

# **CFW KAZAKHSTAN REPORT**

## **KAZAKHSTAN REPORT 16 to 19 June '16. By Terry Stewart.**

Kazakhstan is a very beautiful country, large in size, small in population with a very friendly community. It is not a wealthy country currently but that could change as oil and gas exploration develops. It is listed as 36 on the developing countries of the world and the Gov has health as a priority within its wish list, as it wants to improve its position on the list. Almaty is where the CF Clinic is located, the only one in the country, and mainly for children. There are around 85 children with CF of various ages and a handful of adults as children do not reach adulthood due very poor management of the condition. Data is not kept on the numbers of people with CF, these figures are only estimates. I was advised that 2 adults with CF do not leave their home due to the dangers of bugs and no drugs to deal with the problems.

I had meetings with members of the Kazakhstan CF Association and we discuss plans for the coming 3 days. These members included, Natalia Bouslova, Olga Alexandrova and Indira Bouslova. I suggested that the CF Association write to CFW requesting membership of the Kazakhstan CF Association. This has now been done and approved by the CFW Board. They requested requested CFW to provide a Medical Education Workshop team and sent to Almaty, this was to up skill the clinical professionals look at improving the clinic and make recommendations on the type of drugs that should be used.

I then had meetings with the heads of the hospital, tour of hospital including the lab and CF ward. The CF Ward was dreadful with 4 children in 1 room, this was the size of a normal home bedroom and the mothers of the 4 children slept with them, it was nothing like it should be. This was followed up by a Press Conference at the hospital with, doctors and CF patients' parents, a Q&A this was well received was held so all questions answered, this of course was done to bring attention to the problems and hopefully the decision makers would see some of the issues and start taking note, the press conference was shown on the 6pm news.

I had a series of meetings, one was with medical students advising them about CF and recent advancements in treatment, also spoke about the work CFW does across the world, these students who are inspiring future doctors who want to learn more about CF. this was an extremely interesting meeting and I am sure good things will come from the meeting.

A meeting with the head of local administration that is currently responsible for the provision of antibiotics. (the process requires improvements as it is very bureaucratic when required antibiotics are provided and most of the time are too late to help patients) The objective – is to raise awareness of plans and discuss cooperation and process improvements.

Also spoke to possible corporate sponsors; banks, etc. The pharma companies in Kazakhstan are Roche and Novartis

Working group discussion of scoping/costing of the programme, workshop preparation.

Meeting with the heads of the University Hospital who are keen to become involved including developing a clinic within the site, space is available. This need to discuss further with the local group, there is a lot of politics within these talks.

Further talks with the CEO of the Almaty Hospital who has given the go ahead of having a new CF clinic; it may be over 18 mths before space becomes available. We do have a letter from the CEO agreeing with the decision of building a new CF clinic, this maybe in the existing hospital, which would not be the ideal situation. These decision need to be made by the local CF Assoc due to the political spin offs.

I went back to the CF Clinic without any top medical people with me so I could speak to the mothers who were there with their children. They are just desperate to get improvements within the clinic and I would totally agree with their situation, it is just dreadful, no regard for cross infection due to space problems. The doctors and the head of the hospital all agree that there should be a better clinic, more space, better equipment and up skilling the medical staff.

**MY SUGGESTIONS AND REQUESTS:**

- A medical list of basic equipment needed in a CF Clinic.
- CFW to arrange for an Education Workshop to happen ASAP. This should include; CF Doctor, Physio, Nurse. All accommodation to be paid by CF Association. This needs to happen and this will help in making the decision on what hospital to use. I suggested that once the decision is made the hospital should look at developing an adult clinic as in the coming 2 years there will be at least 10 young people heading into adult care, currently there is nothing for adults.
- Local Assoc. to continue talks with both hospitals and government to get the best and fastest result.
- I have been asked to write to the Hospitals/Government advising them what CFW is willing to do, that is providing an Education Team to up skill their people on up to date CF Care.

Terry Stewart

President CFW