



CHARITY WALK
640 KM FOR 640 KM FOR DRAVET SYNDROME
PATIENTS AND THEIR FAMILIES

PEDRO AGUADO CALDERON
FROM CATALUNYA TO CANTABRIA
Since October 28th to November 11th 2023

1. PRESENTATION

My name is Pedro, and for the past 8 years I have passionately dedicated myself to the world of trail running in the mountains. This connection with nature has been present in me since I was born, since I am from a charming town in Cantabria called Corvera de Toranzo. The rural environment is my true passion, and every time I run up and down the mountains, I feel a special connection with my land.

Two years ago, through a well-known friend, I had the opportunity to join a group of people affected by Dravet syndrome. Since then, I have dedicated myself to running for this noble cause, turning every kilometer traveled into a way to raise funds to support those who suffer from this disease.

In recent months, I have been reflecting on how I can do more to raise awareness about this and other diseases that unfortunately go unnoticed until they touch us personally or in our close circle. I firmly believe that we must make people aware of the importance of acting before we face the problem. If we all come together and work together, we can make a significant difference in the lives of those struggling against little-known diseases.

This is how this project was born, with the aim of increasing the visibility of Dravet syndrome and raising awareness in society about its impact on the lives of affected children and their families. But this is only the beginning; I am firmly convinced that many more projects will come. I want to help with this in any possible way, and as an experienced runner, I feel like my passion for running is my way of doing it.

This project is for all children who bravely fight against any disease. I want you to know that you are not alone and that you have my unwavering support. Every mile I walk is for them, hoping that my efforts can make a difference and contribute to a more empathetic and compassionate world.

Many thanks to everyone who joins this cause, as together we can bring a message of hope and solidarity to those who need it. Every step I run is a reminder that we, as a community, can make a big difference in the lives of those facing health challenges. Let's move forward together!

2. DRAVET SYNDROME

Dravet syndrome, also known as Dravet syndrome or severe myoclonic epilepsy of childhood, is a very severe grade of epileptic encephalopathy that begins in the first year of life.

Characteristic symptoms include:

I. Seizures: Seizures are often prolonged, long lasting, and difficult to control with common anti-epileptic medications.

II. Febrile Seizures: Seizures are usually triggered by fever, but over time, they can also occur without fever.

III. Developmental delay: Affected children may experience delayed motor and cognitive development.

IV. Behavioral problems: They may have behavioral problems and difficulties in speech and communication.

V. Balance and coordination problems.

This disease is caused by a genetic mutation in the SCN1A gene, which plays an important role in regulating sodium channels in nerve cells in the brain. As a result of this mutation, sodium

channels do not function properly, leading to excessive neuronal excitability and epileptic seizures.

Treatment of Dravet syndrome is complex and usually involves the use of multiple antiepileptic drugs to control seizures. However, it is important to keep in mind that not all patients respond adequately to medication, and the disease can have a significant impact on the quality of life of the child and his/her family.

As Dravet's disease is a rare and complex condition, it is recommended that patients be treated by epilepsy specialists and that a comprehensive approach to care be provided that includes complementary therapies and psychosocial support for both the patient and the family. Research in this area is ongoing, and new therapies and approaches are being explored to improve the quality of life of patients suffering this condition.

3. DRAVET SUPPORT

The association “ApoyoDravet”, as said in its website, is a community of people affected by rare diseases with epilepsy and Dravet syndrome. It is constituted in **a collaborative platform**, which brings together patients and relatives, volunteers, and collaborators (scientists, doctors, psychologists, educators, technologists, and other participants). Its objective is to promote scientific research, medicine, technology, and innovation in social intervention to **improve the quality of life of patients** and their family and social environments.

The entity aims to accelerate **scientific research** projects, by promoting the advancement and practical application of science in the field of rare diseases with epilepsy. Thus, it leads a collaborative network of researchers (INDRE) and supports 14 research groups and more than 50 researchers, who work at the scientific forefront: genetic techniques, cell therapy, machine learning, artificial intelligence, nanotechnology, drug development, neuroinflammation. or brain organoids...

Projects in **social innovation** are intended to promote social and educational inclusion, improved general care and home care for patients.



Since 2016, “Apoyo Dravet” has invested more than 450,000 euros in scientific research, with an estimated impact on research of more than 1,500,000 euros; and more than 220,000 euros in social intervention. In 2021 it has developed 30 projects in the fields of social intervention, technology oriented to the affected person and research.

“ApoyoDravet” is a non-profit organization declared of public utility. It is a member of the Spanish Federation of Rare Diseases (FEDER), the Spanish Federation of Epilepsy (FEDE), the European Federation of Dravet Syndrome (DSEF) and the Ibero-American Federation of Support for Dravet Syndrome.

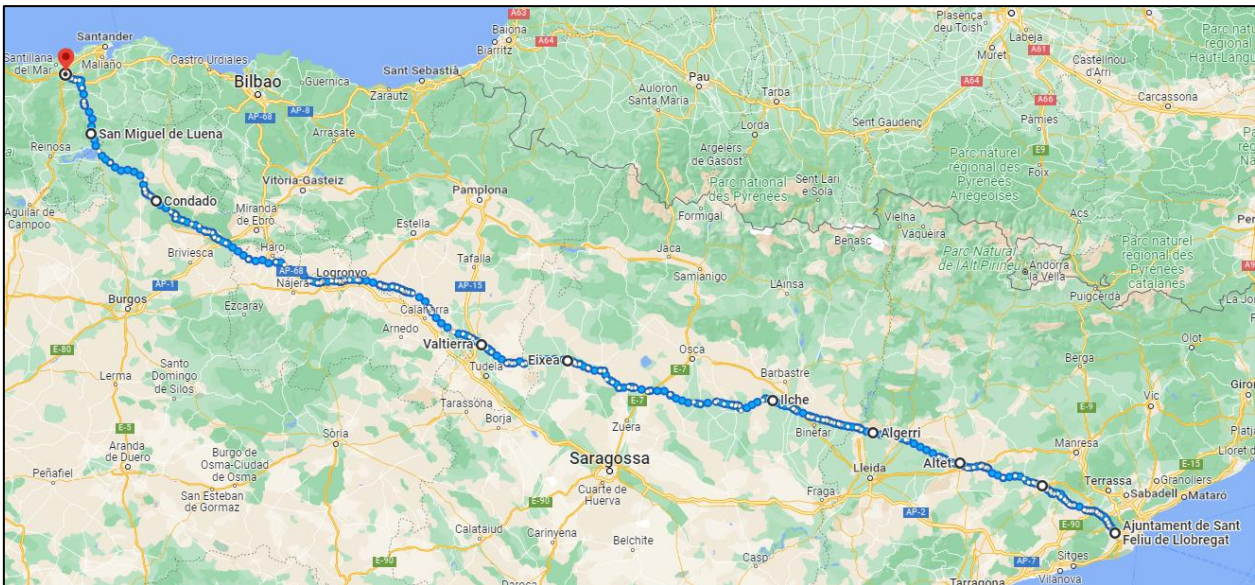
4. THE WALK

This charity walk consists of a route on foot, mostly running and, if necessary, by bicycle, starting from Sant Feliu de Llobregat (Barcelona) to reach Puente Viesgo (Cantabria).

In total there are 640km, divided into 13 stages, one stage per day, with two days of rest every 200-250km approximately.

The journey is estimated to last 15 days.

During the walk towns and cities are visited to grant Dravet syndrome the visibility we are looking for. The councils of some of these towns or cities will be involved to get their collaboration in achieving this visibility of the disease. Part of the walk will be recorded and published on social networks.





The departure of the journey will be from the **Town Hall of Sant Feliu de Llobregat**, the main town of the Baix Llobregat region belonging to the province of Barcelona. It has 45,642 inhabitants according to INE figures in 2022.

The relief of the Sant Feliu municipality is defined by the left bank of the Llobregat river and the first elevations of the Collserola mountain range.

Several streams run through the municipality and conveying the waters of the nearby mountains into the Llobregat river. The most outstanding mountains are Puig d'Olorda (424 meters), Turó Rodó (344 meters) and Penya del Moro (255 meters). The altitude oscillates between 424 meters (Puig d'Olorda) and 10 meters on the banks of the Llobregat river. The urban center stands 22 meters above sea level.



This starting point has been chosen as a family affected by the disease, a resident of this city, has offered to accompany me on my way out to give me encouragement and support to carry out this solidarity journey through the Dravet. I am very grateful to this family for their support. The Sant Feliu de Llobregat City Council also contacted me to communicate their support for the project and offer the necessary help.

The different stages are listed below, where the town or city from which each stage starts and where each stage ends is specified. The kilometers of each stage are also detailed, considering a daily average around 50km.

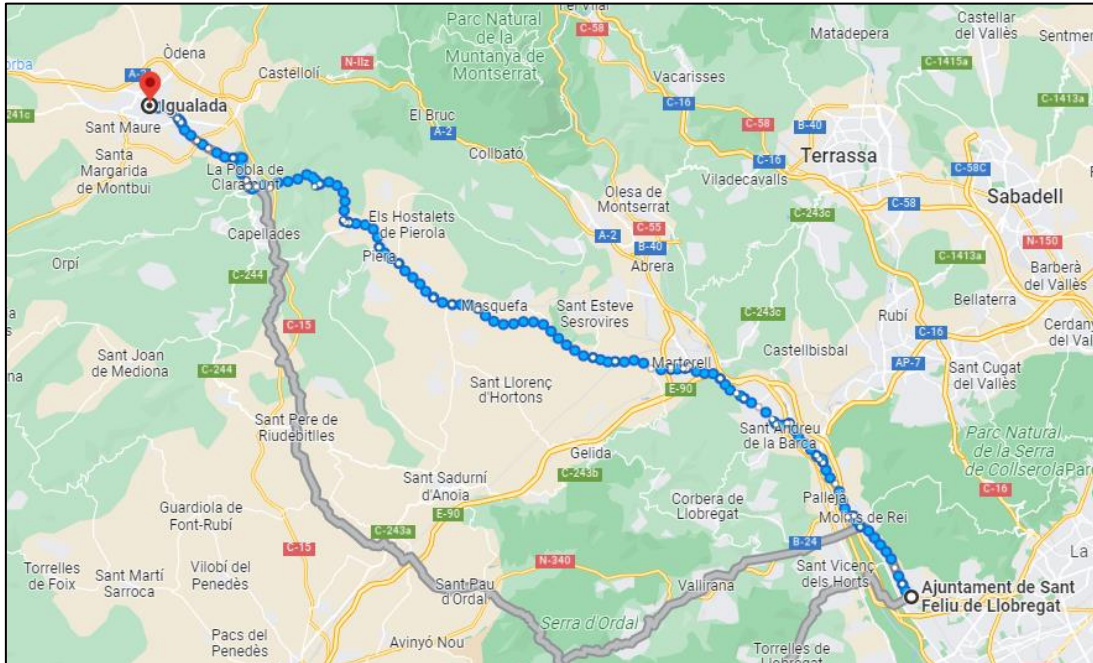
STAGE 1 – DAY 1

Starting point: Sant Feliu de Llobregat Town Hall (Barcelona)

Point of arrival: Igualada (Barcelona)

Kilometers: 51.0

Elevation gain: +720m / -403m



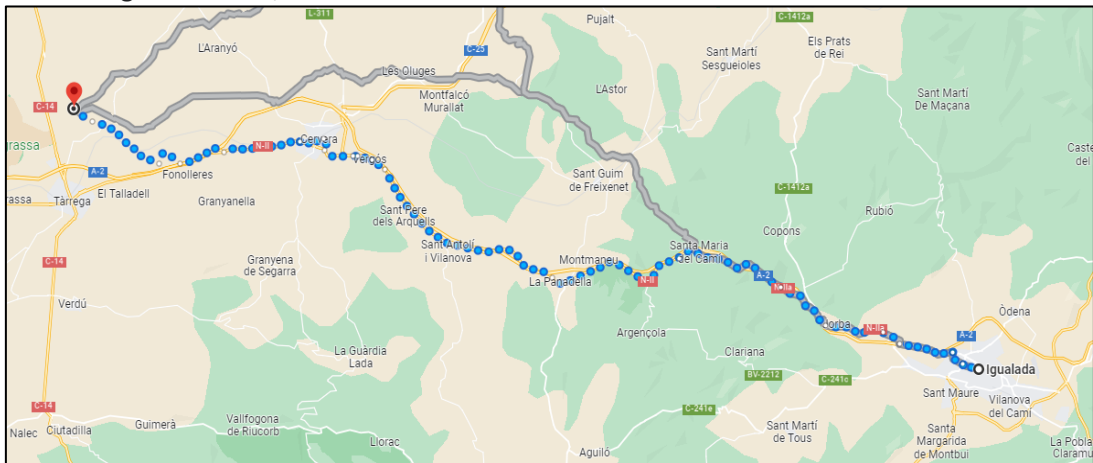
STAGE 2 – DAY 2

Starting point: Igualada (Barcelona)

Point of arrival: Altet (Lleida)

Kilometers: 48.4

Elevation gain: +483m / -457m



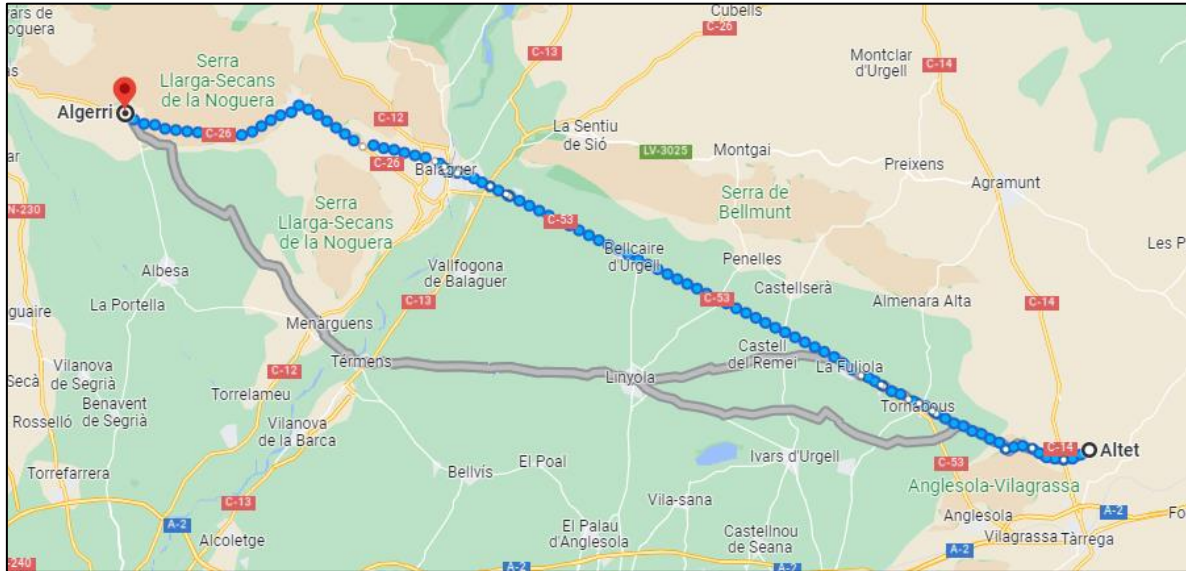
STAGE 3 – DAY 3

Starting point: Altet (Lleida)

Point of arrival: Algerri (Lleida)

Kilometers: 47.3

Elevation gain: +175m / -197m



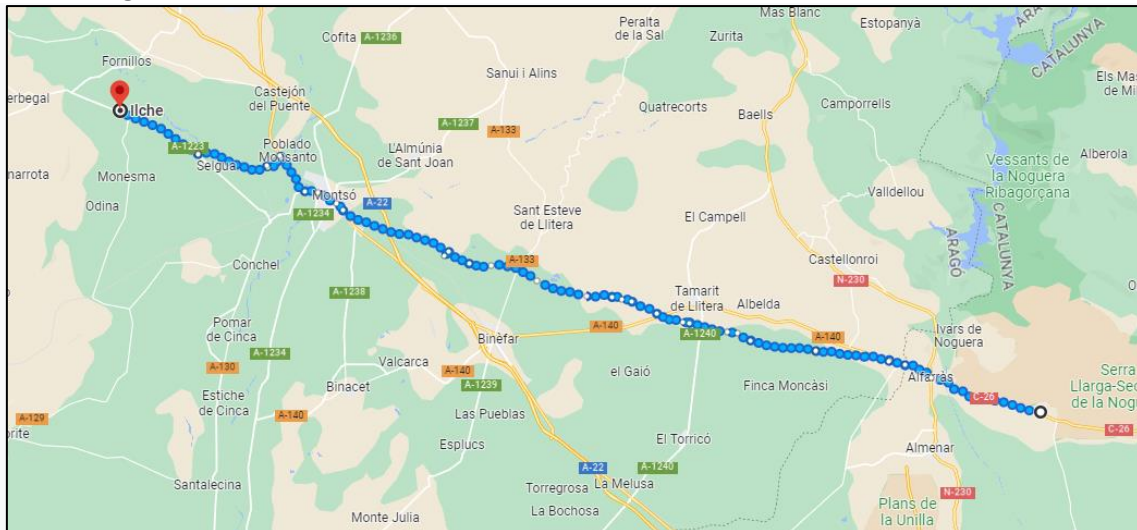
STAGE 4 – DAY 4

Starting point: Algerri (Lleida)

Point of arrival: Ilche (Huesca)

Kilometers: 54.8

Elevation gain: +292m / -318m



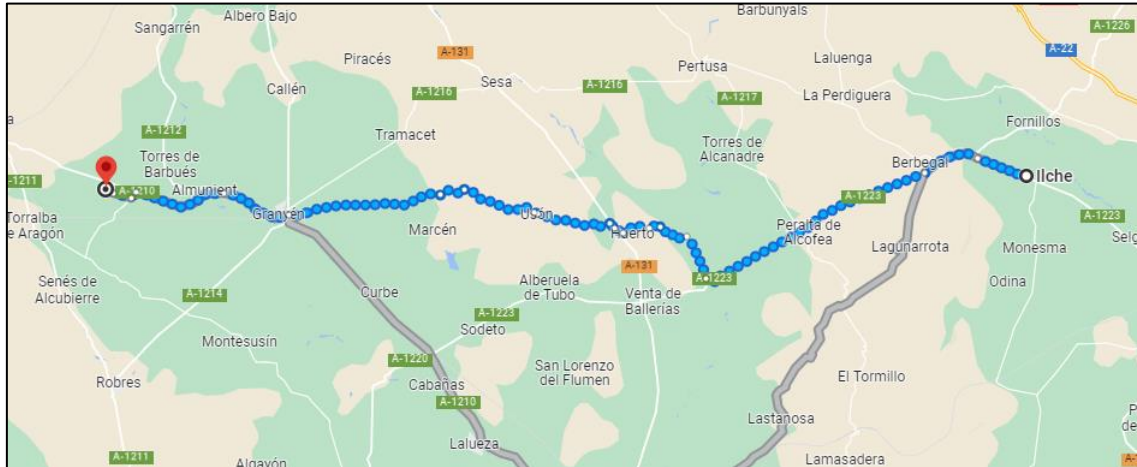
STAGE 5 – DAY 5

Starting point: Ilche (Huesca)

Point of arrival: Valfonda de Santa Ana (Huesca)

Kilometers: 49.8

Elevation gain: +397m / -354m



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STAGE 6 – DAY 6

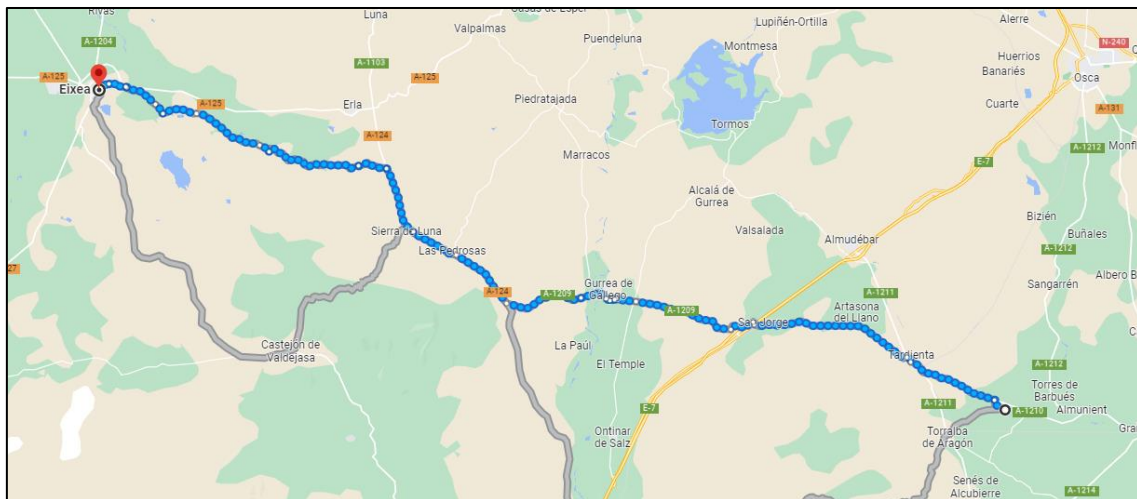
Starting point: Valfonda de Santa Ana (Huesca)

Point of arrival: Eixea (Zaragoza)

Kilometers: 66.2

Elevation gain: +259m / -297m

*In this stage, more kilometers than the average are covered since it is the last stage before the first rest.



*Before stage 7, one day of rest in Eixea is considered

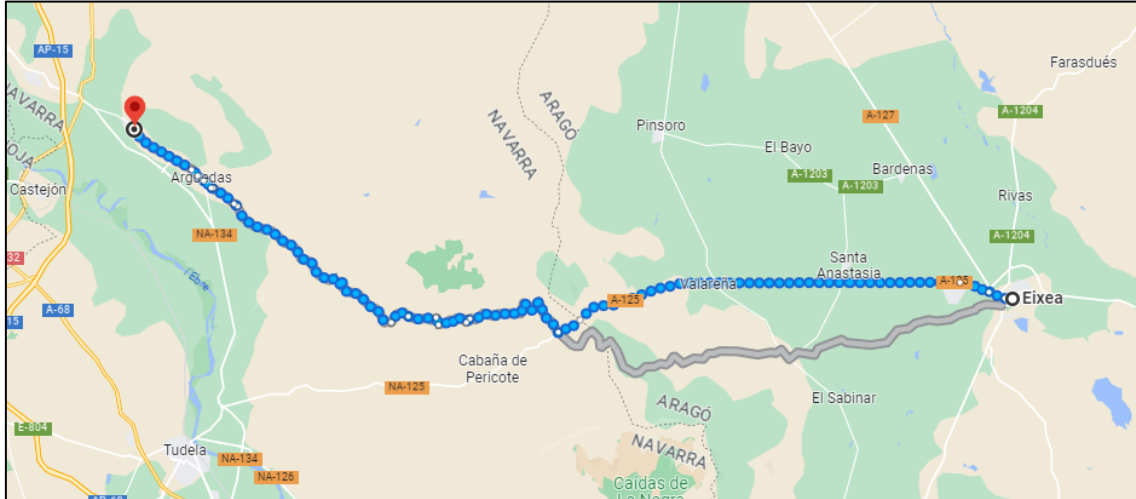
STAGE 7 – DAY 8

Starting point: Eixea (Zaragoza)

Point of arrival: Valtierra (Navarra)

Kilometers: 49.4

Elevation gain: +227m / -278m



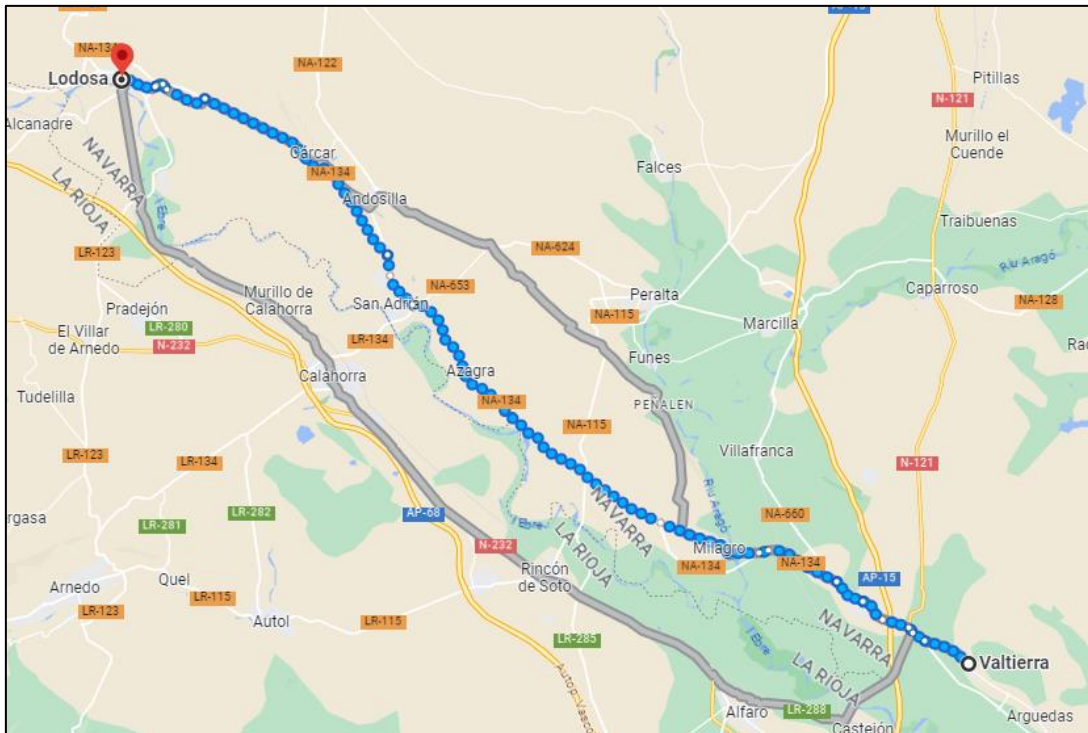
STAGE 8 – DAY 9

Starting point: Valtierra (Navarra)

Point of arrival: Lodosa (Navarra)

Kilometers: 48.1

Elevation gain: +229m / -176m



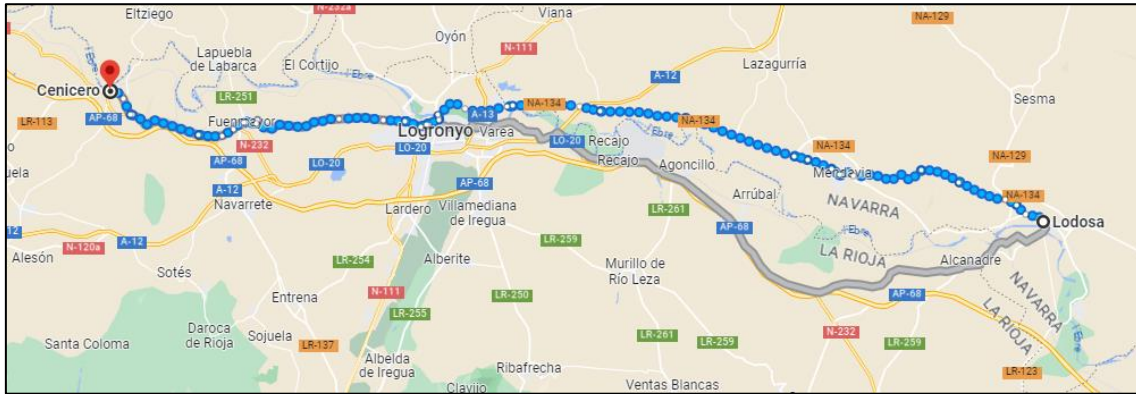
STAGE 9 – DAY 10

Starting point: Lodosa (Navarra)

Point of arrival: Cenicero (La Rioja)

Kilometers: 51.6

Elevation gain: +492m/ -375m



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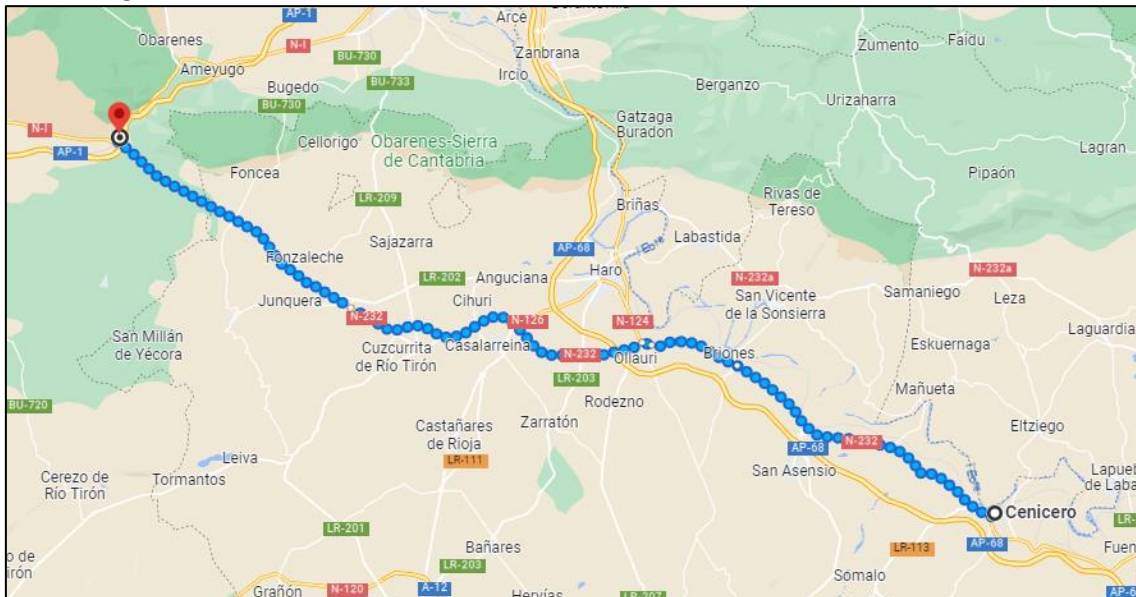
STAGE 10 – DAY 11

Starting point: Cenicero (La Rioja)

Point of arrival: Pancorbo (Burgos)

Kilometers: 45.9

Elevation gain: +442m / -241m



*Before stage 11, one day of rest in Pancorbo is considered

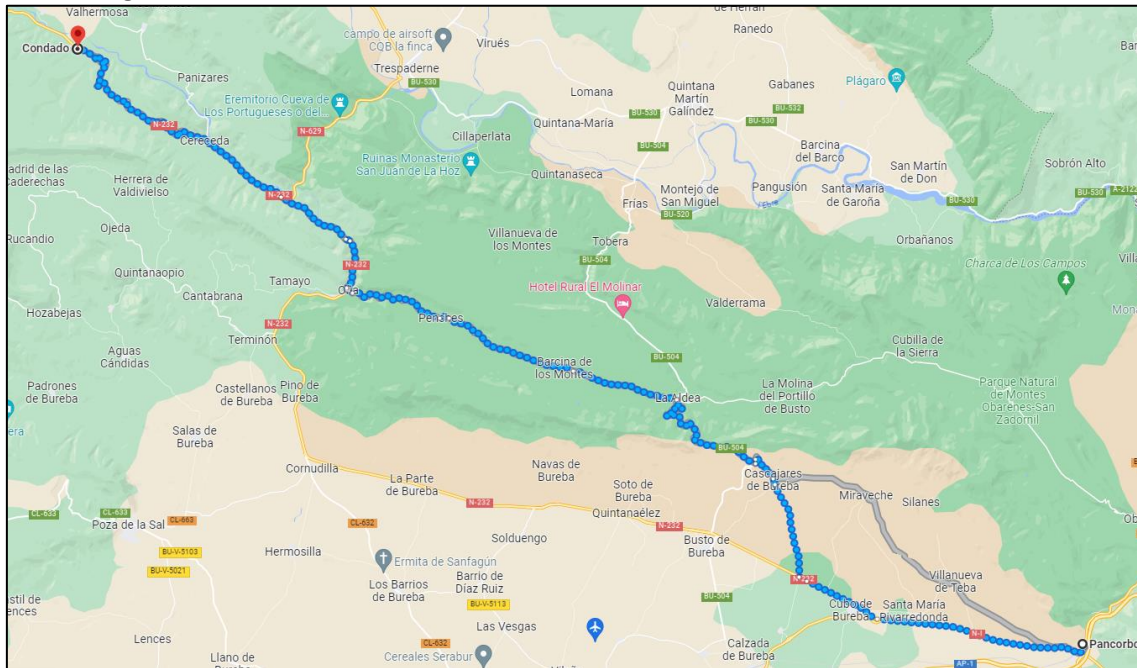
STAGE 11 – DAY 13

Starting Point: Pancorbo (Burgos)

Point of Arrival: Condado (Burgos)

Kilometers: 45.9

Elevation gain: +442m / -241m



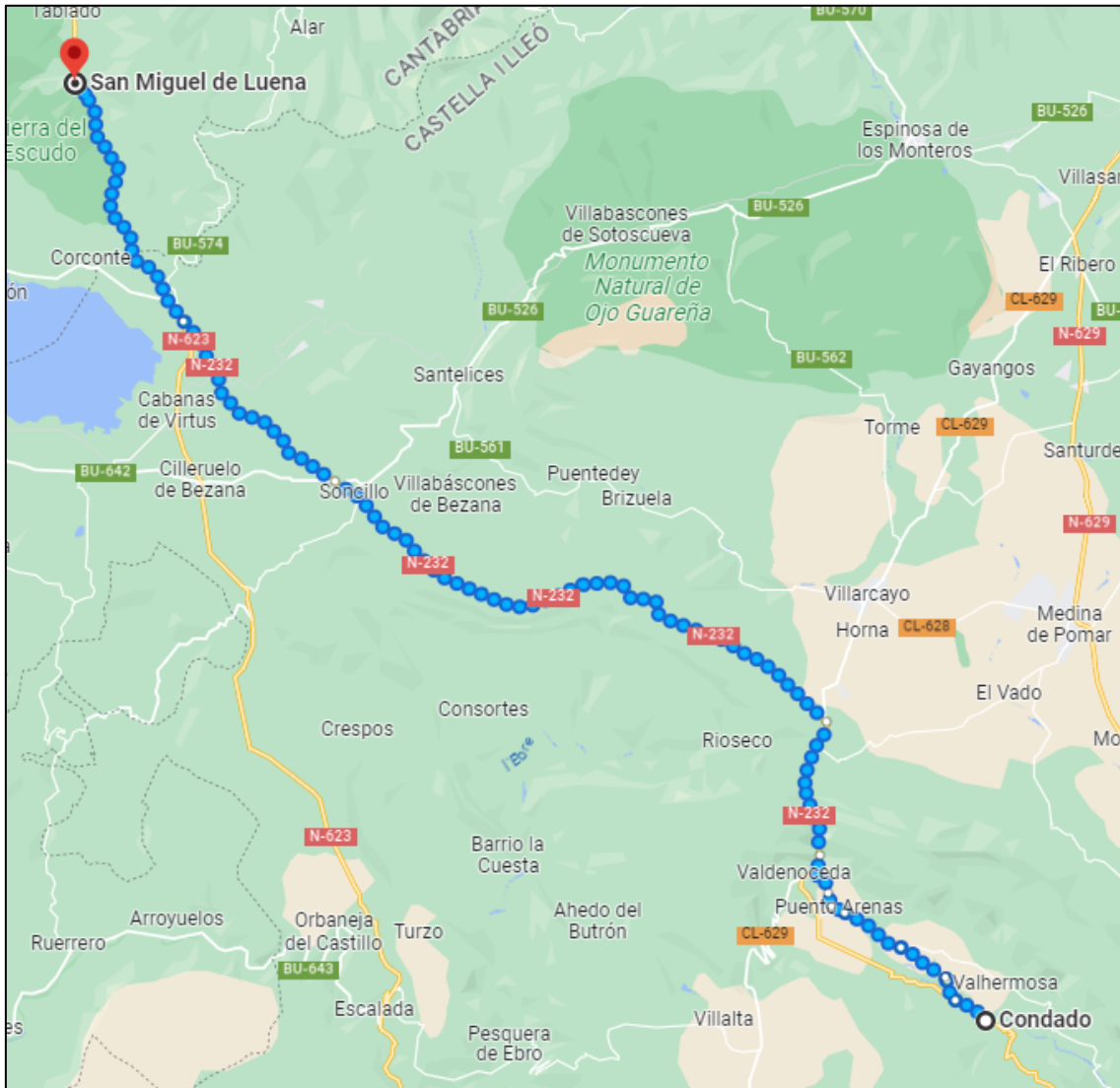
STAGE 12 – DAY 14

Starting Point: Condado (Burgos)

Point of arrival: San Miguel de Luena (Cantabria)

Kilometers: 53.0

Elevation Gain: +813m / -942m

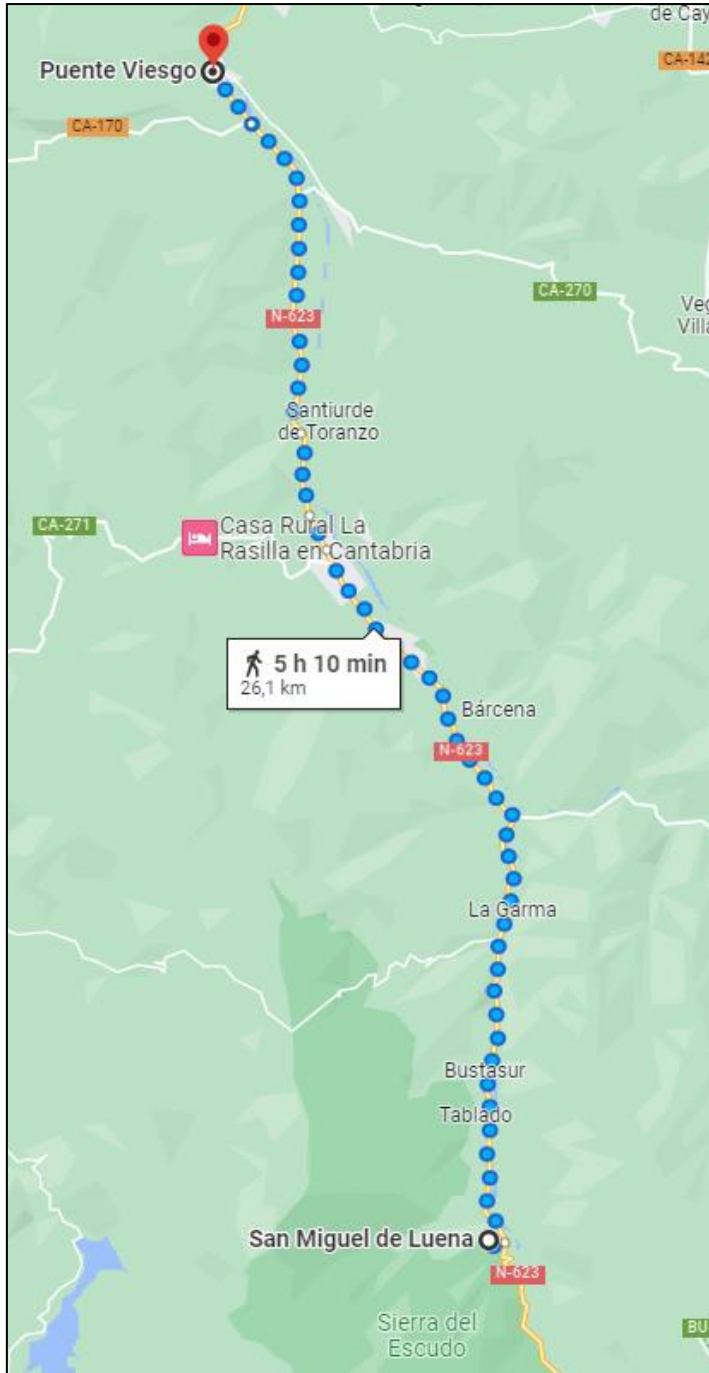


STAGE 13 – DAY 15 (FINAL STAGE)

Point of start: San Miguel de Luena (Cantabria)

Point of arrival: Town Hall of Puente Viesgo (Cantabria)

Kilometers: 26.10





The final arrival of the walk will be at the Town Hall of Puente Viesgo, a town in the autonomous community of Cantabria, located in the Valles Pasiegos region. It is about thirty kilometers from the regional capital. It limits to the north with Piélagos, to the west with Torrelavega and San Felices de Buelna, to the east with Castañeda and Santiurde de Toranzo and to the south with Corvera de Toranzo.

Puente Viesgo is an eminently rural municipality in which there are various natural resources of interest. The main one is the Pas river, which crosses it. There are several salmon farms in this municipality: Covachón, Dos Ríos, Güedes, La Cruz and Puente Viesgo. The orography is quite rugged, from 30 m above sea level (asl) of the Pas River to 816 meters asl from Mount La Cuera, in the southern part of the municipality. Of its mountains, the Castillo peak stands out, with its characteristic conical shape and its rock richness, as well as the southern area of the extensive Dobra mountain range, which occupies the central part of this municipality. The “Alto de Hijas” or “Collado de Trescampo” (292 m), on the road from Puente Viesgo to Los Corrales de Buelna, allows you to pass from the Pas river valley to the Besaya river valley. At the end of the road that goes up to the caves, there is a viewpoint that offers a panoramic view of Puente Viesgo and the Toranzo valley. Lastly, the Hijas and Aés mountains should be mentioned, higher in altitude but gentler in shape, and dominated by extensive deciduous forests, with oaks and beeches. In the rest of the municipality, repopulation trees predominate with eucalyptus and pine trees for industrial exploitation.

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I thank the Puente Viesgo City Council, especially its mayor Óscar Villegas, for their interest in this project and their full support and commitment from the very beginning, offering me their collaboration, with a warm welcome, to finish the charity walk and their help and support in whatever is needed.

DONATIONS:

- **Santander Bank:** ES26 0049 1956 90 2210004385 -SWIFT: BSCHEMM (Santander)

- **LaCaixa Bank:** ES42 2100 2139 61 0200264237 -SWIFT: CAIXESBBXXX (La Caixa)

Please add "PEDRO" in the reason for payment

Once the donation is made, please send an e-mail to: contacto@apoyodravet.eu

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For more donation methods, please consult the website:

<https://www.apoyodravet.eu/quienes-somos/participa/haz-tu-donativo/>

For more info on this charity initiative:

<https://www.apoyodravet.eu/el-runner-pedro-aguado-se-reta-a-recorrer-640-km-de-cataluna-a-cantabria-para-apoyar-a-los-afectados-por-el-sindrome-de-dravet/>

<https://cadenafeeling.es/un-antiguo-vecino-de-corvera-de-toranzo-realizara-640-kilometros-para-apoyar-a-una-nina-con-el-sindrome-del-dravet/>

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