# Approach to the Child of Jehovah's Witness with a bleeding disorder


**TP Conference**

***" FROM IN UTERO AND BEYOND"***

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# Overview

- Case presentation, with patient and clinician journey
- Jehovah's Witness and blood products
- What happens when consent is not given

# Presentation

- 2yo boy presented to local hospital with epistaxis

- FBC: Hb 72, WCC 9, Plt 2

- Parents declined blood products - Jehovah's witnesses
  IVIG x 2 – no improvement
  Theatre – cautery and nasal packing
  Transferred to BCH for further investigation
  Platelet transfusion – plt increment to 127
  BMA: amegakaryocytic marrow

- BG: Ex 35/40 IUGR. Plt at birth 301
  Height, weight & HC <0.4$^{th}$ centile, ?mild dysmorphic features
  12 month history of mild epistaxis, easy bruising

# Our approach

- Discussion with family, respectful of their beliefs and wishes
  - agreement that we would only give blood products without consent in a life-threatening situation

- Jehovah's Witness Hospital Liaison Committee

- Transfusion nurse practitioner - Clare Pedley

- Discussion why other treatments were not an option currently
  eg: EPO, Romiplostim, IVIG, Steroids

- Agreement to start Sytron to aid anaemia (Hb 47)

- Explanation of the need for a BMA, but would require platelet transfusion prior to procedure

# Policy for use when consent is not given for the use of Blood and Blood Products (Including Jehovah's Witnesses)

# Policy

- To ensure that the best interests of children are paramount in the care that they receive whilst respecting the religious beliefs of the patients and their families

  Deeply held core value:

  regard a non-consensual transfusion as a gross physical violation.

- It is not a doctor's job to question these principles, but should discuss the medical consequences of non-transfusion in the management of their specific condition.

- It is essential to establish the views held by each Jehovah's Witness patient/parent as certain forms of autologous transfusion such as blood salvage techniques, haemodilution, haemodialysis, cardiopulmonary bypass, and the use of fractions such as albumin, immune globulins, haemoglobin based oxygen carriers and clotting factors may be acceptable.

# Duties

- **Duties**: Consider alternative treatments were possible and respect the family's religious views but where this is not feasible to act in the best interests of the patient and liaise with Legal Services to obtain a specific issue order for treatment.

- **Best Interests**: The best interests of the child are paramount and if, after full parental consultation, blood is refused, the consultant should make use of the law to protect the child's interests.

- **Specific Issue Order**: may be applied for to provide legal sanction for a specific action, such as the administration of blood, without removing all parental authority.

- **Emergency**: If a child needs blood when they are in imminent danger of death it should be given. A clinician who stands by and allows a child to die in circumstances where blood might have avoided death may be vulnerable to criminal prosecution.

# When does the court need to be involved?

- Those which are absolutely indicated and urgent
  - there is time, a Specific Issue order should be sought from the Courts

*An application to the High Court takes a few hours and can be sought during the night*

- Those which are absolutely indicated and not urgent
  - first point of contact should be the Legal Services Department

- Those which are not absolutely indicated
  - other treatment choice may be appropriate

*"memorandum of understanding"* ***<u>does not</u>*** *constitute consent*

# Obtaining A Court Order

- Family advised of intention to involve Trust's legal advisors
- Trust Solicitors instructed to make necessary application to the High Court for a Specific Issue Order in accordance with Section 8 of the Children Act 1989

  - along with supporting statement from at least one Consultant

  - copies of relevant medical notes

- During office hours, access via Legal Services Department
- Out of hours, Capsticks contacted directly

- Hearings take place in London at the Royal Courts of Justice.

- **Family:**

  Should be kept advised and invited to any case conference

  Advise them to seek their own legal advice

  Advise that the judge will likely need to speak to/hear from them to obtain their views (or put in writing if unable to attend hearing).

  Discuss the possibility that the Child and Family Court Advisory and Support Service (CAFCASS) may also need to get involved as advocate for the child.

- **Clinician:**

  Consider requesting second opinion

  May need to attend court, or be available on the end of the telephone to speak to the judge.

# Court Outcome

- Court order received one week following initial application

*"It is lawful and in GT's best interests that he undergoes the administration of blood and/or blood products on any date considered as clinically indicated by those treating him."*

- The recital to the order provides the Trust will:

1. continue to consult with the First and Second Respondents to the extent reasonably practicable about treatment for GT before blood products are given and will consider at every opportunity whether there is any alternative to the use of blood products which would be clinically appropriate; and

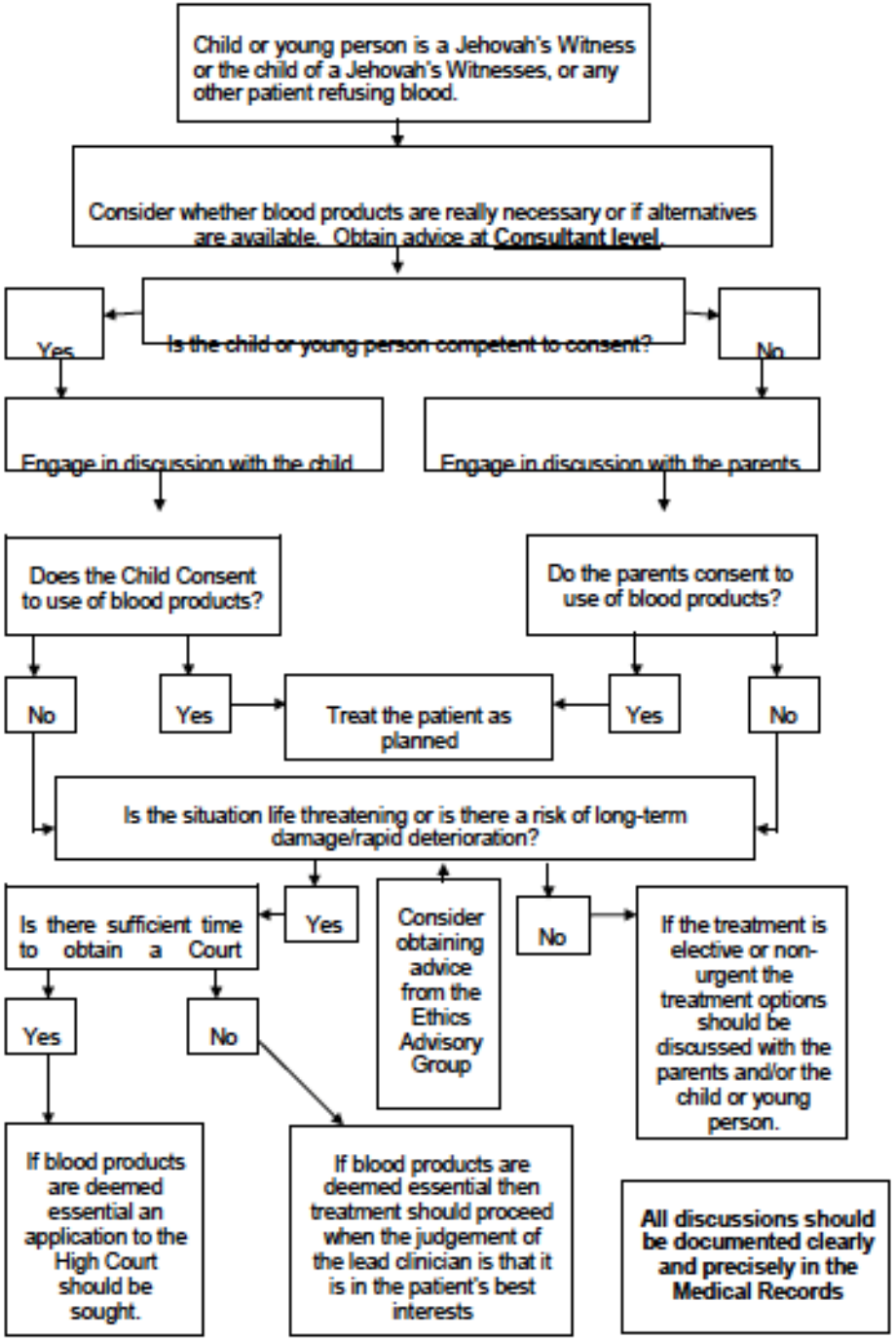
2. Blood and blood products will only be administered when it is clinically indicated in the opinion of the treating doctors as in the best interests of GT and in the opinion of those medically responsible there is no clinically appropriate alternative to administering blood or blood products.

# Clinical Outcome

- Received 2 platelet transfusions with consent prior to court order
  – 1st to cover BMA; 2nd when re-attended with epistaxis and plt count 34

- Fortunately family were in agreement for court order to negate them of the need to consent. Discussions were amicable. They were understanding as long as there were no alternatives.

- Plan for weekly platelet transfusions to manage thrombocytopenia and continue on sytron to treat anaemia.


Child or young person is a Jehovah's Witness or the child of a Jehovah's Witnesses, or any other patient refusing blood.
Consider whether blood products are really necessary or if alternatives are available. Obtain advice at Consultant level.
Is the child or young person competent to consent?
Yes
No
Engage in discussion with the child
Engage in discussion with the parents
Does the Child Consent to use of blood products?
Do the parents consent to use of blood products?
No
Yes
Treat the patient as planned
Yes
No
Is the situation life threatening or is there a risk of long-term damage/rapid deterioration?
Is there sufficient time to obtain a Court
Yes
Consider obtaining advice from the Ethics Advisory Group
No
If the treatment is elective or non-urgent the treatment options should be discussed with the parents and/or the child or young person.
Yes
No
If blood products are deemed essential an application to the High Court should be sought.
If blood products are deemed essential then treatment should proceed when the judgement of the lead clinician is that it is in the patient's best interests
All discussions should be documented clearly and precisely in the Medical Records

# Jehovah's Witnesses and blood transfusions

- Jehovah's Witnesses' literature teaches that their refusal of transfusions of whole blood or its four primary components—red cells, white cells, platelets and plasma—is a non-negotiable religious stand and that those who respect life as a gift from God do not try to sustain life by taking in blood, even in an emergency.

- Witnesses are taught that the use of fractions such as albumin, immunoglobulins and haemophiliac preparations are "not absolutely prohibited", and are instead a matter of personal choice.

- This religious position is due to their belief that blood is sacred and represents life in God's eyes – based on the strict literal interpretation of several scriptural passages of New world Translation of Bible

# The scriptural passages

- ‘Everything that lives and moves will be food for you. Just as I gave you the green plants, I now give you everything. However you must not eat meat that has its lifeblood still in it’. New International Bible, Genesis 9:34.

- ‘Because the life of every creature is its blood. That is why, I have said to the Israelites, ‘You must not eat the blood of any creature, because the life of every creature is its blood; anyone who eats it must be cut-off’. New International Bible, Leviticus 17:14.

- ‘It seemed good to the Holy Spirit and to us not to burden you with anything beyond the following requirements: You are to abstain from food sacrificed to idols, from blood, from the meat of strangled animals and from sexual immorality. You will do well to avoid these things’. New International Bible, Acts 15:28-29.

# Consequences of accepting blood

- Members of the religion who voluntarily accept a transfusion and are not deemed repentant are regarded as having disassociated themselves from the religion by abandoning its doctrines and are subsequently shunned by members of the organization.

- Although accepted by the majority of Jehovah's Witnesses, a minority does not endorse this doctrine.


# Jehovah's Witnesses AND BLOOD TRANSFUSIONS

by Brian J. Wright

## *Their Use of Scripture in Their Blood Doctrine*

Some thoughts from Mum

- How I felt when finding out G was ill?

*"I felt helpless. I didn't exactly know how I felt. It was unreal. Even when I was in hospital with him, it didn't really feel like it was me even on occasions. I just really don't believe my baby, my child."*

- How it felt when the case went to court?

*"I felt relieved somewhat, but also scared that they would take advantage with having the right to give him blood without my consent or without filling me in."*

- How I felt I would be viewed especially to people who didn't know me?

*"I thought people would think I wasn't loving or caring. Nervous they thought I didn't understand the situation. Frustrated because I had to keep repeating the situation to people that looked at me in a judgmental way. My decision would never change regardless of the situation but having the court take over gave me a relief that I wouldn't have to loose the one I love. This isn't a typical way of dealing with the situation but was the only way for me."*

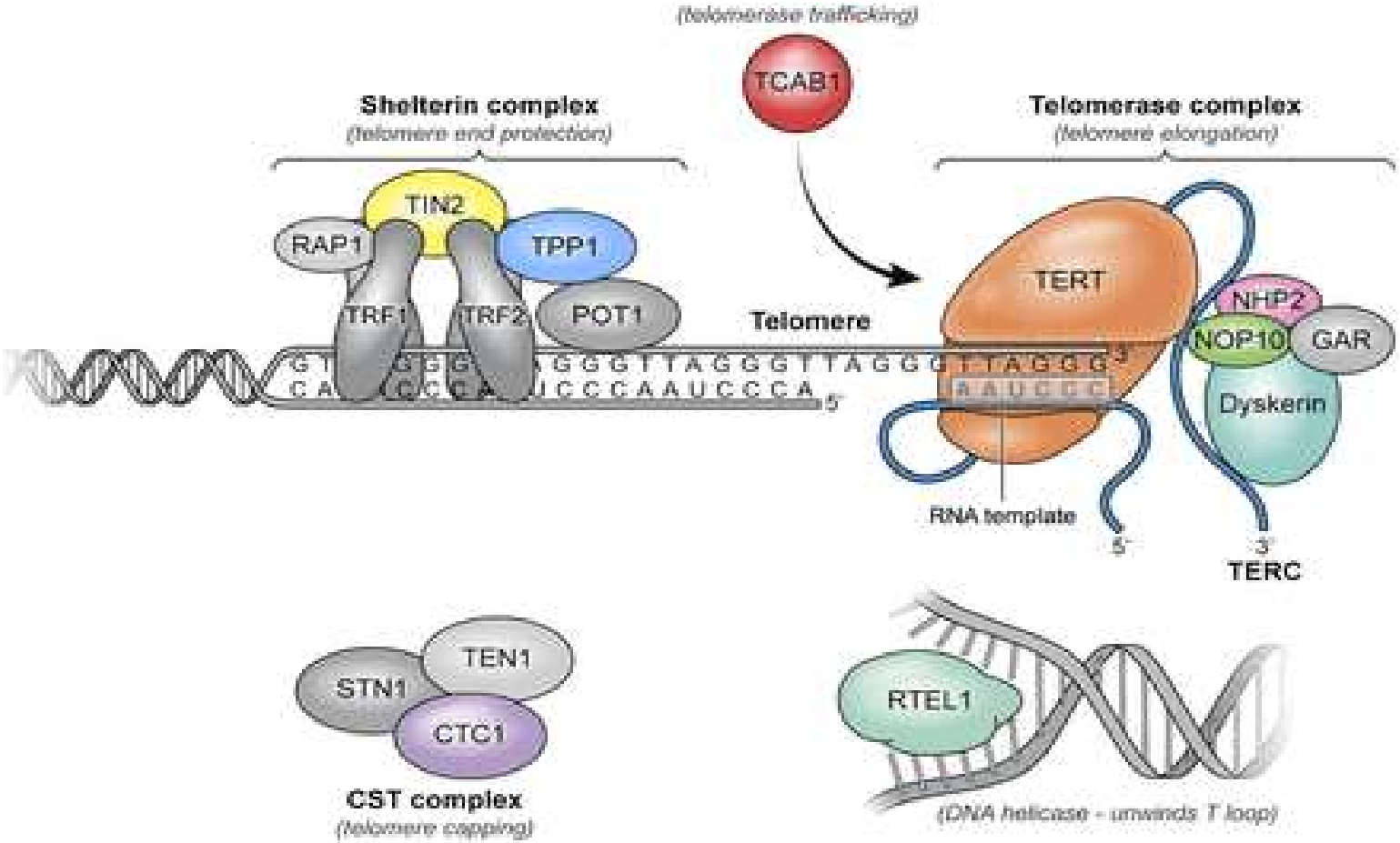
# Outcome for GT

- Bone marrow failure panel showed CTC1 null mutation

  - Conserved telomere maintenance component 1

  - Part of the telomere-capping complex (CST) involved in maintaining telomeric structural integrity

# Components of telomere maintenance implicated in human disease



# CTC1-related disease

- Dyskeratosis congenita has overlapping features with other telomere diseases such as CRMCC
  - *C*erebro*R*etinal *M*icroangiopathy with *C*alcifications and *C*ysts
    - includes Coats plus and LCC (leukoencephalopathy with calcifications and cysts)

- Biallelic, typically compound heterozygous mutations in *CTC1* are known to cause CRMCC

  - a highly pleiotropic multi-organ disease characterized by abnormalities in

    - brain (leukoencephalopathy and intracranial calcifications)
    - retina (retinal vasculature abnormalities)
    - intestinal vasculature (recurrent GI haemorrhage)
    - skeletal abnormalities
    - bone marrow failure

# Next steps for GT

- Court order remains in place and attends for weekly platelet transfusions
- Continues on daily iron replacement to treat anaemia
- Admissions for febrile neutropenic episodes
- Neuroimaging with MRI head
- Ophthalmology assessment of eyes
- Will require bone marrow transplant for progressive bone marrow failure

# Summary

- Case presentation and progress to date, including insight into parental feelings and thoughts of their journey
- Jehovah's Witness beliefs around blood products
- Policy for use when consent is not given for the use of Blood and Blood Products, including obtaining a court order

# Thank You