



## **2008 Marks 19th Winter Ski Camp for Children with CF in Denmark**

By Laura Stadler-Jensen and Lasse Fredrik Jensen

*For the past eight years we've both had the privilege to participate in an annual ski camp for children with Cystic Fibrosis living in Denmark. We are two of five leaders of the camp that take a group of approximately 16 children ages 11-18 for a week of skiing in the Alps. Year after year we look forward to witnessing the remarkable transformation the children go through after spending a week in the crisp mountain air together with other children with CF.*

### **How it All Started**

The Danish Cystic Fibrosis Association organizes these camps and this year marks the 19th ski camp since the first trip in 1990. It's come a long way since then when parents of a child with CF, Peter and Odile Fristrup, organized a ski trip for six children to Sweden. Since then, it has continued to grow and the camp has taken children to destinations in Italy, France and Austria.



The idea for the ski camp came after meeting and then assisting a group of Norwegians with CF who ran in the New York Marathon in 1981. Seeing first hand how much the physical exercise benefited these athletes made Peter realize how much it would benefit CF children in Denmark. He brought this inspiration back home and began to plan a ski trip together for youngsters with CF with his wife Odile and the Danish Cystic Fibrosis Association. Pernille, their daughter with CF, also attended.

After gaining funding from a State funded lottery that allocates proceeds to non-governmental organizations, Peter and Odile had the means to organize a trip. They traveled by ferry to Sweden then took two buses and finally arrived to a small cottage in the Swedish hills by car late at night. Peter recalls, "When we woke up the next day, the children looked out on the snowy hills and asked, 'do we really have to go down on skis from there?'. It was the first time for them to face such a challenge and they didn't know if they could really do it." Peter continued, "I remember how proud they were by the last day when they were bravely flying down the hills."



The following year, the camp was organized through a travel agency and two groups of children participated, one with pseudomonas and one without. Another year there were three teams of children, one group without pseudomonas, one with the chronic antibiotic sensitive PA strain and one with chronic multiple resistant PA strains. Peter and Odile continued to lead the camps until five years ago and today only children without pseudomonas are able to participate in the camps.

“The meaning of the camps was to show the young people that other youngsters were taking the same medications, treatments, etc. and for them to see that it was natural for everyone to live the same way with the same disease. For us it was very important that there were no doctors and no nurses so they could learn to be responsible for themselves and their treatments,” Peter said.

Some of the greatest moments are when we arrive to the mountains. When we travel by bus we normally arrive at sunrise and the kids are welcomed by early morning sunlight that illuminates the awe inspiring white snowy peaks that rise around us as we go higher and higher. It's a completely new environment for them, away from home and everyday life so they can just be free to have fun. Many of the children have never been to the mountains before or even outside of Denmark. It's clear by the looks on their faces that they begin to realize that it's going to be a trip of a lifetime.

### **Benefits for the Children**

First and foremost, the trip gives these children the opportunity to learn to be independent both in terms of being away from home but also with respect to their treatments. Separation from parents is an important part of the trip because many times children with CF are over protected and closely monitored. And even though the leaders come from a non-medical background, they have experience with CF treatments and ensure the children follow their treatment plan. However, the children are encouraged to self manage their treatments. The leaders are also in constant contact with the managing director of Danish Cystic Fibrosis Association who acts as the liaison between the leaders and parents as well as doctors and nurses when necessary.



Before the camp the children provide a full list of the medications and treatments they require. These lists are always kept on-hand by the leaders and they ensure refrigerated medication is delivered to the children at the appropriate times. This past year we made a new rule requiring the children to take one hour of quiet time to conduct their pep-mask treatments (lung physical therapy) and inhalations as needed. Many times the children



return home with a fresh perspective and parents are often amazed at how the child has changed. Odile said, “One parent said to us, ‘how did you teach my child to take their medication on their own without supervision in just one week?’”

Being separated from parents and away from home can be hard for the children. As with any child away from home, it is normal for some to become homesick. In the beginning there was no contact with the parents. That meant an entire week completely separated, which was sometimes harder for the parents than for the children. Then a short message from each child was sent via fax to CF headquarters who would then relay the messages back to the parents. Soon the Internet became the mode of communication with updates and photos posted daily.

These camps also give the children the opportunity to learn from one another. Whether it’s how they cope with school, treatments or medication; they all have a common ground to draw from. The older children often become role models for the youngsters. Being a part of a bigger group of CFers allows the children to relate to one another in a completely different way than they normally do. The benefit of the camp is also for the pure stimulation. The fresh mountain air and fitness they get from skiing allow them to take in more oxygen and improve physical and cardiovascular strength.

For first-timers, ski school is required and is offered to any child returning to the camp if they wish to improve their skiing skills. It’s usually during this ski school experience that the children begin their transformation. As they test their abilities and limits and develop their physical skiing abilities, they also learn more about themselves which they can take home and apply to life. The confidence they build over the week both through skiing and through relating to other CFers allows them to develop and grow in very positive ways.

One of the children who have participated in the camp, Cindy L. Sørensen, shared the following about her experience, “I clearly remember the first time I went on the ski camp. I was 10 years old and I really loved it because we were all the same, meaning we all had to do the same things such as taking our medicine, and I never felt abnormal because of all my medicine.”

“Since then, I have participated in five ski camps and the whole experience has taught me that although I have Cystic Fibrosis I can still do things like normal people can, and I can do my own treatment. It’s really nice go skiing because when you have Cystic Fibrosis you can feel that the fresh air helps you to breath. And because there are older children, you have someone to look up to. You can see that they are doing just fine. These camps have helped me so much because it has made me not feel totally alone with my situation. I can always think about all the others, and know that I have someone who understands me. That is not something either your parents or your friends can help you go through!”

### **Organizing the Camp**

The Danish Cystic Fibrosis Association takes the lead in organizing the camp. They gain the necessary funding and sponsorships, which today normally come from corporations or individual contributions. Each year it is an effort to gain funding but it’s an investment



that's hard to put a monetary value on. The funding gained covers almost all of the children's expenses including transportation, lodging, meals, ski equipment rental and ski passes. The remaining dues are normally paid by the parents, but they can often have some of the fees paid by the Danish social welfare system.

The CF association also processes the children's applications and handles the medical clearance procedures not to mention all of the relating logistical aspects of the camp. It's a year long effort that comes together just in time with the selection process and medical screenings conducted as a concerted effort together with the treatment centers in Denmark.

"We have a unique advantage in Denmark because there are just two CF medical centers. This allows us to have close cooperation with each center to guarantee that there will be no cross-infection," said Hanne Wendel Tybkjær, managing director of Danish Cystic Fibrosis Association. "We have to be very strict with our procedures and ensure that the medical centers comply with the segregation guidelines, which are in line with those defined by the Copenhagen CF center." A full overview of these principles can be referenced in the article entitled, "Prevention of Cross Infections in CF," by Claus Moser and Niels Højby in Issue 7, Volume 1, 2006.

### **Looking Forward to the 2008 Ski Camp**

This year the camp will take place in Alpe d'Huez in the French Alps. The selection process is now underway. This year 15 children from Denmark and the Faroe Islands will attend. Klavs Andreassen who is the camp leader for 2008 and who has been the camp leader for the past three years says, "Although Alpe d'Huez is probably best known as a part of the Tour de France it's also a magnificent skiing area with slopes surrounding the city. We will stay at a humble hotel in the middle of the town with a beginner's slope and lifts just beside the hotel, which will make it very convenient for the children."

Klavs continued, "Every year we try to select a destination in the Alps where it is possible to have the ski school taught in Danish and have dinner served at our hotel. Personally, I'm looking forward to meeting both the new and 'old' members of the CF Ski Team, both kids and the other leaders. The new participants will learn how to take responsibility of their own treatment and in comparison to school trips they're not the 'odd' ones who have to take medicine, PEP-masks etc., so do the rest of the group!"