



The Children's Hospital Trust
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For many of us impacting the life of a critically ill child is as easy as breathing

For many children the simple act of breathing is impossible but you can change all that ...



The BreathEasy
Tracheostomy and Ventilation Homecare Programme
at the
Red Cross War Memorial Children's Hospital

Presented by the Children's Hospital Trust

ONE OF THE FORTUNATE ONES

A few hours after Danielle Bosch was born in a George hospital, she had difficulty breathing and was diagnosed with a "severe cold". She was admitted to the Intensive Care Unit and after little improvement doctors told Danielle's mom that her best option was to be transferred to the Red Cross War Memorial Children's Hospital in Cape Town.

Shortly after her arrival, specialists diagnosed Danielle with Pierre Robin Syndrome; an abnormality of the upper and lower jaw. Danielle's tongue was too far back and obstructed her airway so doctors performed an emergency tracheostomy (the insertion of a breathing device) to help two week old Danielle breathe.

Danielle improved dramatically while staying in the E1 Specialist Medical Ward, which treats cardiac, ENT and tracheostomy patients. Her jaw was monitored for growth and she underwent surgery in July to correct it. Before the surgery Danielle had to breathe with the assistance of her tracheostomy.

But Danielle is one of the fortunate ones, she got to go home. Many children with severe breathing difficulties require permanent ventilation which means for the foreseeable future hospital is their home.

EVERY DAY IN HOSPITAL IS A DAY LESS OF CHILDHOOD

The Red Cross War Memorial Children's Hospital is the only facility in sub-Saharan Africa currently offering a Tracheostomy and Ventilation homecare programme. Elsewhere children are either permanently hospitalised or die prematurely from their underlying illness.

The *BreathEasy* programme at the Hospital currently provides care to approximately 90-100 children requiring tracheostomies and 10-15 of these are on long-term home ventilation. Home ventilation in selected patients is possible since the introduction of essential equipment such as suction machines, ventilators and humidifiers.

But there are challenges:

- In 2000 there were 21 new tracheostomy cases compared to 56 new cases in 2010 thus indicating that the problem is increasing.
- It takes approximately 1 month to prepare a new tracheostomy patient and family before they can safely go home. These trache patients occupy 8-10 of the Pulmonology and ENT beds on a long term basis which exacerbates the problem of shortage of beds in the Hospital.
- As many more children are recovering from ICU and have complex medical disorders, they require on-going multidisciplinary intensive care. Tracheostomy patients require very close monitoring and intensive nursing care.
- Limited resources means the programme cannot expand to meet the increasing demand for this service.
- The Hospital continues to recycle whatever equipment they can through patients no longer requiring ventilation but after 5 years this equipment needs to be replaced.

TOGETHER WE CAN DO SO MUCH MORE

BreathEasy aims to be a sustainable multidisciplinary centre of excellence for inpatient and ambulatory care of children with respiratory disorders that require a tracheostomy and/or long-term ventilation.

To achieve this the *BreathEasy* Programme requires an 8-10 bed inpatient high care unit and a wide range of tracheostomy and home ventilation-related equipment to cater for inpatient and ambulatory care of children with respiratory disorders that require a tracheostomy and/or long-term ventilation homecare.

The benefits of the programme are immeasurable:

- The programme reduces the need for prolonged hospitalisation thus saving the health care system enormous sums of money. By facilitating home-based care of tertiary paediatric patients, the programme shifts the burden of a 'chronic disease' (paediatric tracheostomy) from tertiary hospital-based care to the home.
- Trache-dependent children and their families are ensured a better quality of life through home-based care instead of long-term hospitalisation.
- Without this programme, these children would require long-term hospitalisation and high intensity nursing care. The *BreathEasy* Programme saved the hospital an estimated R40 million in 2010.
- Children requiring the services of the *BreathEasy* Programme often have complex medical disorders that require multidisciplinary care which they have access to at the Hospital.
- The specialist services that directly benefit from the programme include Pulmonology, ENT, Neurology, Neurosurgery and Cardiology.
- The inpatient tracheostomy unit serves as a step-down facility for ICU ensuring the ICU beds are not blocked by long-term tracheostomy patients.

THE BOTTOM LINE

The Children's Hospital Trust needs to raise approximately **R2.3 million** to acquire medical and nonmedical equipment to facilitate the care of trache-dependent children at home. See the detailed equipment list at the end of this proposal.

Sustainability & Impact

The Red Cross War Memorial Children's Hospital is a public tertiary and secondary level State hospital, funded by the Department of Health of the Provincial Government of the Western Cape (PGWC). PGWC currently has an operational budget of approximately R400 million per annum for the maintenance and upkeep of the Hospital.

The majority of staff who run this programme are funded by the Department of Health and all consumables needed to support this service comes from the Hospital budget.

BreathEasy has a 22-year track record providing home-based care with limited resources but maintaining successful outcomes.

With additional support their capacity will grow and be far reaching in terms of being able to assist so many more children both in Cape Town and beyond.

Donor Recognition

Donors will be given due recognition for their contribution to this project in line with the Trust's progressive donor recognition policy. The Trust has an experienced communications team who will coordinate effective media campaigns on behalf of donors to ensure optimum editorial coverage.

Although editorial coverage is not guaranteed, the Trust has an excellent track record for coordinating successful media campaigns. On average donors who are making sizeable donations to the Trust are receiving R1 million plus in editorial coverage; an excellent return on investment.

BANK DETAILS

Local donations

The Children's Hospital Trust
Bank: Standard Bank
Branch: Rondebosch
Account: 07144 3126
Branch code: 025-009

International donations

The Children's Hospital Trust
Bank: Standard Bank
Branch: Rondebosch
Account: 071 433 090
Branch code: 025 009 11
Swift code: SBZAZAJJ
Bank telephone number: +27 21 680 4729

100% of all funds raised goes directly to the Project

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ADDITIONAL INFORMATION

Equipment Required:

Item	Cost/ item	Qty	1 year	3 years	Notes
Manual suction device	399	20	7 980	23 940	
Electric suction machine	4 140	4	16 560	49 680	
Portable ventilator	84 645	4	338 580	1 015 740	
Back up battery for ventilator	11 592	4	46 368	139 104	Used with ventilator
Humidifier for the ventilator	17 563	4	70 252	210 756	Used with ventilator
Pulse oximeter	8 772	4	35 088	105 264	Used with ventilator
Ambubag	155	4	620	1 860	Used with ventilator
Portable oxygen concentrator	39900	2	79 800	239 400	Allows mobility for oxygen dependent children
Pram/push chair	6000	4	24 000	72 000	Needed to transport ventilator with baby/child.
Shona Buggy (special seating)	100 000	1	100 000	300 000	Needed to transport ventilator with baby/child.
Consumables			1 000	3 000	
Educational materials and training			50 000	150 000	Documentary and guide booklet for caregivers
TOTAL			770 248	2 310 744	

BreathEasy

The *BreathEasy* Tracheostomy and Ventilation homecare programme has been running since 1989 and stands out as a model of providing quality health care to tracheo-dependent children through the empowerment of families to care for their children at home.

The programme provides a service for the entire Western Cape as well as treating many children from the Eastern Cape. Individual patients are widely scattered throughout the regions and it is neither possible nor feasible to develop complex multidisciplinary services in regional or district services for only one patient with a rare condition.

A tracheostomy is a life-saving procedure indicated to relieve airway obstruction or assist airway clearance in children too weak to cough. Tracheostomies are indicated in children who require long-term ventilation for any reason, most commonly congenital muscle weakness disorders.

Every child with a tracheostomy has an unstable airway. The child is thus constantly at risk of life-threatening complications such as infection, blockage or dislodgement and subsequent asphyxiation. In inexperienced hands, the child's life will be in danger. The success of this programme relies on the mother or caregivers being trained as the 'tracheostomy expert' because suitably trained medical personnel are simply not available.

The excellence of this programme has been acknowledged through awards such as the National Winner of Marilyn Lehana Caring Award (2005) and national runner-up for the Cecilia Makiwane award to Jane Booth (2007). This programme also stands out as a model to develop other nurse-led specialist homecare services such as peritoneal dialysis, cystic fibrosis, total intravenous nutrition (TPN) and many more.

The Red Cross War Memorial Children's Hospital

The Red Cross War Memorial Children's Hospital is the only dedicated specialist paediatric hospital serving the children of Southern Africa. It is a national asset and handles the worst cases of disease and chronic illness in children under the age of 12. It is often the last centre of hope for little patients. The Hospital manages approximately 250,000 patient visits each year. The Hospital currently has 290 beds which will increase to 310 by the end of 2011.

The majority of the Hospital's patients are from the Western Cape, with cases from the rest of South Africa, Africa and rare instances, the rest of the world. The majority of the Hospital's patients are from poor and marginalised communities. One third of the patients treated are under a year old.

Focus areas for the Hospital include renal and liver transplants, specialised burn care, neurosurgery, cancer treatment, intensive care, HIV/Aids research, TB, re-hydration and co-ordination and management in the care of chronic disorders. The aim of the Hospital is to provide each and every patient with the best medical care, irrespective of parent's income, race, gender, religion or place of residence.

The Children's Hospital Trust

The Children's Hospital Trust was founded in 1994 as the independent Fundraising Arm of the Red Cross War Memorial Children's Hospital when the Hospital was threatened with closure due to lack of funding. Since its inception the Trust has supported the Hospital through upgrading its buildings, purchasing vital equipment and funding critical training and research programmes.

The Children's Hospital Trust's expanded its funding focus in 2011 to include funding paediatric healthcare projects in the Western Cape beyond the Hospital's doors which will have a direct or indirect impact on the services and patient load at the Red Cross War Memorial Children's Hospital.

The Trust is funded from an endowment, ensuring that 100% of all donations received are used towards the projects and programmes we fund. Not a cent is used for administration or operational expenses.