

Subcutaneous Immunoglobulin Therapy (SCIG)

A parent perspective

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- What is SCIG (non medical)
- Our history – how Josie ended up on SCIG
- What the treatment involves
- Our thoughts about it

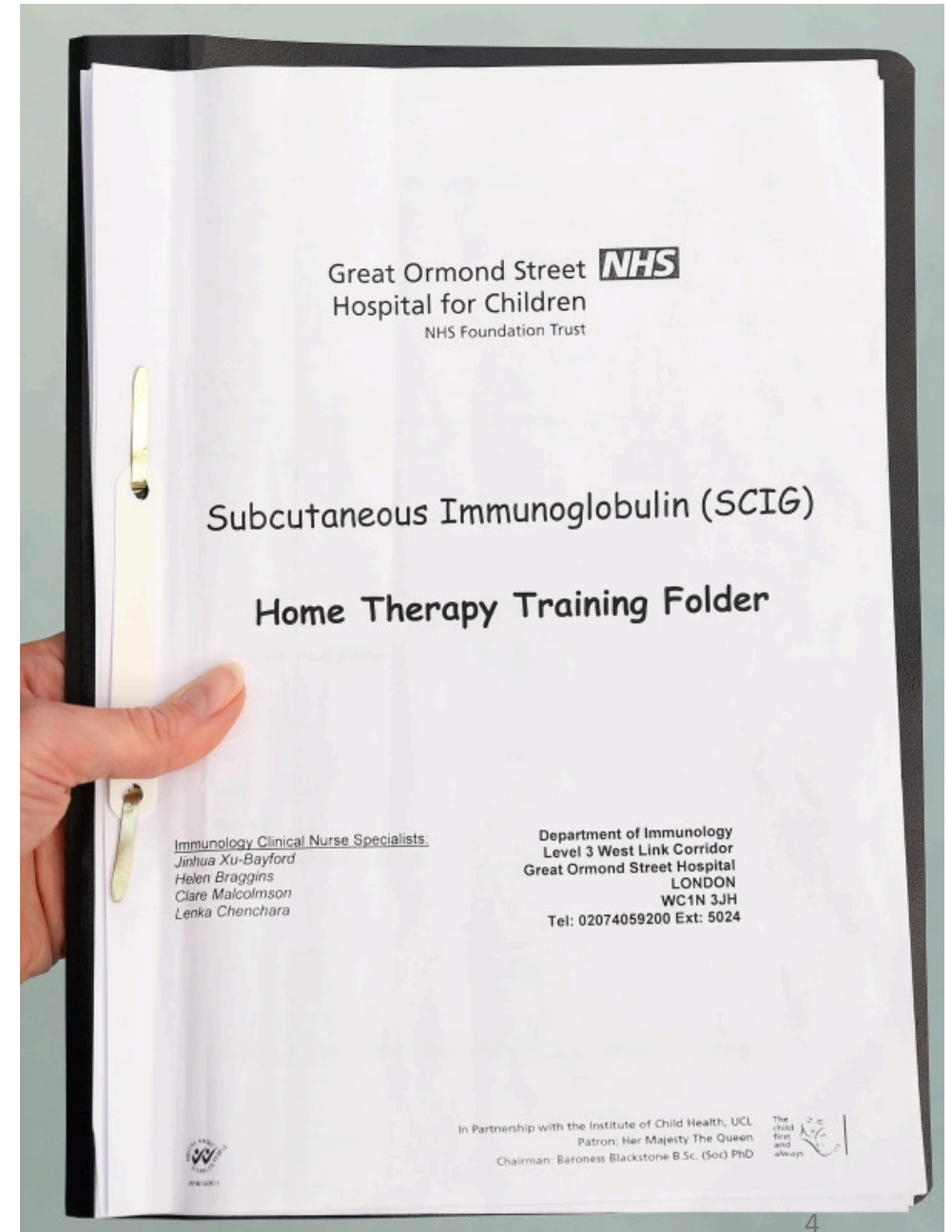
What is SCIG?

- Subcutaneous Immunoglobulin therapy
 - Subcutaneous: under the skin
 - Immunoglobulin: (antibody) is a type of protein used by the immune system to protect against foreign objects
- Blood product made from blood donations
- Clinical trials have shown that for people with antibody deficiency, immunoglobulin treatment results in fewer infections, and the infections that do occur tend to be less serious.
- Also evidence to show that general wellbeing and energy levels are likely to be better when on immunoglobulin.
- In use since 2005

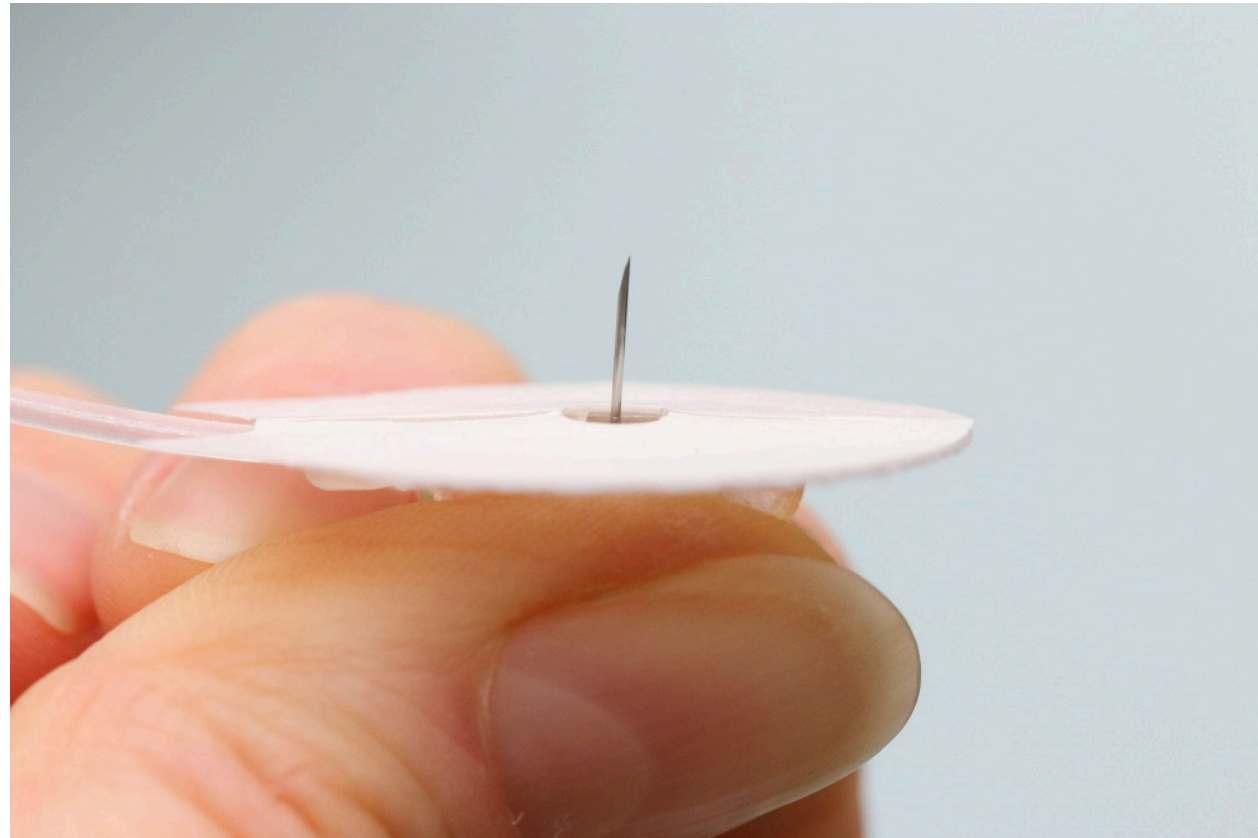


Our History

- Soon after birth, Josie fell very ill with a chest infection
- She was sent to Great Ormond Street Hospital for children
- Recommended immunoglobulin therapy – started with IV and later sub-cutaneous (Josie does not make any immunoglobulin)
- Received training from hospital
- One year later, diagnosed with Bloom by an immunologist
- Immunology has really been a defining theme of Josie's treatment to date



What does SCIG involve?



What does SCIG involve?



What do we think about SCIG?

- Receiving SCIG is an individual's choice (cost vs benefit)
- We think it is worth it for Josie – she is generally well, has not missed any school from illnesses. Has similar number of colds per year as us (2-3)
- If immunoglobulin therapy is needed then we feel subcutaneous therapy has many advantages over intravenous
 - At home
 - On your schedule
 - Less invasive
- It is still a big commitment, it can be very hard giving a treatment to your own child
- Benefit of gaining resistance to diseases eg MMR and chicken pox (to be remembered if treatment stops)