



Big Hearts Matter Youth Newsletter

Issue 31 Winter 2017



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Welcome

Hi everyone, my name is Lexie and I'm the new youth leader at LHM. I am here if you ever have any worries about life with half a heart, or even if you would just like to have a chat. LHM are hoping to improve the Zipper site so its much easier for our Zippers to come together and share stories both over the internet and at face-to-face events, so I will be working on getting you some new and fun events arranged for the future. If you have any interests for events get in touch.

Events



17th March 2018
LHM Open Day

Keep an eye out guys, there will be more events to come! If you have any ideas for events they're welcome.

To speak to Lexie call
0121 455 8982
Zipper Website
www.lhm.org.uk/zipper-zone/
Zipper Chat
forum.lhm.org.uk/





LHM Zippers
Half a heart, not half a life

Fenestration frustration

A zipper journey, written by Thomas Evans (13+ Zipper)



If you would like to share your journey so far, please send it in to lexie@lhm.org.uk and we will put them in our next newsletter.

Hello, I'm Thomas. I'm 13 years old and I have Hypoplastic Left Heart Syndrome. Here's my story about my life so far.

They knew about my heart condition before I was born so I was transported by ambulance to Birmingham Children's Hospital. I had my first open heart surgery, the Norwood procedure, when I was two days old and I spent three weeks in hospital. When I was 3 months old, I had my second open heart surgery, the Glenn procedure, and spent two and a half weeks in hospital. I had my third and final open heart surgery, the Fontan procedure, when I was four years old and spent another two and a half weeks in hospital.

Due to complications after the Fontan procedure, I ended up with a fenestration that was larger that it should have been. This caused my blood oxygen saturations to be in the low 80s, so when I was five years old I had a cardiac catheter to narrow it. This made my oxygen saturations go up to the mid 80s. When I was seven years old, I had another cardiac catheter to make my fenestration even narrower. This made my oxygen saturations go up to around 87%.

During a hospital appointment, when I was eight years old, my cardiologist said "Your heart frustrates me" because he wanted my oxygen saturation levels to be even higher. A few months later I had another cardiac catheter, this time to close my fenestration. I was disappointed that I had to have another one. After the operation, I was surprised at how high my oxygen saturation levels were - they were around 96%!

Nearly five years later, I've just started high school. It has three floors and over twenty classrooms on each one. I walk to and from school, however I get a bit puffed out when I walk up stairs, I don't do PE at school and I have been given a lift pass. Having the catheters has enabled me to be more active. I can now walk at a good speed as long as I'm not walking uphill and swim for a few lengths at a time.

Although it was a frustrating few years when I had the operations, it was worth it in the end.

From Thomas



EGX gaming exhibition

Written by: Lexie Katsaitis

We want to make sure that there are events that interest you. If you have any ideas, get in touch with Lexie either by email or Facebook.

In September two youth members and I were able to attend the EGX gaming event at the NEC in Birmingham.

This was a great event where there was the opportunity to learn, play, watch and try new experiences. There were many booths with so many games for PC, Xbox, Nintendo and Playstation. Some people dressed in cosplay which was very impressive, one even had speakers in his costume so he could walk to his own theme tune. As you can imagine there was so much to see.

The boys were really excited to try new unreleased games and quickly showed their skills, something that Lexie was not on par with! Eduard and Alasdair were very skilled and knowledgeable and taught Lexie very quickly that gaming is no longer a case of jumping up and down and avoiding Pacman ghosts! There was however a 'Retro' area at the exhibit in which the old classics were also available. Sometimes the old classics are the best. Street Fighter, Doom and old school Mario Kart to name a few.



Zipper youth forum

The youth forum will be used in place of the Youth Council. Everyone will have the chance to take part.

Is this something that interests you? Get in touch with Lexie on lexie@lhm.org.uk

Regular meetings either face to face or virtual, to ensure that all ideas are heard and considered.

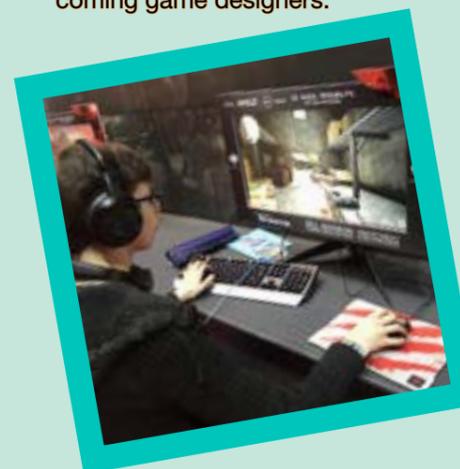
What is the Zipper Youth Forum?

Five Youth members will be invited to be on the zipper youth forum every six months.

A chance to help the voice of the youth members. To make sure you get the support, events and projects you think you need!

A few career talks were available to sit in during the day as well as many universities coming and setting up stalls. These were really useful as they spoke to young people 1-2-1 and gave advice about the career industry within gaming. This included education advice as well as employment advice. Really useful for all of you up and coming game designers.

A particular favourite (and super busy) area of the EGX gaming convention was the board game area. We couldn't believe it either. That is until we were in the middle of a super intense 'Tetris Jenga' game. We cant say that the avid board gamers welcomed the intrusion of a giant tower falling over but we had fun none the less.



PGL Activity weekend in pictures

As you can see, we had a wonderful time!



Contact Lexie

Hey Guys, as I'm sure you can tell Lexie would like to get to know each of you and find out what support, events, projects you like, want or need. If you need to chat about something that's going on, that's okay too! Look out in future as more is coming your way, but for now contact Lexie as shown below.

