

VOLUME 4

DECEMBER 31, 2023

QUARTERLY

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A brave mother's
journey across
four hospitals,
in the Western and
Eastern Cape .

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heartTKIDS SA - heartTKIDS SA - heartTKIDS SA - heartTKIDS SA

SPOTLIGHT ON

Lwano
NORUSHE

WARRIOR BIRTHDAYS
IN MEMORIAM
UPCOMING EVENTS



Beverley with son Grayson, 8, and daughter Lungako Gia, 1.

*They always
say that time
changes things,
but you actually
have to change
them
yourself.*

A DECADE OF CHANGE

A LITTLE UNDER TEN YEARS AGO, IN LATE 2014, A YOUNG MOTHER LOST HER NEWBORN SON AFTER WHAT HAD BEEN A COURAGEOUS 27-DAY FIGHT FOR HIS LIFE. DURING THOSE 27 DAYS, HER CEASELESS RESEARCH INTO CONGENITAL HEART DEFECTS, even getting in touch with a US-based group brought the painful realisation that his life trajectory may well have taken a different course had he been born in a first-world country with greater awareness and treatment of CHD.

Spurred on by this truth, this warrior mother established heartKIDS SA to both honour, a life cut far too short and to advocate for the 1 in 100.

2024 marks ten years since then, 3 652 days, 87 600 hours – and as is expected with time, much has changed since those first courageous yet tentative steps. What has remained constant is the intention to raise awareness and advocate for the lives of all those touched by CHD; which over the years has distilled to a vision to not only be a leading advocate in CHD awareness and education – but a centre of solace for families affected by congenital heart disease.

Allow me to thank the team that works so tirelessly to bring this vision to life. To Charlotte, Virginia, Marilyn, Charles, Deon, Abdi as well as Waheid, Tawwaba, Sharvina, Pavashnie and Roganie from the Durban team; without your personal sacrifice and generosity with your time we would simply not have made the strides we have in the fight for CHD awareness, and am excited to see what you have in store for us in 2024. May it be a year of celebration, recommitment and renewal!

As I reflect on our journey and think of the ever-growing community of warriors and their supportive families, much as she may opt to observe heartKIDS from not too far a distance nowadays, I want to honour Beverley for finding the temerity to become an agent of change in the lives of so many. From Rustenberg to Keiskammahoek to Beaufort West – indeed, Benjamin's short days on this earth, have created a legacy that continues to touch and given hope to so many.

Wishing you all a Merry Christmas, a very Happy New Year, and another ten years of being the change we want to see in this world.

Ha

Luvano's journey has been particularly tough, traversing across several hospitals. Her mother, Nomabhele, has been a rock throughout, and in special recognition, this is their story - in her own words.

SPOTLIGHT ON LUVANO NORUSHE



MY DAUGHTER LUVANO WAS BORN ON 08 JANUARY 2023 AT SS GIDA HOSPITAL in the Eastern Cape town of Keiskammahoek and believed her to be a healthy but smaller baby.

So it wasn't surprising that at her one-week check-up nurses asked that we increase her feeds. On our return for her immunisation on 22 May, the nurses were not happy with her breathing and sent us back to SS Gida Hospital, where it was discovered that she had **low oxygen levels** at 80%.

After conducting X-rays the doctors told us she had a congenital heart defect and had also contracted pneumonia for which she was immediately hospitalised. Over the next seven days the pneumonia was treated but **without much improvement** on her oxygen levels, which prompted transfer to Cecilia Makiwane Hospital in East London.

During those four weeks, the cardiologist found a few anomalies with her heart, but couldn't make a diagnosis due to the severity of her symptoms at the time.

This was followed by a transfer to Dora Nginza Hospital in Gqeberha, where Luvano would be admitted for two weeks- by this time Luvano had also contracted an infection. We were ultimately discharged on 16 June, with a follow up visit scheduled for 17 July.

Luvano was diagnosed with a **Transposition of the great arteries**, where the two main blood vessels from the heart were in an abnormal position. The cardiologist was soon in discussion with Red Cross Children's Hospital and we were given the chance to go home to prepare for our upcoming stay in Cape Town - but before we could do so, Luvano contracted Broncho-pneumonia.

After six weeks of recuperation at SS Gida, Luvano was transferred to Red Cross Hospital, where I had expected the operation would take place almost immediately, but given her ongoing recovery and the waiting list this was not the case - with two attempts for the op abandoned because of her high-risk category.

THE OP

The op was finally performed on 16 Oct, and it was a mixture of relief with waves of **concern, panic and worry.**

Luvano was later transferred from ICU into the general ward and on 31 October was discharged from Red Cross. Given the hospital's transport shuttle to the Eastern Cape operates weekly on Fridays, we expected to be home in a matter of days. You can imagine the disappointed when the shuttle for that week Friday was cancelled without any explanation - and had to wait until the following Friday before we could head home.

After what had been a roller-coaster of emotions, multiple hospitals across two provinces, we were **elated to finally get home.** Tough as it was, Luvano had proven herself to be a warrior. I want to share my special thanks to the heartKIDS SA team that had walked this incredible journey with me, always at my side.

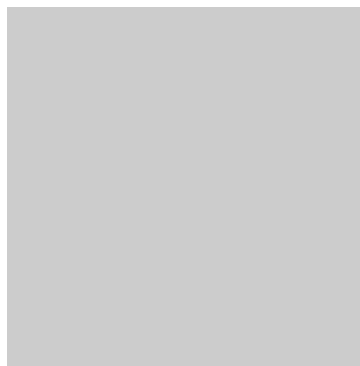
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From the first time we met at Red Cross, Nomabhele has been nothing short of strong and graceful.

She has always kept a ready smile despite Luvano's setbacks and had looked out for the other mothers, sharing whatever it is she could.

So we want to recognise her quiet strength, resilience and positive attitude, and wish her and baby Luvano all the very best moving forward.

Charlotte Lombard
heartKIDS SA



WARRIORS

Birthdays

OCT

Shanaath Chotaii	14/10/22
Zanele Douglas	12/10/22
Rania Daames	26/10/21
Titus Grantham	04/10/21
Katelyn Moodley	07/10/20
Anganathi Jackands	24/10/18
Cebolakhe Shabalala	18/10/18
Gabriel Sayed	21/10/16
Ruche Soldaat	26/10/15
Eksteen Sadie	31/10/14
Sekela Fose	09/10/11

NOV

Elif Plaatjies	09/11/22
Kian vd Westhuizen	03/11/22
Shaka Malinga	19/11/21
Thandolethu Ngwane	06/11/17
Caitelin le Roux	22/11/16
Cole Bosse	28/11/13
Luke February	24/11/11
Unakho Ntshintshi	29/11/04

DEC

Anchen Boonzaier	22/12/22
Mark Simonse	16/12/22
Ziva Goliath	03/12/21
Myla Goliath	03/12/21
Calliyah Willard	03/12/18
Sudias Gaffoor	01/12/17
Bethany King	17/12/17

IN MEMORIAM

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Nkanyiso Ngqandu

01 Feb 2023 – 22 Dec 2023

Ntombifikile Dibakwane

18 Aug 2023 – 28 Nov 2023

Elijah Snyman

23 Mar 2019 – 24 Nov 2023

Likuwe Mzolisa

15 Sep 2021 – 08 Nov 2023

Imbo Msi

16 Apr 2023 – 17 Oct 2023

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GRANDSLOTS

heartKIDS SA



GOLF
Day



PAROW GOLF CLUB







DBN CHRISTMAS PARTY

The KZN team held a Christmas Party at Inkosi Albert Luthuli Hospital radiating festive spirit across the corridors.

Volunteerrrs donned their xmas red and gave small gifts to bring joy to our warriors many of whom are unlikely to spend the holiday season at home.

Amid the fun, doctors & nurses took time to share smiles and warmth with patients, turning the hospital to a place where the spirit of Christmas overcame the challenge of illness, even if just for a moment.



heartKIDS SA Christmas Party





2024 EVENTS

5KM BIG WALK

FEB

CHD Awareness Walks to be held on the 3rd, 10th, 17th and 24th of February in Durban, Cape Town, EL & Jo'burg

KZN GALA DINNER

TBC

Inaugural gala dinner to be hosted by the heartKIDS' KZN team. Date of event to be confirmed

ANNUAL GALA DINNER

28/09

Annual gala dinner in Cape Town. In 2024 we shall celebrate the ten-yr anniversary of heartKIDS SA

CAPE TOWN GOLF DAY

OCT

Annual Golf Day hosted at Cape Town's Parow Golf Club in association with Grandslots