



FOOTPRINTS 4 SAM

... Because I am ...
... And always will be ...



I AM SAM:

- A beloved child
- A beloved son
- A beloved grandchild
- A beloved cousin
- A beloved person
- A beloved creation of God

... I AM - Viable for life



I AM NOT JUST:

- A chest
- A set of lungs
- A pin cushion
- An experiment
- A time waster (One doctor said to me: “Do you know because of the time I have spent with your son, I have people walking out of my waiting room!”)
- Not viable for life





Quality of Life

A Parents Perspective

SAM'S STORY



Samuel John Frederick Platt



- **A long name for a brave fighter**
– little did we know ...
- **Born 09 April 2015 @12h45** – by emergency caesar (2 gynaes in attendance)
- **Weight** – 1.68 kg a small baby in a big body (severe swelling/odema over his entire body – transient TYROSINEMIA)
- **Between 28-30 weeks** (by my calculations closer to 28 weeks) – Height: 40 cm
- **Very little movement in utero** and limited movement thereafter

13.5 months in Nicu

- **3 months on a ventilator**, approx 2.5 months off CPAP and nasal canula – otherwise ET tube throughout
- **6+ blood transfusions**, numerous X-rays and anaesthetics
- **End September:** Superbugs went rife (colonised early in hospital stay) – back on ventilator
- **3rd December:** Port, tummy peg and muscle biopsy (inconclusive)
- **14th January 2016:** failed MIC-KEY OP – led to Peritonitis
- **Peg failure**
- **Loving nurses & incredible Physio support**



2 months in Paeds ICU

- **Home mentioned for the first time in almost 14 months** – Comprehensive team with a comprehensive plan
- **Off Oxygen** – Breathing on his own for the first time
- **Trache = Freedom** (Eating and drinking, floor work)
- **Redo of muscle biopsy** and peg to MIC-KEY
- **Diagnosis finally** (14 months) – Central Core Disease
- **Daily neuro physio** – Rolling over and sitting
- **Dietician and Speech Therapy**
- **Sepsis**



Final Journey

- A leading Children's Hospital
 - **Care** (World Class)
 - **Concern** (Palliative care, multi-disciplinary meetings)
 - **Capable** (Excellent professionals in every possible field)
- Raised the question of: **Public vs Private** (Collaboration or choice between one or the other – Critical healthcare debate)



Sam's Legacy

- Early intervention and appropriate care
- Parents – Recognising the symptoms of Sepsis
- Superbugs – Raising awareness
- Patient & parent advocacy
- Giving children a voice – A right to life –
A life of quality and excellence



Quality of Life

- To be given every chance possible to live excellently despite each child's restrictions
 - To be seen as viable despite the odds (Family, Medical Team & Medical Aid – One Team)
- Public vs Private
- To be loved
- To be safe
- To be special



To be given every chance possible to live excellently despite each child's restrictions

– “I am viable”

- To look at a child **holistically**
- **Medicine** is only one critical component
- **Equipment** – Stay current
- **Professional support** – Mainstream and alternative therapies
- **Eating** – Diet
- **Playing** – Fun (not just Rehab)
- **Moving** – Rehab and moving home (Access to homecare needs)
- **Access** to family and friends



Public vs Private

- Collaboration or choice between one or the other – Critical healthcare debate
- ** Beauty and the Beast –
Care motive or Profit motive



To be loved

- Doctors
- Nurses (Empowering)
- Mum and Dad and family
- A loving happy environment
(Contrasts of different facilities)
- Excellence (Focus on child not on profit)
- Respect my life



To be safe

- Qualified professionals
- One-on-one nursing
- Hygiene (Superbugs)
- Communication and sharing of knowledge and information
- Knowing when to hand over the baton – A relay of excellence
- Parental access to doctors and information
- Mutual respect



To be special

- Unique
- Individual
- Home

... For I am me – Let my footprints count ...



*And now we need to make
the footprints for Sam...*

- Raised nearly R400 000 for children with Rare Diseases.
- Trained other Mums and relatives to help other children with Traches.
- Touched lives and hearts
- Brought Atheists and Believers to their knees.
- Love and forgiveness,
joy despite everything...

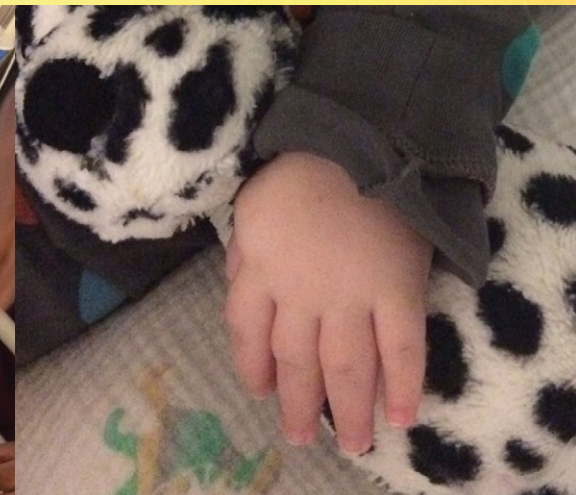


Sam's Footprints...

Our Commitment to our Son is to ensure his bravery and loving spirit lives on through others and that his life lessons save other lives...

A trail of footprints touching hearts and lives, bringing change and hope wherever they go...





Thank you.

FOOTPRINTS 4 SAM



Footprints4Sam