



# *The Spirates of l Estrella*



Rocked on an earth meant for the able-bodied,  
4 adventurers with Spina Bifida will face off  
the tumult of oceans.



[www.spirates.org](http://www.spirates.org)

# Beyond the horizon of disability

Béatrice, Manue, Benoit and Nicolas have all four Spina Bifida, a serious birth defect.

Each of them is affected in a different manner, but they nonetheless share a common point: **they have refused to the settled life they were assigned to.**

## Spina... What?

Spina Bifida is a closure defect of the spine during embryonic development. It requires surgical procedures throughout life.

The consequences are severe and impair different functions: locomotion, bladder and bowel function, cognition, touch sense.



## A true adventure

### Together united!

Béatrice, Manue, Benoit and Nicolas have all four already wandered a lot.

They have now decided to unite strengths and launch a real first: brave the open sea and experience the genuine seaman's life aiming **to produce a documentary film that will allow to differently promote Spina Bifida awareness.**

This adventure is scheduled for August 2023. They will leave the docks of Saint-Malo and reach Ireland and then Scotland, to meet local associations of persons with Spina Bifida.



### A seaman's life

Together with the four fellows, the crew will include Olivia Wattinne who is a paraplegic lady, a camerawoman, a caregiver, a mate and, last but not least, the Captain.

Do not believe they embark on a leisure cruise! Onboard l'Estrella Lab, everybody actively contribute as much as their capacities allow.

When sailing at night, whatever the weather, the members of the crew perform their watches in shifts . 2 hours on the deck, 4 hours of sleep; 2 hours on the deck...

# Production of a documentary film

## A common will!

The whole team fervently wish this extraordinary adventure to lead to communication material and notably a documentary film.

**The primary ambition of the project is to allow the general public, through our experience, to better know Spina Bifida** which affects 15,000 persons in France.

The film will allow to speak about the disease with a different approach. It may play it down and unlock speech on a sensitive topic. The focus will not simply be put on the trip and the sailors. In addition to the scenes of life onboard and the preparation sessions, the microphone will be open to a large number of stakeholders, such as expert physicians and volunteers.



Our adventurers will document their daily life on the ship, the challenges they have to deal with and the human adventure they experience. From the travel planning phase to the final arrival and debriefs, the documentary film aims at relating the stakes of such a project. Matthieu, a professional film editor, will be in charge of the post-production. Matthieu also has Spina Bifida.

A film offers the advantage of being timeless. Nicolas has been part of a mixed team of disabled and non-disabled people in a Siberian expedition. This has led to a film entitled "le Défi Baïkal" (The Baikal Challenge). Six years later, the film still serves as a powerful tool for awareness on hearing impairment and vision impairment.



# *Changeons de vue, the association holding the project*



Illustrating the saying "Alone, I go faster; together, we go further", Clément Gass, a world-class blind athlete, and Nicolas Linder, a recognized visually impaired adventurer who has Spina Bifida, have decided to unite strengths by forming the association **Changeons de vue**.

Each of them, at their own level, has greatly stirred things up. Even if they are both visually impaired, they share... the same vision of life. A world where the disabled persons do not live in a separate universe and can even be an engine for changes in society.

*Clément Gass, born blind, holds several records such as a marathon in autonomy run in 4 hrs and 4 mins.*

## *An adventure for and with ASBH*

The **Association nationale Spina Bifida et Handicaps associés (ASBH)** is actively involved in the organisation of this adventure. It will also greatly benefit from the project thanks to the visibility it will offer. It is one of the major French organisations working in the field of disability.



*Thanks to its 5,000 members and supporters, l'Association nationale Spina Bifida et Handicaps Associés (ASBH) has a countrywide reach and engagement! It promotes research on neural tube defect in general with focus on Spina Bifida.*

*ASBH also offers to the affected persons and their relatives an open ear and access to services through its regional representatives and its communication material.*

# *L'Estrella Lab, a small floating laboratory of humanity*

This 60 foot-long vessel that will host the adventure is a one of a kind sailboat.

The instigator of this project is Olivia. At the time she became paraplegic, Olivia did not want to give up her dreams and she even nurtured the idea of sharing them.

Thanks to the association Hissons l'Étoile, she has decided to make sailing accessible to a wide number of people. By her dynamism she has successfully brought together a full team.

[www.estrellalab.com](http://www.estrellalab.com)



*L'Estrella is continuously evolving has she aims at adapting to each and every of her passengers. With her adaptations (benches featuring hydraulic cylinders, lifting platform, accessible bathroom), l'Estrella Lab is designed to mix disabled and non-disabled crew members.*

*Her maiden voyage occurred in November 2021. L'Estrella Lab will surely help change mentalities !*



# The adventurers



## **Béatrice CIBAUD**

*Aka La Marguerite à Vélo on the social networks*

You will soon get it: Béa has in her life a therapy that matters most: biking! Her sports career is yet much more than this.

At the age of 6, she was diagnosed with Spina Bifida myelomeningocele. Today she mostly uses a wheelchair to move around and she is compelled to strict medical follow-up for monitoring of her different affected organs. But Béatrice has found in sports her best refuge. The more it goes, the more Béa accomplishes incredible bike rides. Last year, she left her hometown in Jura on her adapted bike and was found a few weeks later by the Mediterranean Sea in Sète.

This year, she took part in "1000 bornes" a tremendous 1,000 kilometer-long trip between Lons-le-Saunier and Biarritz performed by a team of disabled and non-disabled people. Her debut in athletics competition has also been sensational! In 2022, she won the title of French champion in javelin and discus throwing and the title of French vice-champion in shot put! She now wants to take up a new challenge: to prove that it is possible to navigate and enjoy sailing, even seated!



## **Benoit FOURCROY**

Born and raised on Côte d'Opale by the English Channel, Benoit has always been restlessly on the move. He has travelled Europe back and forth by train during his student years, equipped with only a backpack and a crutch. In love with Nordic spaces, he has even learned Swedish at university and works now as a translator.

His health worsened about ten years ago which has forced him to use a wheelchair and to organize more constraining day-to-day medical care. Yet his curiosity and his thirst for encounters always trump. Benoit has taken part in "Handirection du Monde", a world tour made by several duos consisting of one disabled person and one non-disabled person. He ended up on the tracks of the volcanic hills of Rwanda and he met local disabled persons. As for sports, he is not left out as he is a wheelchair-hockey player, a sport he is always eager to make know and to develop. He can often be found as the goalkeeper for the French national team.

His philosophy ? "Life is not waiting for the storm to pass but learning to dance in the rain". Offshore sailing is an exciting challenge for him who would never be satisfied with not being onboard!



## **Nicolas LINDER**

*Aka Nico handiroutard on the social networks*

Nicolas has to manage, in addition to Spina Bifida, a severe visual impairment. He has lived for a long time in the protecting bubble of disability, but the least one can say it that he has made up for lost time since after his 30th birthday!

Even if his adventurer's soul has always been present, he initially pursued a standard university curriculum, with the conception that because he was bearing so many disabilities adventure was not for him. He has thus graduated with a master's degree in International Relations. But the thrill of adventure has been stronger than anything. Nothing can stop him since 2014 : expedition in Siberia, mountain hikes, solo rides, travels, etc. He is now a real supertramp, almost like any other ones. If he is not hiking, maybe is he crossing France on a tandem bicycle.

His greatest pride is having been able to get over his locomotion impairments. From a walking ability of a few kilometers accompanied with pain, he has reached a personal best of 79 km in 24 hours. The adventurer and writer Olivier Weber describes Nicolas in one of his books as "a giant of perseverance". After ice, mountains and forests, he has a new horizon - high seas!



## **Olivia WATTINNE**

*The 'Star' of l'Estrella.*

Olivia came naturally to adventure when she was a mere youngster. With a father who is an airline pilot, she has been fortunate to travel and discover the world since her early childhood, first with her family, then all alone. After her studies, she embarked on a 18 month-long world tour. When she came back, another adventure was awaiting: disability. The day she turned 24 she had a bad fall that left her tetraplegic. The stay this time will be at a functional rehabilitation center that she left after 15 months with a residual paraplegia.

As you may have understood, Olivia will be the only disabled person onboard who does not have Spina Bifida. But l'Estrella Lab is her baby. She considered for a while playing it safe and resume her studies, but it is finally other endeavours that have prevailed !

First she hit the road with a not so prone to backpacking friend. The two girls have crossed most of South America and taking up on the way challenges suggested by online followers. Then she got the incredible idea to open new horizons to disabled persons by allowing them to discover offshore sailing. This is how the Estrella Lab project started up!



## Emmanuelle CAINJO

Manue is a native of Morbihan, in Southern Brittany, and she is a sea lover. On earth, she has widely roved, notably in Europe and Africa (Burkina Faso, Togo, Benin, Mali), but her true element is water! In water, she has practiced aquafitness each week for almost 10 years with focus on strengthening her back muscles. Most importantly, however, she has that wild dream since her 40th birthday: to leave and conquer the oceans. The Spirate Project comes just at the right time for her! It adds another dimension to this great dream, giving it more sense: she will realize it and live it with other people who like her have Spina Bifida, and she will take this opportunity to help make this disease known!

## *The objectives*

- 1 To promote, thanks to a documentary film, knowledge on Spina Bifida, a condition that affects 15,000 persons in France and to promote ASBH (Association nationale Spina Bifida et Handicaps associés), the French association that supports the concerned patients and families.
- 2 To heighten awareness on Spina Bifida prevention by vitamin B9 intake before and during pregnancy.
- 3 To unlock speech around rare diseases and around medical conditions of an intimate nature.
- 4 To tighten links between European patient associations by visiting our sister associations in Ireland and Scotland.
- 5 To demonstrate that disability does not prevent from civic engagement by setting up an environmentally friendly project.
- 6 To show that the so-called disabled persons develop other abilities and other strengths to lead fulfilling lives and to be a real asset in our society.

# The trip



We will set sail out of Saint-Malo in Brittany at the beginning of August 2023. We will firstly cruise off the coastline of England and Wales.

After a stopover on Scilly Islands, our next port of call will be Dublin where we will meet our sister Spina Bifida organisation. We will then take the helm again heading to Glasgow for a second meet-up with a Spina Bifida association.

The return journey will mostly be done by van so as to minimize our environmental footprint. L'Estrella Lab for her part will pursue her journey towards new adventures!



# The constraints

They all four have multiple medical procedures to carry out each day. Urinary catheterization, ostomy, enemas, pressure sores no longer hold any secrets for them.

These are not quite easy to manage in usual circumstances, so on the waves, maybe in a middle of a storm, things may become considerably more difficult for them.

Moreover, Béatrice, Manue and Benoit have motor impairments and will have to acquaint themselves with getting around in an ever-moving environment

L'Estrella Lab does be specifically meant to offset those disabilities, nevertheless circumstances at sea still are more complicated when one has a disability.

As for Nicolas, he deals with another disability, indirectly linked to Spina Bifida: he became visually impaired as a result of a medical malpractice. Moving around is complicated for him in another manner as to cling on a pitching boat, it is necessary to be able to aim at the next hold. And above all, they will need to address all the unforeseen events that unavoidably would arise in those sometimes extreme circumstances.

Lastly, with fatigue building up many more aspects of Spina Bifida can arise, like Arnold Chiari malformation that can trigger neck numbing, spasticity or neuropathic pain. As you will have understood it, this adventure will be far from restful!



# The budget

## OBJECTIVE: €53,000

### The travel and its preparation: €20,000

Preparation weekends, administrative costs, travel arrangements, sailboat chartering and crew repatriation.

### Production of the documentary film: €33,000

Material, interviews, onboard filming, travel costs, music copyright, translation, organization of events, screening and broadcasting.

# How to help us

## For individuals

By donating to 'Les Spirates de L'Estrella' on HelloAsso.

By following 'Les Spirates de L'Estrella' on the social networks

 [Facebook](#)

 [Twitter](#)

 [Instagram](#)

 [TikTok](#)



## For companies

We are open to any suggestion.

We can offer you to have at least one member of the team present at film screening in your company, as well as placing your logo in the credits of the film, on our communication material and, for the major sponsors, on the flag of the boat during the sailing.

## TO MAKE A DONATION



[www.helloasso.com/associations/changeons-de-vue/collectes/les-spirates-de-l-estrella](http://www.helloasso.com/associations/changeons-de-vue/collectes/les-spirates-de-l-estrella)



For French taxpayers, any donation is eligible for a 66% tax deduction.

# They support us



**Jean-Pierre Brouillaud**, blind, traveller & writer, member of the Society of the French explorers (SEF).



**Clément Gass**, legally blind, world record man of the marathon and trail in autonomy.



**Muammer Yilmaz & Milan Bihlmann**, aka *les Optimistic Travelers*.

# Contact details



[Spina Bifida France](#)  
[The channel of the Spirates](#)



[Les Spirates de l'Estrella](#)  
[Estrella Lab](#)  
[La Marguerite à Vélo](#)  
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