

INTERVIEW

IF President Cato Lie meets paralympic gold medalist Jesper Pedersen



Source: <https://www.paralympic.org/jesper-pedersen>

MEET CATO & JESPER

The President of the International Federation for Spina Bifida and Hydrocephalus (IF), Cato Lie, interviewed paralympic gold medalist Jesper Pedersen (24), on what it means to lead a happy, meaningful life, with disability.

Jesper won a gold medal in giant slalom and a bronze medal in the super combined sitting at the 2018 Winter Paralympics and five medals at the 2021 World Para Snow Sports Championships Jesper

“Accessibility is necessary for some, like people with spina bifida and or hydrocephalus, yet it is good for everyone”
Cato Lie - IF President

also won four gold and one silver medals at the 2022 Winter Paralympics. Lastly, Jesper took home four gold medals during the 2023 World Para Alpine Skiing Championships.

WORLD SPINA BIFIDA & HYDROCEPHALUS DAY

For Jesper, increased awareness of Spina Bifida and Hydrocephalus (SBH) is essential. The WSBHD is an opportunity to show that the diagnosis does not limit the SBH community and that many people with SBH can live a happy fulfilling life.

For Cato, it is important that, people with SBH are visible, given the opportunity to show how they celebrate life and to connect with the SBH community and stakeholders. This inspired IF's series of webinars on the need for an accessible world. Cato stated that he lives a good life with SB, and this disability should not stop one from leading a happy fulfilling life.



ACCESSIBILITY FOR *ALL*

AMBASSADORS FOR LIFE

Jesper stated that he believes that through his success as a para-alpine skier, he is able to show the world that he can perform just as well as able-bodied skiers. He put emphasis on the ability to ski well with his disability. That this is more important than winning gold medals. He hopes that this will attract the attention of the media and encourage people with SBH to live an active life their own way. Jesper believes that by performing well in his competitions, and working hard to improve his skiing abilities, he can become a role model for the SBH community.

For Cato, being an ambassador for the SBH community means helping, advising, and motivating people with SBH and other disabilities to enjoy life at its full potential.

VISIBLE AND INVISIBLE CHALLENGES

Jesper answered that he has faced numerous visible challenges in his life ranging from inaccessibility of buildings and public transport, to weather-dependent mobility issues, such as using a wheelchair outdoors when it snows.

Another visible challenge that Jesper was disheartened by was the theft of his disability parking card, which gets stolen and sold on the black market. Jesper also mentioned the lack of autonomy at the Norwegian airport, for example, being forced to wait for assistance, lack of disability infrastructure awareness and inaccessibility of public bathrooms as invisible challenges. The impacts of which the public is often not aware of.

Cato confirmed a lot of these examples. For many people all societal barriers are major obstacles to a fulfilling life equal to others. Consequently, Cato has focused, both professionally and privately, on improving accessibility globally and in Norway.



Cato shared a story about a trip to Brussels. For this travel, Cato met with an employee of the airport assistance service at the gate who asked the partner of Cato if he could walk inside the plane. His partner replied, “he can talk”. Cato thought this was a very clever way to show that people with disabilities also have a voice in society and should not be ignored.

BEAUTIFUL MOMENTS TO REMEMBER

Jesper's first response to this question was to quote the lyrics from a Miley Cyrus song. “It’s the climb to the top that’s the good thing, and not when you’re standing on the peak of the mountain.” One of the best experiences in Jesper’s life was skiing in the middle of the summer at Folgefonna glacier with his father, and taking a bath in the fjord. Experiencing such moments with friends and family while training gave Jesper’s life a lot of meaning. Regarding his success at the Winter Paralympics, he put emphasis on enjoying the journey to the top, rather than only enjoying his victories.

Cato replied by saying that some of his most beautiful moments in his life was the birth of his two daughters. That becoming the President of IF and seeing how the Secretary General and the IF staff together with the board have professionalised IF is a proud moment for him. The adoption of resolution WHA76.19 ‘Accelerating efforts for preventing micronutrient deficiencies and their consequences, including spina bifida and other neural tube defects, through safe and effective food fortification’ and speaking at the United Nations Conference of State Parties (COSP) on behalf of the IF are beautiful moments to remember.



“It’s about your mindset, to not look at things as problems, but as challenges. Then do your best to overcome those challenges and become a better version of yourself”

Jesper Pedersen

Cato recommends simply to talk to people. “When I see a physical barrier for instance at a hotel, I will provide advice on how to correct this. This is mostly highly appreciated. It is very important to treat all people with respect and dignity”. He explained that there are such easy things to do that costs nothing, but the smiles generated from such simple pleasantries are extremely rewarding.

A LOOK INTO THE FUTURE

Jesper is hoping to ski professionally until 2026. He is also studying political science at the university of Oslo and hopes to assist para-athletes in recruiting sponsors. Highlighting the lack of funding for para-sports Jesper is open to whatever comes his way. For example, securing a job in international politics. Cato sees himself having a voice and role in disability matters even after his time as resident of IF ends in June 2024 and when he becomes a pensioner in a couple of years.

Looking back at the interview it is clear that both Cato and Jesper are living a joyful, meaningful life with SB. They set an example to the SBH community that a successful, meaningful life is attainable and worth pursuing.

OVERCOMING 1, 2, ... BARRIERS

Jesper said that it’s about your mindset, to not look at things as problems, but as challenges. Then do your best to overcome those challenges and become a better version of yourself. Telling the SBH community to believe in themselves, always try their best and not to be afraid to approach people. According to Jesper, people do not always include those with disabilities from the start, so importance should be placed on the willingness and ability to be the first to make social contact.

10 TIPS FOR YOUNG PERSONS WITH SPINA BIFIDA

1. Find your strengths and weaknesses
2. Build on your strengths to build self-confidence
3. Believe in yourself
4. Don’t be afraid to approach people, take the first step
5. Focus on the things you can do something about
6. Always try your best
7. Be patient
8. Work hard and rest when you can
9. Enjoy the company of family and friends as much as you can
10. Always have fun, whatever you do!

