

# Breatheasy Tracheostomy and Ventilation Homecare Programme

The Red Cross War Memorial Children's Hospital

January – December 2020

## Introduction

The Breatheasy Programme is a unique specialist nurse-led initiative at the Red Cross War Memorial Children's Hospital (RCWMCH). The programme empowers parents of children reliant on a tracheostomy or artificial ventilation for breathing to provide safe care for their children at home. Tracheostomy patients around the world characteristically face lengthy hospital stays. The family-centred training approach at RCWMCH conducted by a multi-disciplinary team provide a supportive environment for caregivers and ensures that children with tracheostomies return home as



soon as they are medically stable. Once home, they are monitored as outpatients by the programme. Family members provide routine day-to-day medical care equivalent to that of a professional nurse (such as changing and suctioning the tracheostomy tubes). Thanks to the generosity of donors, the equipment necessary for homecare is provided by the Breatheasy Programme to families: this includes suction machines, humidifiers, ventilators, as well as a range of associated items required for safe care. Your support helps children live a full life with a tracheostomy.

## Benefits of the Programme

**The connection between professionals in the Breatheasy programme and the caregivers is more than a lifeline to a family in need; it is a bond that builds hope and a vision of the future that wasn't there before.**

Sr Primrose Shabangu is the co-ordinator of the Breatheasy programme at Red Cross Children's Hospital, and she encourages families to be part of the decision-making process and uses that information to educate them in a way that is relevant to them. Her conscientiousness comes through in the confidence of the parents and caregivers. From the moment they enter the programme to the moment their children are discharged, and beyond, these parents are included, informed and inspired. At the time of discharge, families confidently leave the hospital with adequate knowledge, proficiency in tracheostomy care and operation of the machines. The families continue to have the support of the Breatheasy programme and the rest of the multi-disciplinary team through regular outpatient follow-up visits.

*"We try to establish a relationship with our patients prior to the procedure - in this way we identify the strengths of that particular family, which plays a vital role in the training. The Breatheasy programme is unique in this way, because over time we form special relationships with each family."*

*"When you see the mom or caregiver, who was so nervous and so afraid, being able to confidently take their child home, with the tracheostomy tube, it is very satisfying".*

The Breatheasy programme helps caregivers integrate the child back into their own family and into their community. *"I really admire them. At the end of the day, you as a nurse, you're standing on the other end in awe of what are usually young moms in our programme, and they know so much. It just shows and proves how powerful the love of a parent is; you can overcome anything"* - says Sr Shabangu.

The support given to parents and caregivers as they begin their journey of taking control of their children's intensive care, is not limited to their stay in the hospital. Each family who passes through the Breatheasy programme is able to stay connected to the team via a dedicated cellphone line, which includes WhatsApp.

Sr Shabangu says, *"Having them come back for their outpatient appointments and knowing that everything's going well is satisfying as a nurse to give the power and to share my skills with these caregivers"*.



## Children who have benefitted from the Programme

In 2020, **34** new children entered the Breatheasy Programme. **19** children were discharged from the programme over the period following their recovery and extubation – the removal of their tracheostomies once no longer required for breathing. **11** Children passed away. A total of **181** children form part of the programme as of December 2020. For as long as they remain clinically stable, these children continue to be followed up as outpatients. **41%** of children currently managed on the programme require either 24 hour or nocturnal ventilation.

### January 2020 to current

Patients	2018	2019	2020
New Patients having joined the Programme	30	20	34
Discharged: deceased	12	5	11
Discharged: extubated (tracheostomy removed)	19	10	19
Discharged: transferred to adult/other institution	7	0	0
<b>Case load at end of reporting period</b>	<b>154</b>	<b>177</b>	<b>181</b>

Intervention received for the current case load of patients	
Patients with a trache only	106
Patients on long-term home ventilation	75
<b>Total</b>	<b>181</b>



**Far greater numbers of children have in addition benefitted indirectly from the programme, thanks to the availability of beds at Red Cross War Memorial Children's Hospital that would otherwise have been occupied long term by children with tracheostomies and on ventilation.**

## Overall Impact of COVID-19 Pandemic on the Hospital

Hospital Management of the RCWMCH proactively put measures in place to ensure staff, families and children were protected as far as possible. All Breatheasy outpatient appointments were cancelled at the beginning of the pandemic. However, clinics cautiously restarted toward June 2020 with 1-2 patients per day every 2 weeks. Telephonic appointments were scheduled to arrange medication scripts. The Breatheasy team and families adapted successfully to keep our children safe. The hospital assisted with the creation of capacity at metro hospitals adult services by accepting children with emergency issues, as well as accepting adolescents up to age 18 years. As of 21 December 2020, RCWMCH had recorded **244** patients and **212** staff members who had tested positive for COVID; **179** staff members had returned to work. There were 4 recorded deaths of COVID-positive paediatric patients. Patients who passed away had significant underlying comorbidities, with one of the patients having previously been placed on a palliative care plan. There were 3 confirmed COVID-positive staff deaths, and several severe infections requiring intensive care unit admission. [Click here to read the impact report in the South African Medical Journal.](#) [Click here to read the impact report in the South African Medical Journal.](#)



## Equipment purchased from funding provided by donors during 2020

Equipment generally has a life span of approximately 5 years, after which it must be replaced. The precise combination of equipment required by the programme each year depends on the specifics of the patients' conditions in that year. The following table provides an overview of the items procured by the programme for children's home care over the reporting period.

Items (Equipment)	Unit Price	Qty	Actual (ZAR)
IV Stand for C-Mac Monitor, including protection tube	R29,072.46	1	R29,072.46
Resmed RPSII Power Station	R8,388.00	12	R100,656.00
Resmed S9 Power Supply Unit 90W	R1,116.99	12	R13,403.88
Resmed RPSII DC Cable For Airsense	R452.00	6	R2,712.00
Resmed RPS11 DC Cable For Stellar	R442.00	6	R2,652.00
Repair - RMA Service MR850	R350.00	1	R350.00
Resmed Stellar 100 (Ventilator)	R50,715.00	1	R50,715.00
SH Anand Foot Suction Pump	R1,766.00	10	R17,660.00
F&P MR810 Humidifier	R16,040.00	2	R32,080.00
Resmed H4i Stellar (Ventilator)	R2,256.00	4	R9,024.00
Medtronic PM100N Bedside SPO2 Monitor	R17,013.00	2	R34,026.00
Medtronic Dura-Y Sensor x1	R2,969.00	2	R5,938.00
Medtronic Pead Spot Check Clip	R819.00	2	R1,638.00
Medtronic Dura-Y Sensor x1	R2,969.00	4	R11,876.00
Medtronic Pead Spot Check Clip	R819.00	4	R3,276.00
Repair - Stellar 100 (Ventilator)	R3,563.44	1	R3,563.44
Repair - Stellar 100 (Ventilator)	R26,003.51	1	R26,003.51
Repair - Stellar 100 (Ventilator)	R12,202.90	1	R12,202.90
Resmed Lumis 150 ST (Ventilator)	R23,979.13	7	R193,032.00
Resmed HumidAire Cleanable Tub	R1,086.96	7	R8,750.03
Resmed Stellar 150 (Ventilator)	R56,268.70	1	R64,709.01
SH Comfy Vac Handheld Suction Unit	R685.22	15	R11,820.05
Breatheasy Stationery - Grey Boards	R251.00	1	R251.00
<b>Total</b>			<b>R635,411.26</b>



## Patient Story: Sweet Dreams Khumo

The sound of her baby's gurgling is a happy, gleeful sound for first-time moms. For Pretoria mom, Thato Ramoshaba, it's an alarm bell putting her on high alert. Doctors suspect that her baby has CCHS. Congenital central hypoventilation syndrome is rare, and life-threatening. When Thato's baby boy goes to sleep, his central and autonomic nervous system becomes impaired, and the most automatic thing, like taking a breath, just doesn't happen. While asleep, shallow breathing raises the carbon dioxide levels in the body, which normally triggers a breath. With CCHS this stimulation doesn't occur, and breathing can stop.

Khumo stopped breathing within the first few hours of life outside his mother's womb.

Talking about her pregnancy, Thato recalls, *"It was beautiful. I didn't even think that we'd be here actually. It was just a normal pregnancy. The only thing they said was that he's a big baby. But other than that everything was fine."*

She carried Khumo to around 41 weeks and needed to be induced.

*"The birth was very traumatic. I'm so used to people just going into labour, and then you push and the baby's out,"* she laughs nervously as she relates her birth story. After her water broke, she started leaking meconium, and it soon became evident that an emergency caesarian would be necessary.

On the 18th October 2020 Khumo Ramoshaba was born at Kalafong Hospital in Pretoria.

*"It was just amazing. Because of the sedative, I was still drugged, but when they bring him to you,"* her face lights up, *"that was the most beautiful thing."* After holding her beautiful baby in those first few hours of absolute bliss, Thato and Khumo fell asleep. New moms don't sleep very long and Thato checked on her baby upon waking. She noticed that he looked very pale and alerted the nursing staff at Kalafong Hospital. Thato's peaceful reality was shattered in an instant.



Khumo wasn't breathing. They had to resuscitate.

*"When he was born, everything was fine. They brought him to me...and then he just had an episode where he didn't breathe so they had to resuscitate. After resuscitation he was admitted to ICU".*

Khumo was having seizures, and they were able to stabilize him. However, his respiratory system just wasn't coping. In the intensive care unit they started incrementally increasing treatment and support measures from nasal prongs, to a C -pap, and the last option was a ventilator to help maximize his breathing.

*"I was really feeling numb. I didn't know what was going on,"* Thato recalls being jolted into the frightening reality of medical staff fighting for her baby's life. Her perception of being a first-time mom would be altered even further.

*"Every day was just a new thing with him. One day there was progress, and then another day... it was just a rollercoaster. Especially the first month; it was just a rollercoaster. Everything was just going wrong. **But the only thing was, as long as there's still a heartbeat, there's still hope.**"*

Hope is a strong motivator, and everyone who fights to save a life, lives by it. *"At the first hospital they gave the diagnosis after a lot of consideration. But you know, when you read about it, it's like this big thing. So, we just asked for a second opinion; just for clarification. So they transferred us to the second hospital".*

At Steve Biko Academic Hospital, it was confirmed: the diagnosis of CCHS will have lifelong implications for Khumo. He would need a tracheostomy. And Thato would learn to be his full-time nurse.

After two months at Steve Biko Hospital, Thato had learned much about her son's condition and what would be required to maintain his quality of life and health from then on. But this was the beginning of her journey, and she needed help.

*"Because they (Steve Biko Hospital) can't give us the machines, we started looking for help to get his breathing machines, so that's how we came across Red Cross War Memorial Children's Hospital. We spoke to Dr Zampoli here (at Red Cross) and he said that they will be able to help us."*

Steve Biko Hospital arranged an air ambulance to get Khumo and his mom safely to the Red Cross Children's Hospital.

She beams when she recounts their arrival in Cape Town, *"I really wasn't expecting this much progress with him. I've seen a lot of changes. He plays around and laughs and everything. Everything; from the nurses, the doctors, the staff, everything's just different, you know. I'm seeing him for the first time actually like this".*

She reaches out to hold Khumo's hand, and he grips her finger firmly. Thato smiles softly at her son; proud as a mother can be, and hopeful.

Since being admitted to Red Cross Children's Hospital, Khumo and Thato have been in the specialized Breatheasy programme. The hope it brings Thato is evident, and her positive outlook for her son's future is indicative of the confidence she has gained from the Breatheasy team.

The team at the Hospital will be doing a 12 hour long controlled sleep study with Khumo off the ventilator, within safe parameters, to establish what his limitations are exactly. The polysomnography (sleep study) will track heart rate, breathing rate, oxygen and carbon dioxide levels, and give the medical team a better idea of the extent of the breathing abnormalities. It also helps caregivers understand the complexity of the condition and the importance of monitoring the need to be on a Bi -Pap or ventilator.

Although the Breatheasy programme is currently only available at the Red Cross Children's hospital in Cape Town, our reach is national. The impact is felt throughout our magnificent country, and in some cases even neighbouring countries. The programme is helping children like Khumo have what we wish for all children: sweet dreams.

Thank you for helping us help them.

## Parent / caregiver training and support

Once a tracheostomy has been surgically created in the airway of a child, a trachea tube is inserted to keep the opening and airway open. The trachea tube has to be suctioned regularly and also taken out, cleaned and replaced daily. Children on ventilators are considered to be 'high risk' and require additional day-to-day medical care at home.

Parents or alternative primary caregivers of every child who entered the Breatheasy Programme during the reporting period were trained by Sr. Primrose Shabangu and the Breatheasy team to perform these critical functions for their children. In instances without medical complications, parents/caregivers spent approximately four weeks in the ward at Red Cross War Memorial Children's Hospital, during which time they received the necessary training for home care. This included training on the equipment, supplies and medication needed, how to clean the equipment and to change and clean the tracheostomy. It also included training on suction and how to feed, bath and transport children with tracheostomies or on ventilators, as well as how to support their speech development and what to do in an emergency. Training is provided on a weekly basis and performed on teddy bears. The programme was individualised to every child and family for their unique condition, home environment and needs.

In addition, prior to the COVID-19 pandemic, the Breatheasy team facilitated daily group sessions which provide mothers and other caregivers with further support and an opportunity to gain additional information. Currently this is done 2 days a week every 2 weeks with 1 patient at a time.



When ready to go home, all families were provided with a detailed and visually helpful instruction book as well as all the necessary equipment and supplies needed for home care.

At the onset of the COVID-19 pandemic, refresher training was provided with existing families on the programmes. Training focused on general health education, emphasizing the importance of wearing portable humid vents at all times and adequate hygiene.

## Conclusion

Our heartfelt and sincere appreciation extends to our kind and generous donors for providing funding to this special project to purchase the much-needed lifesaving equipment, which would not be possible without your support.

**Your support allows children to live a full life through the Breatheasy Tracheostomy and Ventilation Homecare Programme.**

