

To Vein or Not to Vein?

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Haemophilia Treatment

- Intravenous treatment
- Frequency
 - FVIII – 3 times/week or every 2 days
 - EHL – every 3-5 days
 - FIX – 2 times/week or every 3 days
 - EHL – every 7-14 days



Venous Access

- IV cannula
- Peripheral venepuncture
- CVAD/IVAD
- AV fistula



Prophylaxis

- Major bleeding incident
- First joint bleed
- By the time they start school

Average age 1- 3 years old



CHW Numbers

- Haemophilia & other bleeding disorders – **228**
 - Haemophilia A – 106
 - Haemophilia B – 22
 - Rare bleeding disorders – 38
 - von Willebrands – 62
- Prophylaxis patients – **74**
- Ports or Central Lines - **24**



Children

- Age at starting prophylaxis
- What are their veins like
 - Size
 - Location
 - Previous cannula placement and number
- Treatment regime – type of factor
- Involvement and focus
- Parent dedication



Case study AL

- DOB 05/08/2015
- Term
- Planned elective caesarean – third child
- 3.7kg, 49.5cm
- Swelling on thighs from birth Vitamin K and Hepatitis B
 - Oozing from IMI and also heel prick



Diagnosis

- Bloods – coagulation studies
 - APTT 109
- Referred to CHW – 6 days old
- FVIII <1%
- No family history



Early days

- 6 week immunisations
- Bumped head on change table
- 4 month immunisations
- Superficial bruising as becoming mobile
- 6 month immunisations – change Dr's
- EHL screening visit



EHL Study

- 3 month study visit (9 months old)
 - Presented next day with cubital swelling
 - Required single dose EHL
- 12 month immunisations
- 13 months – fall from couch onto slate
 - Large subgaleal bleed
 - 2 days treatment (3 doses)





Prophylaxis

- 14 months – left ankle bleed
 - IVC – daily doses for 4 days
- **TIME TO START PROPHYLAXIS**
- Regime – twice weekly EHL
- Discussion with family
 - Veins vs port
 - Let's try veins 😊



How will this work?

- Parents willing and keen to try veins but....
- Lived 20 mins from hospital
- Dad part time work



Treatments

- 14 months to 20 months
 - Twice weekly – Monday and Thursday
 - Left hand
 - LMX4 cream
 - Distraction – TV, surprise box, bubbles etc
 - Sat with Dad
 - Played with toys after treatment



Was it smooth sailing?

- For the most part yes
 - AL had good days and not so good days in the beginning
 - Consistency
 - Same seat and table
 - Dad
 - Same vein
 - Me



Problems

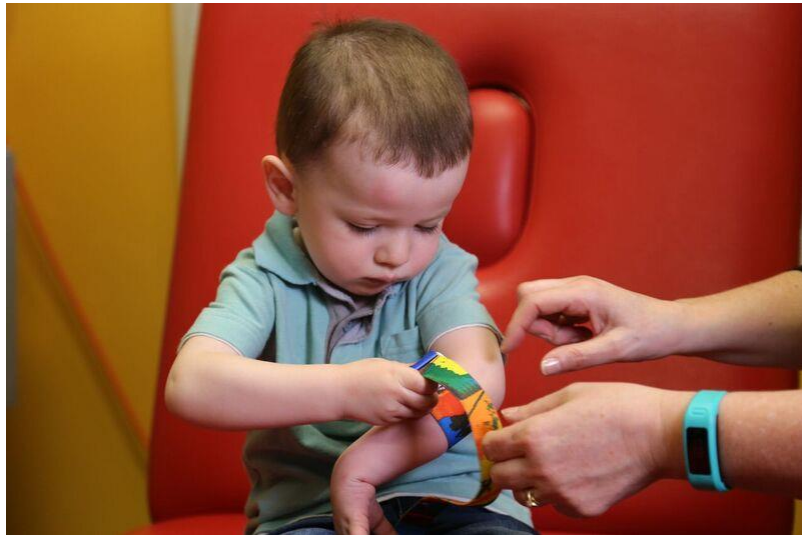
- Grumpy days
 - tired, hungry
- Wiggling
 - bored, wanted to go and play with toys
- Not hydrated or warm enough
- Needle dislodgement
- Difficult to hold hand
- Days off and holidays



Time to learn?

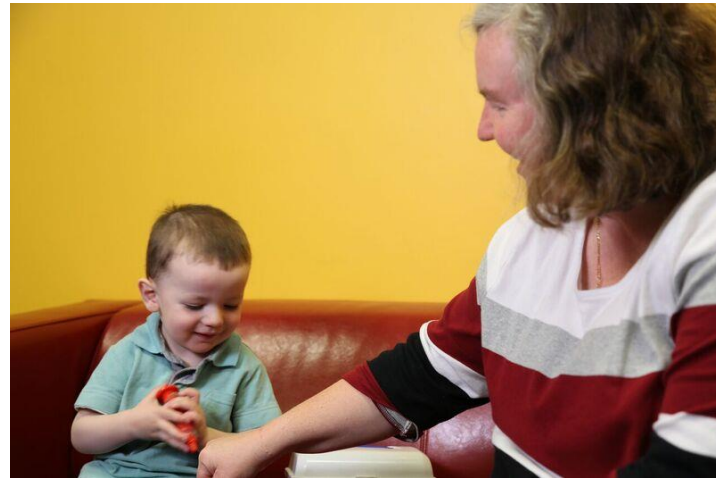
- 18 months – Dad participating
 - Infusing factor, removing butterfly
- 19 months
 - Dad's first attempt – success
- March 2017 – 20 months
 - Home visit





Why was it a success?

- EHL
 - Less needles – only twice a week
- Good veins
- Easily distracted
- Happy child
- Willing parents
- Consistency



Where are we up to?

- Dad performing venepuncture
- Ongoing HTC support
- Dad inserting butterfly for study visits
- Able to do same activities as his older brothers – including camping
- Feature in the CHW Annual Report
- Youngest patient to successfully teach parents venepuncture



