Clubfoot Project

in China













<u>Vision:</u> Prevent problems caused by Congenital Clubfoot

Identified problems are: abortion, abandonment, social exclusion, lifelong disability, physical pain, low self-esteem, low education, poverty, difficulty to find work or a spouse.

Goal: Early identification, referral and effective treatment of Congenital CF

Building up capacity should be done through education, measures to raise awareness and transmission of knowledge and treatment skills in cooperation with local healthcare providers, government, related institutions and NGO's.

Objectives:

- Promote identification, referral and effective treatment of Congenital Clubfoot by lectures and raising awareness measures
- Train personnel of healthcare providers in the Ponseti Method to treat Congenital Clubfoot
- Promote education and guidance for effected families, guardians, caregivers
- Provide Clubfoot braces
- Provide plaster and padding for treatment
- Collect data and photos of cases
- Provide financial support for poorer families and/or orphans directly with project money and indirectly through other organisations and/or individuals providing support

Organization:

Partners in Hope, Inc. Kunming office - 希望之侣机构(美国)昆明办事处 Golden Park Complex H-702, Shizha Interchange, Panlong District, Kunming, Yunnan, China Clubfoot Project Director: I. Lohan

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1. Congenital Clubfoot, Ponseti treatment and situation in China



Congenital Clubfoot is one of the most common congenital (= present at birth) deformities with a worldwide incident rate of about 1-6.8/1000 live births (assumed worldwide rate average 1.2‰). It is a developmental deformity with not exactly clarified etiology. It is seen more in boys than girls. One or two feet can be affected by Clubfoot, which causes the foot pointing down and inwards. Without treatment (not positional) Congenital Clubfoot leads to lifelong disability, can cause for the affected poverty and disadvantages in the society as well as a burden for the society. If no other syndrome or health issue is involved, children normally will be able to walk, but – depending on the severity – on the outer or back part of the foot. The wrong position of the foot has negative influence on joints (knee, hips, back), which can lead to pain. If the foot cannot fit into a normal shoe, the hard callus on the foot might break open with a risk of infection.

The Ponseti treatment method developed by Dr. Ignacio Ponseti has a correction success rate of nearly 100% when used properly and started early. It gained popularity with orthopedic surgeons throughout the world in developed and developing countries and is considered the "gold standard" treatment for Congenital Clubfoot. The Ponseti treatment method involves manipulation, serial casting and in most cases a minor surgical intervention to correct Clubfoot. In small babies the correction procedure may even take less than 2 months. Lastly the feet are braced in order to maintain correction and prevent relapse. Through early effective treatment – if no other health problems involved – a child with Congenital Clubfoot will later be able to walk and run like other people. Here an example of a child with Congenital Clubfoot treated in China:















Jan 20, 2015

Jan 20, 2015

Jan 27, 2015

Feb 3, 2015

Feb 16, 2015

Mar 10, 2015

Mar 10, 2015

In China estimated 16,000-20,000 children are born with Clubfoot every year, but the real number might be very different. When Clubfoot is detected before birth by ultrasound it might lead to abortion and when found out after birth to abandonment of the child by parents not knowing about an early effective and relatively inexpensive treatment. Children with Clubfoot born and kept by their parents in rural areas may not get early appropriate treatment at all. In other cases, a slighter Clubfoot deformity may be dismissed by parents and doctors as insignificant. Children with neglected Clubfoot in China might later receive expensive extensive surgery procedures with unsatisfying long term results while others appear as beggars on streets.



This project aims for saving children with Clubfoot from abortion, abandonment, lifelong disability, poverty, linked emotional and social difficulties, but also for eliminating related burdens for families and society.

2. Clubfoot activities of Clubfoot Project Director I. Lohan in the past

It was **2003**, my 3rd semester of Chinese language study in China, when an orphan boy with Congenital Clubfoot from the local Social Welfare Institute had been shown to me. I looked up for help on the internet and got in contact with Dr. Marc Sinclair in Germany, who was using the Ponseti method to treat Congenital Clubfoot. As a result he and Dr. Norgrove Penny traveled to China in **May 2004** to teach at 2 clubfoot workshops. These were organized with my involvement by "Helping Hands Charity" in cooperation with a local hospital in Guilin, Guangxi, China.

Doctors and medical people from Guilin and other provinces in China had been invited to learn the Ponseti method to treat Congenital Clubfoot. I participated in a workshop as well. Several children with Clubfoot had been casted at these workshops.















At that time the Social Welfare Institute (SWI) in Guilin had 4 children with Clubfoot and after the workshops I was involved in providing treatment for them in cooperation with staff from the SWI, who participated in training as well. Later more children from the SWI in Guilin but also orphans and children from other places in China had been treated at the SWI in Guilin.



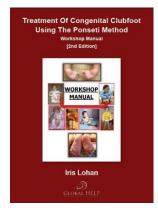






Abduction braces, a very important part of the treatment to prevent relapses, were made locally. In this low cost basic brace, shoes and a bar are connected as one piece.

Involved in support for disabled orphans in China, I continued to keep a focus on Clubfoot. Besides taking care of the treatment of children with Clubfoot in Guilin I conducted seminars about Congenital Clubfoot and its treatment using the Ponseti method at different places in China: 2005 in Hanzhong/Shaanxi; 2006 in Nanning/Guangxi and Guilin/Guangxi; 2008 in Kunming/Yunnan (only info course) and Wuhan/Hubei; 2009 in Nanhai/Guangdong and Shijiazhuang/ Hebei; 2011 in Wuhan/Hubei and (2 workshops) Kunming/Yunnan. I worked on material for Clubfoot Workshops and in 2009 put a Workshop Manual together published by Global HELP in English and Chinese. Revised 2nd editions in English and Chinese were published in 2011. An Italian version followed 2011, a Russian in 2012 and a Polish in 2013. Free downloads are available at:



www.global-help.org/products/treatment of congenital clubfoot using the ponseti method workshop manual/

From Dec 1, 2012 to Apr 23, 2013 I took the opportunity with "CURE international" to investigate for a potential Clubfoot program at different locations in China. In 2013 I was also able to meet up with representatives of "Miraclefeet" and "Walk for life" in China, who had already impacts with Clubfoot programs in different countries. "CURE international", "Miraclefeet" and "Walk for life" expressed interest in Clubfoot work in China, but at that time the obstacle remained to obtain a suitable legal status for me for legal long-term Clubfoot work in China.

With the German organization "ARCHEMED" I took the opportunity to work on a Clubfoot project in Eritrea, Africa employed from **Aug 1, 2013 to Feb 28, 2014.** I was able to improve the project and gained more practical treatment experience but also helpful insights in project development.

In **Feb 2014** I again traveled to China looking for a legal platform for me for long-term Clubfoot work. Fortunately, I came across the US-American Non-Profit Charitable Corporation called "Partners in Hope". The director of the China Kunming office showed interest in the Clubfoot work and decided to take me in at "Partners in Hope". It took time and effort for all the formalities, but after several months I finally obtained a Chinese residence permit for the purpose of work.

3. Official Clubfoot work in China

It is a challenging task to work in China officially on humanitarian projects. The situation in China is quite different compared with developing countries. The society is burdened with competitive struggle, pressure, "face-culture", mistrust, corruption and focus on personal benefit. Time and patience are needed to establish a quality focused sustainable Clubfoot project.

For legal operation in China "Partners in Hope, Inc." - as a foreign NGO - has a partnering Chinese organization, the "International Non-Government Organization Society" (YINGOS).

Moreover, for Partners in Hope's Kunming office working legally on a project the agreement of the government is needed. The procedure to obtain an agreement of the government for firstly 2 years had been successful - the result is the bulky project name "马蹄内翻足教育支持项目" - translated as "Clubfoot-Education-Support- Project".

4. "Clubfoot-Education-Support-Project"



The "Clubfoot-Education-Support-Project" is officially agreed by the government for the period of February 2015 to January 2017. I regard it as the initial start up period and the goal is of course a continuation of Clubfoot work after January 2017.

The funds for 2 years are stated with 400,000\(\cup \) Chinese RMB (currency conversion Dec 31: 61,625.9 US\(\cup)\). This amount is not really much for 2 years and project activities are quite limited. But a registration of a higher sum would put even more pressure on me to get the funds in. Of course, I wish much more money will come in. However, I think that at least the stated amount should be put into a project in order to have – beside positive project outcomes – a better foundation for obtaining future project approvals from Chinese authorities.

Currently Iris Lohan (director), Su Hua (assistant) and Liu Suying (therapist) are employed by "Partners in Hope" working on this project. The place for Clubfoot treatment of cooperating health care providers is currently Kunming, the capital of Yunnan province. At present the Kunming Children's Hospital and the Kunming Municipal Children's Home serve as pillars for good quality Clubfoot treatment. The goal is, that over time through training, supervison, support and practical experience, personell of both institutions will be more and more able to perform excellent Clubfoot treatment using the Ponseti method.

The stated fees of the mentioned institutions for treatment differ; the treatment fees at the Children's Home are much lower than the Children's Hospital's.

Detailed documentation and monitoring of treatment and their results can be used for raising awareness about Clubfoot and its available effective treatment by using different media. Parents of children with successfully corrected Clubfeet can make a helpful contribution for raising awareness through social media. In order to reach impoverished people in rural areas about available effective treatment, it calls for networking with governmental institutions, hospitals and other organisations.

5. Developments 2015

5.1. Kunming Children's Hospital

January 15-16, 2015: Clubfoot Workshop: Theory, practice, 3 children with Clubfoot got casted







Clubfoot Clinic after the Workshop

Clubfoot clinic day normally on Tuesdays. Support for good quality treatment, documentation and parents advice through staff of "Partners in Hope":



5.2. Kunming Municipal Children's Home

February 26-27, 2015: Clubfoot Workshop: Theory, practice, 1 child with Clubfoot got casted







Clubfoot Clinic after the Workshop

Clubfoot clinic day normally on Thursdays. Support for good quality treatment, documentation and parents/carers advice through staff of "Partners in Hope":

















May 31, 2015: Children's day celebrations







Nov 23, 2015: Two training sessions for staff of the organisation "Sunrise" Focus on taking care of children with Clubfoot in casts and correct wearing of braces



<u>Dec 21, 2015: Training for staff of the organisation "Half the sky"</u> Focus on taking care of children with Clubfoot in casts and correct wearing of braces



5.3. Bilingual Awareness Flyers printed in March 2015:





5.4. Participation in Child-Worker-Conference in Yunnan March 24-28, 2015:

Networking; raise awareness - using Bilingual Awareness Flyers

5.5. Treatment record papers - below last revised papers

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5.6. Declaration of consent - below last revised version

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5.7. Parents Flyers: Information, instructions and serving as appointment card



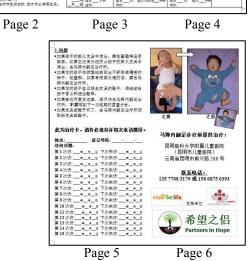


Page 6





Page 5



5.8. Until December 31, 2015 altogether 66 children because of Clubfoot were enrolled at the Clubfoot clinics at Children's Hospital and Children's Home:



Iris Lohan - Physical Therapist, Bobath Therapist, Clubfoot-Education-Support-Project Director with Partners in Hope, Jan 11, 2016



Iris Lohan - Physical Therapist, Bobath Therapist, Clubfoot-Education-Support-Project Director with Partners in Hope, Jan 11, 2016



5.9. Examples of children's Clubfoot correction results and braces provided for free











April 20, 2015







March 10, 2015

April 21, 2015



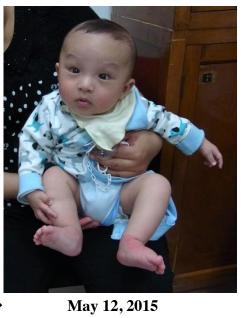




March 17, 2015

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March 23, 2015

July 14, 2015







May 5, 2015

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November 3, 2015

December 8, 2015

6. Conclusion

China is a huge nation with far more than 1.3 billion people and various challenges as an emerging country. Despite of enormous economic achievements, poverty and insufficient medical care continue to exist.

Every year thousands of children are born with Clubfoot in China. Children are aborted, abandoned and too many face a future of disability and poverty.

In China, a vision to prevent problems caused by Congenital Clubfoot on a larger scale calls for long term commitment. After several years living in China facing difficulties of various kinds, I am working with Partners in Hope on effective ways to improve the current situation.

By correcting idiopathic Clubfoot in early life and preventing/treating relapses well, it saves children from lifelong disability linked with emotional and social difficulties. They can get the opportunity to play later an active role in the society. The effort is worth it: Lives get changed.



Iris Lohan - Physical Therapist, Bobath Therapist, Clubfoot-Education-Support-Project Director with Partners in Hope, Jan 11, 2016