

The Lancet Commission on Global Surgery Teaching Case

> Entrepreneurial Leader Collection BAB306/ MARCH 2015

CURE HYDROCEPHALUS SETTING A COURSE FOR SUSTAINABILITY

In 2000, when Dr. Benjamin Warf left his position as chief of pediatric neurosurgery at the University of Kentucky to establish a hospital in Mbale, Uganda, no one expected a ground-breaking surgical procedure to be born. The standard treatment for hydrocephalus, known colloquially as *water on the brain*, was to insert a shunt into the ventricles of the brain to drain excess cerebrospinal fluid (CSF). (See **Exhibit 1** for description of hydrocephalus.) Working in a low-resource area with a limited supply of shunts and a high incidence of hydrocephalus, Warf pioneered an alternative, low-cost treatment which many came to accept as a more suitable intervention for children with acquired hydrocephalus.

Work started in Uganda when Warf noticed the severe disease burden in children with hydrocephalus. The condition caused heads to expand due to an excess of fluid in the brain. It afflicted one in 500 births worldwide, 79% in low- and middle-income countries (LMICs) which lacked essential lifesaving care. It was estimated that there were over 6,000 new cases of hydrocephalus per year in East Africa, most caused by neonatal infections (a minority congenital) and therefore preventable. (See **Exhibit 2** for incidence of hydrocephalus.)

Compounding the problem, mothers and babies often received poor treatment. Florence Kalikwani, nurse manager at CURE Children's Hospital of Uganda (CURE Uganda),

 $Copyright @ 2015 Babson College. \ All rights reserved. \ No part of this publication can be reproduced, stored or transmitted in any form or by any means without prior written permission of Babson College. \ Included in the Lancet Commission website/book by permission.$

This case was prepared by James W. Quinn of Case Consulting LLC and Genevieve Barnard of Babson College under the direction of Kate McKone-Sweet, Professor at Babson College, John Meara, Associate Professor at Harvard Medical School and Program Director of the Program in Global Surgery and Social Change, and Sarah L.M. Greenberg and Johanna Riesel, Fellows in the Program in Global Surgery and Social Change at Harvard Medical School, and Leonard Schlesinger, Baker Foundation Professor at Harvard Business School, for class discussion rather than to illustrate either effective or ineffective handling of an administrative situation. The funding for this case was provided in part by the Leonard Schlesinger Fund for Global Healthcare Entrepreneurship at Babson College , The National Cancer Institute and the Harvard Medical School Center for Global Health Delivery-Dubai. It is not intended to serve as an endorsement, source of primary data or illustration of effective or ineffective management.

CURE Hydrocephalus: Setting a Course for Sustainability BAB306 / MARCH 2015

explained. "There is a real challenge with stigmatization. When you talk with mothers who have arrived at the hospital, some will say, 'I've been a saint with my husband, but once I delivered this child, he abandoned me. He says that in the clan, in the family, they don't deliver such children. So he told me to find my own way with that child."

Warf and his colleagues at CURE Uganda understood the physical and social burden of hydrocephalus and the challenges of treating it using a shunt. They developed a new surgical procedure which avoided the use of shunts: endoscopic third ventriculostomy/choroid plexus cauterization, or ETV/CPC. Investigation, research, and outcome measurement had shown the ETV/CPC procedure produced better health outcomes than the shunt. This culture of documentation, research, and scientific publication remained in Mbale beyond Warf's leadership tenure. Recognition for this work came from many quarters, notably the MacArthur Foundation *genius award* to Warf in 2012.

CURE Uganda performed 869 surgeries for hydrocephalus in 2013, or about twice as many as had been performed at the same hospital in 2006.

CURE International, the parent organization of CURE Uganda, operated charitable hospitals and programs in 30 countries worldwide. CURE International supported the hydrocephalus program (CURE Hydrocephalus) to increase the capacity for performing these procedures both in CURE Uganda and in other hospitals. Initially, surgeons from Zambia, Nigeria, and Nepal trained in Uganda and began performing the new procedure at their hospitals with the rate of surgeries varying by country. By fall 2014, the CURE Hydrocephalus program comprised 15 global sites treating 2,500 patients annually.

Since the hospital opening in 2000, the position of medical director had passed from Warf to Uganda-born Dr. John Mugamba, and on January 1, 2015, to Dr. Peter Ssenyonga, also Ugandan. As medical director, Ssenyonga (and Mugamba before him) oversaw the training of surgeons from around the world who came to study the ETV/CPC technique at the CURE hospital in Uganda. Ssenyonga worked closely with the executive director for CURE Uganda, Derek Johnson, who managed hospital administration and operations. After leaving the role of medical director at CURE Uganda, Warf became medical director of the CURE Hydrocephalus program, part of the parent organization CURE International. In early 2015,

Warf and Charles Howard, CURE Hydrocephalus operations director, set out to assess the organization's performance and sustainability, with the goal of doubling the number of hydrocephalus surgeries performed across the network to 5,000 in the next five years.

The CURE team had several reasons to feel confident about these goals: a new modality for surgery, research findings supporting the effectiveness and efficacy of ETV/CPC, and institutional support from CURE International. Nonetheless, more analysis was needed in order to determine whether the current model for physician-screening, site-selection, support, and training was the best to achieve growth in total number of surgeries performed, and whether the model worked better in some regions than in others. The team wondered how this medical innovation could be shared with other low- to middle-income countries as well as high-income countries.

Healthcare in Uganda

Uganda, with a population of more than 37.5 million in 2013, was experiencing an under five mortality rate of 69 per 1,000 live births. Data from the World Health Organization (WHO) in 2013 showed this rate below the regional average of 95 per 1,000 live births but above the global average of 48.^{1,2} Almost half the population (48.7%) was under age 15, placing Uganda among the youngest nations in the world. Among deaths for those under age five, 21% were neonatal (within the first 30 days after delivery).³ WHO data from 2010 showed the principal causes of these deaths were prematurity (38%), birth asphyxia and birth trauma (28%), and sepsis and other infectious conditions (19%). Post-neonatal deaths for those under age five (1-59 months) were caused mainly by pneumonia (22%) and malaria (19%).⁴ (See **Exhibit 3** for Uganda health statistics.)

¹ World Health Organization, "Uganda: Health Profile," http://www.who.int/gho/countries/uga.pdf?ua=1, accessed December 2014.

² Ibid.

³ World Health Organization, "Maternal and Child Health:Uganda,"

http://www.who.int/pmnch/media/membernews/2011/ugandabackgroundpaper.pdf, accessed February 2015.

⁴ World Health Organization, "Uganda: Maternal, Child, and Adolescent Health Profile," http://www.who.int/maternal_child_adolescent/epidemiology/profiles/neonatal_child/uga.pdf, accessed February 2015.

CURE Hydrocephalus: Setting a Course for Sustainability BAB306 / MARCH 2015

Within the region, per capita healthcare expenditure averaged over \$100, whereas the average in Uganda was only \$40. In 2001, signatories of the Abuja Declaration including Uganda promised to "allocate at least 15% of their national budgets to health." However, Uganda's national expenditure reached only between 8% and 9%, and the number of healthcare workers such as physicians, nurses, and midwives fell far below the regional average.⁵

There were six levels of public healthcare facilities in Uganda, and all worked through referrals. Lesser maladies were directed to lower level facilities, whereas more serious cases were directed to second or third level facilities. No payment was required for a patient visit to a public healthcare provider. However, patients were required to pay for drugs or medical supplies purchased from a pharmacy or elsewhere, if the healthcare facility did not provide them.⁶ Such costs sometimes became prohibitive, causing patients to seek treatment at private or non-profit hospitals. For example, CURE Uganda did not charge for care or supplies. CURE Uganda, widely known for its high level of specialization in the neurosurgical needs of children, focused particularly on hydrocephalus, neural tube defects, spina bifida, and brain tumors.

A Medical Treatment Innovation

Soon after Warf arrived in Uganda in 2000 and opened a neurosurgery hospital, he confronted the immediacy of children suffering from hydrocephalus. He explained.

Right away it was obvious that our number one problem was hydrocephalus. We saw scores of people coming through the gates, mothers carrying babies with large heads, which presented an immediate problem. Why were there so many cases? We don't see hydrocephalus in these numbers in the United States. How were we going to treat it? Shunts, the tube that goes from the brain to the belly –

⁵ Tabu Butagira, "Government Spends Shs2,500 a Month on each Citizen's Healthcare," *Daily Monitor*,

http://www.monitor.co.ug/SpecialReports/Govt-spends-Shs2-500-a-month-on-each-citizen-s-healthcare/-/688342/1971734/-/ourux1/-/index.html, accessed December 2014.

⁶ Excerpted from World Bank Country Data: Uganda, as drawn from Richard M. Kavuma's article, "Uganda's Healthcare System Explained," *The Guardian*, http://www.theguardian.com/katine/2009/apr/01/uganda-healthcare-system-explained, accessed December 2014.

which is how hydrocephalus had been treated in the U.S. and still is in most places -- were expensive. Even the best shunts failed, half within two years. The average kid had three shunt revisions after the first one. Once past infancy, the soft spot closes. It's an emergency, and they die from shunt malfunction. We were putting shunts in these children and sending them to northern Uganda, southern Sudan, or western Kenya.

CURE International provided 50 shunts of the style Warf had used in the United States at a cost of \$650 apiece. Fifty was all they could offer. Warf sought a second supplier. The International Federation for Spina Bifida and Hydrocephalus (IFSBH) offered an inexpensive shunt made in India called the Chhabra Shunt. It cost only \$35 and was free for select partners.

Warf ran a randomized clinical trial in Mbale comparing the two shunts. He had an unlimited supply of the inexpensive shunts and only 50 American shunts. He commented, "We followed up with children from a one-year period and published a paper in 2005 in the *Journal of Neurosurgery* showing there was no difference at one year in shunt failure rate or infection rate." This research provided helpful information resulting in shunt-based treatment for a greater number of patients than the initial 50 shunts would have allowed. The likelihood of failure for both types of shunt was similar, so neither type could be expected to last a full lifetime.

Putting them Together

Warf feared patients treated at CURE Uganda might experience a shunt failure and simply disappear. He described an opportunity to examine alternative treatments. (See **Exhibit 4** for a diagram of this procedure.)

People started doing endoscopic third ventriculostomy (ETV), putting an endoscope into the brain and looking on a TV camera, making an opening in the base of the brain in the floor of the third ventricle to allow a new escape route for trapped fluid. The Norwegian government donated equipment, and I invited a pediatric neurosurgeon from the States who'd done several of these to come and

stay with me for a week. We did 20 of them that week, and I became about as experienced as he was.

The team in Mbale soon confirmed what others had found. The ETV procedure was more successful in older children than in babies. Warf looked at old literature and rediscovered an outdated procedure called *choroid plexus cauterization* (CPC). It had achieved modest success in the early twentieth century before shunts were invented. This process cauterized choroid plexus tissue, which produced cerebrospinal fluid (CSF) in the ventricles of the brain. It destroyed some of the tissue and decreased the amount of CSF produced. When CPC was introduced, the tools, techniques, and anesthesia were unsafe, and mortality rates ran high. Warf explained his concept for combining ETV and CPC in a new procedure.

Doing ETV in kids day after day, I wasn't confronting the choroid plexus as they used to do. They drilled holes on both sides of the skull and inserted a big, rigid scope. I had this little flexible endoscope. I could look all over the brain and access the choroid plexus on both sides right from the baby's fontanel. I thought adding CPC to the ETV, which we now do safely, might make a difference. This had never been done before, so we started doing it.

The Mbale research team began collecting patient outcome data early in the process and published a paper in 2005 showing a statistically significant improvement in the success rate for treating hydrocephalus in babies under one year of age. The new ETV/CPC procedure required less medical infrastructure and post-surgical maintenance. It was suitable for about two-thirds of hydrocephalus patients, while one-third still required shunt treatment. Additional clinical trials examined the five-year outcome of treated infants and provided further support for the new ETV/CPC procedures. Comments on the new procedure included the following:

ETV revolutionized how we treat hydrocephalus, especially in infants under one year old, the majority of those we see. To put it in perspective, half of Uganda's 36 million population is under age 15, which means you're looking at a pediatric population. About 70% of our patients come with hydrocephalus. A large population of patients with hydrocephalus in infancy needs to be treated. If you

CURE Hydrocephalus: Setting a Course for Sustainability BAB306 / MARCH 2015

can treat patients successfully without using a shunt, you've nailed it. (Dr. Peter Ssenyonga, medical director)

ETV is more sustainable from an economic and risk standpoint and much less invasive than a shunt procedure. We know shunts are going to fail, so each failure means surgery and a hospital stay. That costs a lot to the community and to patients' families: lost economic productivity, inability to care for other family members at home, and risk to the patient. For every successful ETV candidate, it's a one-time surgery, a one-time hospital stay. One and done! (Derek Johnson, executive director for CURE Uganda)

ETV put us on the map. We've built our reputation on it. We've preached the gospel: ETV, ETV, ETV. We want to be sure we're preaching the right thing, so we compare outcomes [between shunts and ETV]. We see patients here from different parts of the country and also from Congo, Sudan, and Kenya, people from diverse backgrounds. That means this can be replicated elsewhere. (Dr. Edith Mbabazi, research director for CURE Uganda)

Toward a Sustainable Model of Treatment and Surgical Education

From the outset, physicians and administrative staff at CURE Uganda focused on training surgeons in the new ETV/CPC procedure. Warf explained.

We got early funding that allowed us to bring committed neurosurgeons from developing countries. They were putting shunts in kids and wanted to spend time with us. We brought them here for three months, and I personally stood at their side and taught them. Day after day, we'd do about 20 procedures a week. They became quite competent because our volume was so high, and we had funding to supply equipment to set up at their home institutions.

Program leaders did not typically identify potential partners and invite them for on-site training in Mbale. Rather, CURE Hydrocephalus hosted a well-integrated professional website to attract potential applicants online and listed three basic qualifications: 1) Have a national certification to perform surgery; 2) Have an employer willing to host the program at a hospital; and 3) Be proficient in English. Some exceptions had been made to these qualifications; for example, CURE Uganda had also trained Francophone neurosurgeons in ETV/CPC.

Those interested in learning about ETV/CPC contacted Warf and his team in Uganda, and arrangements were made. Training physicians at CURE Uganda began in 2005 with surgeons from Zambia, Nigeria and Nepal. Over time, the training program was formalized to include twelve weeks on site at CURE Uganda, and completion of a minimum of 50 ETV cases and 25 shunt placement procedures.

After successful completion of the training program, CURE International provided ETV equipment for ongoing use by surgeons at their home institutions and, in conjunction with a manufacturer, kept the equipment current and operational. CURE also provided the capability to capture and report on output and outcomes data and sponsored a full-time care coordinator to serve social and spiritual needs of patients at each partner site.⁷ Training, equipment, and setup costs for each surgeon trained in Mbale totaled \$103,000. (See **Exhibit 5** for cost breakdown.) Leading up to 2014, doctors from around the world joined the CURE Hydrocephalus 15-site network. (See **Exhibit 6** for graduates of the CURE Hydrocephalus program as of 2011.)

CURE International helped support growth of this program, as did the strong board and Ugandan leadership. All contibuted to the results and long-term hopes for surgical education and global treatment of patients.

Support from CURE International

Funding from parent organization CURE International was critical for early success. A large influential non-profit, it reported \$103 million in 2012 revenue and \$124.5 million in total assets. Founded in 1996, CURE International maintained a presence in over 30 countries with headquarters in the United States. Its physicians and staff had performed more than

⁷ Program description based on and excerpted from the CURE Hydrocephalus website, "For Doctors: The Training Program," http://cure.org/hydrocephalus/#for-hydro-doctors, accessed January 2015.

167,000 surgeries, treated more than 2.4 million outpatients, and trained over 7,200 medical professionals.⁸

A distinguishing characteristic of CURE International was its faith-based approach. The organization presented itself as inclusive and its mission as follows: "CURE International transforms the lives of disabled children and their families in the developing world through medical and spiritual healing, serving all by establishing specialty teaching hospitals, building partnerships, and advocating for these children."⁹ This focus helped CURE Uganda take a holistic view of treatment and consider program growth in other countries.

Global health clinics, hospitals, and NGOs attracted caring, selfless, empathic personnel, many willing to work at a discount in challenging circumstances. Florence Kalikwani, nurse manager at CURE Children's Hospital of Uganda, believed CURE was different.

We are different because first, we are specialized in the treatment. And second, I have been a nurse for over 30 years, but I have never seen or worked in a facility like CURE where we employ a 50-50 healing philosophy (physical-spiritual). Many parents come here when they are downcast, stressed, or depressed. They have given up hope. In fact, we hear mothers confess later that they came with the purpose of abandoning their children and leaving. But the way they are talked to here, even the spiritual part of it, by the time they leave they are changed people.

At the local level, CURE Uganda undertook community education to overcome misunderstandings about hydrocephalus and convey a message that the disease was treatable. Communication initiatives included creation of five parent groups, outreach by members of the spiritual center, and advertising by radio, television, and print. Despite these efforts to educate, many people remained uninformed, although word had spread beyond Uganda to Kenya, the Democratic Republic of the Congo, and South Sudan.

⁸ CURE International website, "About CURE," http://cure.org/about /, accessed January 2015.

⁹ CURE International Form 990, 2012, Description of Organizational Mission, http://cure.org/downloads/site/financial-accountability/2013/cure_990.pdf, accessed January 2015.

Strong Board Capacity

Another step taken to build organizational capacity was the development of a strong board, with Janet Museveni, first lady of Uganda, one of the founding members. Dr. Julie Bataringaya joined the board as a result of her association with Charles Howard, who had preceded Johnson as the hospital's executive director. A physician who had studied health policy, planning, and financing at the London School of Hygiene, as well as tropical medicine and health economics at the London School of Economics, Bataringaya had worked previously with the Uganda Ministry of Health and its office of public/private partnerships. She had co-authored documents shaping relationships between the public and private health sector in Uganda. Bataringaya commented on the interests and expertise that brought her to the board. "I have knowledge of the national and sub-national health planning processes and local health systems. I undertstand the local context, traditional and societal beliefs, and the causes of morbidity and mortality."

The board also included a leading Ugandan businessman who, on several occiasions, had offered personal resources to support the program, a deep network of connections to regional business leaders, and innovative ideas for advancing the work. Another board member was Uganda's high commissioner to Kenya. Other members were drawn from hospital staff and CURE International, thus providing shared commitment as well as a range of perspectives and expertise.

Shared Leadership, Ugandan Leadership

Warf understood it was critical to develop Ugandan leadership for long-term sustainability of the program. When Warf and his family decided to return to the United States, Dr. John Mugamba, a Ugandan-born neurosurgeon trained in South Africa, succeeded him as medical director. Warf had taken an early interest in Mugamba's career, deciding to train and retain him. Mugamba described his first meeting with Warf, which took place before he moved to Mbale for training.

When I met Dr. Warf at a party one evening, after introductions he said we needed to talk. He asked if we could keep in contact, and I said fine and gave him my email. He contacted me, and we got to know each other, and he told me all

CURE Hydrocephalus: Setting a Course for Sustainability BAB306 / MARCH 2015

about endoscopy. I thought if I were to spend time with him in CURE, just a few months, I would learn that skill and have it to take elsewhere. I accepted to come for three months, and it went to six months. Now I've been here ever since July 2005, about nine years.

In time, Mugamba took over entirely, assuming responsibility for training surgeons and students in neurosurgery. This progression changed Mugamba's professional experience and overall job satisfaction. In his previous job, he did not have the resources to practice skills he had learned during his training in South Africa. CURE helped close the resource and opportunity gap.

Bataringaya observed the uniqueness of this situation. "In other environments, you may find that when one expatriate leaves, he or she is replaced by another expatriate. In the case of CURE, when Dr. Warf left, Dr. Mugamba ably succeeded him. In the end, sustainability and country ownership are promoted."

Results in Mbale

A number of indicators suggested steady, sustainable progress at CURE Children's Hospital of Uganda. Strong morale extended to physicians, administrators, and support staff who shared the role of greeting mothers and babies arriving at the gates in Mbale. In 2014, the hospital was on track to complete its highest number of hydrocephalus surgeries (950), although CURE Uganda was approaching full capacity at current staffing and budget levels. (See **Exhibit** 7 for surgery history at CURE Uganda.)

The operating budget for the hospital seemed secure, given strong support by the parent institution. Total spending to run the hospital was \$10.125 million during the period from January 2001 to June 2013, or about \$810,000 per year. (For additional details on financial statements and contribution sources for CURE International, see reports at https://cure.org/about/financial-accountability/.)

The Mbale hospital continued to be the best site to train future practitioners of ETV/CPC, with North American surgeons beginning to visit Mbale as they expanded work in highincome countries. Training in the United States presented a challenge. Warf said, "We don't

have high enough volume here at Children's in Boston. It makes it hard to train someone. That's why we have people come to Uganda. They can do 20 procedures a week, and the training is very efficient." Ssenyonga echoed Warf's analysis. "What somebody does in a year, they can do here in a week, and that's high volume. You can master the skill. This is an incredible facility. It's like a well-oiled machine. People can come to train and to secure the equipment they need to perform the same activity in another place. It's everything: personnel, equipment, and patients."

The Work Ahead

CURE Hydrocephalus leaders believed 2015 and the years ahead represented an inflection point for the program. The Mbale hospital, CURE Uganda, was operating near or at full capacity, and it had emerged as a model for clinical training and care. An annual caseload of 1,200 hydrocephalus surgeries appeared within reach. As the need for post-operative care increased, the demand on physician time was expected to grow. "I think we're looking at 24hour service in the next 10 years. The way we handle our follow-ups is going to change," said incoming Medical Director Ssenyonga.

Current Program

The CURE Hydrocephalus leadership team considered how to manage and support the evolving network of surgeons trained at CURE Uganda. Only a few home sites were performing surgeries in any volume, with Zambia (1,777 surgeries since 2007) and Tanzania (703 since 2011) examples of high productivity. Surgeons at other sites had performed fewer procedures despite the same training and ongoing support. (See **Exhibit 8** for impact of surgeons trained at CURE Uganda.) Former CURE Uganda Executive Director Charles Howard had recently been hired as operations director for CURE Hydrocephalus. His work would entail visiting each program site to evaluate why some were more productive than others.

As they looked to 2015, the CURE Hydrocephalus team faced sustainability issues. They needed to consider how to assess performance, how to improve the selection and training of surgeons, what new goals should be established, and how to prepare for continued growth.

Global Strategy

The mission of CURE Hydrocephalus (https://cure.org/hydrocephalus/#about-hydro) focused on the developing world, which had the highest volume of cases and the greatest need. Many believed the new surgical approach should be spread not only in Uganda and other low-resource settings, but also to high-income regions of the world.

Excitement sprang up around the innovative activity and concerted effort of hundreds of committed physicians and staff working across the CURE Hydrocephalus network. Yet standard practice in the United States and elsewhere in the developed world remained unchanged; shunt-based procedure was the norm. There were several potential explanations for slow uptake of the ETV/CPC procedure in the developed world. Economic incentives could influence a surgeon who built a practice on the shunt-based procedure. Bias existed for techniques designed in developed countries and/or taught in their medical schools. It was possible some believed this procedure had been designed specifically for developing countries and therefore was not applicable to patients in the developed world.

Warf and his colleagues at CURE hoped to advance awareness of and interest in the innovative ETV/CPC procedure by publishing research in peer-reviewed medical journals. Their initial research was published in 2005.^{10,11,12} These three papers provided support and momentum for the work. Warf had recently engaged neurosurgeons from seven centers in North America to accompany him to Uganda for training. This created the possibility for training others as the procedure gained exposure and relevance. It was estimated that fewer than 200 hydrocephalus procedures in the United States had been carried out using ETV/CPC, mostly by Warf.

¹⁰ Warf, Benjamin C. "Hydrocephalus in Uganda: the predominance of infectious origin and primary management with endoscopic third ventriculostomy," *Journal of Neurosurgery: Pediatrics*, 102.1 (2005): 1-15.

¹¹ Warf, Benjamin C. "Comparison of 1-year outcomes for the Chhabra and Codman-Hakim Micro Precision shunt systems in Uganda: a prospective study in 195 children," *Journal of Neurosurgery: Pediatrics*, 102.4 (2005): 358-362.

¹² Warf, Benjamin C. "Comparison of endoscopic third ventriculostomy alone and combined with choroid plexus cauterization in infants younger than 1 year of age: a prospective study in 550 African children," *Journal of Neurosurgery: Pediatrics*, 103.6 (2005): 475-481.

BAB306 / MARCH 2015

Warf created a communication plan for 2015 to improve global awareness. He and colleagues identified venues and communication tools to include: hosting and speaking at medical conferences, seminars, and other events; publication in peer-reviewed journals; and using websites/social media. Launching a global messaging strategy was a challenge for everyone at CURE Uganda. This included Warf and colleagues in the United States, as well as leaders at the hospital in Mbale. The central questions were: who was responsible for communicating this message to physicians and patients worldwide, and how should they approach this marketing and education challenge?

EXHIBIT 1 Graphic Showing Hydrocephalus

What is Hydrocephalus?

Infant hydrocephalus is one of the most common abnormalities affecting the nervous system of children around the globe. Sometimes referred to as "water on the brain," infant hydrocephalus can exist at birth or be acquired. Hydrocephalus is an abnormal medical condition that develops when the normal flow and absorption of cerebrospinal fluid (CSF) in the brain is hindered or blocked resulting in excessive accumulation of fluid in the ventricles of the brain. Left untreated, in addition to pain and suffering, infant hydrocephalus leads to significant brain damage, severe developmental delay, blindness, and ultimately death.



Source: CURE Hydrocephalus website, "About Hydrocephalus," http://cure.org/hydrocephalus/#for-hydro-doctors, accessed December 2014.

EXHIBIT 2	Incidence	of Hydro	cephalus.	Uganda and	d Globally
	menuence	origuio	copilatas,	O Sunda un	I Olobully

	UGANDA	UNITED STATES
Cases of congenital hydrocephalus/1,000 live births	~0.50	0.50-1.00
Cases of post-infectious infant hydrocephalus/1,000 live births	~0.75	0.50-1.00
Overall number of cases of infant hydrocephalus/1,000 live births	0.7-1.4	1.00-2.00
Total number of new infant hydrocephalus cases per year	1,000-2,000	3,950-6,000
Number of live births/year (2012))	1,400,000	3,950,000
Number of active neurosurgeons/100,000 population	0.10	1.44

Sources:

http://www.worldneurosurgery.org/article/S1878-8750(10)00045-8/pdf, accessed December 2014. http://www.ninds.nih.gov/disorders/hydrocephalus/detail_hydrocephalus.htm, accessed December 2014. http://www.cdc.gov/nchs/fastats/births.htm, accessed December 2014. http://www.acshpri.org/documents/ACSHPRI_Surgical_Workforce_in_US_apr2010.pdf, accessed December 2014.

EXHIBIT 3 Uganda Summary Health Statistics

	UGANDA	REGIONAL	GLOBAL
Population living in urban areas (%)	16	39	53
Gross national income per capita (PPP int. \$)	1,120	2,594	12,018
Total fertility rate (per woman)	6	5	2.5
Life expectancy at birth (years)	57	58	70
Healthy life expectancy at birth (years)	49	50	62
Under-five mortality rate (per 1,000 live births)	69	95	48
Adult mortality rate (probability of dying between 15 and 60 years per 1,000 population; male/female)	389/360	343/298	187/124
Maternal mortality ratio (per 100,000 live births)	360	500	210
Prevalence of HIV (per 100,000 population)	4,262	2,774	511
Incidence of malaria (per 100,000 population)	24,597	18,579	3,752
Prevalence of tuberculosis (per 100,000 population)	175	303	169

Source: WHO Uganda, http://www.who.int/gho/countries/uga.pdf?ua=1), accessed July 2014.



EXHIBIT 4 Video: Dr. Benjamin Warf of Boston Children's Hospital Explanation of Hydrocephalus, Shunts, and ETV/CPC



Source: https://www.youtube.com/watch?v=Kg_Yy3ONhjM, accessed December 2014.

EXHIBIT 5 Training and Support Costs



Source: CURE Hydrocephalus website, "About Hydrocephalus," http://cure.org/hydrocephalus/#about-hydro, accessed January 2015.

EXHIBIT 6 CURE Hydrocephalus Program Graduates as of 2015

- John Mugamba, Uganda: Current trainer.
- Kachinga Sichizya, Zambia: In Network.
- Femi Bankole, Nigeria: In Network.
- **Sushil Shilpakar, Nepal:** Not formally engaged with CURE Hydrocephalus. Expected to join network in January 2015. Needs equipment updates.
- **Phan Nguyen and Tran Minh, Viet Nam:** Lost contact, but expect to bring back into program in 2015.
- Marcel Sincari, Moldova/Angola: Currently not in network.
- Rezina Hamid, Bangladesh: In Network.
- **Thomas Dakurah, Ghana:** Lost contact. Expected to join network in January 2015. Needs equipment updates.
- Shabani Hamisi, Tanzania: In Network.
- Patrick Kamalo, Malawi: In Network.
- Sulaimen Konneh, Liberia: Currently not in network.
- Hagos Biluts, Ethiopia: In Network.
- Oumar Diallo, Mali: In Network.
- Inocente Mayanda, Angola: In Network.
- Ibrahim Souare, Guinea: In Network.
- Eva Timoteo, Mozambique: In Network.
- Stalin Manicas, Honduras: In Network.
- Luc Malemo, DRC-Congo: In Network.
- Vincent Wekesa, Kenya: In Network.
- David Kitya, Uganda: In Network.
- Justin Onen, Uganda/Zambia: In Network.

Source: CURE Uganda.

EXHIBIT 7 Surgery History CURE Uganda

(NR: Not recorded)

YEAR	NUMBER OF SURGERIES	NUMBER OF HYDROCEPHALUS SURGERIES	PERCENT OF HYDROCEPHALUS SURGERIES
2006	831	NR	NR
2007	918	NR	NR
2008	844	NR	NR
2009	886	NR	NR
2010	919	651	71%
2011	1,194	719	60%
2012	1,105	854	77%
2013	1,139	869	76%
2014	1,148	946	83%

Note: WHO 2014 figures are estimates based on Janurary to June performance. Source: Provided by CURE Uganda.

EXHIBIT 8 Regional and Global Impact of Neurosurgeons

Trained at CURE Uganda

CURE Hydrocephalus Treatment Location (HTL) Affiliates - Country Locations	Hospital(s)	Type of Hospital	Number of CURE- trained surgeons	ETV 2013	Total Procedures 2013
CURE Uganda	CURE CHU	Private Not-for-Profit (NFP)	2	421 (48%)	869
CURE Zambia	Beit CURE	Private NFP	1	78 (29%)	273
CHTL Nigeria	Lagos UTH	University teaching hospital (public)	1	28 (34%)	83
CHTL Tanzania	MOI Hospital	Government teaching hospital	1	106 (29%)	365
CHTL Malawi	Queen Elizabeth Central Hospital (CECH)	University teaching hospital (public)	1	54 (27%)	197
CHTL Guinea	(1)Kipe Hospital, (2)Private Hospital (name not recorded)	(1) University teaching hospital (public), (2) Private hospital	1	23 (30%)	77
CHTL Mali	Hospital of Mali	Government hospital	1	149 (69%)	217
CHTL Bangladesh	Bangladesh Medical College and Hospital	NFP Teaching Hospital	1	5 (24%)	21
CHTL Ethiopia	1)Tikur Anbessa Hospital (Black Lion Hospital), (2)Zewditu Hospital, (3) Myungsung Christian Medical Center	(1) Public teaching hospital, (2) Government hospital, (3) Private NFP (Christian)	1	19 (15%)	128
CHTL Honduras	Hospital de Valle		1	3 (38%)	8
CHTL DRC	Heal Africa Hospital	Private NFP (Christian)	1	1 (5%)	20
CHTL Mozambique	Maputo Central Hospital	Public university teaching hospital	1	0	0
CHTL Angola	Associação Espinha Bífida e Hodrocéfacia de Angola (ASBIH-A)	National Spina Bifida and Hydrocephalus Hospital (government)	1	5 (6%)	84
CHTL Kenya	Kenyatta National Hospital	National Hospital (government)	1	0	0

Source: Provided by CURE Uganda.