



# Living with vWD

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# Outline

- (Mis) Diagnosis
- Joint Bleeding in Type 3 vWD
- Strategies to control bleeding in target ankle
- Pain Management
- Social adjustments
- Outcomes and what the future holds

## Mis (Diagnosis)

- Son, Zac, initially diagnosed with haemophilia A after severe bleeding from frenulum at age 1
- No family history
- Continued to have severe bleeds that were slow to stop even with treatment- especially nose bleeds
- Finally did further testing, and diagnosed with Type 3 vWD on Xmas eve at age 3

# Mis (Diagnosis)

- Further investigations for family
- Both parents Type 1 vWD
  - Speaking with families realised common bleeding history
- Younger sister Type 1 vWD
- Once Zac diagnosed with vWD and received the right products they worked like magic to control bleeds



# Joint Bleeding in Type 3 vWD

- Early misdiagnosis meant bleeds when young often lasted days and were under treated
- Under treated as on-demand rather than primary prophylaxis
  - only short periods of prophylaxis
- Joint damage as a result
- Target joint in left ankle developed

# Strategies to control bleeding in target joint

- Radiosynovectomy for left ankle
  - Just recovering at last conference
  - Unsuccessful
- MRI to assess ongoing joint damage
- Fusing of joint considered
  - Recommended to help control constant pain
  - Difficult for a child to understand

# Strategies to control bleeding in target joint

- Surgery arthropathy synovectomy
  - Supported by hospital staff
  - Decided to go private to speed up process
  - Significant amount of FVIII plasma products required
  - 1 week in hospital



# Strategies to control bleeding in target joint

- Surgery arthropathy synovectomy
  - Recovery slow, over 3-6 months
    - Air cast boot
    - Wheelchair
    - Crutches



# Strategies to control bleeding in target joint

- Current treatment
  - Now everyday as a preventative for other joint – his knee was a target joint when his was younger
  - Prior to operation in 2007 was every second day

# Social Adjustments

- General public unsure what vWD is
- Zac at a new school this year
- Other children question whether can they catch the disease not understanding
- Stories of children hitting Zac to see what happens

# Outcome

- Pain free days
- Zac can walk – occasionally run without pain
- Able to be active





What will  
the future  
hold???