

Local families with bleeding disorders

Support for families, by families



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Family Stories Series

Jacob's Story

Severe Haemophilia B

Jacob was diagnosed at 6 months old with severe Haemophilia B. There had been no history of Haemophilia in the family, so it was all a bit of a shock, and a huge learning curve.

Jacob is under the wing of the amazingly supportive Evelina Hospital, at Guys and St. Thomas'. Shortly after his 1st birthday, Jacob had his Port-a-cath fitted, and began his prophylaxis treatment.



For the first 3 years, his treatment plan was twice-weekly, but due to medical advances, he is now treated once-a-week.

Treatment is given at a time that makes him "stronger" for his expected activity schedule, and he is involved in everything just like every other kid in his class.

Jacob has been on multiple ski trips, and lives life to the full.

With the support of the community we all share stories and advice that help each other through the new hurdles we experience, as our boys grow.

Jacob has created a number of videos to share with members showing how he is living life to the full, and how he manages his treatment. To view these videos and read other family stories, visit the Family Stories page of our website

<http://www.bleeding-disorders.co.uk/jacob.html>

We would like to extend a special thank you to all the families who have contributed to this important series of experience-sharing stories, in particular, the children with haemophilia who have allowed their photo to be shared.

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info@bleeding-disorders.co.uk



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Local families with bleeding disorders is a registered charity in England and Wales (1186979).

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