

**... MY SON:
LIVING WITH HIS INVISIBLE ILLNESS**

THE BEGINNING

It's a BOY!





The Prince is Here!



After 14.5 hours of labor my
one and ONLY Prince was
born...

- * Zaharion Marcellus Johnson
- * 8 lbs. 5 oz.
- * 21 inches long
- * Healthy Bundle of Joy

Perfectly Imperfect

THE UNKNOWN BEGINNING

I remember it like it was yesterday:

- * Zarrieya's cheerleading competition

What should have been a 45 minute ride home from Grand Rapids, MI, quickly turned into 1 hour and 45 minutes

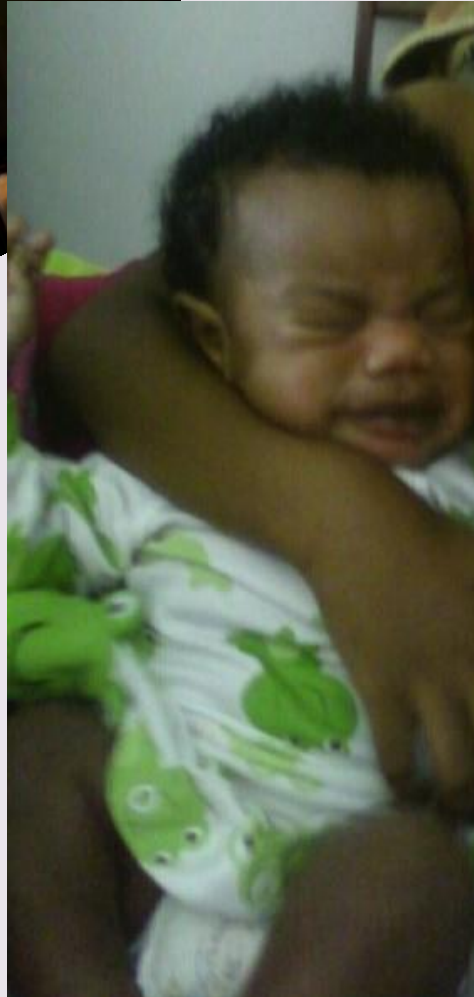
- * The only music to our ears was Zaharion's crying.

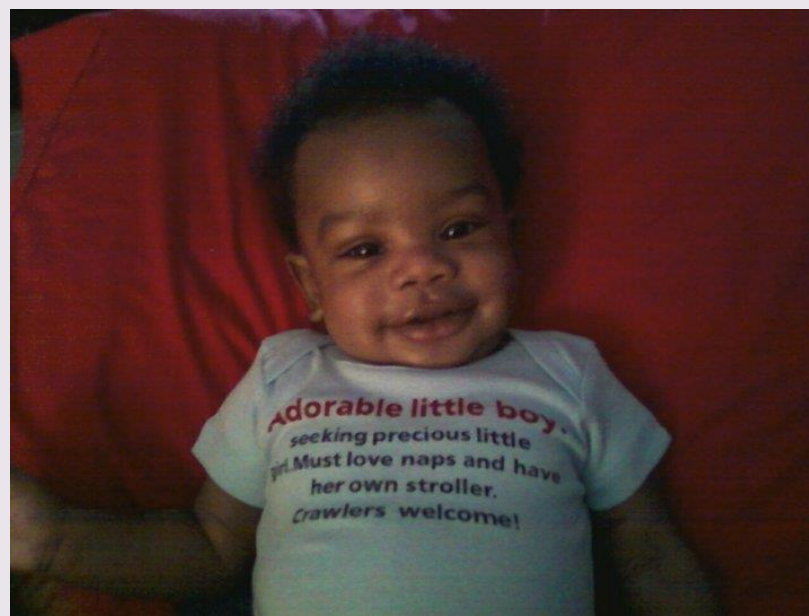
- * Nothing I did was soothing him

- * I rubbed his feet and his cheeks, I showered him with kisses ALL while trying to remain calm

- * **LAST** and most **DANGEROUS** choice: I took him out of his car seat so that I could nurse him, while my Mother was driving on the highway.

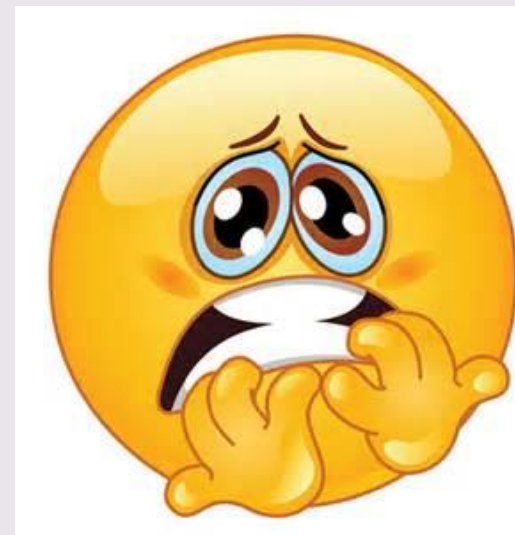
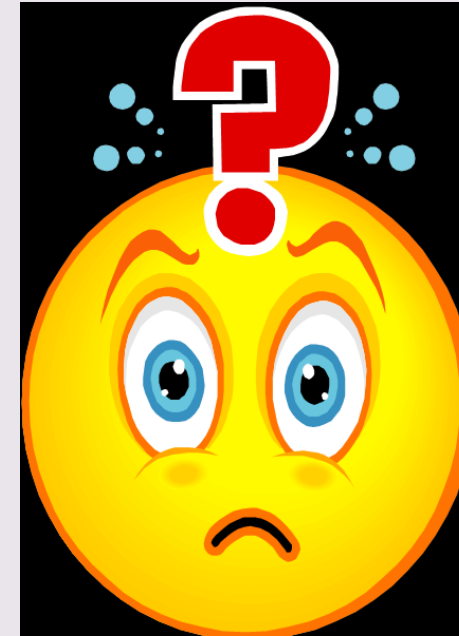
- * In that moment, I would have done anything to see his infectious smile, that I had just saw 2 hours earlier.





WHEN THE CRYING STOPPED...

- Home from Cheerleading Competition, Zaharion is still crying. I had tried everything possible to soothe and nurture him.
 - Every 10 minutes he would stop
- After about an hour, my Mommy took him to give me a moment to rejuvenate. Sitting on the couch across from her, she rocked him and kissed him...she rubbed his feet...the crying started again. Maybe he has to burp? She lifted him up against her chest and began patting his back. Within 2 minutes, he laid his head on her shoulder. That was my WARNING sign!
 - Remember saying, “Mommy, something his wrong with him. He is NOT a shoulder baby. He cries every time anyone tries to lay his head on their shoulder. I know that he just stopped crying, but something isn’t right.”
 - Mommy, “Your right, he is not a shoulder baby.”
 - Me:, “Lets look at his face? He can’t be asleep that quick. Sit him up.”
- Just has she was lifting him off of her shoulder and turning him around, he let out this piercing cry and I remember hysterically screaming, “HIS EYES ARE ROLLING!! OMGOSH! LOOK AT HIS FIST! WHY IS HE JERKING! WHAT IS WRONG WITH MY BABY!”
 - Crying uncontrollably, I call **911**



PANIC ROOM...PANIC ATTACK

- Ambulance arrive within 10 minutes
 - Seemed like 50 million of the same questions
 - Remember thinking, “This is like the song that never ends.”
 - Remember asking (while crying uncontrollably), “Why are you asking me the same questions I just answered? Didn’t dispatch relay the information? WAIT...what are you doing with my baby? STOP...your making him cry more. Now my daughter is crying? Couldn’t you have asked me to ask her to leave the room? She’s 8 for God’s sake!” STOOOPPPP!! *Another seizure begins*
 - Blame game
 - “It’s your fault he had another seizure!” Mommie, why are you so calm? Can’t we just drive him ourselves?” OMGosh...just give me my baby!” As the EMT says, “Mom, we know it’s easier said than done, but please stay as calm as you can because he....
ANOTHER seizure **2 minutes of post** *ANOTHER seizure*
 - Game of Silence
 - After seeing these 3 seizures back to back, I remember standing in the middle of the living room, with a blank stare and my lips had stopped moving. My head was spinning...everything/one EXCEPT my son was a blur
 - I hear the EMT’s say, “We have to get...” “Now.” “Mom, you can rii...” “Not the back..”
- VS
- What they actually said, “We have to get him on the ambulance NOW! We can finish these questions later. Mom, you can ride in the ambulance but you’ll have to ride in the front, because we need to keep him stabilized.”



Step 1

TRY to remain Calm Rubontay

You absolutely CANNOT remain cam



Step 2

The EMT’s are simply following their procedures. Asking questions is part of the process.

These people need to do less talking and more driving



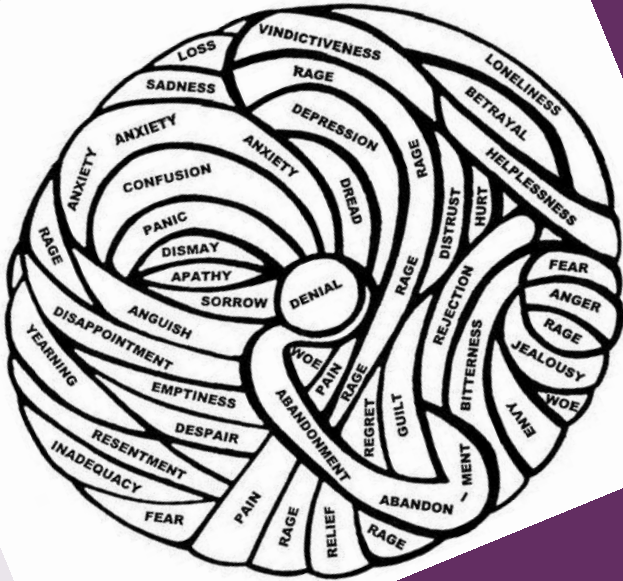
Step 3

They have to stabilize him as much as possible before transporting him

“Screw this! Pick Toot up and drive him yourself”

THE E.R.

A TANGLED "BALL" OF EMOTIONS



Welcome to the Bronson Battle Creek
Emergency Department.

LOGISTICS vs REASSURANCE

- Once again, 50 million questions
 - Who are you?
 - What happened?
- Where were you doing prior to his seizure?
 - Are you sure?
 - Is this the first?

EMOTIONALLY UNSTABLE

- Frustrated
- Doubted
- Not believed
- Does the first experience really mean I'm not "wise" enough to have knowledge.
 - Guilt
 - Blame Game
 - FURIOUS

Ticking TIME-BOMB

MOM ON FIRE...



RIDE ALONG





FIRST IMPRESSIONS

- Smiles
- Greeted at the door
- **AKNOWLEDGED**
- More questions
 - But this time was different
 - Vitals. Chart.
- Ask Mom. **REPEAT**
- Battle Creek Health Systems could use some tips
- Let me Introduce myself...
- **VALIDATION**

welcome

Pediatric Neurology & Neurosurgery at Bronson Children's Hospital

We're proud to be southwest Michigan's only children's hospital, providing children with specialized neuroscience care from diagnosis to surgery.



While You're Here

- » Your Rights
- » Your Safety
- » Your Stay
- » Your Care Team
- » Food
- » Support Services



Children need special doctors, nurses, equipment and treatments. That's what we offer at the region's only children's hospital. Everything about our pediatric care is specially designed just for them.

ADMITTED

- Home away from home
 - “Mom, what formula does Zaharion drink.”
 - He is nursed
 - We love it when Mom’s say they nurse. Good for you Mom! And because you nurse, you can order room service up to 5 times each day.
 - Feeling of validation during my mental chaos



- In the next 24 hours, Zaharion will have multiple test in order to determine the cause of the seizures
 - Hospital Social Worker will be around to talk to you
 - It’s common to not find anything the first time so don’t be alarmed.
 - Questions are normal so please don’t hesitate to ask. Right now, it’s going to seem like a lot of “I don’t knows” until he has completed all the testing.
 - Because he is only 4 months, some test may be more challenging because he will have to go with the nurses and he won’t smell your scent
 - Is there a reason why I cannot go with my son?
 - Are you TELLING me or ASKING me?



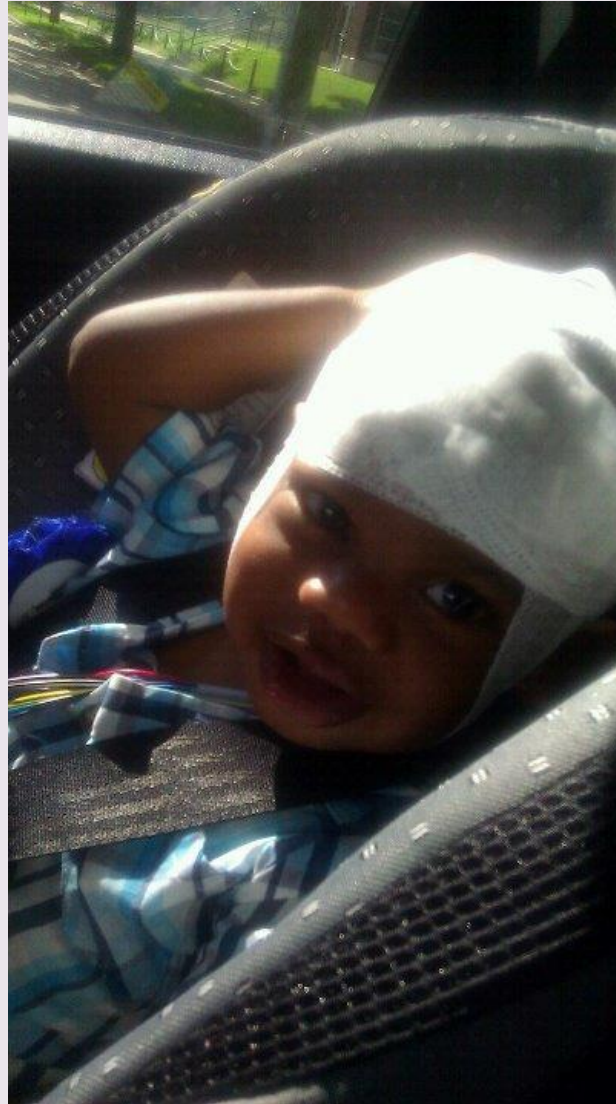
DISCHARGE DAY

THE NEXT 7 MONTHS

- Seizures increased
- Still NO call from the Social Worker from January
- In and out of the E.R.
- Several EEG's attempted but were unsuccessful
 - Time of day of test
 - How am I supposed to keep an infant awake all day until test
 - How am I suppose to keep him calm when I'm told not to give him anything by mouth an hour before
 - Because that's really going to happen
- Continuous calls to the Neurologist
 - Overnight EEG FINALLY scheduled...for August 3rd...Toot's 1st birthday

HAPPY 1ST BIRTHDAY TOOT!

AUGUST 3, 2011



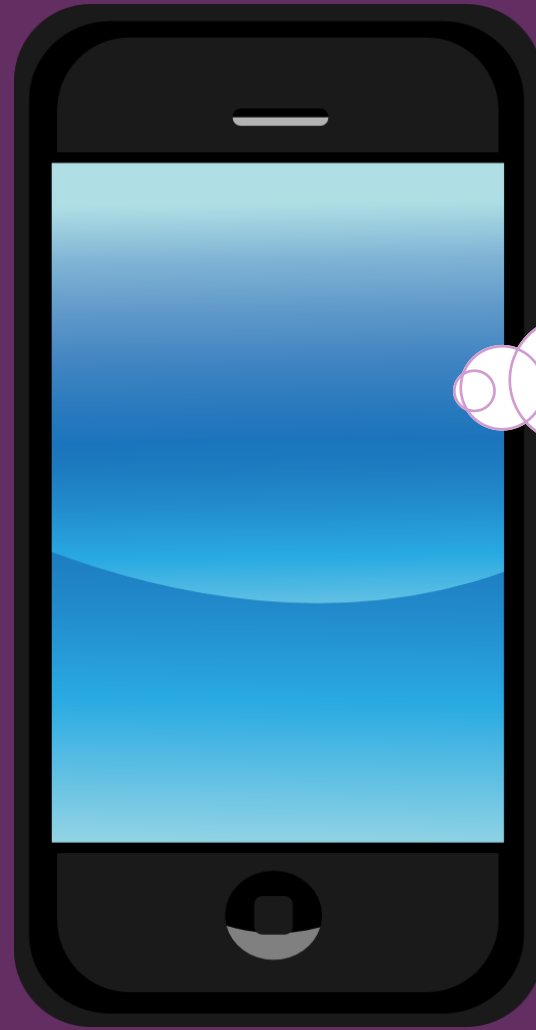
THE WAIT...



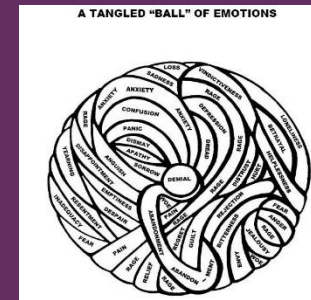


- The results can't be taking this long.
- Are they really that busy?
- **THINKING:** It's been like 2 months
- **ACTUALITY:** 2.5 weeks, but my mind kept telling me different
 - By this time I am already expecting worse. I simply felt in my gut. I began to prepare myself for the phone call.
- 3 weeks later and my caller ID finally said Pediatric Neurology

September 2011



Epilepsy



No matter how much I prepared myself for this phone call...I still was NOT prepared.

OCTOBER 2011

*** HIS BEHAVIOR IS EXTREME**

- VERY AGGRESSIVE

*** FIRST APPOINTMENT SINCE TESTING AND RECEIVING TEST RESULTS**

- 6 – 10 seizures a month since having testing until now
- No environmental changes
- His behavior
 - Is this common?
- Etc.

***CSHCS**

- FIRST MENTIONED
- NO idea what it is
- What is it?
- Does he qualify?
- Maybe later
- Resource?
- Why hasn't anyone ever mentioned this?

“Invisible” Social Worker that I NEVER heard from

***SSI**

- Applied?
- A process = patience

NOVEMBER 2011

Michigan Department of Health and Human Services
CSHCS
PO Box 30734
Lansing MI 48909



For questions and/or problems, or help to translate, call the Beneficiary Help Line at 1-800-642-3195 or TTY 1-866-501-5656.

Spanish: Si necesita ayuda para traducir o entender este texto, por favor llame al telefono, 1-800-642-3195 or TTY 1-866-501-5656

Arabic: TTY 1-866-501-5656

إذا كان لديكم أي سؤال، يرجى الاتصال بخط المساعدة على الرقم المجاني ١-٨٠٠-٦٤٢-٣١٩٥

November 1, 2011

XXX
XXX
XXX MI XXXXX

Dear Applicant:

Welcome to Children's Special Health Care Services (CSHCS), a program that focuses on family-centered services for children with special health care needs. We help families get needed services for children with CSHCS.

XXX has CSHCS coverage from January 2011 through January 2012.

Your doctor sent us information that shows that XXX qualifies for CSHCS for ~~new Diabetes Mellitus without complications and uncomplicated diabetes~~. We will mail you a Client Eligibility Notice (CEN) soon. The CEN lists approved medical providers that XXX can see for services related to this diagnosis.

What does CSHCS cover?

Enclosed is information about what CSHCS covers. You can get more information on our website at: www.michigan.gov/cshcs

What do families need to know about Local Health Departments?

Local health department staff work with CSHCS to serve your family. Your local health department will contact you soon to share contact information and additional assistance.

Questions? Call either your local health department or the Family Phone Line:

**LHD Info
Family Phone Line at 1-800-359-3722**

We look forward to serving your family.

Children's Special Health Care Services

Enclosures

THE JOURNEY AHEAD

- Life hasn't been the same since I received that FIRST phone call telling me that Zaharion...my baby...has been diagnosed with Epilepsy
 - His behavior
- Life altering decisions
- I've question, blamed, and beat myself up
- I felt like I had failed as a Mother; his nurturer
- I felt like I was now neglecting my 8 year old daughter
- I still had NOT heard from the Social Worker so naturally, I began to think "they" didn't care; my son was just another "Epilepsy Patient"
- Was I going to be prepared for the continuous doctor appointments?
 - Was I going to responsible?
- Was I prepare for the uncertainty?
- Was I going to learn to ASK for HELP?



Epilepsy and learning

Children with epilepsy have the same range of intelligence and abilities as other children. However, some children with epilepsy will have learning difficulties.

This is usually due to a coexisting condition, such as an underlying brain abnormality, or it might be related to the child's frequent seizures.

Sometimes, medication is a contributing factor as it may cause drowsiness or hyperactivity. When a learning difficulty is identified in a child, there are strategies available – both medical and educational – that can be implemented. Talk to your epilepsy counsellor about any concerns you might have.

LOST

&

OVERWHELMED



Supports?

Family

Adjustments

Employment

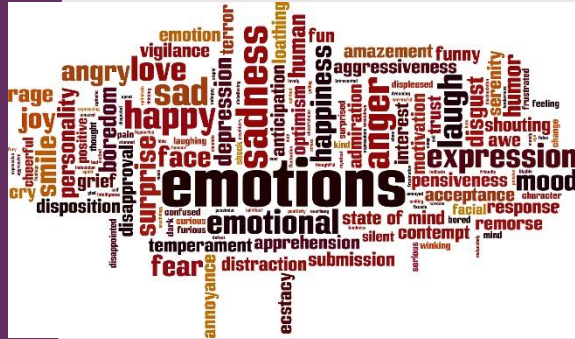
Health Insurance?

Sensory Processing Disorder

AS THE TURNS



ADHD



Parasomnia



KEEP
CALM
AND
WEAR PURPLE
FOR EPILEPSY

Insomnia



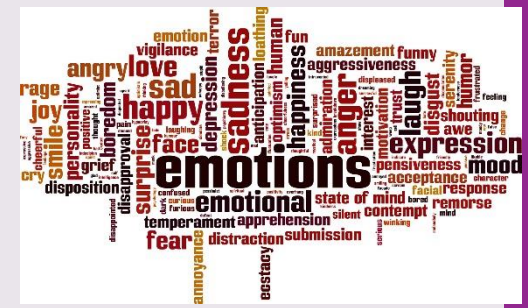
Anemic



Learning Delay



Night Terrors



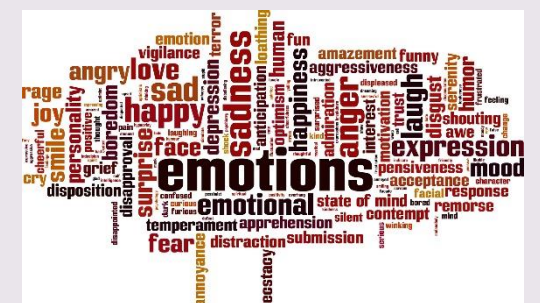
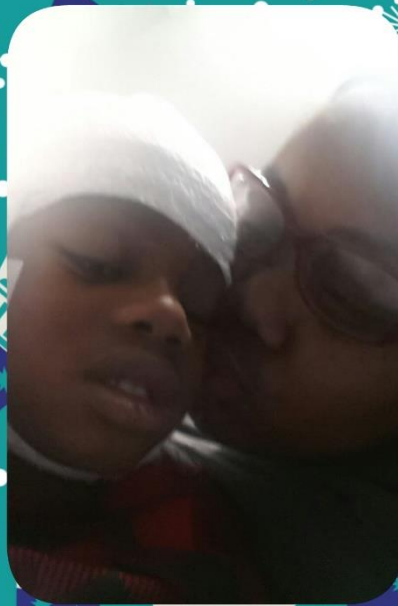
DETROIT CHILDREN'S HOSPITAL

- Referred by his Neurologist in Kalamazoo to DCH
- Agrees that Zaharion has been “struggling” for a while
- Agrees that his brain is “unique”
- UPFRONT and HONEST
 - Intensive testing
 - The end result will either be brain surgery or the VNS once all testing is completed.

HEALTH INSURANCE DISAPPOINTMENT

- Trying to set up transportation
 - Local CSHCS at Health Department
 - Can't be arranged through them, must call United Health Care
 - United Health Care
 - Can't be arranged through us, must be arranged through Medicaid
 - Medicaid
 - Can't be arranged through us, must call United Health Care and ask for CSHCS
 - United Health Care
 - CSHCS Department
 - “I don't know what you are referring too? Please Hold...You have to call Medicaid”
- Medicaid
 - Can't be arranged through us, must call CSHCS
 - ALREADY TRIED THAT
 - Call back and ask for a Medical Social Worker
- United Health Care
 - CSHCS
 - Social Workers
 - Someone will call you back tomorrow
- Local CSHCS at Health Department
 - FORGET IT! I have spend 2 hours going back and forth. I am furious! I don't want to be reimbursed for anything! I will pay for a hotel and my own mileage.”
 - “SO SORRY! This is ridiculous! You are entitled to these benefits let me make some phone calls.”

2 hours vs 15 minutes
NO SUCCESS vs SUCCESS
Same questions



Santa Visits Anywhere

Children's Hospital of Michigan: Detroit Medical Center



Ronald McDonald House

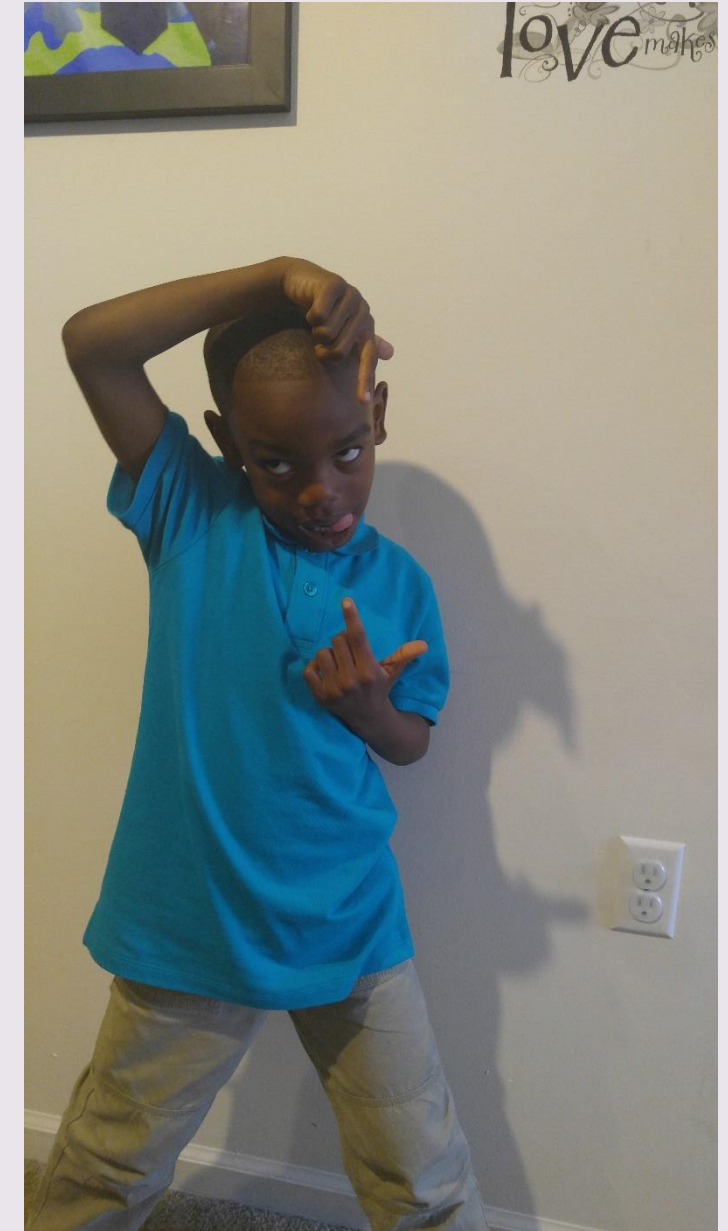
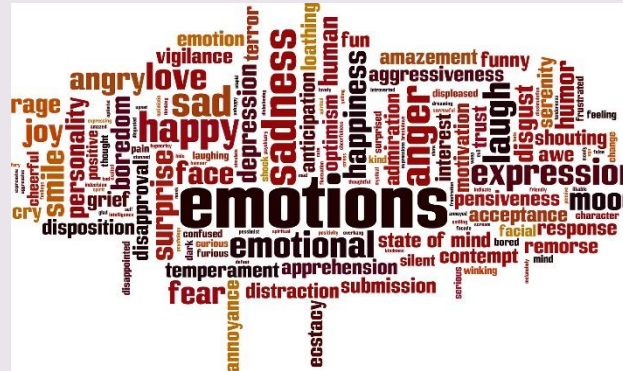
THE DOC IS IN

- Test Results
 - Not what they wanted
 - Not what I wanted to hear = NOW WHAT?
 - Such a waste of time
- New diagnosis
 - Cortical Dysplasia
 - EXCUSE ME? Am I being punked?
 - Tell Ashton Kutcher He can come out now.



LOST
&
OVERWHELMED...AGAIN

WHERE ARE WE NOW

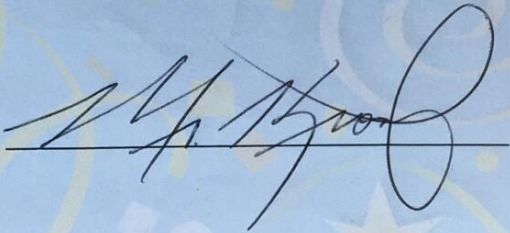


June 10, 2016

This certificate awarded to

Zaharion Johnson

for successful completion of Kindergarten



June 10, 2016
Date



WE WEAR PURPLE FOR TOOT

Brains are just as important as boobs



#November

#NationalEpilepsyAwarenessMonth

#BrainsMatterTOO

#DareTo...Get Educated

Stay Connected



Keeping up w/ Toot



keepingupwithtoot@gmail.com