**Medical Experience with a Holiday camp in the Swiss Alps for CHS-Patients**

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From August 20th to 28th 2011 a holiday camp for 6 CHS-adolescents and young adults took place for the first time. All participants were ventilated only during the night.

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| Participants | Genetic pattern of PHOX2B expansion | Age | Ventilation pattern |
| C.A. | 20/25 | 21 | diaphragmatic pacing  |
| C.C. | 20/30 | 29 | PPV via tracheostomy |
| F.L. | 20/27 | 15 | non-invasive ventilation (cardiac pacemaker) |
| M.L | 20/25 | 21 | PPV via tracheostomy |
| N.S. | 20/26 | 17 | non-invasive ventilation/diaphragmatic pacing |
| O.D | 20/26 | 23 | non-invasive ventilation (cardiac pacemaker) |

**Initial idea for the project**

The local homecare team is currently taking care of two kids with CHS. This concept with a care adapted to the individual needs of the patients had been presented in Sestri Levante in 2007 resulting in valuable friendships and contacts between the Swiss ambassadors and those from the Italian Association Congenital Central Hypoventilation Syndrome (AISICC).

**Main goals of the camp:**

* holiday experience for participants without having their parents around
* to allow parents holidays without their kids, which they had to monitor permanently before
* a suitable program for the participants (adjusted to their age).

The costs were split between the participants and the 3 associations/foundations according an agreement. The costs per participant amounted to 1 991 Euro (1500 Euro paid by the organizing committee, 491 Euro at the expense of the participants).

**Program**

Participants stayed in a bed and breakfast close to the regional hospital of Visp (650 metres above sea level). For the transport to their daily activities a Minivan was rented.

Activities

All of the activities were accompanied by a medical person as well as an tourism specialist:

* biking/white water rafting ( 1400m a.s.l)
* excursion up to an altitude of 3500 metres above sea level including the visit of an ice cave in the glacier
* hiking after going up in a simple open gondola (2000m a.s.l)
* downhill biking and swimming in hot springs (2 300m a.s.l)
* excursion to Zermatt (3 100m a.s.l)
* mini-golf
* family party

**The medical challenge**

The main challenge consisted of providing the participants with the medical security which they are used at home. With their application participants had to fill in a comprehensive questionnaire about their medical situation.

**The medical security**

To provide maximum security the following emergency services had been informed about the holiday camp:

* central office for emergencies (telephone number 144)
* the local helicopter rescue team (Air Zermatt) knew they had to take off immediately in case of an emergency
* the intensive care department of the local hospital (right next to the bed and breakfast) would take over of in case of possible emergencies or necessary observations.

Furthermore we organized:

* oxygen systems for the hotel rooms as well as a portable oxygen bottle
* additional portable Capnograph/SaO2-device
* the medical persons were always carrying a Ambu-Mask and a portable oxygen bottle

**Monitoring during the night**

We hired 5 Italian speaking specially trained people for this task. We had an emergency plan for possible short notice drop outs. A planned night shift with 2 people could be reduced to 1 person thanks to the excellent instructions the participants had brought from home. Medical problems were solved immediately in a correct and professional way.

**Regular adaption of the CHS-Patients to the reduced oxygen level in increased altitude**

So far the reaction of patients suffering from the CHS to the decreased oxygen level is merely unknown, except there had only been a few anecdotal records. The same day the SaO2 and EtcO2 were measured within 135 minutes on the following altitudes: 650 m, 1800 m and 3400 m. The measurements were made at rest after a period of 1-2 minutes of steady state.

The following charts sum up the measurements, which were made for safety reasons:

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| --- | --- | --- | --- |
| SaO2 | 650 m  | 1800 m | 3400 m |
| 6 CHS-patients | 97.0 | 95.5 | 92.8 |
| 6 healthy controls | 98.3 | 96.3 | 93.3 |
| Et-CO2 | 650 m  | 1800 m | 3400 m |
| 6 CHS-patients | 37.3 | 33.5 | 31.8 |
| 6 healthy controls | 32.8 | 32.5 | 27.2 |

The patients adapted without any problems to the altitude of 3500 metres just the way the healthy persons did. Both groups reacted with increased ventilation to the decreased partial pressure of the oxygen, which was shown in decreased C02 tension in the air they were breathing out.

Once reached the top the patients as well as the healthy test persons had to climb 97 steps within an ice cave. They were told to take several breaks on their way. Those who didn`t take a break (among the two CHS-Patients) were complaining about headaches, dizziness and had to be supported shortly at the top.

**Summary**

Considering the high medical standards the organization of such a camp is possible in an area not directly taken care of by a university clinic. Thanks to a good organization problems can be solved immediately. The participant and their parents were very pleased and grateful as measured by a psychological questionnaire (see report of Dr. Morandi et al).