



Making life better for sick and disabled children in Sussex and Surrey

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Make a sick child smile this Christmas

Jonathan's story

Last year, we spent Christmas together as a family in hospital. In The Royal Alexandra Children's Hospital (The Alex) in Brighton to be more specific. Most people would consider this their worst nightmare, but after the year we'd had, it was a really happy time for us all.

This is because my son Jonathan, who is now 21 months old, has spent his whole life in hospital. He was born extremely premature at just 24 weeks of pregnancy. I'd had a scan the week before where my husband, Odum, and I found out we were having a healthy little boy. My daughter Vanessa, now five years old, was so excited to be having a baby brother.

When I went into labour, the first hospital I visited told me the baby wouldn't make it, because they didn't have the facilities and other local hospitals didn't have space. Amazingly, in the morning my contractions stopped and so we asked to be transferred to a hospital in Southampton (which was three hours away from where I was). They told us there was a huge risk because if he was born in the ambulance, he wouldn't have a chance and I would also be putting my own life in danger, but we knew we had to try.



“He weighed just 1lb. He was completely formed and looked absolutely perfect – just very tiny”



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After a long labour, Jonathan was finally born. He weighed just 1lb. He was completely formed and looked absolutely perfect – just very tiny. We couldn't hold him and he was taken immediately to be put into an incubator and wired up to a ventilator. As we were getting ready for them to move Jonathan (now five weeks old) to The Alex in Brighton (I'd been travelling every other day by train from our home, which was a six hour return journey), we were suddenly told we needed to make arrangements for Jonathan's death.

There had been a potentially fatal complication with his intestines, which no-one could have predicted. He would need surgery first thing the next morning, but he might not make it and we would need to make a decision about what to do in the event of any unexpected problems.

You shouldn't have to decide whether your child should live or not. Of course you're going to try everything and hope for the best. At this stage, hope was all we had.

In those hours, Jonathan fought for his life and made it through the operation. He recovered over the next few months, undergoing several procedures.

Last August, when Jonathan was five months old, we finally moved to The Alex and he's been there ever since. We hope he'll be able to come home in the New Year, but we're constantly in limbo and every day is uncertain. He gets so much attention from the amazing staff there and he loves them all – he's special and he knows he is. His sister has spent a big part of the past two years in hospital visiting her brother too, but she doesn't get angry. She's so proud of her brother and all he's been through.

A few weeks ago, we had to leave our home in Hastings and we're temporarily living at the hospital, while we find somewhere close by. When Jonathan gets out, he'll need to be minutes away from the hospital because it could be a matter of life and death. He needs us now more than ever. So for now, this is our home and our only option.

We're not sure where we'll be this Christmas, but we know if we're in hospital, it won't be an issue for the kids. Last Christmas was lovely; there was a great spirit. We're thankful to the staff and to Rockinghorse Children's Charity for making it special for Jonathan and especially Vanessa – both received lots of presents on the day and the charity's support made a huge difference to us. While it wasn't a typical Christmas, we all spent the day together as a proper family. **Hopefully next year we'll have Jonathan at home and that's the best Christmas present we can ask for.**

Please consider making a donation to Rockinghorse so that the charity can continue to support children like Jonathan at Christmas and all year round.

Thanks for reading our story and best wishes and good health for the festive season.

Angelika Bak

P.S. If you are a UK taxpayer, Rockinghorse can claim an extra 25% on your donation. All you have to do is sign the gift aid form at the bottom of the first page. Thank you.

Rockinghorse helps ensure no child is forgotten at this magical time of year – they bring Christmas trees, deliver presents and help bring some normality to these young people's lives. Rockinghorse's work doesn't stop after 25 December. They work hard all year round to support sick and disabled children near you. Your gift can make a difference to hundreds of children like Jonathan, not just at Christmas but throughout the entire year, so please give what you can and in 2012, make sure you choose Rockinghorse.

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