

Dear Website reader,

St Joseph's Home shares with you some of our beautiful stories we have published in our newsletters since Spring 2014. We invite you to go down memory lane with us. We conclude with the latest story which was published a few weeks ago. We trust you will enjoy and find inspiration in what has been achieved.

Kind regards,

Alrika Hefers

Manager: Resource Development

Thetha/ Praat/Talk newsletter: Spring 2014



Our little star, Albrige Swarts

In June 2010 Albrige Swarts (4½ years) was admitted to St. Joseph's Home with Acute Lymphoblastic Leukaemia (ALL). On his initial admission, doctors advised that he would have to stay for an extended period and that he had already faced many health challenges. He had already battled pulmonary TB and ALL symptoms like progressive pallor at various hospitals prior to being diagnosed with ALL at Red Cross Hospital. He has also been away for most of the time from his brothers, sisters and grandmother who live in Middleburg, Eastern Cape. Added to that, he had to battle a number of relapses after treatment sessions.

From being a normally quiet, shy boy, he has now turned the corner. Albrige has learned to speak isiXhosa fluently and is no longer afraid to articulate his opinion. At present he is also able to visit his mother in Welgemoed during the weekends. She also attendend his school concert and saw her son perform on stage! *This little STAR has had a rough time and truly can be called a miracle child.*



Thetha/Talk/Praat newsletter: December 2014

Fahiemah (9yrs) from Tafelsig suffered a severe traumatic brain injury five months ago when she was hit by a taxi. With a prognosis of "guarded" she was admitted three months ago for rehab: paralysis of all four limbs, receiving all her feeds via Naso-gastric feeding and unable to use her voice. Against all odds, she has shown a remarkable recovery, improved attention and swallowing. She needs no feeding support and has started eating by herself. Three weeks ago, she surprised all when she started speaking! She now even attends the school on site and is learning to walk. Fahiemah says the first words were "mamma" and "pappa". She also knows all the names of her therapists at St Joseph's Home and thanked them...using her own voice! Soon, she will be reunited with her family. Fahiemah has brought sunshine into the Home with her radiant and lively eyes, reflecting a true fighting spirit



Fokus, 21 December 2014.mp4

A double miracle: A bumpy road from pre-school to grade R



Ashica's story

*Five years ago **Ashica** was admitted to St Joseph's Home. Only six months old, she showed developmental delay and was underweight for her age, weighing only 3,79kg. Feeding her was a challenge for the nursing staff. She had difficulties with sucking and swallowing. Her mother died two weeks after she was admitted to SJH. During her first year at SJH she was readmitted to Tygerberg Hospital three times with pneumonia. Despite all this she developed into a normal, healthy toddler. Her weight improved and at 14 months she started to learn to walk.*

Turning two, she was enrolled in our preschool. In the class room setting. She was a slow learner and struggled to follow instructions. She attended preschool for three years.

With daily stimulation and encouragement, Ashica blossomed into a very special child. Progress has been achieved in her overall development. Her fine motor skills have improved and she can even complete a 10-piece puzzle. Emotionally she has changed from an introverted shy child to one with self-confidence. She even assumed the role of "teacher's assistant" by helping her younger classmates. This year she has progressed to grade R and proudly wears her school uniform. Her grade R teacher reports that she has adapted well to her new setting and routine.

Ashley's story:

Ashley was admitted to SJH at the beginning of 2011 with a chronic condition. During his first admission he started to attend the preschool and was discharged after 13 months. His father, the sole breadwinner, was unable to work due to illness. As a result, the family lived below the bread line.

In August 2013 Ashley (3 yrs.) was readmitted to SJH, due to non-compliance of his chronic medication. During his second admission results of a neuro-developmental screening indicated that he had low muscle tone and global developmental delay. He was re-enrolled in our preschool.

Initially he displayed an untamed curiosity and was viewed as being hyperactive. Despite his "busyness", he was able to settle down to the class room routine and structure.

In line with the holistic approach of SJH patient care, he received input from the multidisciplinary team which included rehab therapy, nursing care and support from the social workers. Developmentally he improved on all levels. Socially he acquired the ability to interact with his class mates and is able to carry out instructions given to him.



Left: Zeenat today and right is Zeenat when she was admitted



Zeenat (4yrs) is a spastic quadriplegic, admitted for severe malnutrition and her prognosis on admission was poor. Her chronic debilitating condition will require full-time and life-long care. Thanks to Zeenat's grandfather, she was admitted to Paarl Hospital who immediately contacted SJH for admission. She has now been at SJH for just over six months, is sitting up and is no longer malnourished. Despite adverse home conditions, this young girl has never given up. As soon as she is ready for discharge, our social worker will liaise with the social workers in Paarl to find a suitable placement for Zeenat where her grandfather will be able to visit her.

Thetha/Talk/Praat: Special Edition 2015

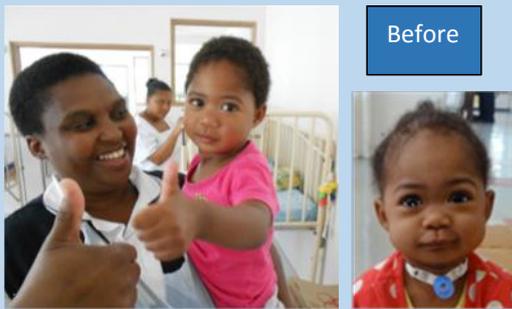
Baby Read's journey from shoebox to home



Baby Read was admitted to SJH at the beginning of 2015 with Tuberculosis (TB) and had also been HIV+ exposed. His mother passed away the day after his birth. He was a premature baby weighing only 740 grams.

Neither his maternal grandmother, staying in the Eastern Cape, nor the biological father, or his aunt could take care of the baby. Baby Read found a caring community at St Joseph's and became a real attention seeker. His size demanded an innovative plan and the nursing staff devised an upright shoebox inside a cot.

The social worker of Communicare investigated the possibility of the paternal grandmother fostering Baby Read. In August it transpired that the paternal grandmother had passed away. Fortunately, the sister of the grandmother was prepared to take care of him and came from George to fetch him. She has also raised the father and is now the primary caregiver for baby Read. Arrangements were made and "granny" arrived at SJH on September 7 to see her "grandchild" (whom she had never met before). "Granny" accompanied by the father and cousin, saw Baby Read for the first time. He was also given the Xhosa name: *Sisipho* which means "Gift from God". The "granny" was so happy about her grandson and stayed at SJH until his hospital appointment on September 10, before leaving for George. ***Against all odds, Baby Sisipho was taken in by his paternal family and it was not necessary to place him in alternative care.***



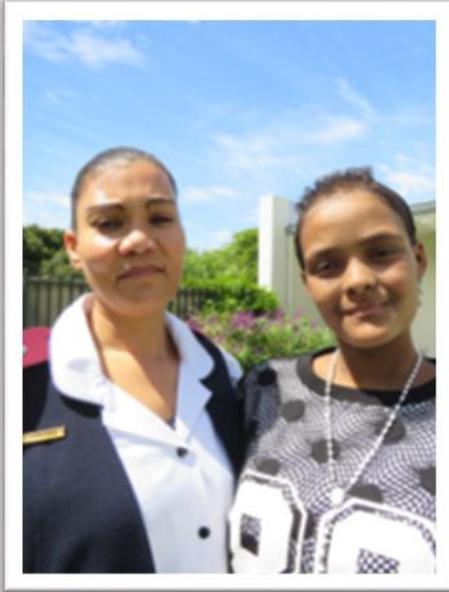
Thumbs up for Zarah!
Sharing good news
with our readers

Zarah was admitted to St Joseph's nearly two years ago when she was only six months old. She was born with Pierre Robin Sequence and a cleft palate. She required a tracheostomy and gastrostomy after birth. She was transferred to St Joseph's for ongoing specialised medical care.

Initially, Zarah found it difficult to trust people and resisted interaction. She would sometimes cry inconsolably when approached by someone unfamiliar. Her development was severely hampered by feeding difficulties as she required alternative feeding via the PEG method (stomach). Later, she struggled with the initial oral food intake and resulted in sensory issues regarding food. Therapy focused on the latter and she was introduced to a soft food diet. Self-feeding and chewing were also encouraged.

Zarah is currently 2 yr. 6 months and has recovered remarkably. She underwent a bronchoscope in December and surgery in January 2016 to restore her cleft palate. According to Matron Audrey Gourrah, Zarah has become a star in Basil Ward and assists other children during meal time.

Jokingly, the staff refers to Zarah "as the self-appointed head prefect of Basil ward".



Our model
patient never
gave up

We share Sara-Lene's story

Sarah-Lene (pictured here with Sister Agnes Coetzee) was admitted as a cancer patient to SJH in July 2010 when she was only 13 years old. Application for re-admission was made in November 2015 when she suffered a relapse. She had already turned 18 and SJH was left with a difficult decision of re-admitting her. SJH was still her place of choice to recuperate and she was admitted in December last year.

She visited the hospital twice a week for treatment. She relapsed, became very ill and the doctors then considered a bone marrow transplant. After testing her family for a match it was found that her mother was half a match and her oncologist decided to proceed with the transplant in April 2016. After a period of her feeling very ill and being admitted to hospital thereafter, it was found that the transplant had been a success. She is now in remission. Sarah-Lene is still at SJH because she needs to go to hospital for treatment second week. Once the doctors are happy with her condition, she will return to the care of her father in Somerset West who will drive her to hospital every second week.

Sarah-Lene has always put on a brave face and NEVER complains. She was unable to complete her Grade 12 this year. She is, however, determined to finish her Grade 12 in 2017.

Sarah-Lene is a wonderful role model for the other children in the ward and they follow her lead. We will be sorry to see her leave as she has been a good influence. The way she has handled her illness is remarkable as there have been quite a few challenges and ups and downs and disappointments and although she has become depressed at times, she has always remained polite and a real 'lady'. She is an inspiration to everyone and her parents can be very proud of her, according to St Joseph's staff.

Going Home...We say goodbye!

Thetha/Talk/Praat: Winter 2015



When Elize came to SJH, she was just a small baby who earned her the nickname "graatjie" (fish bone). Her health improved so much that she could be discharged, and return to her family. Here, she is spending a few minutes with Gretchen (right), SJH social worker, before leaving with the social workers of the department. Staff nurse Mackenzie and two of Elise's friends also came to wish her well.



We will miss you! As the winter holidays approached, St Joseph's said goodbye to **Donna-lee** who left the Home to join her family in Delft. She came to the Home as a small baby and had various operations during this time. Last year she gave her first steps and has since then, never stopped dancing. She brought sunshine to the ward and will be missed. Here, she is with her father and twin brother.



Time to say goodbye to Troy! For a period of ten months St Joseph's was his home. Originally from Gauteng, he was the unfortunate victim of a car accident. Wishing him well are the rehab staff while giving his mother a warm hug.



When **Adriaan Fortuin** was admitted to SJH in 1995 he was only six months old. After nearly 20 years at SJH, he has found a new home with his family at Citrusdal. He will stay with his cousin, Aunt Blommie, on the farm. Transport to his new home had to be postponed several times, since he had so many farewell parties to attend with all the children. He has a wonderful disposition and a very infectious laugh, as matron Audrey Gourrah, SJH nursing manager likes to point out. He took it upon himself to escort first timers to SJH and the school to introduce them to the teachers. He finally completed grade 11 followed by computer courses arranged by SJH. Being his field of interest his intention is to start an internet café on the farm.



Creating healing spaces for young patients

Proudly we can say, God's ways are not our ways and there is a purpose for everything. God can do miracles.

- Sister Priscilla: Ward Sister

A success story

Six months ago, 15 yr. old Justin, was referred to St Joseph's Home from an acute provincial hospital. He had suffered a traumatic brain injury after falling from a bunk bed. A shunt was inserted to drain the fluid in his brain. It was not effective and repeated surgical reinsertions led to extensive brain damage. He was then referred to SJH for palliative care. On arrival, he was bedbound, unable to communicate or perform basic tasks, such as feeding himself. His level of consciousness was depressed and he did not respond to verbal interaction.

Within three months Justin improved immensely. With the comprehensive care of physio-, occupational- and speech therapists, he progressed to sitting up in bed with support. Initially a struggle, he was soon able to sit in a wheelchair for extended periods and stand with the help of a standing device.

As Justin became more alert and responsive, his visual abilities improved. He was able to fix on and follow objects across his visual field, which assisted in communication. The feeding tube was removed and his hand function to grasp and release objects also improved. He began to eat independently and was able to write for short periods. From not speaking, and after much intervention and persistence, Justin regained his ability to talk in full sentences. Cognitively, he also showed significant improvement and attended St Joseph's School. He has since been discharged and now attends a special school near his home. **(Shortened version of original story).**



Miracle child celebrates special Valentine's Day

In July 2014, two months after her birth, **Tshi-So** (held here by her uncle) was admitted to St Joseph's Home (SJH). She was referred from Tygerberg Hospital with an infectious disease and severe malnutrition. Tshi-So's mother died a month after her birth. No family could be traced and Tshi-So became an orphan.

During her time at St. Joseph's, she suffered various complications related to her illness. Good and professional care however, ensured better health for baby Tshi-So.

A Congolese pastor, living in Cape Town, came forward. He knew the mother when she was still alive and informed Tshi-So's maternal uncle about her admission to St Joseph's. The uncle showed interest in fostering her after discharge.

Initially, there were plans to move back to the Congo and take Tshi-So with him but this presented a challenge as Tshi-So was born in SA and no proof of family ties could be found.

The uncle then decided to settle in Cape Town and was found suitable to foster Tshi-So. After several home visits, the uncle and his partner arrived on February 14 to take Tshi-So home, as their new foster child – appropriately on VALENTINE'S DAY!

A Christmas Story of Hope and Good Tidings



Lee-Hansay required 24 hr specialised nursing care between visits to Red Cross. Thea Patterson assists little Lee-Hansay taking her first steps.

A spirited Lee-Hansay says YES to recovery!

This is the story of her journey, by Michaela Purchase— speech therapist at SJH.

Little Lee-Hansay arrived at St Joseph's on 13 January 2017 for ongoing rehabilitation after sustaining extensive burns across her body, predominantly to her arms and face. She also has a history of cardiac defects, foetal alcohol syndrome and complex social issues.

When Lee-Hansay arrived at St Joseph's she was unable to speak and eat, and refused any food as a result of long-term nasogastric feeding. She even struggled to tolerate touching food. After many therapy sessions, often in joint therapy with occupational and speech therapy combined, Lee-Hansay started to tolerate certain food orally. We encouraged her to also try eat and drink by herself but soon noted that she struggled to swallow liquids safely it was going into her lungs. Therapy continued and it took months for Lee-Hansay to be able to eat a full bowl of porridge or puree; now she insists on eating the full ward diet of rice, meat and vegetables! Although she still struggles with liquids, she manages small sips of water, via a spoon and shows improvement in her swallowing coordination.

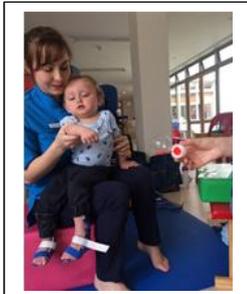
Whilst we worked on getting Lee-Hansay off nasogastric tube feeding, she also received therapy to encourage her speech and language development. She has shown drastic improvement, far beyond what would be expected of a little girl who has been through so much trauma. Lee-Hansay is now able to understand what others say to her and she follows simple instructions. She is also able to imitate words she hears, use some basic words spontaneously and she loves to try to sing along to songs. Lee-Hansay is a delightful child who has brought so much joy to everyone at St Joseph's.

During December we will say goodbye to Lee-Hansay, as we have found a foster care couple who will give her all the love that she deserves!

Note: "Red Cross Children's Hospital (RCCH) is now in possession of a state- of- the- art laser machine. This machine is fantastic as it reduces the appearance of scars. A course of six sessions are usually given. It produces quick visible results, just one session and one can already see the difference. As a beneficiary of the Phoenix Foundation, Lee- Hansay already had some laser surgery to her face this month and as I said the results speak for itself. The scars on her face are already flatter (was raised before).

A special story shared but not published in a Thetha/Praat/Talk.

We reflect on Boetie Herman and his mother who travelled from Citrusdal on a weekly basis for a full year to receive SJH's dedicated rehabilitation services.



Herman was a normal baby boy from Citrusdal, with slight delayed milestones as a result of the fact that he was born prematurely at 32 weeks. Herman had just started sitting independently at eight months, when one day he developed a rash and a fever. On route to the pediatrician he became lethargic and a few hours later he was on a ventilator in the ICU at Cape Gate Medi-Clinic. On 08.02.2016 this little body went into septic shock, and a few days later the MIR showed massive brain damage. The neurologist diagnosed Herman with acute necrotizing encephalopathy a few days later.

“Boetie Herman” as we called him, commenced therapy at St Joseph’s Home on March 29, 2016. The doctors upon investigation found that he has a very rare genetic defect, which made Herman extremely vulnerable to germs. As a result of this diagnosis, Boetie was seen as an Out-Patient for rehabilitation in the form of block therapy for a year.

He has a very difficult type of CP called dystonia. Initially, when therapy started we had very little active movement to work with, but as time passed Boetie Herman recovered more and more. Therapy consisted of a standing regime, aqua therapy, parent training, positioning in and out of the Buggy as well as joint therapy sessions with Occupational therapy and Speech Therapy.

Herman is a severely affected little boy, and as a result of his complex clinical picture the biggest results were seen during joint therapy as in the pictures. It may look easy, but it is the physiotherapist’s job to facilitate a good position in order for Herman to activate and train specific muscle groups. In order for therapy to be effective the positioning and the activity chosen need to be specific and well thought through to ensure success! Research has shown multiple times that the brain learns new skills with success!

Aqua therapy was especially fun for Herman as he enjoyed water even before the incident. In the water Boetie would smile and laugh as a result of the fact that he was able to kick a ball, play with a ball and roll over with facilitation from the physiotherapist.

Upon discharge Herman was able to control his head in sitting whilst paging through a book; he tolerated standing in the standing frame for up to 45 minutes; Sit and play with the assistance of a facilitator as well as walk a few steps with maximal support. To the untrained eye it might seem as if we achieved very little, but Herman achieved a lot and flourished in the SJH therapy departments.

After a year of therapy Herman was referred back to private therapists who continue the work we started at St Joseph’s Home.

Mother and child: A special story about care @SJH!

A full circle of St Joseph's patient care!

Cynthia Lakay (left), a former patient at SJH, never thought she would be visiting her son, Angelo (right), at the same hospital she once called her home. Thetha*Talk*Praat caught up with her while Angelo was undergoing therapy in the Occupational Therapy (OT) section. Cynthia had TB of the spine and was a patient here from 2001 to 2002 and attended St. Joseph's Special School. Today she leads an independent life, enrolled for a business administration diploma and cares for her son, Angelo.

Angelo suffered a freak accident, was admitted to Red Cross Children's Hospital and referred to St Joseph's. He was diagnosed with transverse myelitis, after minor trauma to his spine. Transverse myelitis is a condition in which a section of the spinal cord becomes inflamed. During an inflammatory response the myelin, or protective fatty coating on nerve cells, is damaged or destroyed, resulting in weakness or paralysis, pain, and sensory dysfunction. Autonomic, or involuntary activities such as breathing, digestion, heartbeat and reflexes can also be affected. Part of Angelo's thoracic spine (middle of the spinal cord), has been affected. This has resulted in paralysis of part of his trunk and legs, slight weakness in his upper limbs and has affected his bowel and bladder function.

On admission he was unable to sit without support and arrived in a buggy, which provided maximum support. He has been receiving regular Physiotherapy and OT to address his areas of weakness. His balance while sitting has improved and he has progressed to a self-propelling wheelchair. He is now able to sit at a table, and engage in fine motor activities.

Angelo is a charismatic and charming young man who is motivated to get better. His positive energy is contagious and is definitely his biggest asset in overcoming his physical limitations, says occupational therapist, Asgereee Dalvie. **(Picture below: Cynthia, Asgereee and Angelo).**



What SJH has taught me

"SJH taught me to be independent and live in my own flat. I have learnt all the life skills here. I have even learnt how to speak Afrikaans!" says Cynthia, mother and FORMER PATIENT

