

# **DYING WELL: GIVING TERMINALLY-ILL CHILDREN ACCESS TO PEDIATRIC HOSPICE CARE**

*A story of Rachel House:  
The First NGO Pediatric Hospice Care in Indonesia*

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**MercyCorps**

*This case study is part of the CHMI case study series.*

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CHMI identifies, analyzes and connects programs working to improve health and financial protection for the poor. CHMI works through a [network of partner organizations](#) in 16 countries where there are large numbers of private health care providers. CHMI is funded by the Bill & Melinda Gates Foundation and the Rockefeller Foundation.

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## GLOSSARY

List of Acronyms	Definition
<i>Askeskin</i>	Health Insurance Scheme for Poor
CHMI	Center for Health Market of Innovations
JPS	Social Safety Net
<i>Jamkesmas</i>	<i>Jaminan Kesehatan Masyarakat (Health Insurance for the Public)</i>
<i>Posyandu</i>	Community-based integrated maternal and child health posts
<i>Puskesmas</i>	Sub-district health center
<i>Pustu</i>	Assisting health services at village level
RSCM	Dr. Cipto Mangunkusumo Hospital
RSIMC	Ichsan Medical Center Hospital
SIF	Singapore International Foundation

## 2. EXECUTIVE SUMMARY

The incidence of childhood cancer is increasing worldwide including in Indonesia where there are about 140 cases per year per million people below 18 years. In the greater Jakarta area with a population of over 12 million people, there are an estimated 650 new cases of children with cancer per year. Indonesia, with a population of over 220 million people, has an estimated yearly incidence of 11,000 new cases of childhood cancer; most of these occur in families that cannot afford to pay for the medical treatment expenses.”<sup>1</sup>

In 2006, *Yayasan Rumah Rachel*, or Rachel House pioneered the Pediatric Palliative Care in Indonesia concentrating on providing palliative care for children with terminal illnesses such as cancer and HIV, particularly for the poor. Through a process of trial and error, RH has fought their way in providing palliative care (pain and symptom management) that otherwise was not available for the children of Indonesia.

### 2.1. The Study

A case study to document RH was conducted by Mercy Corps from February to March 2011 to assess the methods and strategies adopted by the program to handle barriers and challenges to delivering palliative care (in non-hospital setting) to the children in Indonesia; and since the program is the first of its kind in the country, to document the lessons learned. The study focused particularly upon the networking and referral strategies adopted by the program. The Study Team conducted 6 in-person interviews representing the funders and implementers, most from the public health, medical, or finance background. Due to the sensitive nature of the program, the Study Team was not able to conduct field visits and interviews with the beneficiaries.

### 2.2. Findings

Palliative care presents diverse challenges including “clinical, educational, institutional, regulatory, financial, and attitudinal barriers;”<sup>2</sup>with the key barrier being the unfamiliarity of Palliative Care culturally and clinically in the general public and within the medical community in Indonesia. The unclear government policies and the lack of technical guidelines on hospice care in Indonesia exacerbated the

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<sup>1</sup><http://www.yoai-foundation.org/english/profil.php> (accessed on 1 March 2011)

<sup>2</sup><http://www2.edc.org/lastacts/archives/archivesmarch00/editorial.asp> (accessed 20 March 2011)

complexities of getting the resources RH needed to launch and implement the program. RH's founder Lynna Chandra and the RH team had to operate completely independently to obtain the necessary facilities, financial and human resources, and technical assistance to get started.

Following are the key findings about success factors for RH:

### **Creating access despite the challenges (e.g. unclear hospice regulations)**

The interviewees indicated that the hospice regulations in Indonesia for non-hospital setting operations remain unclear. The government regulated palliative care in 2007 by the Ministry of Health's decree no. 812/Menkes/SK/VII/2007 that legalized the work of hospice care particularly in hospitals.<sup>3</sup> The lack of clarity in hospice regulations has meant that RH had to set up its very first inpatient hospice under the umbrella of an existing hospital, and conducts its home care under the same hospital license.

### **Dedicated 'Champion':**

The Team found that the RH's overall system was driven by a dedicated Champion from the initiation to a mature stage of the program lifecycle. RH was initiated by Ms. Lynna Chandra, who throughout her work has connected RH with donors from private entities, philanthropic groups, the Singapore Ministry of Foreign Affairs, Singaporean and Australian palliative care community and professionals. She continues to supervise the operations, working closely with RH's General Manager and team members on the day-to-day matters.

### **Network: Finding and Managing Resources**

To address the significant resource challenges faced, RH adopted an innovative strategy of networking. The RH Team used networking on various levels, starting from attracting palliative care trainers from the palliative care communities in neighboring countries to obtaining funding and other form of assistance for RH's needs. Its network consists of private businesses and corporations, local NGOs, private and public hospitals and clinics, *Puskesmas*, and individual partners including health professionals, social workers, parents and families of the children, and business entrepreneurs and legal/accounting professionals.

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<sup>3</sup> See <http://www.spiritia.or.id/Dok/skmenkes812707.pdf> (accessed on 1 Feb 2011)

When establishing the Board of Directorship for RH, Ms. Chandra, an ex-investment banker, invited her personal network from the business and the legal professions in Indonesia to join and serve as RH's Trustees and Directors. Through this network, unlike most pediatric palliative care program whose key challenge is financial support, RH has been able to maintain a stable financial status. Initiated with seed funding from Ms Chandra and her friends and a successful Gala fundraiser organized by The Prestige Magazine for the high net worth society of Jakarta in 2006, RH has since been able to consistently meet its financial needs over its 5 years of operation. Since its inception, Ms. Chandra and RH team have raised funds from the private donations to cover its annual operating cost which is running at an estimated rate of US\$130,000 per annum (data per Feb 2011). With an on-going financial commitment from the private donations, coupled with strong financial management from the RH's Board of Directors, RH remains financially sustainable.

In the search for mentorship and trained palliative care professionals to provide training for the first batch of pediatric palliative care professionals in Indonesia, Ms. Chandra sought and found support from the palliative care community in Singapore and Australia through her personal network. A major feat for RH was the 2-year pediatric palliative care training program organized by the SIF in 2008.

The ability to attract trainers from overseas has also allowed RH to expand its network amongst the medical and healthcare communities in Indonesia. To cultivate a strong palliative care community, RH invites participants from a wide variety of healthcare professionals to attend the training it hosts.

### **Referral Strategy**

As palliative care is a relatively new concept in Indonesia, the RH team has their work cut out for them. Not only do they have to introduce the concept to the patients and their families, the team has had to introduce palliative care and the role of palliative care to the hospitals and public health clinics that they approach for collaboration. Compared to marketing for curative care where patients seek the physicians, getting patients for RH has involved a long educational process. RH team spends a large amount of their time conducting basic palliative care education through either private or public forums.

RH seeks the patients through a referral system within its network in four ways:

- Individual physician to physician referrals
- Referral from institutions such as hospitals, local NGOs, *Puskesmas*

- Field visits to the areas where the children are located
- Field visits to hospitals

Despite the absence of performance monitoring mechanisms and indicators, The Study Team indicated that the best indicator applied to measure RH's program performance appeared to be the responses and experiences from the children and their families. On their website and several publications, RH documented individual stories of the children they took care of, where it would then be used to advocate regulation on hospice palliative care in Indonesia further.

Based on a book written by Diane Meier (2005), "Ten Steps to Growing Palliative Care Referral," RH has gone through at least four of these steps such as making solicitation to clinicians, educating key members in healthcare centers about palliative care; recruiting the champions (physicians and community leaders) to support palliative care and the related activities, selecting a team position to generate referrals; engaging with physician colleagues and involving/up-dating them about the palliative care provided for their patients.<sup>4</sup>

Based on the key findings, The Study Team would recommend the followings:

1. There appears to be the need for an apprenticeship program that could be implemented through on-the-job trainings. Thus, the transfer of knowledge, social capital such as networking, and confidence can be developed through apprenticeships.
2. Facilitate peer-peer groups consisting of parents/families of the children to enhance sharing of experiences in hospice care. This forum could indirectly be a channel of network to build awareness of pediatric hospice home care and to get feedback on RH's services.

### **3. BACKGROUND AND COUNTRY CONTEXT**

#### **3.1. Era of Health Innovation**

Indonesia, like other developing countries in the region, is on the brink of major health improvements. With constant economic growth and increasing commitment from the government, private sector, and

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<sup>4</sup>Meier, Diane, "Ten Steps to Growing Palliative Care Referral", *Journal of Palliative* (2005); 8(4): 706-708

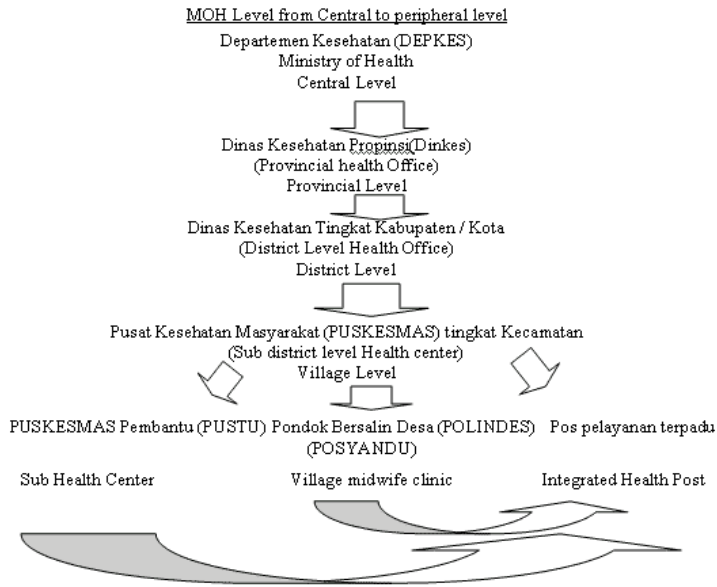
the community to meet the needs of citizens, health care and health programs in Indonesia are poised for a major breakthrough. This is true for many types of interventions including communicable disease tracking, mobile health insurance, cross-subsidized private hospitals, and palliative care for cancer patients, and accreditation for quality midwives.

The term 'Health Innovation' itself is becoming familiar in healthcare circles but it remains ill-defined and unheard of in a broad context, especially by those who remain living below the poverty line and do not have access to the health services they need. Stakeholders claim that superior 'Health Innovation' has the potential to enhance operations, regulate performance, change poor behaviors, finance health care, and improve quality of services, namely for the poor.

### **3.2. The Health System**

The Indonesian health system became decentralized in 2001 following the passage of the regional (district) autonomy law in 1999 as one of the early products of the governmental reform era. The locus of local health care services are now at the sub-district level where the local community is served by sub-district health posts known as *Puskesmas*, mostly managed by physicians. To further reach local community members, there are usually two or three sub-health centers or *Pustu* at the village level which are administered by nurses. The organizational structure can be seen in the figure below. Private hospitals are also present at the village level, working hand-in-hand with the health providers at *Puskesmas*. These private hospitals are run by various entities such as private clinics owned by physicians and midwives, religious based organizations (*Muhammadiyah* foundation for instance), and local NGOs (such as a low cost, quality clinic run by *Yayasan Kusuma Buana* and HIV/AIDS clinic runs by NGO *Hati-Hati* in Bali).

**Figure 1: Organizational Structure of Health System.**



*Source: www.searo.who.int*

Networks of private health providers are a promising mechanism to expand the supply of quality health services as they achieve economies of scale in training, procurement and marketing, and allowance for rapid expansion to increase coverage, improve financial access by standardized prices, and ensure quality and brand recognition.<sup>5</sup>

### 3.3. Palliative Care in Indonesia

Center to Advance Palliative Care (CAPC) at Mount Sinai Hospital in New York defines palliative care as an interdisciplinary care that aims to “relieve suffering and improve quality of life for patients with advanced illness and their families.”<sup>6</sup> Palliative care works with but is not a substitute of other treatments. Palliative care “decreases length of hospital and ICU stays and eases patient transitions between care settings. This results in increased patient and family satisfaction and compliance with hospital care quality standards.”<sup>7</sup>

<sup>5</sup> USAID, “Private Health Sector in Indonesia: A Desk Review”, 2009.

<sup>6</sup> See <http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc> (accessed 20 March 2011).

<sup>7</sup> See <http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc> (accessed 20 March 2011).

Palliative care in Asia has grown since it was first established in Seoul, where a hospice clinic was built in 1965. As of 2005, as many as 115 countries out of the 234 countries in Asia have at least one hospice or palliative care service.<sup>8</sup> Palliative care services started in Indonesia in 1992, at the *Dr. Soetomo* Hospital in Surabaya. As of today, adult palliative care services can only be found in five main provinces in Indonesia (described below). However, patients needing palliative care are spread throughout the thirty-three provinces in Indonesia. Furthermore, in observing the abundant needs of the patients, the number of physicians capable of providing palliative care services remains limited.

Pediatric palliative care has been defined and described by the World Health Organization, the Institute of Medicine, the American Academy of Pediatrics, as “individualized, integrative care that is provided for children with life-threatening conditions. The care starts at diagnosis, continues through the trajectory of the illness, and is directed at the underlying illness and at the physical, emotional, social, and spiritual needs of the child and family”.<sup>9</sup> Pediatric palliative care aims to “prevent or relieve pain, offer children and their families the emotional and spiritual support they need, respect families’ choices, values, and cultural traditions and help children and families to make decisions and to live as normal a life as they can.”<sup>10</sup>

### ***Hospice Home Care in Indonesia***

Palliative care is not the same as hospice care. New York University Langone Medical Center stated that “palliative care may be provided at any time during a person’s illness, even from the time of diagnosis. And, it may be given at the same time as curative treatment. Hospice care always provides palliative care. However, it is focused on terminally ill patients - people who no longer seek treatments to cure them and who are expected to live for about six months or less.”<sup>11</sup>

Currently, there are limited documentations on the statistics of hospice home care services in Indonesia for the adults and children. However, The Study Team found there are at least six hospitals in five provinces that provide hospice home care services for adults: DKI Jakarta (*Dr. Cipto Mangun Kusumo Hospital/RSCM and Dharmais Cancer Hospital*), DI Yogyakarta (*Dr. Sardjito Hospital*), East Java (*Dr.*

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<sup>8</sup> Seminar on Palliative Care Development in Asia, Graduate Medical School Singapore, 2008

<sup>9</sup> See [http://www.internalmedicineneeds.com/index.php?id=495&cHash=071010&tx\\_ttnews\[tt\\_news\]=52326](http://www.internalmedicineneeds.com/index.php?id=495&cHash=071010&tx_ttnews[tt_news]=52326) (accessed 15 Feb 2011)

<sup>10</sup> Marilyn J. Field and Richard E. Behrman. “When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.” NAP Publishing 2003

<sup>11</sup> See <http://palliativecare.med.nyu.edu/what-is-palliative-care/different-0> (accessed on 1 March 2011)

Soetomo Hospital), Bali (*Sanglah Hospital*) and South Sulawesi (*Wahidin Sudirohusodo Hospital*). Amongst those hospitals, at least three of them currently provide pediatric hospice home care services. The Team also found that several NGOs such as *Yayasan Kanker Indonesia (YKI)* provide hospice outpatient services for adults and refer their pediatric patients to RH.

### ***The regulations of home care versus inpatient***

The current government regulation on palliative care (published in 2007) legalized the work of hospice palliative care in hospitals. Hospice or *Rumah Singgah* is included in the regulation although not elaborated upon further.<sup>12</sup> However, the hospice home care model for non-hospital settings is rarely seen nor their stories documented in Indonesia. Thus, the regulation for the hospice home care model for non-hospital settings remains unclear.<sup>13</sup> An NGO or non-hospital institution wishing to provide hospice home care must in the meantime work under the umbrella of a hospital.<sup>14</sup>

### **3.4. Social Entrepreneurship: The Rising of Champions**

Indonesia, like other countries, is experiencing the growth of social entrepreneurs. As a new comer in the social market, it raises a question, “What makes Social Entrepreneurship”? Social Entrepreneurship is “about applying a practical, innovative and market-oriented approach to social, economic and environmental problems which transforms and benefits society. A social entrepreneur is one who has created and leads an organization, whether for-profit or not, that is aimed at catalyzing large scale and systemic social change through the introduction of new ideas, methodologies and changes in attitude. Social entrepreneurs create innovative, hybrid organizations that look like businesses – indeed, they may be set up as for-profit organizations - but their bottom line is social value creation.” The social entrepreneurs are expected to bridge the gaps between action and policy that are caused by limitation of time, money, programs and personnel.<sup>15</sup>

In Indonesia, social entrepreneurship is developing in various sectors such as education, rural development, livelihood; health and environmental. The Schwab Foundation for Social Entrepreneur presented *Social Entrepreneur of the Year of Indonesia (2007)* award to Bambang Ismawan, the founder of *Bina Swadaya*. Mr. Ismawan works on educating rural agriculture community through publishing

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12 See <http://www.spiritia.or.id/Dok/skmenkes812707.pdf>. Ministry of Health Regulation no. 812/Menkes/SK/VII/2007

13 Lynna Chandra. Personal Interview. February 2011.

14 Ibid

15 See [http://www.ey.com/ID/en/About-us/Entrepreneur-Of-The-Year/2009\\_SEOY\\_Article](http://www.ey.com/ID/en/About-us/Entrepreneur-Of-The-Year/2009_SEOY_Article) (accessed on 1 March 2011)

*Trubus*, the first agricultural magazine in Indonesia. The other example is Ambrosious Ruwindrijarto of the *Telapak* Foundation (Schwab's Social Entrepreneurs of the Year 2008) for his leadership in promoting environmental sustainability through introduction of non-cyanide ornamental fish and coral to market.<sup>16</sup>

Together with Ernst & Young, The Foundation initiated Social Entrepreneur of the Year in 2010. The award selected the top entrepreneurs who had demonstrated great contributions to solving the social issues in Indonesia. "They cover many sectors and include industrialists, manufacturers, and service providers, thus proving the breadth and depth of business activity alive in Indonesia today."<sup>17</sup> Despite the growth, social entrepreneurs remain difficult to find in Indonesia.

### 3.5. Financing

There has been a series of attempts to improve health care financing, particularly for the poor, such as the provision of 'Health Insurance for the Poor' or *Asuransi Kesehatan Masyarakat Miskin (Askeskin)* in 2004. *Askeskin* was instituted as a new health card system for the poor to replace the former *Kartu Sehat*, which was a part of the Social Safety Net Program. *Askeskin* can also be used to access in-patient services in private hospitals. This form of health insurance then evolved into the Community Health Insurance program or *Jaminan Kesehatan Masyarakat (Jamkesmas)* in 2008. Cancer and HIV/AIDS related medicine are covered by *Jamkesmas*.<sup>18</sup>

In addition to governmental sponsored insurance, other forms of financing are offered by International donors. In 1996, World Bank implemented a pregnancy voucher program in Pemalang District, Central Java. The vouchers were distributed by midwives to poor pregnant women. During the project period, the number of district midwives doubled and midwives' coverage of villages reached 95%.<sup>19</sup> Private low cost health insurance in Indonesia is rare. An example of the private low-cost health insurance program in Indonesia is the dengue fever health insurance (50.000 IDR or \$5USD/year) offered by *Asuransi Central Asia (ACA)*<sup>20</sup>.

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16 See <http://www.ey.com/GL/en/About-us/Our-alumni> (accessed on March 1, 2011)

17 See [http://www.ey.com/ID/en/About-us/Entrepreneur-Of-The-Year/2010\\_Finalists-Announcement\\_Press-Release\\_EN](http://www.ey.com/ID/en/About-us/Entrepreneur-Of-The-Year/2010_Finalists-Announcement_Press-Release_EN) (accessed on 1 March 2011)

18 See <http://batam.tribunnews.com/2011/02/22/penderita-hiv-bisa-berobat-pakai-jamkesmas> (Accessed 3 April 2011)

19 World Bank (2006). "Making Services For The Poor: Nine Case Studies From Indonesia", pg. 4

20 See <http://www.aca.co.id/product.aspx?id=20> (accessed 1 March 2011)

## 4. MODEL OVERVIEW OF RACHEL HOUSE

GOAL	CORE COMPONENT	MARKETING ACTIVITIES (Acquiring Patients)	OUTPUT	MONITORING
Access to Palliative Care (Cancer and HIV)	Home Visits	Raising awareness in: 1. Medical community - through public hospitals, Puskesmas and public health volunteers, and with individual health professionals) 2. General public – through NGOs, media and media publications	Patient and Patient’s family satisfaction (ie. The ability to manage patient’s symptoms and keep pain at bay)	“Best indicator is the response from the children and the parents/families”
	Palliative care education for caregivers (parents and families)	Referrals	Caregivers’ ability to manage patient’s symptoms with confidence	
	Grief counseling	Counseling to ensure caregivers resume normal life after the death of the patient		
	Palliative care education to the surrounding communities	Referrals	Support for patients and families	

## 5. MODEL

### 5.1. Background and History

#### 5.1.1. The Story of Rachel: Passion Turned Into Innovation

RH was established in 2006 by Lynna Chandra, who was inspired to action following the death of her friend, Rachel. While Rachel had the best of medical care throughout her long battle with cancer, it was love and friendships that made a difference in the final days of her life.

Rachel's battle started Lynna thinking about the less fortunate individuals who would not have the means or access to medical care to reduce painful symptoms often associated with cancer and HIV, and sometimes without caregivers in cases where parents have died or are working to earn a living. The excellent medical care afforded to Rachel at the end of her life along with the love and support from her friends and caregivers made it possible for Rachel to live a full and happy life to the end. This is the model of services Lynna wanted to make available for the children facing terminal illnesses in Indonesia.

## **5.2. Business Model**

### **5.2.1. Champion**

Champions play a significant role in the initial stage of program life cycle. These champions created a sense of urgency, built their teams, developed a vision, actively communicated with others to secure buy-in, and empowered others to take action, kept up momentum, worked hard to continue innovation in the face of the pull of tradition and the old ways of acting and thinking.<sup>21</sup>

RH founder, Lynna Chandra, is one of many rising social pioneers in Indonesia. In her interview, Lynna Chandra stated, "At the time it was launched, there was no pediatric palliative care similar to RH in Indonesia." Through her initiation, she established not only the institution of RH but also linkages between RH and private and institutional donors and palliative care professionals from neighboring countries such as Singapore, Malaysia and Australia; and more importantly, linking these palliative health care professionals and the terminally ill children and their families. Her network is getting stronger as RH becomes a referral center of pediatric palliative care for 9 hospitals, and in 2010 referrals from children hospitals in Singapore and Sydney for returning Indonesian nationals.

### **5.2.2. Finding the Model That Works: Catering to the needs**

The journey began with a plan for a 60-bed hospice as a huge demand was anticipated. While waiting for the architectural designs for the 60-bed hospice to be completed, Ms Chandra began searching for a location to lease to begin its pilot program. This proved to be more difficult than she had anticipated.

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21Kotter, John. P and Dan S. Cohen. Heart of Change: Real Life Stories of How People Change Their Organizations. Boston:Harvard Business School Press, 2002.7)

Ms. Chandra told of how landlords and neighborhoods refused their presence and referred to them as a “house of death”.

In mid 2008, with the first medical team assembled (consisting of 1 doctor and 5 nurses), RH launched its first home-based care program. This proved a great challenge, especially while operational permits remained unclear. Eventually, in December 2008, RH inked an agreement with *Ichsan Medical Centre* (RSIMC) in South Jakarta that allowed it to launch its very first 3-bed inpatient hospice care under RSIMC’s hospital license.

The 3-bed inpatient facility provided an excellent ground for training, both the medical community in the referral process and the patients and their families in the concept of palliative care. At that stage, RH was receiving referrals from the pediatric oncology units in *Dharmais* Cancer Center and later, RSCM Hospital. RH team quickly found that the only patients who were willing to be admitted to the inpatient hospice facility were those from out of town. Ms Chandra added that this is because children when ill, typically preferred to be at home, in the security of their own environment and surrounded by their immediate and extended families, regardless of how basic their houses may be. Home-based care is also more convenient for parents, as most need to continue to work to earn a living for the family.

This led to the eventual decision to close the 3-bed inpatient facility at RSIMC in late 2010, with RH focusing all its resources on home-based care operated from 3 satellite centers covering the North Jakarta, West & Central Jakarta and East & South Jakarta.

### **5.2.3. Networking: Finding and Managing Resources**

To speed up the process of acceptance by the medical and healthcare communities of palliative care, RH adopted an innovative strategy of networking. Network is defined as “a group of providers that are loosely joined to deliver services to specific population groups. Each provider is a separate entity and retains its own branding.”<sup>22</sup>

When RH successfully negotiated the 2-year training program from SIF in Singapore in 2008, the Core Team of participants RH assembled included key players from various sections of the community who it hoped would spread the palliative care knowledge to the wider community. The Core Team included the

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22 CHMI (2010) Health Innovation Models. Center For Health Market Innovations (CHMI)

pediatric oncology team and nurse administrator from *Dharmais Cancer Centre*, nurse educator and doctor from *Carolus Hospital* (with a reputable nursing school), a nurse from *Puteri Kasih Indonesia* (a Catholic organization with a wide outreach medical clinic in the poorest parts of Indonesia), a social worker with Coalition of Health Indonesia (“KUIS”). This sharing of knowledge amongst its network quickly became the core principle with which RH operates.

It is also through close collaborations and sharing of resources with one of the NGOs in its network that RH managed to successfully launch its services into the HIV community. In late 2009, RH teamed up with LAP (*Lentera Anak Pelangi*) to provide medical and psychosocial assistance to children affected and infected with HIV. Whilst LAP led in the areas of psychosocial care, RH led in the medical care needed for these children. This successful partnership led RH’s journey into the HIV community to provide palliative care for the infected children.

RH’s Team infused the concept of networking in its sharing of knowledge and education resources with other NGOs and public and private healthcare providers, in its funding mechanisms and its business processes as well as the referral mechanism. Christine Cassel, the Vice President of Robert Wood Johnson Foundation emphasized the importance of networking between pioneers and other institutions such as hospitals, foundations, charity organizations, civil society organizations, or faith-based organizations to equip them with the clinical facility, expertise, and funding to establish care. Establishing networks thus becomes a common hurdle during the inception of palliative care programs.<sup>23</sup>

When Lynna Chandra formed RH, the only resources she had were her personal and professional network and her passion for the cause. Ms. Chandra, an investment banker by profession, invited her personal network to join RH as the Board of Directors. Currently, RH’s board consists of business professionals and a pediatric oncologist. Unlike most pediatric palliative care programs whose key challenges lie in gaining financial support, RH has successfully increased and maintained a stable financial status.

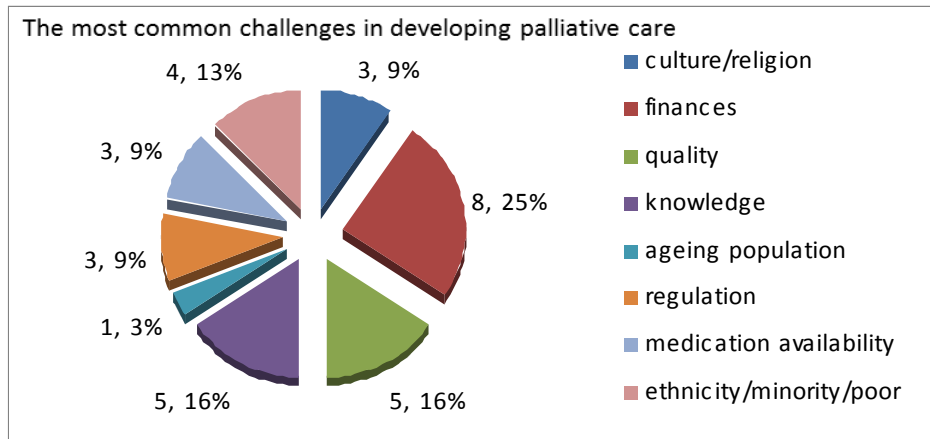
Having an extensive experience as an investment banker provided her with ample access to private companies, philanthropic organizations and funders. She said since its inception, funding has thankfully

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<sup>23</sup> Robert Wood Johnson is a charitable organization dedicated to health care issues considered one of the leaders in palliative care in the U.S See <http://www.milbank.org/pppc/0011pppc.html> (accessed 1 March, 2011)

not been an issue for RH, compared to the challenges for her to get hospital “buy in” to palliative care, due largely to lack of awareness. This was in sharp contrast to other pioneers who were perhaps physicians, clinicians, or individual with access and influence at hospital institutions but did not have immediate access to funding.

Graph 1: The Most Common Challenges in Developing Palliative Care



Source: Dermot, E (2005). *Advocating hospice and palliative care: challenges, contexts and changes. Report of the 2nd Global Summit of National Hospice and Palliative Care Associations, South Korea*

#### 5.2.4. Knowledge Resources

In the search for mentorship and trained palliative care professionals, Ms. Chandra sought and found support from the Singapore palliative care community through her personal network. A 2-year training program was organized by SIF in 2008. Currently, RH receives additional training from a network of palliative care health professionals from Australia.

#### 5.2.5. Facility Resources

At the initial stage of the program, RH faced challenges in getting the facility for the location of its pilot inpatient service due to a combination of the lack of awareness of hospice care in the general public (leading to the service being tagged the “death house”) and the lack of clarity of the government regulation with respect to hospice services outside the hospital setting. In 2008, through its network, RH was given a permission to use a facility at RSIMC, a private hospital in Bintaro, South Jakarta and operated its first inpatient pediatric palliative care service under the hospital’s permit.

### **5.2.6. Referral Strategy**

As palliative care is a relatively new concept in Indonesia, the RH team spends a large amount of their time building awareness in the community about palliative care and its role; introducing palliative care to the health providers, related health providers (such as health volunteers, social workers etc), policy makers, patients and their families, the general public through media.

Compared to marketing for curative care where patients themselves seek out physicians, getting patients for RH involves a long educational process. RH does this by a referral system within its network in four ways:

- Individual physician to physician referrals
- Field visits to the areas where the children are located (home visits)
- Field visits to the hospitals where the children are treated.
- Referrals from local institutions-hospitals, local NGOs, *Puskesmas*.

The ‘marketing’ or awareness building strategies is used in parallel with the referral system. When a nurse visits a hospital, she meets the physicians and other health practitioners providing information and ‘educates’ them on pediatric palliative care, and the role of palliative care within the entire continuum of care. Critically, the role of palliative care provided in the homes of the patients when patients are discharged to spend their last days at home.

Currently, RH’s patients are referred by partner hospitals such as RSCM, *Dharmais Cancer Hospital*, *Sulianti Saroso Hospital*, *Koja Hospital*, *Tarakan Hospital*, *Cengkareng Hospital* and Community Health Centers throughout Jakarta, Bogor, Tangerang and Bekasi, especially those that are in the poorest areas. Many patients are also referred from the 14 Community Health Centers that are in the districts and villages of RH’s service areas. As of now, RH has provided care for more than 108 patients and the number of patients continues to increase. In contrast, in 2008 when they first launched their services, they had only nine patients.

### **5.2.7. Operations model: Satellite system**

RH’s operational current model consists of carving out the Greater Jakarta area into three satellites: covering West & Central Jakarta, North Jakarta, and East & South Jakarta. Each satellite is managed and operated by a nurse. This division is aimed at enhancing the nurses’ mobility and increasing their travel

time efficiency. To avoid Jakarta's traffic jams, RH's nurses have also decided to travel by motorcycle rather than by car<sup>24</sup>.

RH defines their area of operation based on poverty level, number of children with HIV/AIDS and cancer, early detection data they compiled from the *Puskesmas*, and lastly, referrals from *kader* or midwives. The geographical areas covered are mostly located in the urban slums as such Plumpang, North Jakarta, a hamlet near Jakarta Harbor which is densely populated by blue collar workers.

Nurses play vital roles in operating the satellites. They are in charge of managing the satellites, sharing information about RH's services to hospitals and health providers, acquiring new patients, providing the care to the patients and training to the caregivers, acting as advocates who mediate between patients/families with physicians and also chaplains who help during bereavement. Their presence helps build better communication between physicians and families to avoid miscommunication and frustration.

#### **5.2.8. Under the umbrella of a network of physicians**

The interdisciplinary concept of palliative care entails the teamwork amongst physicians- between the main physician who is treating the patient in a hospital and the palliative care physician. The sharing of control of the patient care cannot be shifted entirely to nurses. Some studies support the findings of The Study Team that physicians are "often reluctant to share control of patient care with non-physicians. However, hospice care plans are dependent upon the physician's approval and hospice welcomes the physician's input on care."<sup>25</sup>

In order to cope with this issue, RH is supported by a well respected pediatric Oncologist and an equally well respected pediatric Immunologist as medical consultants. The pediatric Oncologist works at *Dharmais Cancer Hospital*, and the pediatric Immunologist at *RSCM*- both hospitals are recognized nationally as the leading public hospitals for cancer and HIV/AIDS, respectively. The consultants will have to review and assess every case that is referred to RH to ensure that the patients meet RH's admission criteria set and that curative treatments are no longer viable. These consultants will also work

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<sup>24</sup> 24 Rina Wahyuni. Personal Interview. March 2011

<sup>25</sup> McGorty, K and Bornstein, B., "Barriers to physicians' decisions to discuss hospice: Insights gained from the United States hospice model," University of Nebraska, Lincoln. 2003

with RH's nurses to prepare the plan of care for each patient, including the regular review of the patients' status with respect to the plan of care. Most importantly, these consultants also serve as a legal authority responsible for the overall care of the children.

### **5.2.9. Services offered**

#### **Home visits**

When making the plan of care, nurses use the latest prognosis as the baseline information to determine the frequency of home visits and the appropriate care (i.e. Pain and symptom management) required. "Based on the latest diagnosis, we would scan the available information and group it onto three different categories: red, green and yellow. Code red is used for children with cancer at the late stages. Under the red category, the visit would be done three to four times a week. Children with HIV/AIDS and with severe malnutrition are marked green and home visits will be scheduled two to three times a week. Code yellow is used for children whose nutritional condition is normalizing and required occasional monitoring to ensure stability and home visits will be scheduled once a week.<sup>26</sup> In addition, during these home visits, RH nurses will also work to prepare the patient and the caregivers if death is near. This sets the stage for the post-death grief counseling where RH nurses work closely with the family or a particular caregiver to ensure they return to their day-to-day lives.<sup>27</sup>

#### **Post-death grief counseling**

The post-death grief counseling starts at the time of diagnosis (as discussed above) and extend beyond death, attending to the grieved parents and family members<sup>28</sup>. The counseling comforts the parents and caregivers in accepting death as a natural event and helps them to move on and return to normal life-an approach not adopted by the curative health care system.

#### **Palliative education for the parents and families**

Through home visits, RH nurses educate parents on how to manage the child's pain and symptoms. The education sessions involve an in-depth discussion of the child's medical condition and the plan of care

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26 Rina Wahyuni. Personal Interview. March 2011

27 *ibid*

28 Feudtner, Chris. " Collaborative Communication in Pediatric Palliative Care: A Foundation for Problem-Solving and Decision-Making". *Pediatr Clin North Am*(2007), 54(5): 583–ix

appropriate for the condition. The education includes the use of the pain scale (a tool to recognize level of pain through facial expression) to measure the level of pain, and using the result of the pain scale analysis to appropriately measure the amount and frequency of the medication. Other topics include proper hygiene such as the method of bathing, feeding and how to clean wounds. The objective of the training is to empower parents to provide the best care to their children-giving them confidence to manage what could be at times the most painful conditions. Parents would often better cope with the post-death grief if they feel they had done their best for their children, including caring for the symptoms.

NGOs refer some children to RH when the parents of the children are no longer alive and when the caregivers are elderly grandparents. In such cases, RH accompanies the elderly and coach them how to take care of the children step by step.

#### **Provision of milk, medicines, and transportation within the network of RH**

Local NGOs work hand in hand with RH to cover the services needed by the children. This includes providing medicines for the children that are not covered by *Jamkesmas*. Currently, *Jamkesmas* covers medicines for cancer and HIV treatments up to certain limits and with conditions applied. For those who need additional medicines, milk and transportation, RH and the local NGOs work together through referrals and information sharing.

As an example, RH works with the local NGOs to supply *opioids*, a type of pain killers usually provided for the children that has limited supplies in the market. Access to *opioid* especially oral *morphine* or *opioid* analgesic for cancer pain relief in Indonesia is still limited<sup>29</sup>. Since 1986, WHO has globally endorsed the country members to include *opioid* on the rational drug policy.<sup>30</sup> This type of medication is very important for treating severe pain among cancer patients as they can not be substituted by other type of therapeutic medicine.<sup>31</sup> In Indonesia, *opioid* provision is controlled under a rigid system due to the fear

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<sup>29</sup> Rina Wahyuni, personal interview (March 28, 2011)

<sup>30</sup> See Who/Edm/Qsm/2000.4 "Distribusi: Umum World Health Organization Organisasi Kesehatan Sedunia Obat-Obatan Narkotika & Psikotropika Meraih Keseimbangan Dalam Kebijakan Pengendalian Opioid Panduan Penilaian World Health Organization Organisasi Kesehatan Sedunia."

<sup>31</sup> *ibid*

of drug abuse<sup>32</sup>. Therefore, Indonesian Ministry of Health and The National Agency for Food and Drugs Control created a monitoring and tracking system to control and limit the provision and distribution of *Opioid* from *PT Kimia Farma* (the sole distributor of *opioid* in Indonesia) to only be available upon the request of the pharmacies (with a prescription by legal physicians.<sup>33</sup> Due to this drug policy, the *opioid* have limited supplies in the market.

### **5.3. Human Resources**

RH's team is made up of the following: (1) operational team (2) regional advisors (3) board members. The operational team includes a general manager, two medical consultants, four nurses and four support staff. The operational team is in charge of day to day implementation in the field.

The regional advisers consist of a team of volunteers who helped in the initial establishment of RH. They provided and continue to provide mentoring and advise in the following areas: palliative medicine, hospice nursing, fundraising, finance and accounting, IT & website management, branding and corporate ID. RH has the following boards: board of trustees, supervisory board, executive board and a fundraising committee. The board members, which include Ms. Chandra, support one another to maintain RH's operational and financial sustainability.

### **5.4. Target Population**

RH is targeting children of 0-18 years old with terminal disease (cancer) and chronic illness (HIV/AIDS) in need of palliative care. In addition to the patients, RH also extends their services to family members to cope with their bereavement after their love ones have passed away.

As mentioned above, RH defines their areas of operation based on poverty level, number of children with HIV/AIDS and cancer, early detection data they compiled from the sub district health post

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<sup>32</sup> Soebadi RD, Tejawinata S. "Indonesia: Status of Cancer Pain and Palliative Care", *Pain Symptom Management* 1997;8(6):423-4.

<sup>33</sup> Keputusan Menteri Kesehatan RI No 791/Menkes/ SK/VIII/2008: Daftar Obat Essensial Nasional(DOEN),

(*puskesmas*), and lastly, referrals from cadres or midwives. The geographical areas covered are located in the urban slums such as *Plumpang*, North Jakarta, a hamlet near Jakarta Harbor which is densely populated by blue collar workers. The geographical arrangement of the satellite posts aims to ease the travel time of the nurses in providing the homecare and maximize the quality and frequency of care given to patients and families.

## **5.5. Challenges**

### **The lack of compassionate palliative health professionals**

According to Ms. Chandra, skill and knowledge are not the only requirements to work in palliative care. There is another requirement she looks for beyond clinical aptitude – nurses and physicians who would do the job with a full “heart and compassion”. These qualities reflect how prepared and willing the health professionals would be to work with children and their families, often from the poorest communities. The families depend on the nurses and physicians for support and medical assistance and often reach out to them after working hours. In addition, compassionate health professionals enhance the trust building process between the families and the nurses and physicians.

### **Limited access to certain medicines due to the absence of palliative regulations**

In a country where palliative care is not yet widely recognized, there is as yet no regulation on availability of pain medicines. Without a rational national drug policy, a palliative care program that requires effective pain medication cannot exist. For palliative care to grow, the Indonesian government needs to create policies that encourage hospice establishment, review the controlled drug policy to make effective pain medicines available, and where possible, adjust government insurance for the poor to cover pain medications.

### **Contradiction to ‘ought to’ principle amongst physicians**

The concept of palliative care, particularly hospice home care, remains a topic of debate in Indonesia, especially amongst physicians. Some argue that the practice of palliative care contradicts with the ‘ought to’ principle adopted by the Indonesian physicians. “Hospital ought to give the medical care and shall not refuse to give treatment to the patient regardless their prognosis.”<sup>34</sup> This situation could present major

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34 See <http://badanmutu.or.id/index.php?id=172> (Accessed April 03, 2011)

barriers for RH in getting more referral physicians who would adopt the concept of hospice home care. Ms. Chandra added curative treatment needs to be measured against the quality of life of a patient. “When curative treatment is no longer working and all options have been exhausted, then this need to be communicated to patient and family to allow them to choose if the patient wishes to either continue to battle on with curative treatments or to spend the remaining days at home with the security of nursing care at home that works to manage the patient’s pain and symptoms.”

### **Perception of “letting go”**

Discussion on death is a difficult process as the death of an infant or child is deeply mourned amongst most Asian cultures.<sup>35</sup> “People may prefer to keep the dying children in the hospitals to ensure that everything possible can be done for them, otherwise they may feel guilty for not doing enough.”<sup>36</sup> In Indonesia, there is a perception that one should try the best one can to help one’s loved ones. The interviewees indicated that most of the parents/families had a hard time to let go of their children. In some cases, “the children eventually passed away after the parents let them go.”<sup>37</sup> The interviewees who are nurses indicated that the process of ‘letting go’ has been one of the most challenging for the parents.

### **Perception of pain endurance**

The interviewees indicated that the patients’ parents have a high “tolerance” to witnessing the pain and suffering in their children, as they associate these symptoms with their “fate”. This is a cultural challenge for RH whose main principle, as is the core component of palliative care, is to reduce the pain and suffering of the children. The interviewees indicated that this sense of resignation in the face of horrific pain as a key challenge in providing palliative care for the children.

### **Perception that palliative care represents a failure to cure**

Referring sick children to palliative care is not an easy decision for many physicians because by doing so, they feel they have failed in providing cure for the patient. The RH team continues to work with the medical professionals in the partner hospitals to encourage timely communication of patient’s medical condition, especially when patients are at the final stages of their illnesses. In fact, according to many

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<sup>35</sup> Sandra L. Lobar; JoAnne M. Youngblut; Dorothy Brooten, “Cross-Cultural Beliefs, Ceremonies, and Rituals Surrounding Death of a Loved One”, *Pediatric Nursing* (2006), 32(1): 44-50

<sup>36</sup> Ibid

<sup>37</sup> Lynna Chandra. Personal Interview. March 2011

studies on palliative care, most physicians do not know how to talk with the family due to their emotional state.<sup>38</sup> Such patterns cause miscommunication and frustration in daily treatment.<sup>39</sup>

## 6. IMPACT

When asked about the performance monitoring mechanism and indicators, the Study Team indicated that the best indicator of the program's performance adopted by RH appears to be the response from beneficiaries-the children and their families. Although the program monitoring mechanism has not been developed, success stories of RH are well documented. The lives of so many children have been greatly affected by the care provided by the RH Team and the individual stories are documented for advocacy purposes.<sup>40</sup>

Based on the literature review on steps to grow palliative care described by Diane Miere in the journal titled "Ten Steps to Growing Palliative Care Referral"<sup>41</sup>, RH has implemented at least four out of the ten steps described as follows:

### 1. Solicit support from staff

The Study Team found that passion and compassion are key factors driving the staff at RH. By adding criteria of who can do the job with "heart and compassion", RH has conducted screening of the staff early on, to find human resources who share similar passions. During the interviews, The Study Team indicated that the intrinsic factor of helping the children appears to have motivated the staff to support the work of RH.

### 2. Recruit a respected champion

The early process of creating a successful program includes the RH team's selection of several well respected physicians as champions of the program, and community leaders to become supportive allies. Ms. Chandra used her network to identify the physicians and nurse champions- those who are not only respected for their skill and knowledge, but also able to work with heart and compassion. This step was

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38 Ibid

39 Twycross, R.G. "The challenge of palliative care ", *International Journal of Clinical Oncology* Volume 7, Number 4, 271-278, 2002

40 Pradipto, D. RH General Manager. (February 12, 2011).

41 Meier, Diane. 2005. Ten Steps to Growing Palliative Care Referral. *Journal of Palliative* 8(4): 706-708

not a simple one - it took her more than two years to find the physicians, and currently she is still looking for more compassionate nurses with the heart to serve RH's patients.

### 3. Select a team positioned to generate referrals

"Teams led by a well-regarded physician from a respected specialty have an easier time generating referrals than those with a lower profile leader."<sup>42</sup> Both the medical consultants at RH work at two nationally recognized public hospitals. In addition, the physicians and nurses received scholarships and trainings on palliative care from Singapore (as described in the earlier sections).

### 4. Remember the physician is the client

Nurses at RH actively work to build awareness of palliative care in the medical community by approaching the health professionals particularly the physicians at the hospitals, *Puskesmas*, and individual physicians within the RH network. The interviewees indicated that many of these physicians have contacted the nurses for referrals after the nurses informed them about the palliative care services at RH.

## 7. GROWTH PLANS

RH is now preparing to open a new palliative care satellite in *Pasar Rebo* to serve the community in East Jakarta and its surrounding areas.

Realizing the need to share the knowledge to the wider community (medical and non-medical), RH management is working to establish RH as a 'center of excellence', where RH will serve as a reference education center for pediatric palliative care in Indonesia.

In the medium term, RH is planning to provide an inpatient service that would look to stabilize the conditions of the children before returning them home to spend their last days. Ongoing training and briefings will also be given to the program's nurses to enhance their ability to conduct palliative care<sup>43</sup>.

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<sup>42</sup> ibid

<sup>43</sup> ibid

## 8. FINANCIALS

According to Ms. Chandra, RH receives funding for its operational needs from private donations and gifts. Since its inception, RH continues to receive donations from both individuals and corporations. Assistance has come not only in the form of money, but donors also provide facilities and services such as office space for free of charge, office supplies (computers, fax machines, tables, chairs, ACs, etc.), equipment to establish hospice care and assistance with IT solutions.

Fundraising is ongoing to ensure there will be adequate funds to run RH's program. From the initial years, the fundraising activities have been supported by friends and strong supporters of the cause. RH does not pay for their office rent, vehicle, and electricity as those expenses are funded through donations. For instance, both their office space at *Graha Indramas* in *Slipi* (West Jakarta) and in *Bintaro* are donated by members of RH board.<sup>44</sup>

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44 Lynna Chandra. Personal Interview. February 2011

## ANNEXES

### ANNEX 1. LIST OF INTERVIEWEES (PRIMARY RESEARCH)

No	Name	Role In Organization	Location	Interview Date
1	Lynna Chandra	Founder of RH	Jakarta	14-Feb-11
2	Allya Shyahrial	Outreach and Nurse Coordinator	Jakarta	14-Feb-11
3	Dedy Pradipto	General Manager	Jakarta	14-Feb-11
4	Susi Susilawati	Nurse & Satellite Manager , Jakarta Utara	Jakarta	18-Mar-11
5	Rina Wahyuni	Nurse & Satellite Manager, Jakarta Barat	Jakarta	18-Mar-11
6	Dr Edi Tehuteru	Doctor Consultant (Medical Consultant at RH, and Oncologist at Dharmais Hospital)	Jakarta	18-Mar-11

### ANNEX 2. SECONDARY RESEARCH

Title	Author	Location (e.g., book, journal, website link)
Asia's first palliative care research and training centre to be set up in Singapore Seminar on Palliative Care Development in Asia	DUKE NS & Lien Foundation	<a href="http://www.lienfoundation.org/pdf/eldercare/Lien_Duke-NUS_press_release_F_Press_18Mar08.pdf">http://www.lienfoundation.org/pdf/eldercare/Lien_Duke-NUS_press_release_F_Press_18Mar08.pdf</a>
Advocating hospice and palliative care: challenges, contexts and changes.	Elizabeth Dermot	Report of the 2nd Global summit of National Hospice and Palliative Care Associations, South Korea
"Barriers to physicians' decisions to discuss hospice: Insights gained from the United States hospice model,"	McGorty, K and Bornstein, B University of Nebraska, Lincoln. 2003	
"Collaborative Communication in Pediatric Palliative Care: A Foundation for Problem-Solving	Feudtner, Chris	Pediatr Clin North Am(2007), 54(5): 583-ix <a href="http://www.ncbi.nlm.nih.gov/">http://www.ncbi.nlm.nih.gov/</a>

and Decision-Making”.		pubmed/17933613, 2007
“Cross-Cultural Beliefs, Ceremonies, and Rituals Surrounding Death of a Loved One”, Pediatric Nursing (2006), 32(1): 44-50	Sandra L. Lobar; JoAnne M. Youngblut; Dorothy Brooten,	<a href="http://www.medscape.com/viewarticle/525639_1">http://www.medscape.com/viewarticle/525639_1</a>
Childhood Cancer Is Curable	Indonesian Childhood Cancer Foundation	<a href="http://www.yoai-foundation.org/english/profil.php">http://www.yoai-foundation.org/english/profil.php</a>
Defining Palliative Care	Center to Advance Palliative Care (CAPC)	<a href="http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc">http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc</a>
Distribusi umum world health organization organisasi kesehatan sedunia obat-obatan narkotika & psikotropika meraih keseimbangan dalam kebijakan pengendalian opioid panduan penilaian world health organization organisasi kesehatan sedunia.	WHO/EDM/QSM/2000	<a href="http://www.painpolicy.wisc.edu/publicat/00whoabi/00whoabi-ind.pdf">http://www.painpolicy.wisc.edu/publicat/00whoabi/00whoabi-ind.pdf</a>
Daftar Obat Essensial Nasional(DOEN)	Keputusan Menteri Kesehatan RI No 791/Menkes/ SK/VIII/2008	<a href="http://www.ino.searo.who.int/LinkFiles/Home_DOEN_2008.pdf">http://www.ino.searo.who.int/LinkFiles/Home_DOEN_2008.pdf</a>
How to Change the World: Social Entrepreneurs and the Power of New Ideas	David Bornstein	<a href="http://www.pbs.org/opb/thenewheroes/whatis/">http://www.pbs.org/opb/thenewheroes/whatis/</a>
Heart of Change:” Real Life Stories of How People Change Their Organizations”. Boston:Harvard Business School Press,( 2002).7	Kotter, John. P and Dan S. Cohen.	<a href="http://hbr.org/product/heart-of-change-real-life-stories-of-how-people-ch/an/2549-HBK-ENG">http://hbr.org/product/heart-of-change-real-life-stories-of-how-people-ch/an/2549-HBK-ENG</a>
Innovations in End-of-Life Care	Cynda Hylton Rushton DNSc, RN, FAAN , 2000	<a href="http://www2.edc.org/lastacts/archives/archivesmarch00/editorial.asp">http://www2.edc.org/lastacts/archives/archivesmarch00/editorial.asp</a>
Improving Access to Pediatric Palliative Care	Internal medicine news, 2011	<a href="http://www.internalmedicinews.com/index.php?id=495&amp;cHash=071010&amp;tx_ttnews[ttnews]=52326">http://www.internalmedicinews.com/index.php?id=495&amp;cHash=071010&amp;tx_ttnews[ttnews]=52326</a>
“Integrating Social Entrepreneurs into the “health for all” Formula.”	Drayton, W., Brown, C, & Hillhouse, K, 2006	Bulletin of the World Health Organization (2006), 84: 8 <a href="http://www.who.int/bulletin/volumes/84/8/06-033928.pdf">http://www.who.int/bulletin/volumes/84/8/06-033928.pdf</a>
“Private Health Sector in Indonesia: A Desk Review”,	USAID, 2009	

Pioneer Programs in Palliative Care:Nine Case Studies	The Robert Wood Johnson Foundation	<a href="http://www.milbank.org/pppc/0011pppc.html">http://www.milbank.org/pppc/0011pppc.html</a>
Rachel House		<a href="http://www.rachel-house.org/newsletter/200611.php">http://www.rachel-house.org/newsletter/200611.php</a>
Social Entrepreneur Of The Year	Ernst & Young	<a href="http://www.ey.com/ID/en/About-us/Entrepreneur-Of-The-Year/2009_SEOY_Article">http://www.ey.com/ID/en/About-us/Entrepreneur-Of-The-Year/2009_SEOY_Article</a>
Social Entrepreneur Of The Year	Ernst & Young	<a href="http://www.ey.com/ID/en/About-us/Entrepreneur-Of-The-Year/2010_Finalists-Announcement_Press-Release_EN">http://www.ey.com/ID/en/About-us/Entrepreneur-Of-The-Year/2010_Finalists-Announcement_Press-Release_EN</a>
Sulitnya Mencari Social Entrepreneur di Indonesia!	Okezone.com	<a href="http://economy.okezone.com/read/2010/06/18/320/344270/320/sulitnya-mencari-social-entrepreneur-di-indonesia">http://economy.okezone.com/read/2010/06/18/320/344270/320/sulitnya-mencari-social-entrepreneur-di-indonesia</a>
Ten Steps to Growing palliative Care Referral	Diane Meier	<i>Journal of Palliative, 2005. 8 (4) : 706 -708</i>
“When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.”	Marilyn J. Field and Richard E. Behrman.	NAP Publishing 2003

## ANNEX 3. RESEARCH METHODOLOGY AND NORMATIVE FRAMEWORK

### Research Questions

***How does RH deliver palliative care to terminally ill children with cancer and HIV/AIDS in Indonesia?***

The goal of the study was to identify the contributing factors and key barriers of program implementation of RH Pediatric Palliative Home Care model. The case study explored the structure, activities, business model, and growth plans of RH and the ways in which the program has delivered pediatric palliative care in Jakarta, Indonesia.

### Research Design

The study was designed using questions developed with input from internal and outside resources. The interviews consisted of 40 main questions from 6 categories, with related sub questions for several of them (see annex 6). All questions were open ended. At the beginning of the interview, respondents were asked a question about their general experience on developing pediatric palliative care in the non-hospital setting.

### **Interview Procedure**

The interviews were conducted over a six-week period between February and March 2011, on the implementation of the RH Pediatric Palliative Home Care model in Indonesia. The Team interviewed 6 participants representing funders and implementers of the program consisting of business professionals and health professionals. Interviews were recorded with verbal consent obtained prior to the interviews. None of the interviews were tape-recorded.

### **Sampling and Study Subjects**

The interviews were conducted with employees of RH. A sample size of 6 people was used and the sampling method applied was convenience sampling. Participants were selected based on the researcher approaching them and subsequently requesting their willingness to participate. The majority of the study participants were found through iterative scans of innovative health programs in Indonesia as well as personal and professional networks. See Annex 1 for a list of interviewees.

### **Piloting the questions**

The questions were piloted on February 2011, in an in person interview with an employee of RH.

## **ANNEX 4: LESSON LEARNED**

This study would like to underline several key findings:

1. Developing a palliative care program such as RH requires a synergy between social entrepreneurs/pioneers and funders, philanthropists, religious leaders, private sectors, hospitals, palliative care professionals (nurses, physicians, chaplains), and also the government. Though identifying contributors can be challenging at first, their endured collaboration will fill in the gaps of the resources required, such as palliative care and bereavement professionals, donors and policy makers as well as the need for community awareness/outreach.

In the case of RH, Lynna Chandra uses her personal network with the Singaporean palliative care community and Australian palliative care professionals and links them with her colleagues from *Dharmais Cancer hospital*, RH's nurses as well as the wider medical and medical related communities. Through this network, she bridges and connects those different stakeholders creating a strong web of influence and support for the birth of pediatric palliative care in Indonesia.

2. Lack of awareness of the role of palliative care and the traditional or cultural perspective on pain endurance still hamper the development of hospice or palliative care in Indonesia. The public should be encouraged to know their rights on end of life issues and be made aware of the availability of the option to spend their last remaining days at home with competent care to manage the pain and symptoms. At the same time, physicians and oncologists in particular, should be encouraged to communicate to patients the availability of palliative care that could compliment curative treatments, and help manage the pain and symptoms associated with terminal illnesses.
3. Family involvement in the decision making process when developing a proper treatment and pain management plan is imperative. This would require medical professionals to help the family understand fully the prognosis to enable the family to better prepare the children facing the terminal disease and therefore better able to cope with the end-of-life stages.

## **ANNEX 5: RECOMMENDATIONS**

From the key findings above, we would like to highlight several recommendations for RH to move forward:

First is the need for apprenticeship program which should be done through on the job training? Thus, the transmission of knowledge, social capital such as networking and confidence can be developed. Through apprenticeship, the mentor can personally engage their protégé with their network and over time

relinquish part of their responsibilities to others. By the time regeneration occurs, the entity has a new leader ready to step in.

The second recommendation is to develop a peer support group consisting of families/parents of cancer survivors or parents whose children have passed away battling cancer. The peer support group can help nurses by sharing their experiences and knowledge with other parents whose children are receiving palliative care. Additionally, a peer support group can represent the community in advocating and making appeals for palliative care policies by giving testimonies on the impact of pediatric palliative care to the government.

## **ANNEX 6: LIST OF QUESTIONS**

### **I.MODEL**

#### **Program Description**

1. Main line of business for organization (if different from or broader than the program to be studied):
2. What are the program's mission/goals? Who had the vision to launch this program/product (i.e., is there a champion or visionary)?
3. Provide a detailed description of the program: Describe in detail the business model, any innovative aspects (eg., use of technology), and distinct components.
  - 3.1. Is this a replication/adaptation of another innovation (e.g., another model that exists), is it a new/proprietary innovation, or a mix? If so, what was it based on?
  - 3.2. Do you have organizations or models that you aspire to be like within your geography, in other geographies, or in other industries?
  - 3.3. How has the program evolved since its launch? (If already answered, skip this question)
  - 3.4. How is your organization structured? Provide a chart of the organization if available.
  - 3.5. Is the government involved in this initiative? If yes, what part of the government? If a partnership between a government and a private entity how is the partnership structured?
  - 3.6. Do you have partners? If yes, how did you form the partnership(s)?

#### **Human resources**

4. Who is leading the implementation effort for this program/product?

4.1. How large is the team for this program/product?

4.2. What specific roles and responsibilities does each position have? How do you attract qualified personnel and retain current employees (e.g., competitive pay)?

4.3. How do you evaluate staff?

Do you feel there is a shortage of human resources/technical capacity in the market for the kinds of expertise you require to run this program/product? Which specific skills?

Were any new cadres created to deliver care? If yes, which ones? What have been the merits of doing this?

### **Target Population:**

What is the target population for this program?

If program targets consumers/patients:

5.1. Geographic location?

5.2. Income-level? What income quintile do the majority of your consumers fall into? In what ways does your organization interact with the poor? Do you also specifically serve non-poor segments?

5.3. Age/gender group?

5.4. Other (e.g., people with particular disease)?

5.5. What type of provider does the program target?

6. What was the rationale for selecting this target population?

6.1. What is the size of your target population? How big is the population that your current services potentially serve? (e.g., If you target women in 3 Districts, what is the female population of those districts.)

6.2. How many people do you actually provide services to (i.e., numbers actually served)? (If appropriate/available, please provide detail on numbers per month or per year for individual services, E.g, 150 IUD insertions per month and 460 courses of oral contraceptives per month.)What portion (%) of the target population do you actually serve? (number of people served divided by total target population).

6.3. How long did it take to get to this level of coverage?

- 6.4. Do you have plans for reaching even more individuals within your current target population? What are these plans?
7. Do you expect to expand the target population?
  - 7.1. If so, who else do you plan to serve and why?
  - 7.2. How do you plan to expand the population?
8. How do clients/patients find out about the program?
  - 8.1. Do you use any advertising/marketing strategies? How do you communicate to low-income consumers about the value of your product?
9. Is the population that you are currently serving the same as your original target population? To your knowledge, is this what was originally intended or expected?

**Challenges:**

10. What are the program's key challenges? Please describe the key challenges detail:
  - 10.1. What, if anything, have you done to address these challenges?
  - 10.2. How could you be better supported in meeting these challenges?

**Additional Questions:**

11. Have you received any external technical assistance for this program/product? If so, please describe.
12. Does the program/product have competitors? If so, please describe them (please select all that apply and provide a brief description):
13. Do you work with informal providers (people who delivery health products or services with little or no formal training, e.g., "village physicians", drug sellers, traditional healers)? If so, in what capacity?

**II. IMPACT**

14. Do you track results? If so, how do you track your results?
  - 14.1. What are your primary indicators?
15. What have been the results thus far?
  - 15.1. Areas where you feel you have achieved success to date

15.1.1. What data illustrates that success?

15.2. Areas for improvement

15.2.1. Is there data that you use to isolate the areas for improvement?

(Try to get actual data, if available.)

16. Have you implemented a monitoring and evaluation plan for your program/product?

If you have implemented evaluation(s) of your program/product:

16.1. Who conducts the evaluations?

16.2. What is the methodology?

16.3. Would you be able to share the results with us?

17. Have you documented (qualitatively) your program/product's operational evolution (i.e., a qualitative case study)?

### **III. GROWTH PLAN**

In the past year is the demand for the program/product growing, stable, or shrinking?

19. What is the potential demand for this program/product?

20. What are the growth plans for the program/product?

(1) Replicating (i.e., entering new domestic/international markets); (2) Scaling (i.e., expanding market size); (3) Expanding the scope of services of products offered

### **IV. FINANCIAL**

21. What kind of (if any) external assistance would be useful for you to achieve your growth objectives?

Please describe.

22. What are your annual revenues?

23. What are your current sources of revenues and what percentage of total revenues can you attribute to each source:

*1. Out-of-pocket payments*

*2. Government contracts*

*3. Insurance or voucher payments*

*3.1. Government*

*3.2. Private*

*4. Donor funding*

*4.1. Foundations*

4.2. *Bilateral aid agencies (DFID/UK, KFW/Germany, USAID/US)*

4.3. *Multilateral aid agencies (e.g., World Bank, Global Fund)*

5. *Membership/subscription fees*

6. *Other*

24. How much initial funding was required to launch the program/product?

25. What were the sources of your initial funding?

26. Have you taken any loans or equity investments? From what source?

27. Do you subsidize specific populations and/or services?

27.1. Do you cross subsidize any services across populations?

28. Do you use any kind of risk pooling, insurance, or voucher mechanisms? If so, please describe

29. If applicable, please describe how you have priced your services/product.

30. On what basis do you determine your prices?

1. *Prices are set to meet operating costs*

2. *Prices are set to allow the facility to make a profit/surplus*

3. *Prices are set to be competitive (follow up about competition's pricing)*

4. *Prices are set to make the services affordable to the market*

5. *Different prices are charged to consumers/patients with different abilities to pay (follow up with question about how willingness or ability to pay is determined)*

6. *Mix (please specify)*

7. *Other (please specify)*

31. What are your annual operating costs?

32. Does your program/product generate enough revenue to cover its operating costs?

33. What is the program/product's current financial performance?

1. *Earning a profit or surplus over costs*

2. *About breaking even*

3. *Losing money*

4. *Other (please specify)*

## **V. CONTEXTUAL FACTORS**

38. Were there any major barriers to program/product implementation? Please describe.

1. Human capital

2. Technology

3. Regulatory

4. Infrastructure

5. Financing

39. Describe the regulatory environment for the program/product you offer?

39.1. Is your product regulated? By what body/regulation/law?

39.2. Are there particular regulations that have been a challenge or barrier for you?

39.3. Are there any regulations that have helped your program/product?

39.4. Which of the following statements best describes your view of regulations as they relate to this program/product?

1. Regulation is a burden

2. Regulation is a support/help

3. Regulation is not relevant

40. Is your program a part of a union, association, or network of private providers? If so, please name and describe these organizations/associations and your affiliation

Case studies were compiled and edited by the Results for Development Institute, managing partner of CHMI. For information regarding dissemination, contact [chmi@resultsfordevelopment.org](mailto:chmi@resultsfordevelopment.org).