

# Pitt Hopkins Syndrome and a Family Ski Holiday in Montgenèvre (FR)

"Catherine, Just wanted to thank you for helping us have a fabulous holiday last week in Montgenevre. We all had a brilliant time! I have attached some photos for you and will send some others. Please feel free to use them in any way that will help the charity.

I cannot begin to tell you what a difference it makes for us to be able to ski as a family and include Emily. She loved it and we had a great mix of us piloting the dual ski and Francois from ESF skiing with Emily!

A fabulous holiday all round! If there is anything else I can do to support the charity, please do say. Best wishes" Victoria





## General Feedback on Montgenèvre and Inclusive Ski Holiday

" We have booked to go back to Montgenevre next year so if you could reserve the dual ski then that would be amazing. We arrive on Sunday 16th Feb for one week.

We had a fantastic family holiday and it was lovely for Emily to be out with us skiing all day. She enjoyed her sessions with Francois Claude but the freedom of being able to ski with her in our wider group was brilliant.

The resort worked really well for us, the only issue we had was getting on the lifts. We didn't have a problem last year at all, but this year found that some of the lift attendants despite being asked to slow the lift didn't or left it too late. Emily ended up under the lift on a couple of occasions! We dusted her off and she was fine but it was a little stressful! I think it didn't help because the weather was very warm and the snow had melted on the entry into the lift zone for the dual ski. Andy therefore found it difficult to push Emily across the rubber mats to get her into position. It was much easier last year when there was snow on the mats. Anyway we made it work and realised that we had to insist the lift attendants stopped the lift - by the end of the week we had it sorted!

Our chalet worked well again for us, there are some steps up to the chalet but they are quite deep and so we were able to push Emily up each step easily in her buggy. We had one flight of stairs in the chalet which we carried Emily up once a day. Our room was on the first floor and the same level at the dining room and lounge so we only had to use the stairs with Emily once to go out and then when we got back. The rooms are spacious with plenty of space for Emily's chair.

*I have transferred a donation for the charity and once again thank you for your fabulous support. "*Victoria

### Background story:

Emily was born with Pitt Hopkins Syndrome and this is her second family ski holiday to Montgenèvre. It is a totally inclusive, accessible and life-enhancing ski trip and ski resort! **Pitt Hopkins Syndrome** (PTHS) is a **rare** genetic condition that causes moderate-to-severe intellectual disability and developmental delays, breathing problems, gastrointestinal issues, and recurrent seizures. Approximately 500 PTHS patients have been identified worldwide, but there are many who remain undiagnosed.

The Walker family stayed at https://www.lepotdemiel.com/home

#### 10 March 2019

Ski 2 Freedom @ski\_2\_freedom would like to thank @EsfMontgenevre for all their help in making this accessible and inclusive dream ski holiday become a reality for Emily and her family. The guided dual-ski (guided sit-ski) was donated by @ski\_2\_freedom from funds donated to the charity by Madame Victoria Cervera.

#### @EsfMontgenevre @montgenevre.esf @montgenevre

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