

# A Year of Transformative Scale



RACHEL HOUSE

*Palliative care went from nobody's business to everybody's business*

December 2014



## Our impact NUMBERS

1550



Lives touched

1606



Community  
volunteers educated

1323



Medical  
professionals trained

312



Nursing &  
medical students  
trained

This year, the wife of the Governor of Jakarta, Mrs Veronica Basuki, announced her wish for palliative care to be available at every District Hospital in Jakarta. Overnight, Rachel House was propelled on the path towards transformative scale; and the seeds that we had patiently planted over the years blossomed to bring forth a health system that is now ready for palliative care.

### **“Business as usual” - with expanded coverage**

In late 2013, we expanded our coverage to involve community volunteers - empowering them with the necessary skills and knowledge to help provide home-based palliative care for children from the marginalised communities living with cancer or HIV. The trained volunteers under our *Community Network in Palliative Care* (“CNPC”) Program are now collaborating with medical professionals at primary health centers in Jakarta (who are also included in the palliative care training) to bring the much-needed care to patients at home.

2014 also saw the beginning of our work in designing the curriculum for accredited palliative care short courses for nurses under the *Clinic-in-a-Box Program*. Our *Clinic-in-a-Box* Program will be piloted in 2015, in collaboration with the National Nursing Association (PPNI) and the nursing faculties of several major universities, to equip nurses with home-based palliative care skills and financial skills to allow nurse to practice independently. It is our hope that the “Clinic-in-a-Box” trained nurses combined with the CNPC trained volunteers will help alleviate the suffering faced by many today due to the critical shortage of medical professionals in Indonesia.

### **Our Gratefulness & Thanks**

The awesomeness of the journey in the last 12 months is something that none of us could have predicted. The part we played was simply to stand ready for the occasion. I am grateful to the entire Rachel House team who stood up to the challenge, and most of all, to all our faithful and wonderful supporters – volunteers, partners and donors - who continue to champion the cause and rally around us. Thank you.

*Lynna Chandra*

## Towards a sustainable healthcare delivery in Indonesia

# Establishing the palliative care ecosystem

As we look at the work accomplished, we reflect on our journey and look towards the future.

In the beginning, the dream was to build a safe haven to care for children with life-limiting conditions. The dream captured the hearts of many who came to rally support for the cause. This marked the launch of Rachel House and the plans for building Indonesia's first purpose-built children's hospice.

When the service was piloted at a 3-bed inpatient hospice, we heard again and again the cries of the little ones who begged to go home. After months and years of chemotherapy and invasive treatments, they pleaded to go home to be close to their friends. In response to this plea, our nurses traded their uniforms for helmets and jackets to travel the crowded streets of Jakarta to reach these children in their homes.

8 years and more than 400 children later, Rachel House is today an acknowledged leader in home-based pediatric palliative care service in Jakarta. Our nurses have become the "model" nurses invited to share their knowledge at hospitals and nursing faculties, and participate in difficult case discussions at Cipto Hospital (the largest National Referral Hospital in Indonesia) attended only by Professors and Doctors.

However, much more is needed. As Indonesia's President Jokowi said, "thousands of people have been dying at home...and 500,000 people sick at home (in Jakarta)" without access to medical care (*Reuters News "Indonesia Nationwide Healthcare Plans"*).

This harsh reality led us to commit to building the palliative care ecosystem to help ensure that pain and symptom management is accessible by all, from primary to tertiary care setting, to prevent and relieve suffering. We are working to empower health professionals at public hospitals and Puskesmas, while reinforcing the community's capacity through our education programs.

2015 will be an exciting year for Rachel House, we hope you can join us as we build the palliative care ecosystem in Indonesia and transform the healthcare system for generations to come.

*"We have the knowledge, the skills, the drugs...there is no reason for children with life-threatening conditions to die in pain and suffering...if we can't care for these children who are the most vulnerable, then we have lost some of our spirit and our humanity."* **Joan Marston**, Chief Executive of International Children's Palliative Care Network

## Establishing a palliative care ecosystem

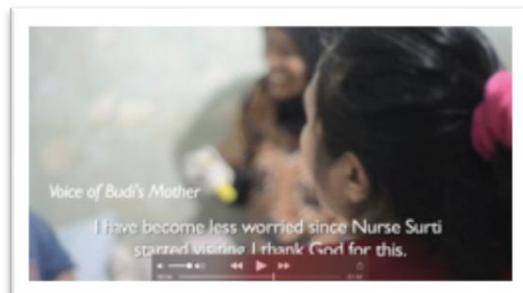


## The lives we touched...

Budi was a little boy of 5 who lost his sight during his battle against Neuroblastoma (a nerve-related cancer that commonly affects children). After multiple surgeries and chemotherapy treatments that failed, he was referred to Rachel House in April to help manage the seizures and pain he was experiencing.

In spite of his conditions, Budi was a happy boy who loved rattling a coin box or anything to generate a sound. His hands were constantly searching for things to touch, hold and feel. His mother's face was one he would often pull close to him – nose to nose, while he whispered to tease her.

[Read more](#) and watch [the video](#) produced by one of the summer interns documenting Budi's journey with Rachel House, and how our nurses provided support during this heartbreaking journey.



### Which would you miss most?

*"A week ago, I would have said sight without hesitation; would have assumed most people would answer the same. Now I want to sink my hands into a sack of rice grains, close my eyes and feel, and feel, and feel."* **Carissa Lim**, Summer Intern at Rachel House, commented after visiting Budi.

## .... & the impact we are making

### Paving the way for change

Recognising the increasing demand for palliative care knowledge among the medical professionals, Rachel House hosted a roundtable discussion in March to discuss ways for palliative care curriculum to be incorporated in nursing curriculum in Indonesia and explore the collaboration needed to make this possible.



The groundbreaking event was attended by key players in healthcare and education in Indonesia, including senior representatives from the Ministry of Health, Ministry of Education and major universities and hospitals as well as the heads of National Nursing Association, National Bachelor of Nursing and Diploma of Nursing Associations.

**Dr. Suresh Kumar**, an expert in community-based palliative care from India and the Director of WHO Collaborating Center for Community Participation in Palliative Care and Long Term Care, joined the discussion and called for a dedicated community to be empowered to provide home-based palliative care for people living with chronic and life-limiting conditions.



[Read more](#) about how this event made important progress in underpinning the key issues to be addressed in order that palliative care can be made available for all in Indonesia.

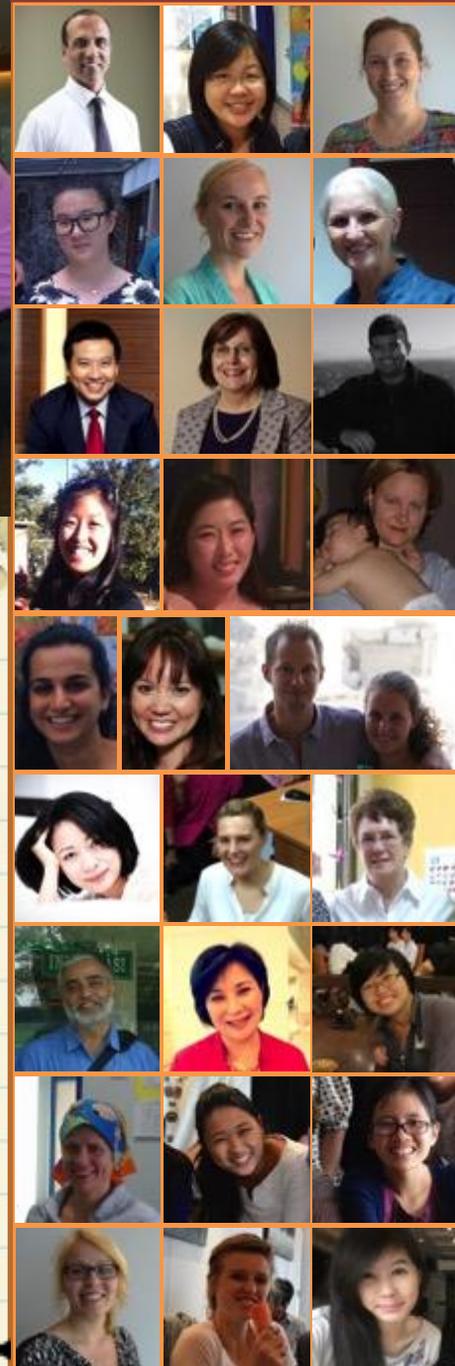
From all over the world they came and helped champion the cause...

## The angels who helped made it all possible

"With tender care and gentle maneuvering she sets to helping care for the precious girl's rash and inflammation...This is what the nurses at Rachel House do from day to day. They travel on motorbikes to provide care, support, love, encouragement, medicine, education and kindness to children that are in need of palliative care." **Summer Shepherd**, a student nurse intern from the U.S.



### Our wall of Blessings



#### By Joyan Tan, a student intern from Yale-NUS (Singapore)

The first patient I met on a home visit was a tiny little baby boy named Andi. He was HIV positive. He was only 4 months old, and had the tiniest fingers and toes.

Many thoughts filled my head as we walked away from Andi's house that day. Andi did nothing to deserve all this pain and suffering. I went away thinking, man, life can be really unfair to some people.

It made me realize just how much of a blessing Rachel House is to these families. The nurses and staff at Rachel House see the suffering and go out of their way to alleviate it.

They never stop at "Wow life is so unfair!" They go beyond, and give their all in order to help one more child live the rest of their remaining days without pain.

[Read more](#) about the volunteers' experience at Rachel House.

[Watch](#) the videos that our interns produced