

# Ava's Journey

Cancer, chemo, blood and beyond

Presented by Kelly Stokes, Ava's Mum



BBTS  
2019



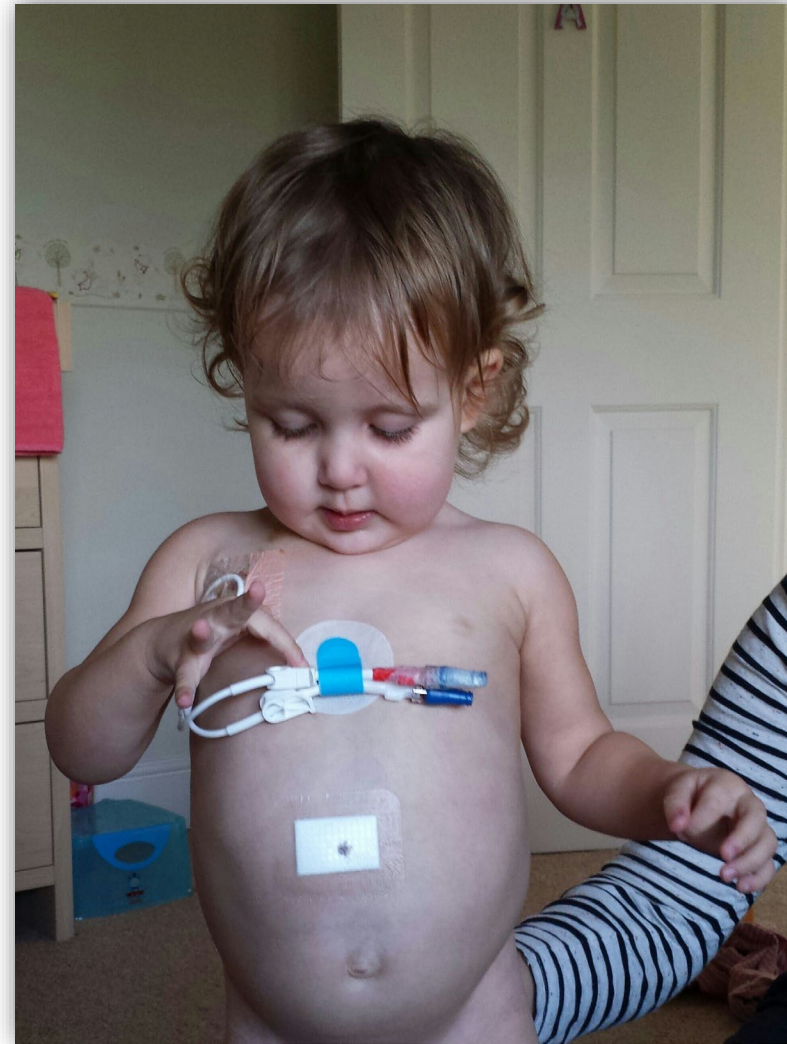
British Blood  
Transfusion Society

#BBTS2019

# About Ava

- Healthy baby, born full term, no complications
- At 16 months old
  - recurrent chest infections
  - severe nappy rash
  - night sweats
  - swollen abdomen
- At 19 months old, after many trips to the GP, she was urgently referred to Alder Hey Children's Hospital

- Full Blood count and profile were normal
- Peak AFP level was 438,957  
(normal is less than 10!)
- Ultrasound, CT scan and liver biopsy carried out
- Diagnosis
  - High Risk, Pretext 3, Hepatoblastoma
  - Metastatic lung disease



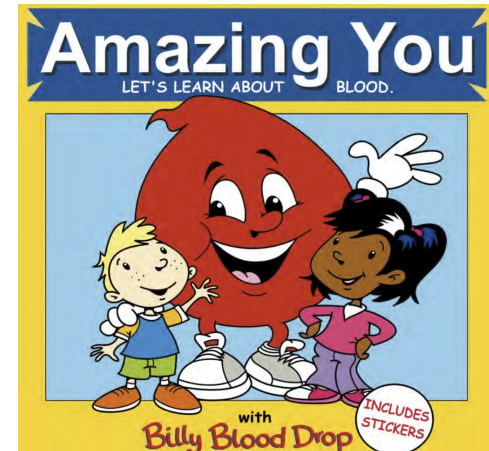
# Treatment

- Intensive chemotherapy started within 1 week of diagnosis at Alder Hey Children's hospital
- Cisplatin, Doxorubicin and carboplatin on an 11 week cycle
- Initially tolerated treatment well
- After 18 days of treatment, she began requiring support to recover
- Side effects included hair loss, vomiting, febrile neutropenia, high frequency hearing loss, severe drop in all blood counts and required nutritional support via PN then NG tube



# Billy Blood Drop

- First red cell and platelet transfusions 18 days after treatment commenced
- Received an information pack from the Nurses which really helped
- Billy Blood drop became a family favourite with Ava and her then 4 year old brother Alex!
- Prior to diagnosis we had little to no knowledge of blood products/transfusions or how crucial they were in the treatment of cancer
- Transfusions became part of our lives as treatment progressed
- At the end of this treatment, Ava had received;
  - 14 red cell transfusions
  - 20 platelet transfusions



# Transfusion Reactions

- After approx. 10 red cell transfusions Ava had a reaction
- Developed a hive like rash on her neck, face and head and often spiked a fever
- Transfusion was slowed and antihistamine given
- Prior to further transfusions antihistamines given pre transfusion

# Transfusion Reactions

- A week later, similar reaction occurred to platelets
- Anti-histamine was administered
- Further reactions occurred during the next transfusions
- Was given both anti-histamine and hydrocortisone
- This combination worked and no further reactions occurred
- Explanation given was that she had developed an allergy due to the frequency of transfusions (we had been warned of this)

# Surgery and Transplant

- Good response to chemotherapy in both liver and lungs
- Initially scheduled to undergo surgery to resect her liver
- Cancelled on the day of surgery due to concerns about surgical margins
- MRI scan showed how close the tumour was to her portal vein and hepatic artery
- Liver transplant was her only remaining option
- Only listed after a successful thoracotomy to remove the remaining lung nodules and further 'mop up' chemotherapy
- Listed for transplant on 23 July 2014

# Liver Transplant

- On 2nd August 2014 Ava had her life saving liver transplant at Birmingham Children's Hospital
- Short period of intensive care and HDU
- Discharged home after 18 days
- Long term regime on immune suppression medication, tacrolimus
- Talk to anyone who will listen about organ donation!



# Life after...

- Ava was 2 ½ years old at the end of treatment and in remission
- Within 6 months she was back to nursery
- Doing most activities of children her age
- Adjusted well to her situation
- Quickly regained weight and began to develop normally once again



# 2016...

- April 2016, 20 months post treatment, Ava became quite poorly
- Suffered recurrent ear and eye infections
- Excessive bruising after minor bumps/falls
- Pale, lethargic and high temperatures
- GP visit unsatisfactory
- On instinct, took Ava to Oncology day case the same day
- FBC showed a reduction in her red & white cells and platelets (neutrophils were 0)

# Cancer.....again!

- Bone Marrow Aspiration revealed Acute Myeloid Leukaemia (AML)
- Cytogenetics confirmed this was treatment induced Secondary AML
- Treatment began the day after diagnosis, at Alder Hey
- More intensive chemotherapy treatment included Fludarabine, Cytarabine and Daunoxome
- 2 rounds of this treatment were planned

# Billy Blood Drop returns!

- As a result of her pancytopenia, red cells and platelets were transfused often
- Due to the use of fludarabine, Ava was issued with an alert card and required irradiated blood products going forward to reduce the risk of Transfusion Associated GvHD
- Pre-transfusion doses of Hydrocortisone and Anti-Histamines were given due to previous reactions

- Transfusions again became the norm
- The difference in Ava after a red cell transfusion was AMAZING!
- This picture shows how pale and lethargic she was at the beginning of the transfusion



- And by the end...
- Significant increase in energy
- Happier
- Positive
- Ready to play



# Transplant...again!

- First round of treatment did not put her into remission
- A 2nd round was not recommended- unlikely to result in remission and only make her more poorly
- Ava's only hope of a cure, was a stem cell transplant
- We were warned of the significant challenges Ava faced going into transplant:
  - It is preferable to be in remission, the results are superior
  - Ava had been extensively pre-treated - susceptible to the toxicities and co-morbidities of transplant

# A trip down the M62!

- Ava was ultimately offered a cord blood stem cell transplant at RMCH under the care of Prof Rob Wynn
- Reduced toxicity transplant
- Drugs used were Fludarabine, Treosulfan and Thiotepa
- The cord blood was mis-matched for better leukaemic control – they wanted some GvHD to kill off the remaining leukaemia cells
- Following diagnosis on 12 May 2016, Ava was transferred to RMCH on 13 July 2016

# Reset the system!

- We hit the reset button on Ava's immune system on 21 July 2016





- The next 4 to 5 weeks were pretty awful
- Ava suffered many side effects associated with conditioning treatment
- She was platelet dependant for most of her admission and required regular red cell transfusion too
- new cells took longer than expected to engraft, but once they did, her blood counts recovered well

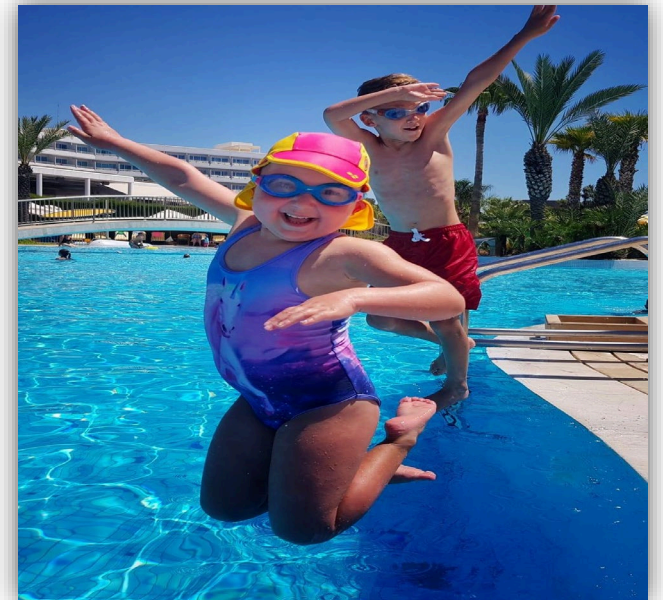
# Timely Transfusions REALLY matter

- During this treatment Ava had 25 platelet and 8 red cell transfusions
- That's 45 platelet and 22 red cell transfusions over BOTH treatments
- The blood products were **ALWAYS available** when they were needed
- The difference they made to Ava was visible and **she knew** it would make her feel better
- Without the work that you do, patients like Ava simply would not survive treatment!

# Today

- 5 years post liver transplant and 3 years post stem cell transplant
- Happy, cheeky, well 7 year old and at school full time
- She loves Gymnastics, singing and dancing
- There are ongoing, late effects that she has to deal with
  - Chronic GvHD of the lung
  - Mild GvHD of the skin
  - Chronic Kidney Disease (low level)
  - Hearing loss

**But with the help of the amazing NHS these are all regularly reviewed and well managed.**



# forAva Foundation

*Being there, always and forAva*

- Inspired by Ava's Journey, we founded the **forAva Foundation**
- We support children and their families in isolation providing Be There Boxes and bags to bring smiles and help with distraction from their treatment
- We also raise awareness of:
  - The importance of giving blood/platelets
  - Childhood cancer
  - Organ and cell transplantation
  - Organ and stem cell donation and how to register
- You can follow our story here :
  - @forAvaFoundation (Facebook)
  - @forAvaFriends (Twitter)
  - [www.forava.co.uk](http://www.forava.co.uk)



# Thank you for listening!



[www.forava.co.uk](http://www.forava.co.uk)