

# Cleft Care Foundation Indonesia



September 2014

*Every child deserves a smile*

## FAREWELL JANTI

It is with great regret and sadness that we announce the resignation of our co-founder and Board member, Mrs Tri Wijantisari.

Having given so much of herself since the very beginning of Cleft Care and being very much a part of the journey towards CC becoming a Foundation, Janti has decided it is time to take some new directions.



Janti's work for the Foundation has been invaluable. She is a founder, Chair of the Board of Patrons and always a very generous volunteer. Without her there would be no Cleft Care Indonesia Foundation.

Janti, we wish you well in your new ventures. You will always be a part of the Cleft Care family.

## Statistics Update

To August

	YTD
New patients seen	70
Mass operations	0
Spoon feeders	74
Nutritional Packages for Patients	335
Splints	82
Orthodontic nipples	34
Closed cases	179
Presentations	56

## UNIVERSITAS CIPUTRA

We are pleased and privileged to announce that once again we have First Year Business students from Universitas Ciputra on board raising funds and spreading awareness of CCFI in the Surabaya community.

The expectations of the students are that in becoming 'ambassadors' for a particular business, or in our case, a charity, they will integrate academic knowledge with practical experience in selling and marketing. Of course those 38 students who have joined the CCFI group are also learning about cleft issues and the work carried out by the Foundation. Not to mention meeting specific targets.

We thank the university for inviting us to be a part of this initiative for the fourth time, along with several other businesses and charities.



Presentation to students



Student group



Business vendors (Lisha, Clara, Lia, Manju & Toni in 2<sup>nd</sup> back row)



CCFI parent Ibu Tantri, an employee at the university, with her daughter Calista.

## A VISIT TO BLITAR

Emma and Clara made the long journey to visit the cooler city of Blitar for a presentation at Puskesmas Gandusari. This puskesmas is a 24-hour facility, the staff including a doctor, a dentist, 11 midwives and 5 nurses.

Our contacts there were the mother of Ima, one of our patients, and Ibu Vivi, a midwife who informed us about three cleft children, all from the same village. Ibu Vivi also told us about five more patients in the village of Glegok, not far away. One of the reasons put forward about this is that it is a result of the eruption of Mt Kerlud in 2013; there could be ground water pollution, a possible cause of clefts. CCFI will be in contact with the Department of Health in Blitar to bring this to their attention.

We certainly know that the number of clefts in the Sidoarjo area has risen since the mud flow in 2006 (which by the way continues to erupt).

In the meantime we are able to support those children coming to our attention both because of CCFI presentations and our contacts with midwives. And indeed, as a result of this visit to Blitar, we have two new mid-wives as partners.



## A GROWING COLLABORATION

CCFI has had a working relationship with Dinkes (Health Department) in Ponorogo since 2007, when they helped us to arrange transport to bring our patient Marini to Surabaya for surgery. Since the new partnership with Citra Medika Hospital in Mojokerto just last year, CCFI has referred nine patients to the hospital, a much more convenient arrangement.

Until recently this relationship had been only via phone and email but this distant collaboration all changed on June 5 when Clara was able to give a small presentation to Mr Hariyono and Mr Devin, the two Dinkes employees responsible for cleft children in the Ponorogo area. Until mid 2014, 191 cleft cases have been recorded in their department, not all who have had surgery yet.

As a result of that small meeting, Clara, Endang and Board member Yani made the five-hour journey to Ponorogo again on June 27, this time to present to 27 people from some of the Puskesmas centres in the Ponorogo area. What a wonderful opportunity to reach out and inform those working in public health about both the Foundation, and also about general cleft issues.

CCFI provided transport costs for those who attended this event and also a small snack. We feel this was money well spent. Already CCFI has received three new patients from the Ponorogo area as a result of this presentation. We are confident this number will grow.



### **FACT FILE: PRE CLEFT SURGERY COMPLICATIONS**

The most common reasons why children cannot receive cleft repair surgery are malnutrition and medical conditions like diarrhoea, pneumonia and Tuberculosis (TB) (all very easily preventable in many developed countries) that make them unfit for surgery.

### **POST CLEFT SURGERY COMPLICATIONS**

The most common complication after surgery is bleeding and breakdown of the wound due to a lack of understanding of post-operative care.

The ability to manage both these complications successfully means fewer cleft children will suffer due to ignorance and poverty, more cleft children will be able to receive free surgery and more children will receive surgery with minimal complications.

## PATIENT STORY

This case was a special one for us because the parents were so young and inexperienced. They needed a lot of support. Dewi's parents were only 15 and 17, married with a religious ceremony, but too young for a government marriage certificate, quite a common situation in more remote areas. Also Dewi's father had no job so their financial situation was very difficult.

We heard about the case from Mrs Siti, the village midwife and made the initial home visit. We realized very quickly that there were many problems, initially because the parents were not so cooperative, but they needed help in so many areas, not just hygiene, breastfeeding and preparing milk but also basic support in caring for a newborn baby. Where to begin? We were very grateful at the time to have the support of Siti, the midwife, and also Dewi's maternal

grandfather. But his situation was also difficult, his wife having previously left him with two younger children, his only income being that of his work as a pedicab driver.

Apart from practical and emotional support, we were able to support Dewi with nutrition packs for 8 months during her surgery journey, and also with financial support for transportation at the time of her surgery.

Dewi had her lip surgery at four months, and finally the successful palate surgery when she was one year old in June 2013. We closed the case only recently, having decided to monitor Dewi's health for a year after the surgery.

This was a challenging case but, as we always hope, one with happy, supportive parents in the end and a baby with a beautiful smile.



At left: Dewi pre and post surgery



At right: the happy family



*...because every child deserves a smile*

*...and this is what it's all about...*

Just recently the staff were delighted to welcome to the CCFI office not one, but two families post-surgery, making their final visit before their cases are closed. As you can see, it's (almost) smiles all round.



Arcelia with parents Bapak Silverius & Ibu Selly (note Arcelia is still wearing the splints to protect her wound)



Orvalona with parents Bapak Miftah & Ibu Erti with happy, supportive Aunty

## Contact Us

Jl. Simpang Dukuh no. 7, Surabaya 60271

[info@cleftcareindonesia.org](mailto:info@cleftcareindonesia.org)

International Hotline: +62 812 30 50 22 17

Indonesian Phone Number: +62 31 70 78 70 70

[www.cleftcareindonesia.org](http://www.cleftcareindonesia.org)

## Make a Donation

YAYASAN CLEFT CARE INDONESIA  
FOUNDATION

PT CIMB NIAGA TBK, Jl. Raya Darmo 75  
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