

DECEMBER 2022



heart**KIDS** SA QUARTERLY

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FULL CIRCLE: A NEW NORMAL REVISITED

Our first Newsletter of the Year opened with thoughts on navigating our “new normals”, and cast a spotlight on one of our Warriors, Unakho - and as one pens this final edition of 2022, it cannot but seem we have gone full circle.

One of our heartKIDS SA stalwarts is faced with the unenviable challenge of negotiating her “new normal”. Having recently received a diagnosis of lymphatic cancer, Charlotte will be taking a step back from heartKIDS to focus her energies on her recovery. Our unending prayers and love go out to her, Deon and the family.

In the same breath, one must also revisit the use of “new normal” in the context of strife and challenge, as indeed Unakho’s story calls us to.

Because as the clock struck midnight on New Years Eve and we toast and ring in the New Year, a girl in East London may well smile that much wider, and hope that much bolder for her dramatic “new normal” - **with her new heart!**

With this incredible story of hope and silver lining to close the year that was, we wish and trust you have enjoyed a very Merry Christmas, and may 2023 bring you more Silver Linings than dark clouds.

SPOTLIGHT ON: Unakho Ntshintshi

02 November 2022

Unakho got sick at school, collapsing and was admitted to St Dominics' where she was diagnosed with an arrhythmia, and the plan was made to install a pacemaker along with arrangements for transfer.

16:00, 08 November 2022

Transfer to Groote Schuur via ambulance.

19:32, 13 November 2022

I booked the bus ticket for my trip back to East London

05:00, 14 November 2022

I was woken by a call from one of the nurses to say that Unakho's doctor wanted to see me in the ward. As I rushed down to the ward a rush of fears and emotions gripped me and felt my legs near failing me.

"Is my child okay?" were the only words I could utter, and sensing my anxiety she was quick to reassure me that not only was she fine - but they had **found a heart for her!**

A miracle! I knelt down to praise and thank God for the family of our donor, and in a flood of tears proceeded to Unakho's ward where she excitedly shared the news again and we shared a **prayer** of thanks for God's blessing.

It's a blur how many people came to share their congratulations at the news, with Dr Cupido amongst some of them - and once consent forms were signed one of the doctors asked Unakho if she was perhaps a little scared and true to form she responded with a bold, "No!" which had the doctor somewhat shocked in disbelief. I couldn't help but be proud of her enormous courage.

She echoed this sentiment when after being briefed on the high-risk nature and survival rate of the heart transplant she was clear:

“

However small, I am taking that chance

Fourteen hours into the surgery the doctors informed me things were not looking good, yet strangely, I felt a calmness that my daughter had known the associated risk and **still** made the choice to go under simply at the hope for a better quality of life.



SPOTLIGHT ON: **Unakho** Ntshintshi

01:00, 15 November 2022

Unakho came out of surgery and the doctors shared that they had put her on an ECMO machine to help alleviate pressure on the hearts and lungs. Obscure as it may seem, whilst the effects of the anaesthetic remained, I was so happy when she recognised my voice.

Much as the doctors were confident that the surgery had been a success they did share that her old heart had collateral arteries and veins that were bleeding, so they would continue to monitor her and should the bleeding not stop they would then take her back to theatre.

04:07, 15 November 2022

The doctor indicated that the bleeding had not stopped so they would need to take her back to theatre. Thankfully, I was aware that Unakho does have a tendency to bleed post-op as the same had happened after a previous op at Red Cross - so I knew they would sort it out and had trust in that team.

08:00, 15 November 2022

Yet another consent signed, for the exploration of the sub-aortic arch - but one did so because I knew they were doing what was best for my daughter, and into theatre she went.

13:05, 15 November 2022

Doctor shared that everything went well. They had discovered some form of stenosis and they had corrected it and it was now down to, "wait and see" - and because the heart was now working the ECMO machine was removed.

● ● ●

Unakho has continued on her path to recovery, with her visits to the physiotherapist ongoing and waiting a biopsy. Though amongst her wishes for her 18th birthday was to be surrounded by family and not in hospital, we could only deliver one of those; and my husband and kids were able to make the trip and have her 18th birthday at the unit.

Our story is a testimony, a testimony to the benefits of palliative care and surgery, to not only get the best quality of life but to extend its expectancy to allow the time and space for a miracle.

And a Miracle we have seen

Nonnie



Unakho's mother, Nonnie



2022

Kian vd Westhuizen (03 Nov)

2021

Titus Grantham (04 Oct)
Rania Zana Daames (26 Oct)
Shaka Malinga (19 Nov)
Ziva + Myla Goliath (03 Dec)

2020

Katelyn Isabella Moodley (07 Oct)

2018

Cebolakhe Shabalala (18 Oct)

2017

Thandolwethu Ngwane (06 Nov)
Sudias Ahmed Gaffoor (01 Dec)

2016

Gabriel Joel Sayed (21 Oct)
Caitelin Nicole le Roux (22 Nov)

2015

Ruche Grace Soldaat (26 Oct)

2014

Eksteen John Sadie (31 Oct)
Vetali Govender (21 Nov)

2013

Cole Martin Bosse (28 Nov)

2004 Unakho Ntshintshi (29 Nov)



IN MEMORIAM

Thingo Mbanjwa

10 Feb 2022 - 04 Oct 2022

Uyanda Baba

24 June 2021 - 05 Oct 2022

Esethusipho Spelman

28 Mar 2018 - 14 Nov 2022

Zayleigh Ferrie

06 June 2022 - 29 Nov 2022

Jade Sibanda

05 Aug 2021 - 13 Dec 2022

...and the others who may not have been brought to our
attention.



EMONK ROAD / SHOW

06-08 DEC

Working with Unakho's mom, Nonnie, we were able to bring some smiles and carry our message of CHD awareness to the Cecilia Makiwane and Frere Hospitals in East London





Warrior parent, Pavashnie Naidoo took some time to put a smile on the faces of children at the Inkosi Albert Luthuli Central Hospital.

Well done Pavashnie!





Big **congratulations** to Warrior parents Andre and Leizle who finished the arduous Wines2Whales mountain bike race.

They completed the gruelling 3-day stage race in honour of CHD with their heartKIDS SA proudly on display!





Parow Golf Club played host to our Annual Golf Day on the 28th October and what an incredible turn out it was. Thank you to every single one of the golfers and supporters that attended.

As special thank you to our sponsors Instruments SA, Farbers Coach Works, Coca-Cola, Mica Hardware, Heart FM, Price Rite Supplies and Parow Golf Club.

Parow Golf Club went above and beyond and made heartKIDS SA one of the beneficiaries of their "Classic Golf Day" held in November, with a share of the proceeds coming our way!



UPCOMING EVENTS:



11 FEB

CAPE TOWN

08AM Sea Point Promenade

EAST LONDON

08AM Orient Theatre

IT'S TIME!!

Join us for the 5th annual heartKIDS SA Big Walk (5km) to raise awareness on Congenital Heart Defects (CHD), and for our little warriors born and living with CHD.

Buy your tickets or donate to our cause on: www.quicket.co.za

Get in touch!

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