# Activity report Mongolia 11.-17.5.2018

Participants: Bayalag, Tulgaa, Suvdaa, Raoul, Corinne, Madleina.

#### Friday, Saturday 11.+12.5.18

After Bayalag and Suvdaa gave 2 days basic and refresher course, we added some more specific information and discussed the existing questions. There were 16 participants coming from the aimags Selenge, Bulgan, Darkhan, Orkhon, Arkhangai, Uvurkhangai and MANDAL (one of the two intersoums of Selenge). It was a good, very interested group and their knowledge at the end of the course seemed to be profound. The main problems they encounter in their aimags is the lack of support from their employers (no extra time or salary for their work). We got the detailed report showing numbers examined and treated from the aimags Bulgan, Darkhan and Mandal intersoum. Their numbers match the expected distribution of diagnosed types. Difficulties were in compliance for follow up examinations, not reaching all the newborns because of distance (soums) or ignored by the parents. In all aimags (except Orkhon who has 2 screeners) at the course there was only one screener per aimag. No working expert system. The head of the Sükhbataar hospital participated partially in the course and promised to support the DDH screening.

#### Sunday, 13.5.18

On the long journey back to Ulanbataar we visited Mandal intersoum hospital, where they have over 750 births per year. Warm welcome by the head of the hospital. We visited the hospital and checked the ultrasound machine.

#### Monday, 14.5.18

After our strategic meeting in the morning Tulgaa joined us while visiting Maternities 1, 2 and 3. Maternity 3 presented us a highly motivated team leader with an amazing Expert and feedback system, neatly documented. They requested a second Ultrasound machine in order to do the controlling of Type B hips in Maternity 3. They also requested regular refresher courses. They are willing to also start treating Type C/D hips in the future. They already organized a specific room for the second ultrasound machine for the follow ups. Maternity 1 and 2 were visited and both showed improved quality in imaging, they still have to improve in accuracy of filling in the technical data of hipscreen (i.e.: birth dates, types, side labelling). They appreciate the Swiss supervising feedback and assured to answer our questions/suggestions at least with a short ok.

#### Tuesday, 15.5.18

On the first day at NCMCH we had a short meeting with Enkhtur (director of NCMCH), who reassured his full support.

Afterwards Tulgaa presented us 26 patients, out of these were 10 surgical cases. The Swiss surgeons will have to decide which ones should be presented to them in September. Out of the others there were only a few DDH patients. The day was very well organized. Existing ultrasound pictures and x-rays were presented via Hipscreen on a beamer. Unfortunately there were still many patients, who were screened, but their pictures could not be found in the database due to unknown causes, also from hospitals who regularly upload in hipscreen. We stressed again how crucial the complete documentation of all examined hips (screenings and follow ups) is. Especially also for the credibility of our screening program regarding the accusations we face with the Trauma Centre.

### **Wednesday**, 16.5.18

Second big day at NCMCH. Thanks to a DDH-mother facebook group, we had a full consultation day with 41 patients mainly from that group. According to Tulgaa and Bayalag false information was spread. Tulgaa got involved in that group and made public that Swiss specialists would be at NCMCH that day. So we saw several patients, who had seen multiple "experts" regarding their children's hips, mainly the Trauma centre and Dr.Budee (former head of Trauma centre as children's orthopaedist). According to B SMOPP is accused of producing missed cases yet the Trauma Centre is not willing to supply us with evidence and documentations of such cases. So we had to rely on the information given by the parents and the handwritten diagnosis in the health booklets. From the seen x-rays we could not understand their conclusions. We absolutely understand the confusion created in the parents through getting different and so diverse opinions. We did our best to revaluate and explain our point of view on the best treatment strategies for the specific cases. Although we had a good impression of the parents reactions towards our explanations, Bayalag fears, that 80% of these patients will continue to consult with the above mentioned "specialists". Out of these 41 patients, there were also several non DDH-related pathologies.

We were confronted with a few peculiar cases where the initial screening finding didn't match the evolution (Verlauf). One of them was a possible true deterioration of a Type A /B? hip.

Considering a large number of the presented cases, which had visited Trauma centre and received a DDH diagnosis and treatment we got the impression of malpractice. Furthermore we learn that the number of surgically treated dysplasia at TC has significantly increased apparently to 600 cases 2017. In their eyes this is the proof of the inefficiency of our screening program.

To almost all patients who visited the Trauma centre an expensive (50 USD) specific Russian herbal/mineral mixture was prescribed. According to rumours the doctors receive a certain cash back from the pharmacies.

Due to these long consultation days the strategic meeting with Bayalag was very short. We discussed the following matters:

## 1. Active Hip-Commission with defined members

- Certificates for screeners inclusive recertification all 5 years
- For recertification (i.e.: 200 images uploaded on hipscreen) and refresher
- Recommendation of members: Paediatrician, neonatologist, children's radiologist, children's orthopaedic surgeon, epidemiologist, public health specialist, member of SMOPP as external expert
- Build a expert system, choose course teachers
- Evaluate difficult cases
- Secure the adherence to the guidelines of DDH(also in Trauma Centre and also SMOPP) CIRS

O Differentiates between DDH or secondary dysplasia
Bayalag: there was a hip commission. It never worked, Vice Minister was the head. B is not sure if a second try will succeed, this has to be discussed again and is one of the tasks for September.

## 2. Secure the expert system (equivalents of time or salary guaranteed)

B: supposes to have 10 Mongolian experts: they have to take care of private hospitals, 21 aimags, 3 maternities, 1 expert will responsible for 3 sites. They have to check all cases, follow ups, treatments, coverage. The extra work should be payed. (100Dollars/month/screener) If SMOPP would be registered in Mongolia, this extra payment specific for experts should be legal since SMOPP is a non governmental organisation. Otherwise she will have to get the agreement of MOH. She proposes to finance this extra salary trough fees from hip screening courses held at the private hospitals. These private hospitals should be included in the hip screening program but will mandatorily have to upload all pictures on hipscreen and pay annual license fees. Budget planning was asked for, which we will provide according to our Swiss courses.

#### 3. Secure the work for screeners (equivalents of time or salary guaranteed)

B: the experts will be responsible for this by contacting the administration of the hospitals for securing the work of the screeners.

### 4. National guidelines for management of DDH

B: a guideline already exists at MOH but it is old (uses Graf typology). TC is starting a new screening program to screen at 6 months with x-ray. MOH is the one who will decide which guideline is approved. In September it will be important to find a consensus.

## 5. Surgical team

B brings up the concern that there should be a senior orthopaedic surgeon with at least 5 years of experience after specialisation (Facharzt). In order to be allowed to operate but also and more importantly to have more powerful influence in the discussions with Trauma centre. If it is not possible, B will try to outsmart the systems regulation by handing in Harry's application (or other senior orthopaedic surgeon).

### 6. Coxitis Study

Surprisingly we learn that the Mongolian team is awaiting the study proposal from Switzerland. It seems that B informed the Swiss team a while ago that Batulgaa (children's radiologist at the outpatient department) is the responsible researcher on the Mongolian side and responsible for collecting data and samples. The punctures are performed by him self. He would like to receive another instruction and would like to be contacted ASAP by Michael or Nicole.

### 7. September meeting

- The date will be fixed ASAP
- B tries to gather members from MOH, the national medical quality commission, TC, families of treated children

- B will find out if the discussion should be in French since TC has a strong collaboration with the French orthopaedic society
- The idea is to present scientific data, to debate on cases
- Aim is to find a consensus on a national guideline for diagnosis and treatment of DDH