



Hi! My name is Helen Griggs. I was born with a large haemangioma above and behind my left knee. Soon after, I also developed severe eczema, which helped cause the thin skin over my birthmark to become dry and crack. This is why, at three months old I had a badly ulcerated haemangioma.

It all started 8 or 9 weeks after I was born. My papa noticed that there was something about my birthmark that just didn't look right. He could see too that when he dabbed it dry I wasn't happy even though he was very gentle.



My papa and mama took me to the doctor, but he said it was alright and not to worry as it would shrink in time. My papa and I were not so sure but thought we should trust the doctor. A week later I stopped kicking my leg because my birthmark bothered me a lot. So, my mama and papa took me back to the doctor again. The thing is, I know it sounds silly now, but I couldn't tell the doctor what was wrong with me. He's a strange man in a strange room with lots of distractions... and me only ten weeks old. Anyway, I knew my parents knew what was bothering me even if they didn't know how to make me better because they are with me 24 hours a day. They bath me, they feed me, they play with me. They know when I'm happy, they know when I'm sad. They know a lot about me, things that no one else could because I tell them everything in my own way. The doctor told my parents there was nothing wrong with my birthmark, because nothing ever goes wrong with them. Instead I may have an infected hip, which was unusual as I was so young. Off we went the very same day, to our local hospital. The paediatric doctors were very kind but I was very frightened and unhappy. They kept on pinning me down and sticking big needles in me to get my blood. I screamed and cried harder and louder each time they tried and failed - it hurt me a lot...!! My parents were crying too now because of what the doctors were doing to me and because no one would listen to them! We must have seen 4 or 5 doctors that day in Ward 24. I remember my papa tried to explain to each one of them that he was so concerned about my birthmark but they would not listen. They just kept asking if I had any brothers or sisters so they knew whether papa and mama were just "over anxious".

We went back to the hospital two days later. No trace of an infected hip could be found but by now my birthmark really hurt lots! There was sticky liquid coming out of it and it smelt worse than my nappy. I wasn't going to straighten my leg for anyone...!!!

**Over the course of the next 9 weeks I spent 3 weeks in a hospital bed...**

- . The surgical doctors pumped me full of intravenous anti-biotics.
- . They took swabs but didn't properly check the results.
- . They gave me more oral anti-biotics.
- . One surgeon would say dress it daily with *Mepitel* and bandage. Another would say leave it open.
- . In between my week long stays in hospital the doctors would send me home and tell my parents to 'keep my leg straight'.
- . After they realised that this wasn't going to work they tried putting a plaster cast on to keep my leg straight. But my birthmark just festered underneath because they didn't leave a big enough hole to manage the wound.



My ulcerated and infected leg after 5 weeks of conventional treatment

All through my 9 long weeks of suffering my parents were asking questions. Among these questions were those concerning possible laser treatment. These are some of the answers they received:

- . **We have never heard of laser treatment for ulcerated haemangiomas.**
- . **Yes we have heard of it but I am too young.**
- . **The wound is not at the right stage yet.**
- . **Laser treatment would leave bad scarring in later life.**

Luckily my parents have friends in the United States and Europe so they were able to learn more about what was possible. With their own research, a great deal of forceful insistence and the invaluable help of one paediatric doctor at the local hospital, my parents managed to get me to a special haemangioma clinic at Great Ormond Street Hospital, London.

**This is where the story of my recovery begins.**

Dr.Harper and Dr.Syed, who run the clinic, wasted no time in assessing my condition. They took the time to listen intently to my parents' story and had a close look at my leg. Together with my parents the doctors decided that the best option would be a single course of laser treatment.



This is my leg after 9 weeks of conventional treatment at our local hospital



# LASER TREATMENT

My parents and I learned that there is a lot of miss-information in the medical profession about what laser treatment can be used for and what its effects are on the patient. Let's take some of the answers that the doctors gave my parents:

. *I am too young for laser treatment.....*

This may be true for some types of laser treatment for other conditions or if you wanted to eradicate the whole haemangioma. However, if laser treatment is used to help heal ulcerated haemangiomas then it can be used with babies just a few weeks old, babies just like me.

. *The wound is not at the right stage yet.....*

I still had an ulcerated and infected haemangioma after 2 months of conventional treatment. The surgeons at my local hospital said that my wound was '*not at the right stage for laser treatment.*' Again, this is true if you wanted to completely eradicate the haemangioma. My laser treatment was only used to help my ulcerated leg heal. It could have been done just one week after my leg had become ulcerated and anti-biotics had proven not to work. I received just one course of laser treatment at GOS 4 days after leaving our local hospital and within 4 weeks my leg had gone from being badly ulcerated to completely healed.



from this  
with 9 weeks of conventional treatment



to this



from this  
in 4 weeks with laser treatment



to this

. *Laser treatment would leave bad scarring in later life.....*

Yes it would if you were attempting to eradicate the whole haemangioma! If you are using laser treatment to assist the healing process of ulcerated haemangiomas there is no scarring in later life. As can be seen from the picture above, normal skin is beginning to form over the previously ulcerated and laser treated areas of my leg.

**The three-fold benefits of laser treatment are:**

- 1 The laser penetrates 1.2mm into the haemangioma, effectively quarterising the blood vessels so the haemangioma can heal rapidly.

- 2 The laser beam temporarily kills off the nerve endings in ulcerated areas, dramatically reducing pain.
- 3 Laser treatment helps to eradicate any traces of infection in the wound.



### How did they do it..?

Together with my papa and mama I went to the laser treatment theatre. They stayed with me until I was asleep (general anaesthetic).

The doctors cleaned my wound with a special gel that dissolves crusty bits without causing further damage to my leg. Crusty bits aren't good because infection can get in underneath. They could also see more clearly now where the laser needed to go.

Dr.Syed performed the laser treatment which, as I said before, penetrates just 1.2mm under the ulcerated part of the haemangioma. It effectively quarterises all the unnecessary blood vessels in its path, temporarily kills the nerve endings - which come back in about ten days - and helps to eradicate any traces of infection.

My leg was then dressed and I was back with my parents within an hour.



### What did they do next..?

I was in Alice ward at GOS for 3 nights in total. The nurse showed papa the best way to clean and dress my leg and then I was allowed to go home.

Every day for the next three weeks my papa would bath my leg in a very small amount of potassium. This helped to prevent any infection returning. My leg was then dried with a warm hair dryer so nobody needed to touch my wound.



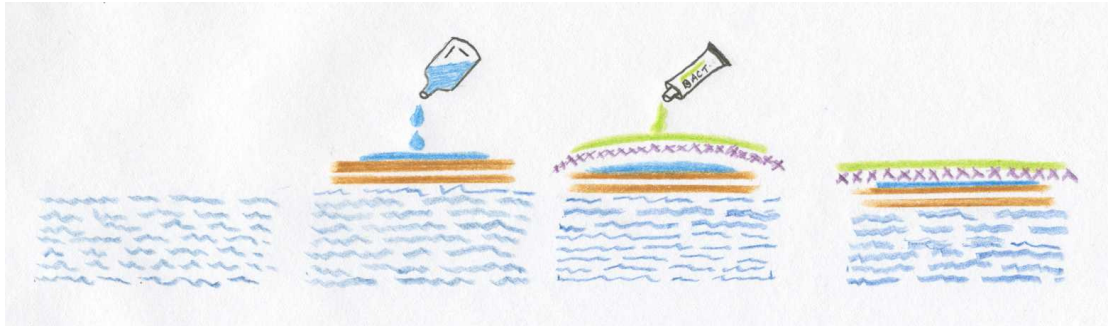
Papa would then use these materials to dress my leg.



## How did they dress my leg ..?

In my local hospital they used dry *Mepitel* and plain bandage. This was not wrong in theory but it was not quite right either because *Mepitel* by itself did not help the wound to heal.

After my bath a special dressing would be made up as follows:



Seven layers of thick *gause* to prevent my leg from bending too much

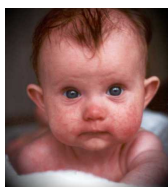
Two layers of *Sorbsan*. The top layer moistened with sterile water

On top of this a sheet of *Mepitel* with a thin layer of *Bactroban*

Final dressing

- . The thick layers of *gause* helped to keep my leg straight.
- . The *Sorbsan* helped to draw out any unwanted body fluid whilst still keeping my wound moist.
- . The *Mepitel* helped stop anything sticking to the wound.
- . And most importantly the *Bactroban* helped keep any infection away.

It was **very important** to make this dressing up separately and apply it all in one go so as not to cause me more stress. The whole dressing was then held on in the normal way with bandage and tape.



## How did my leg progress over the next 4 weeks..?

From the moment I came round from the anaesthetic I was relatively free from the intense pain I had suffered for the last two months. My parents could see such a change in me - I was a happy baby again...!

The photographs on the following pages show the progress of my ulcerated leg after laser treatment.



After 9 weeks of conventional treatment



Here my haemangioma was cleaned and laser treated



4 days after laser treatment



7 days after laser treatment



10 days after laser treatment



13 days after laser treatment



16 days after laser treatment



19 days after laser treatment



22 days after laser treatment

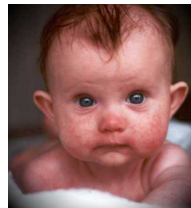


25 days after treatment



30 days after treatment

It took just 4 weeks for my leg to completely heal. Now all I need, twice a day, is vaseline on my haemangioma to keep it supple and a layer of tubifast to protect it from my scratching.





**This has been my story. I am now better and can smile again. However, I went through a lot of unnecessary suffering on the way.**

I don't want to blame anyone for this. I just want to draw attention to what is happening. That way maybe other small children like me won't need to suffer as much.

If you are a medical professional please think of the following:

- . Listen to our parents. They have real concerns and are not necessarily 'over anxious'. They know us far better than you ever could and they have a lot of invaluable information to give to you.**
- . Treatments change. It is possible that your colleagues are more specialised in a particular area and know more about these changes and advances. If that is the case, please refer your patients to them. It would save patient suffering, maintain respect and confidence in the medical profession and in many instances it may be more cost effective. (One course of laser treatment and three nights in hospital at GOS has to cost less than three weeks in a local hospital bed , two teams of doctors, nursing staff, intravenous drugs, tests, splints and plaster casts.)**
- . Please, Please - Put Patients First!**

Thank you for taking the time to read my story. If you have any questions then my mama and papa would be glad to help. Their e-mail address is:  
[steph3590@yahoo.co.uk](mailto:steph3590@yahoo.co.uk)

## Helen Griggs

P.S. A big hug and thank you to all the staff at GOS. For listening to us, for making me better so quickly and for taking such good care of us. Especially to Dr.Syed (laser surgeon), Dr.Harper (eczema specialist) and to Jane for my beautiful dressings.

## UPDATE:

I am now eight years old. Thankfully I do not remember anything of what I went through as a baby. Although I still have eczema I have not had any more problems with my haemangioma since my laser treatment.

As you can see from this recent photo, my leg has progressed very well and although there will always be some scar tissue the haemangioma should improve even more as I get older.

