

AYANNA

my journey continues



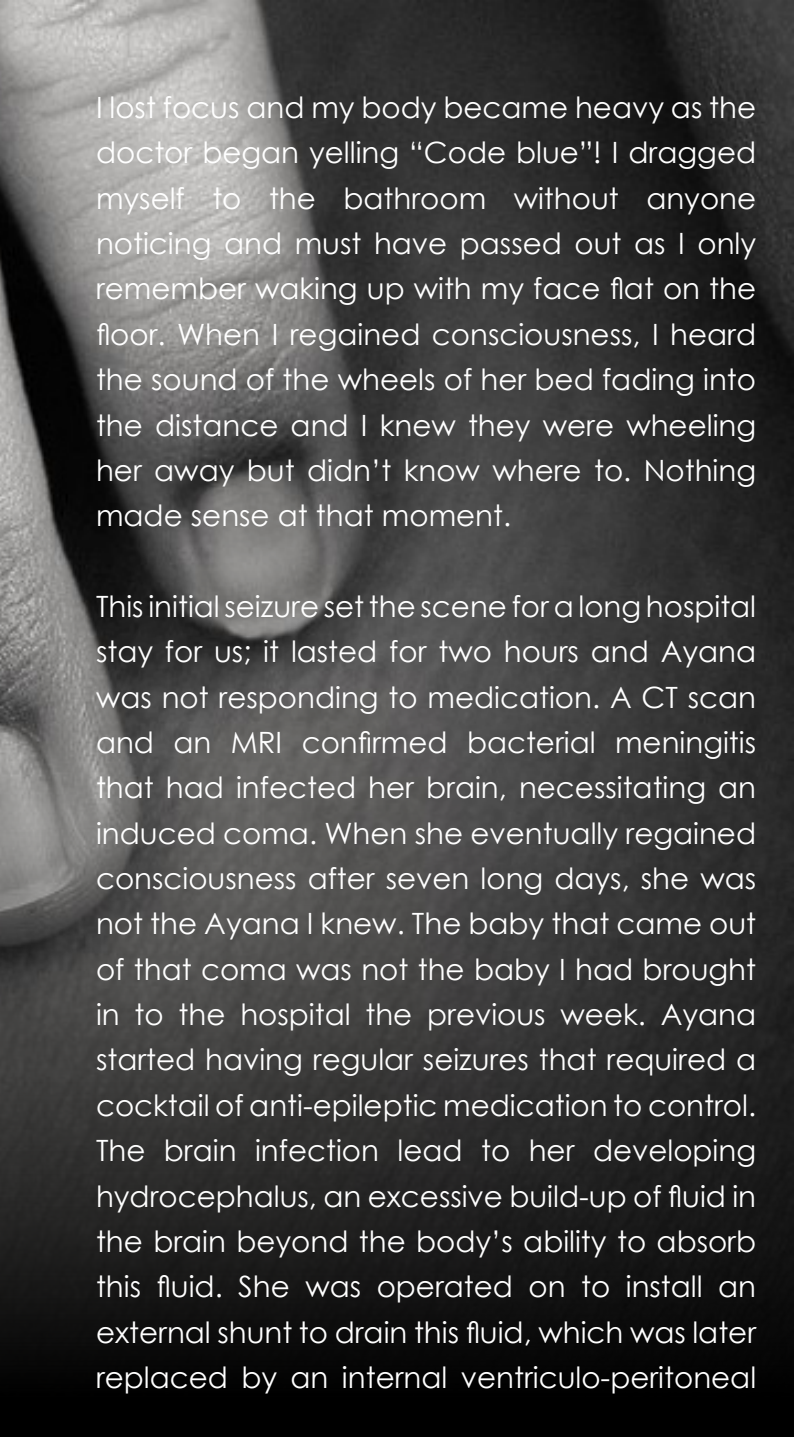


Ayana was born on 31 December 2016 weighing 2.39 kg at Parklane Hospital, Johannesburg, following an uneventful pregnancy and labour. She developed normally like other children, reaching all her milestones accordingly and started kindergarten at 14 months.

Due to the typical infections that newbies at daycare pick up, Ayana had a two-weeks-in then two-weeks-out pattern at school. With just a few months in kindergarten, she fell ill and we accepted it as the usual fortnightly illness and recovery pattern; however she did not respond to medication as always. The GP prescribed antibiotics to which she also did not respond. Additionally, she was now becoming lethargic. Her paediatrician suggested that the prescribed medication be allowed a few days to exert its effect and for us to bring her in should she be lethargic the following day. Needless to mention, her condition did not improve; she instead woke up very weak the following

day and was admitted to the Morningside Mediclinic paediatric ward on the 26th July 2018. Ayana refused to eat completely the day following her admission and an attempt to force-feed her yoghurt in the early evening made us notice signs of a possible stroke. The left side of her face was droopy, she was unable to move her lip to swallow her food and she could not move her left side. I cleaned her mouth and said to her dad, "Something is wrong." As those words left my lips, Ayana had a seizure. Thankfully, the doctor was doing his rounds at the time and was a few steps away from the ward when the seizure began.





I lost focus and my body became heavy as the doctor began yelling "Code blue"! I dragged myself to the bathroom without anyone noticing and must have passed out as I only remember waking up with my face flat on the floor. When I regained consciousness, I heard the sound of the wheels of her bed fading into the distance and I knew they were wheeling her away but didn't know where to. Nothing made sense at that moment.

This initial seizure set the scene for a long hospital stay for us; it lasted for two hours and Ayana was not responding to medication. A CT scan and an MRI confirmed bacterial meningitis that had infected her brain, necessitating an induced coma. When she eventually regained consciousness after seven long days, she was not the Ayana I knew. The baby that came out of that coma was not the baby I had brought in to the hospital the previous week. Ayana started having regular seizures that required a cocktail of anti-epileptic medication to control. The brain infection lead to her developing hydrocephalus, an excessive build-up of fluid in the brain beyond the body's ability to absorb this fluid. She was operated on to install an external shunt to drain this fluid, which was later replaced by an internal ventriculo-peritoneal

(VP) shunt. During this period it was determined that Ayana had suffered severe brain damage and was diagnosed with spastic cerebral palsy – with her regularly having three different types of seizures and excessive muscle spasms.

During her time in hospital she had recurring bouts of septicaemia. This not only extended her stay in hospital, but also resulted in her VP shunt being infected, which meant reverting to the external shunt while waiting to replace the VP with a new one. The cause of recurring infections was pin-pointed after extensive analysis of her immune system. Results from a study of her immune system showed low levels of a protein call mannose-binding lectin that plays an important role in eradicating infectious microorganisms from the body. Individuals (especially babies and children) with mannose-binding lectin deficiency are thus at higher risk of serious infections such as pneumonia and meningitis.

“

I lost focus and my body became heavy as the doctor began yelling  
“Code blue”!

”





After admission on 27 July 2018, Ayana was finally discharged on 3 January 2019. During her time in hospital, our baby was operated on seven times, suffered from multiple infections and now requires a cocktail of medications on a daily basis to have some sense of normality. She suffers from several seizures daily, and whilst the structure of both her eyes and ears were determined to be normal, how much she sees and hears has been significantly impacted. Ayana can no longer walk nor sit; yet since leaving the hospital she has been on ongoing physio, occupational, speech, visual and hydro-physio therapy.

Although she can no longer do anything she was able to do prior to the hospitalization, Ayana has made strides in terms of progress. She used to have an average of 23 seizures a day and is currently on 6 seizures a day as her neurologist continues to work hard on her having no

seizures at all. There is now also deliberate hand movement that is mostly noticeable when she has eye or nose irritation as she is able to reach for her face to relieve the itch. The young lady has developed her own way of communicating with us, has learned to ingest food orally and has not developed any negative musculo-skeletal issues normally associated with spastic cerebral palsy. She has a feisty personality and is quick to let you know when she's unhappy with something or someone.

My wish is to take Ayana to NeuroSolution  
Center of Austin also known as Austin  
Center For Developing Minds  
[www.austincdm.com/](http://www.austincdm.com/)

for intensive daily physio, occupational, speech and red light therapies that would require a month-long stay in Texas, USA. The travel, accommodation, treatments and purchase of her personal therapy equipment will cost no less than R1 200 000.

“

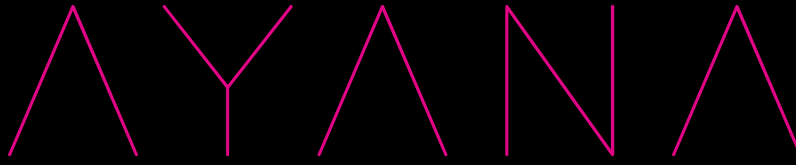
Ayana can no longer  
walk nor sit

”





Item	Description	Cost
Zoom Consultation	Initial consultation with Dr Cordell Miller	<b>\$515.00</b>
Home Care Plan Zoom Training	A program designed specifically for Ayana in preparation for her intensive therapy, that we will have to carry out at home.	<b>\$1 545.00</b>
Intensive Therapy	A month long daily intensive therapy. (4hrs daily)	<b>\$9 270.00</b>
Return flights (3 pax)	Ayana, mom, caregiver. Due to Ayana's inability to sit on her own, she cannot travel economy.	<b>\$25 049.08</b>
Accommodation	One month hotel stay close to the facility	<b>\$3 700.00</b>
Ground transport	One month car rental to get Ayana to and from the facility.	<b>\$3 373.81</b>
Meals	Lunch and dinner for mom and care give for a month.	<b>\$2 448.73</b>
Laser	Equipment needed for pre and post care to aid in rehabilitation.	<b>\$8 100.00</b>
Stimpod	Equipment needed for pre and post care to aid in rehabilitation.	<b>\$2 995.00</b>
Laser Stand	Equipment needed for pre and post care to aid in rehabilitation.	<b>\$250.00</b>
Rezzimax	Equipment needed for pre and post care to aid in rehabilitation.	<b>\$599.00</b>
Fisher Wallace	Equipment needed for pre and post care to aid in rehabilitation.	<b>\$699.00</b>
Miscellaneous	Provision for follow up virtual consultation and other medical needs she might require that are not listed above.	<b>\$15 000.00</b>
TOTAL (in USD) <b>TOTAL (in ZAR)</b>	Calculated at exchange rate of \$1 = R22.00 (Provision for exchange rate increase)	<b>\$73 544.62</b> <b>R1,617,984.64</b>



I have a dream that Ayana's journey will enable other parents with neurodivergent children to reach out to all corners of the world, leaving no stone unturned in the quest to find assistance. I dream of Ayana being the center of a ripple that will spread beyond my family's situation and that she will enable other families to gain access to therapies with overwhelming costs. I dream that individuals and organizations that are able to extend a helping hand will reach out to improve the lives of those living with various medical conditions that dampen the quality of their everyday lives. I dream of beginning with Ayana and paying it forward. If you would like to donate towards Ayana's journey, kindly use the provided account details.

<b>Bank:</b>	First National Bank
<b>Account Holder:</b>	The Ayana Children's Foundation
<b>Account Number:</b>	63059581752
<b>Branch Code:</b>	250955
<b>Swift Code:</b>	FIRNZAJJ