease.

How is it diagnosed?

The most useful diagnostic method is the sweat test when the baby's sweat tastes salty. Genetic analysis is then carried out to confirm the diagnosis. Currently there is no cure for this genetic disease, but an early diagnosis can lengthen the life expectancy of the affected person and improve their quality of life.

Cystic fibrosis

Questions and Answers

Types of treatments

Diet: a person affected by CF should take care of their diet to maintain their health. This involves eating a nutritionally balanced and hipercaloric (diets with increased meal frequency but not size) diet as this helps their body stay healthier and prevent infection.

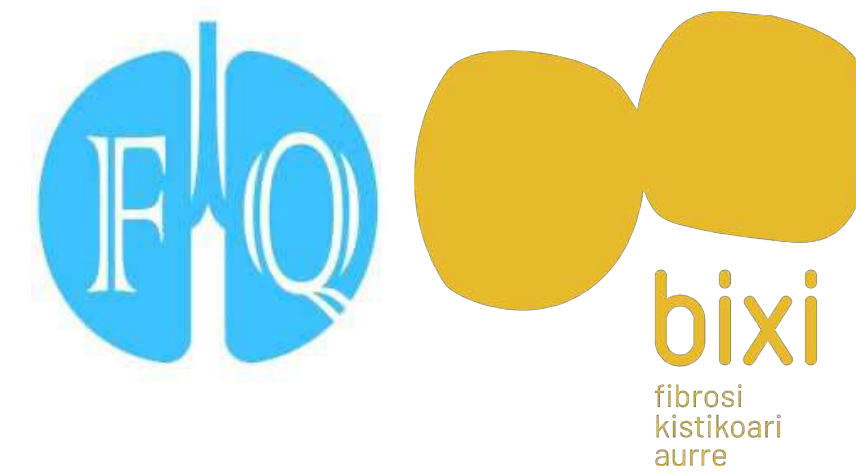
Antibiotherapy: Antibiotherapy has been one of the determining factors of the best prognosis for CF. It is used to fight both chronic bronchial infection and exacerbated infections.

Respiratory Physiotherapy: This is daily bronchial cleaning in order to prevent the accumulation of mucus in the bronchi and prevent infection.

Physical Exercise: Physical exercise helps maintain lung function and also to keep both muscles toned and bones strong.



2. bixi association



Bixi association

Why Bixi

What is bixi?

Bixi Association (Bixi means "live" in Basque) was formed by a group of friends with the objective of helping people affected by CF and their families. It is linked to the ARNASA Association.

What is the aim of BIXI?

It helps people affected by CF and their families by campaigning for improvements and support for them.

Bixi association

Current support for families

What is the current situation?

As in all cases of disability, an assessment of the disease is made and a percentage of disability aid is allocated on the basis of that assessment. The financial support is very limited and families usually do not get any kind of aid. Any support they receive is thanks to the support from the different associations.

What kind of support are they asking for?

People with CF usually require 24-hour specialized care and assistance. It is a degenerative and uncertain disease with care normally falling on their parents or family members. Carers are often unable to pursue their own lives or normal jobs so we believe that those responsible for the sick person's care should receive a decent pension or benefit. If parents go to their jobs, who will care for their sick children?

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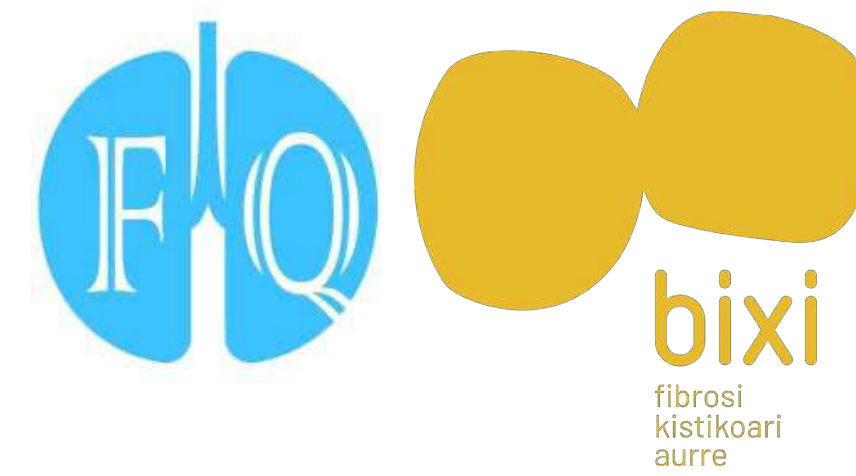
Housing and space for home treatment

Should housing meet some special condition?

After conventional medical care is provided in a hospital, the sick person must continue to receive treatment in their own home. In fact, very often the complete treatment is offered in their own home. However, to carry it out, the home must meet a number of conditions, such as adequate space. A decent home for the sick person is necessary. Many families rent small homes where all resources are used to meet the demands generated by the disease. Moreover, for families with 2-3 children, a larger number of bedrooms is required.

What type of place does a person affected by CF require?

A person affected by CF needs a bedroom, a private space for their physiotherapy sessions and to follow their treatment, that is, a space adapted to this type of care.



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Health system and administration of CF healthcare

What is the relationship between the health system, the administration and the people affected by CF?

In Biscay, Cruces Hospital is the centre for CF care and where medical treatments are provided. BIXI requests that, in addition, physiotherapy and other technical treatments should be offered here. Moreover, BIXI believes that parents should receive training so that they can provide the most effective care possible.

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What does BIXI want to achieve?

BIXI would like to see the following for the people affected by CF and their families:

First, recognition, an invisible disease and we believe this fact makes the way even more difficult.

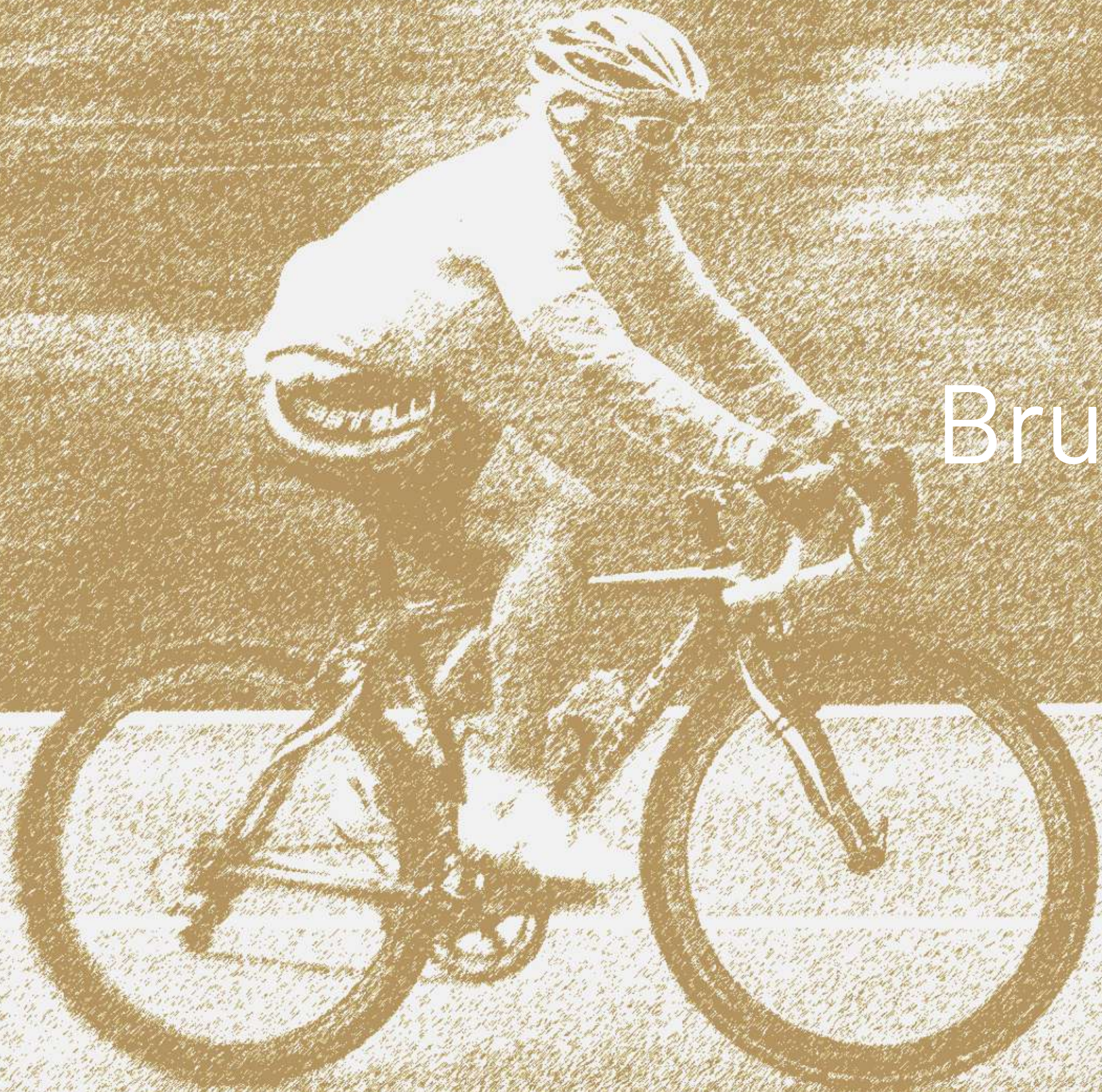
Secondly, administrative and financial assistance as mentioned above, that is:

1. Decent pensions for carers.
2. Home ownership so that people affected and their families can manage the disease easily with the right facilities in the home.
3. The provision of physiotherapy and therapies by the government.
4. Training In different types of therapy for the sick person and their families for optimal benefit.
5. General recognition of this invisible disease, because they are not sufficiently valued
6. Financial and administrative resources and rights those affected.

And, finally, BIXI wants to demonstrate in Europe what the realities of living with the disease are for those living with people affected by rare diseases.



3. Solidarity action



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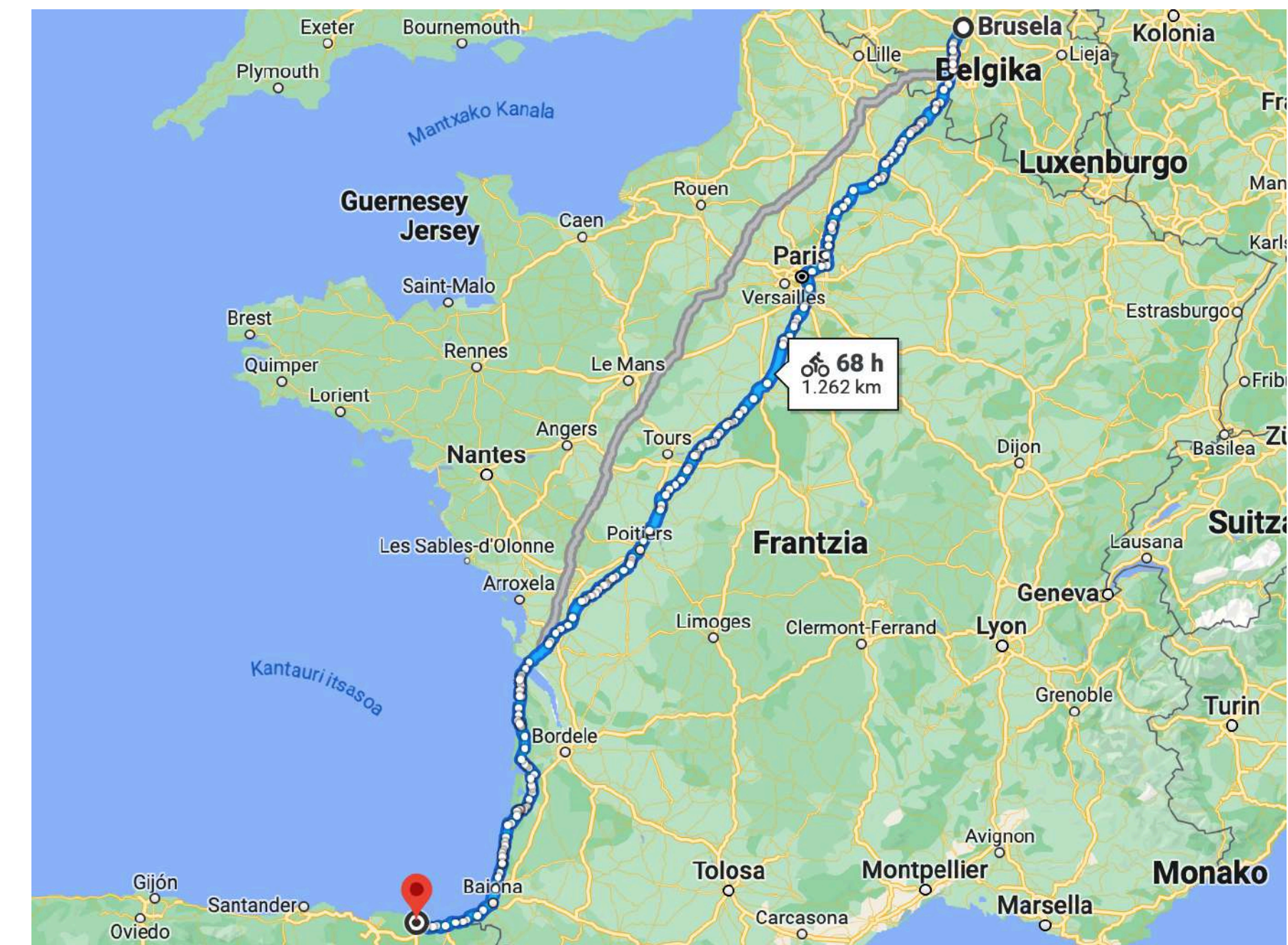
Brussels - Ondarroa

Activities to inspire solidarity

From Brussels to Ondarroa by bicycle

What does the activity consist of?

To spread knowledge about the condition of people affected by CF and their families, we will make our way from Brussels to Ondarroa by bike and disseminate information about this situation in Brussels and also in different cities we encounter along the way.



Activities to inspire solidarity

From Brussels to Ondarroa by bicycle

Who is the driving force of this action?

Seber Uribe and the team that make up the BIXI Association

Fundraising

BIXI will organize a **crowdfunding** campaign for fundraising and to secure the finances for the trip.



Activities to inspire solidarity

From Brussels to Ondarroa by bicycle

What does BIXI want to achieve with this activity of solidarity?

First, BIXI wants to go to Brussels to show the European Union our situation and secure some commitments from the public authorities. Next, we will make a tour by bike in stages until Ondarroa and spread information about the issue in different towns and cities we meet along the way. During our journey we will go through three countries: Belgium, France and Euskal Herria (Basque Country).

It is a social and solidarity activity using bicycles as a means of transport since we believe it is the proper way of doing sport and, at the same time, promote healthy and sustainable habits.

Why Brussels-Ondarroa?

BIXI wants to expand boundaries and, since we want to approach the administration, What better option than Brussels? We believe that this action must be international, and we will go through three countries before returning home. We invite everyone to join us in this initiative.



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