

# Hannah's Story



*Hannah Phillips with her family*

Hi there. My name is Hannah and I am one of the many people that suffer from rare heart diseases, my disease is Ebstein's Anomaly. I was born on the 23rd May 1995, even though I was meant to be born on the 21st July 1995.

I am 12 years old now and am finding it hard to cope. At the moment I would rather be in hospital than anywhere else, and the reason why is that I'm always having these little attacks and I don't know how to cope with them or what to do when they happen!! Not only is this hard but I have also just started secondary school and I'm finding that hard anyway.

I have been at this school for a while now but I am finding it hard to make friends and be myself.

I feel that the worst thing about being me is the fact that I have to have all these appointments all the time, but the worst of worst is going in for surgery, even though I have had three operations in the eleven years and I have lived, to me it is life threatening. I always think to myself, "oh my goodness, oh my goodness will I ever open my eyes again? Will these be the last few words I ever say... or will I ever see my FAMILY and FRIENDS AGAIN?" I hate that feeling - it's the worst. When I go into surgery I have this really weird feeling that my friends won't like me because I'm the odd one out.

The thing I am also not that keen on is what the doctors say. They say that these attacks are normal and that they are not harmful. I don't really believe them that much and I panic and work myself up all the time. The only good thing when I have an attack is that I know that someone will always be there no matter what, and that they will check up on me from time to time.

At school I have a buddy. Her name is Eileen and she is in the same class as me so she comes with me everywhere. Just to be on the safe side of things. There is also another girl in school who looks after me well, her name is Hannah just like me and she has known me ever since I was born. She is helpful if I am having an attack at school or on the way home, and if she is there she will always have a rough idea of what to do. Having her as an older friend is the best - she is always there for me no matter what happens. I have many other friends but I have known them ever since I started primary school and I don't feel like I'm making any new ones.

I have 1 sister and 2 brothers. They are all younger than me and I get to boss them around which is really fun. I love having friends that I have got now. We go to the movies and go round to each other's houses. All the people like Hannah are family friends and every year all our mums go away and all the dads and the kids go out bowling and then for a pizza. I have another friend called Charlotte and her mum works for the Pals office in St Thomas' hospital, and if I ever have a problem I can always go to her. Apart from my condition I think that life is OK, and even though I am not making any new friends at school, I know that Charlotte, her Mum, Hannah and so on will always be there. My favourite subjects are French, because my mum is French and I speak it really really well, and Drama, because I like it and I feel I am good at it. I love having friends like Hannah and Eileen and all my family, friends, nurses, doctors etc.

Even though I have Hannah, Charlotte and Eileen and so on, they are not children like me and don't always know how I feel, or what to do with me, and they probably get bored of me going on about my condition, especially as at the moment I'm always going on about it.

I would love to meet someone my age or older than me who has a heart condition because I have met some babies like me but not really anyone of my age. At the moment I feel like I'm the only one in the world that has this problem!! I think the thing that ECHO is planning for older children and teenagers like me will be great and I'm really looking forward to it!

**Hannah Phillips**