

# Alfie's Story



*Nicola with Alfie (on the right) and Charlie*

## The initial discovery

Alfie's condition was diagnosed at week 20 of my pregnancy at King's hospital in London where I was going for regular scans because I was having identical twins. At this time, the hole was small and we were told that many of these holes close by birth so we crossed our fingers and hoped for the best. When he was born at our local hospital, the initial echo was promising, but by the time he was 6 weeks old he began developing symptoms of heart failure such as breathlessness, tiredness during feeding and

projectile vomiting. This was accompanied by long, long evenings of relentless crying, which we thought at the time was down to colic. At this point in time, the relationship between these symptoms and his heart condition had not been made explicit to us, however, even without this knowledge we knew that he was not thriving as he should because his weight gain was so different to that of his identical twin brother. Whereas Charlie's curve hopped up the centiles in big steps, Alfie's growth curve crept along, always below the bottom line. I knew that I was feeding the babies the same diet of breastmilk and that both babies were keen feeders, so we had to investigate why he was not progressing as he should. A long saga of visits to our GP and our local hospital followed, however, it seemed to me that no-one made the connection between his symptoms and his pre-existing heart condition even though we pointed it out on each visit. As a mum, all I knew was that Alfie was not well and until I got to the bottom of the matter, I could not rest or just attribute his discomfort to wind or possible reflux. Meanwhile, I began chasing his appointment for a follow-up echo. Although we had been told when he was born that he would have a follow-up scan 'in two months', there was no sign of the appointment and after telephoning my local hospital, we found that he and his twin brother were not currently on the waiting list for the next clinic. By now Alfie was now nearly 10 weeks old, and we were getting even more anxious about him and his symptoms.

## The Hole gets larger

Finally, Alfie was sent to the Rapid Response clinic at the Evelina, and the echo showed that his small hole had now become a moderate to large VSD. He also had an enlarged heart and liver, which was possibly causing him the discomfort. A plan of action to stabilise his condition with drugs was put into place until he was seen at the outreach clinic in a month's time. Even though surgery was highly likely, we still did not really prepare ourselves for this fact. I suppose in the backs of our minds we were hoping that his hole would still close by itself. We don't know if it was down to the drugs, Furosemide and Captopril, but within a week or so, the vomiting and the evening crying seemed a lot better. When he was seen again at the outreach clinic, we were told that open heart surgery was definitely his only option and that it needed to happen during the next 4-6 weeks. I felt numb on hearing this news because it confirmed to me the fears that I had carried with me since week 20 of my pregnancy - that our baby did have a heart condition and he definitely would need an operation.

### Taking in the information

Even though Alfie's operation was 'routine' it certainly was not routine for us. We were still trying to get to grips with these facts:

- we were new parents
- we had two babies
- one of the babies had a hole in the heart, which had not closed
- the hole had got bigger
- it was having an effect on Alfie's body which was causing him discomfort
- drugs were needed to control the symptoms of heart failure
- he would need surgery soon
- the procedure he was going to have would be open heart surgery

During the time of trying to digest this information, it became even more noticeable that Alfie was

struggling because people would often stop us and say,

“Are they twins? One is so much bigger than the other!”

These comments were very upsetting for us to hear. Sometimes we would explain Alfie's situation, other times we would just smile and move on quickly. At the outreach clinic, we had been handed a copy of Echo and I began to read and reread the information and articles in it, thinking that it would be good to talk to other people. However, by the time I had spent the day looking after the twins, and before I had found out about the joys of putting them down for a lunchtime nap, there never seemed to be time to make contact.

## Contacting Echo

It wasn't until we received a date for Alfie's operation that I think we really began to start digesting all that we had been told and what was going to happen to him. One day, just before his operation, I felt like I was going to explode with thinking and worrying about his surgery. I felt terrible by the fact that during my pregnancy I had not found out more about congenital heart disease and its related symptoms in babies, so that I could've pushed for Alfie to have a follow up echo much earlier on in his life. Even though I have fantastic friends and family, I just needed to make contact with other people whose children had had heart surgery, so I logged onto the Echo website and posted a message. I kept checking, and was astounded to have received replies on the message board as well as to my e-mail account. It was a relief and a great comfort to enter into discussions with other parents about emotional and practical issues - I only wish I had made contact sooner. I also found that the links from the site to useful organisations such as The Children's Heart Federation were invaluable in providing information about his condition and treatment. It was also at this time that I contacted the outreach service which was to prove an invaluable source of support during the weeks to come. We cannot thank Emma Simmonds enough for her kind and patient manner with which she dealt with all our queries and concerns.

## Alfie's recovery

It has now been just over a month since Alfie left the Evelina. His operation went well and his recovery has amazed me - he was in intensive care for less than 48 hours and his main worry seemed not to be the pain he was in but when he would be getting his food! Due to the fluid restrictions, he started solids straight away and he has not looked back since! Home life is beginning to get back to a more normal routine, which now involves Charlie and Alfie sitting in their 'Bumbos' on the kitchen table eating banana and peach flavoured baby rice! His wound has healed up really well (the scab has nearly all dropped off) and we are now looking forward to giving him his first proper bath! He will be back at the Evelina soon for a check up, however, until then we are just going to enjoy being a family again.



*Alfie in Conal Austin's capable hands*

## Echo membership

Although nothing could take away the worry when Alfie had his surgery, it really helped us to feel that there are other people out there who have been through similar experiences. We only wish that we had known about Echo earlier, particularly when Alfie's hole was first identified at week 20 of my pregnancy. One of the worst things about this whole experience was the fact that we did not know enough about the symptoms of heart failure and what to look out for. Even though this knowledge would not have changed the surgical outcome, it may have helped us to push him through the local appointments system a little quicker.

We'd just like to finish by saying a big thank you to Echo, and to the staff at the Evelina. The messages of support sent to us from other members of Echo really helped us and stopped us from feeling so isolated. We feel extremely proud to be the 500th members, and hope that we can support other families in the future.