

In Bosnia with ~4 milj inhabitants 50 individuals with CF are known, but a big dark number is expected. A few are above 18 years old. The country is divided into 10 cantons, each responsible for organizing their own health care which therefore differs a lot from one canton to another. The knowledge of CF varies extensively. The diagnosis is often suggested by parents who see ill individuals in the hospital, but far too late in the disease progress. Once having had the diagnosis a contact with a physician may be offered, but not for all. Most have never seen a physiotherapist. Drugs, including pancreatic enzymes are often not available within the country and inhalation devices haven't existed until the recent donation from Pari. But to what extent drugs for inhalation are available varies a lot. Information lacks about optimal use of the nebulizer system, including proper cleaning routines.

The situation of CF care in Bosnia is very difficult due to organization of health care within the country. People are suffering. However families and care givers are eager to learn and spread information about modern CF care, to start organizing adapted, regulated CF care for individuals in different severity levels of the disease, but focusing on preventive care.

Day 1, parents and patients

About 35 individuals of whom 4 had CF (1 adult, 2 teenagers and 1 three years old) and 2 physiotherapists from the Sarajevo Paediatric Hospital participated. Several cantons were represented. A translator helped during the whole day. Aiming for a good base the workshop included facts about CF, the progress of the pulmonary disease and the negative spiral the increased respiratory work has on the chest and spine if not taken care of early. Questions on varying levels were brought up and made it obvious how different the knowledge level is. Based on big frustrations patients were eager to discuss their specific problem and having an answer to what is the best treatment for their child – whether what they are doing now is good enough. Much of the prepared material was used, but far from all. Patients attending were instructed and showed how to use the different techniques and the different parts of physiotherapy. A lot of time was spent on questions.

Day 2, physiotherapists and physicians

The organizers were not sure about how many participants to expect. Seven arrived; 1 paediatrician, 1 pulmonologist and the chief physiotherapist from the Sarajevo Paediatric Hospital, from another canton 1 paediatrician and 3 physiotherapists in a recently opened pulmonary spa which is now open to CF patients too. A few participants may seem negative, but the questions and discussion became reasonable and fruitful, participants listened to each other. Most of the prepared material was used, focusing on preventive care but also discussing treatment when admitted to hospital. The participants were very engaged. The paediatrician from the spa wanted to be instructed in the use of the different airway clearance techniques. A young CF patient allowed us making it possible to show how to instruct a child.

We were told that participants were satisfied with both days.