



## **The Zurich Clubfoot Concept, based on Bonnet-Dimeglio Insights from Parents of Clubfoot Children**

### **For the CERN Open Geneva Hackathon 2016**

Outcome of the Telephone Conference on March 29<sup>th</sup> 2016,  
essentially recaptured by Philip Dönhoff  
April 15<sup>th</sup> 2016

#### **Participants of the telephone conference**

- **Ursula Issler**, Expert and protagonist of the Zurich Clubfoot Concept
- **Various parents** from Switzerland and Germany having children with high score clubfeet
- **Hackathon Team**: various experts from different disciplines (software designer, medical student, developer of clinical solutions etc.)

#### **Concrete examples from parents participating**

- One Mother had clubfeet herself with a lot of bad experiences. She herself has a trauma, remembering casts and operations from her own childhood. Today she still has issues concerning operations. Presently she is doing everything possible to avoid her daughter having the same experience. After her medical professor (and clubfoot specialist) was not able to recommend an alternative to classical therapies, she dived into heavy research and eventually came to Ursula Issler. After relocating to Zurich she began her daughters' treatment immediately after birth. Today the feet are in great shape.
- One Child with Arthrogryposis is in treatment with the Zurich Clubfoot Concept and today by the age of 20 months is able to walk normally. Even doctors are surprised of this outcome.
- One mother's son is 14 years old today. They started treatment with Ursula Issler and the Zurich Clubfoot Concept straight after birth. Additionally they were in Montpellier a few times having supervision from Frederique Bonnet-Dimeglio. Today the boy can live an absolutely normal life. He never had any problems with his feet; today he even plays tennis and handball.
- One mother has twins, which are three years old today. One of the two was born with clubfeet. The treatment began straight away in Zurich. Today it is hardly recognizable that one child had clubfeet. Nevertheless the treatment lasts on to prevent regression.



- One mother tried first the Ponseti and then the Zukunft-Huber therapy. Since she did not see the expected improvement in her child's condition, she started looking for alternatives. After a long search she found Ursula Issler and since then she is in therapy with the Zurich Clubfoot Concept, experiencing an extremely positive development and feeling very safe.
- A boy with two clubfeet, who is now 15 months old, was crying all the time when he had to wear the rigid casts used by Ponseti. The parents changed the therapy toward the Zurich Clubfoot Concept and now are travelling 300 km 3 times a week. For them it's no question, that it's worth it!

### **Personal experience from the parents' perspective**

- A child normally develops consciousness from the beginning. Although some doctors may claim that there are no traumas due to surgery or wearing rigid casts over long periods of time, the child will - even subconsciously - remember these experiences for its entire life.
- Dealing with doctors doesn't seem to be an easy issue for all parents. Some parents feel exposed to contrary opinions, depending who they are speaking to. Some doctors just say, there is no need for worries, the situation is fine whilst others paint a dramatic picture. In sporadic cases doctors even advised parents to think about an abortion after giving the diagnose "clubfoot". Some parents do not dare to go against the establishment of the clinic, even if they think something must be wrong.
- If you have access to information on clubfeet and you are active, it is no problem to start the right therapy very quickly after birth, what is very important. The right information and communication with the parents is very important too. It is very helpful, when experts take the time to explain the things happening.
- The therapy by Bonnet-Dimeglio is time-consuming. It is not only the therapy itself, but due to the rarely spreaded Infrastructure (physiotherapists, orthopedical-surgeons and -technical experts at their home base, many parents have to travel a lot to go through the therapy. That is very demanding for child and parents.

### **Experience from the experts perspective**

- Depending on how perfect the correction is, the children can do every sport. But the therapy lasts for about 16 years and it is necessary to follow the therapy absolutely consequently. The child has regress immediately if the rules are not exactly followed. That is the equal fact in all methods. That's what one always an imperative to remember.



- Treatment with the Zurich Clubfoot Concept based on Bonnet-Dimeglio is tricky with its fine movements. It is likewise difficult to explain and to learn. It's difficult to teach the hands, because the requirements are very complex and there is only a thin line between doing things right or wrong. To get exactly the right spots during the handling of the tridimensionality is the difficult part. In addition every child is different per se and has special needs. An application to get in touch would be wonderful. It would help to gain confidence for the parents and also the learning therapist.
- Asked for the difficulties: sometimes after tenotomy minor difficulties occur. Some children have problems with the skin. In that case special creams help out, but if the child has neurodermitis with open skin, one has to stop the therapy.
- There have been only rarely points, where parents have dropped the Treatment. Off course there are moments where parents discouraged, but never to that extent where one seriously gives up. The results are very convincing. A few parents have stopped because of personal issue, such as moving away.
- Both motion and pressure are important, whereas the signal of direction is more important than the pressure. The biggest source of error in the practical work is the wrong direction of rotation. If you obtain the right rotation, the pressure is secondary. A typical negative result is the midfoot-break. The small bones are cartilage and very soft.
- At the end every method is as good as the people doing it. In addition it depends on the child. Some children are working very well others less well. All these methods will not work out, if they are inconsequently or not well executed. In this sense the progress of the Bonnet-Dimeglio method is equally dependent on the high quality work done by the therapists. Today not so many therapists are keen on learning the method yet. That has many reasons: Not only is it very time-consuming and hard to learn. It also requires an extremely high rate of identification. In this sense Ursula Issler is a very special archetype, making everything possible for "her" children.

### **Zurich Clubfoot Concept based on Bonnet-Dimeglio**

- All of the parents in the conference who are familiar with the Zurich Clubfoot Concept based on Bonnet-Dimeglio are enthusiastic concerning the outcome of the therapy. The proactive and child friendly therapy supports the body (and does not work against the body). At the end the most convincing argument is to look at the results: The best you can get!
- The darker side is that the therapy is very time-consuming and can be personally expensive, due to the traveling. It is a mission and that has to be organized. You see the therapist on regularly base 3-4 x per week at the beginning, then once a week, have daily work for ½ hour at home and have to see the surgeon once every six months. Depending on the childs growth one needs a regular renewal of the orthosis.



- The therapy based on the Zurich Clubfoot Concept is not only highly effective for clubfoot patients. It is also successful in other issues like Arthrogyposis. For all cases it is important to start treatment very early, no big breaks within the treatment. Every party involved has to be very-very precise and the supervision by an experienced expert is extremely important.
- The health insurances have a diverse approach, depending on country, rates and other aspects. In Switzerland the Zurich Clubfoot Concept based on Bonnet-Dimeglio is generally accepted in contrast to the German health system, where the health insurance companies only partially take over the costs, depending on the particular tariff.
- We see different thinking in different methods: The main difference to other methods is the treatment of the 3 dimensionality. Whilst some methods focus on the rotation point in the mid foot or on the knee, the Zurich Clubfoot Concept works with rotation at the back of the foot. Furthermore the therapy proceeds in small steps, so one can see and react to relapses very fast.
- Currently available comparative studies are to be seen critically, as summarized in <http://jbjs.org/content/91/8/2041.2.full>. That makes argumentation rather difficult. You can only make studies of the results when the children are fully grown.

### **The wish toward the Hackathon**

- Having the sock as a technical product would be very helpful to apply the method. The Hackathon-project is a big help to pass on the technique to young therapist. It can help the parents to be more precise, enables quality control for professionals and parents, supporting both teaching and learning. It will be a big help to gain confidence.
- The foot is the most complex and most important issue, as it has to carry a lot of weight. Nevertheless it would be great, if we are able to develop something for the feet first that can later be transferred to other groups of patients: Hands, Back etc. The techniques and the requirements are similar.
- The project makes people from different stakeholders look onto the subject clubfoot. It increases the overall awareness for the topic.