



Big Hearts Matter Youth Newsletter

Issue 32 Spring 2018



Youth forum Youth activities '18 Career Fairs Youth story Sports FAQ Guess who?

Welcome

Hi everyone,
Lexie here, its been a busy few months with lots and lots going on. I've been lucky enough to meet some of you either at events, open days or online and cant wait to meet the rest of you guys.

From the youth events being booked for 2018, the new youth forum starting, the road show hitting the road and the new youth social media theres lots of news. Read on to see whats been going on.

Lexie

Upcoming Events

- The Eden Project - 1st - 2nd June '18
- Activity Weekend - 17th- 20th Aug '18
- Career Fairs - Multiple dates & locations



To speak to Lexie call
0121 455 8982
Email
lexie@lhm.org.uk
Zipper Chat
forum.lhm.org.uk/



LHMzippers



LHM_zippers_members



LHMZippers/LHMYouth-group



Zipper youth forum

Written by The Youth Forum and Lexie

In our last Newsletter we told you about the up and coming Youth Forums for Little Hearts Matter. We thought we would introduce you a bit more to this terms Youth Forum.



Thomas is 14 years old. He is really interested in computer programming, science and technology. When he is not off walking he loves to watch Top Gear. Thomas is an asset to the Youth Forum, always coming up with great ideas and joined as he likes helping other and representing LHM Youth Members.

Colbie-Kate volunteers at a few organisations as she likes to make a difference. You'll either find her acting and singing or watching other act or sing. Colbie-Kate joined the LHM Youth Forum to both help others and to meet new people.



Evangeline's has many hobbies that include playing her harp, writing stories, acting, drawing and watching movies. She joined the youth forum to share her ideas, to get advice on her heart condition and to help others.



Eduard is now in college so has been able to turn one of his hobbies (game design) into an education. He also hopes to turn this into a career. Eduard joined the youth forum to give the youth members a voice and help in any way he can.



If being in the next youth forum (June 2018) is something that you're interested in get in touch with Lexie asap!



Youth activities 2018

Written by: Lexie Katsaitis

We have some great activities booked for 2018 and you're invited. Bare in mind however that there are only so many spaces and it is first come first served.

Your siblings are invited too!

The Eden Project - 1st - 2nd June 2018



One Night Residential Cornwall Spaces Limited

If you are interested in coming along to this new youth activity, get in contact with

Lexie asap.

01214558982

lexie@lhm.org.uk

Activity Weekend- 17th - 20th August 2018



Three Night Residential Lincolnshire Spaces Limited

If you are interested in coming along to the youth activity so many have enjoyed before, get in contact with Lexie asap.

01214558982

lexie@lhm.org.uk



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LHMZippers/LHM youth-group

Telephone - 0121 455 8982

Career Fairs 2018

Written by Lexie



Thinking about the future can be stressful, especially when it comes to life after school. College, work, uni, apprenticeships, traineeships. The list of opportunities is endless BUT whats best for you? Everybody is different. You have a choice.

We want to make this less stressful for you and we are going to do this in a number of ways. Firstly, I has put a list of career fairs around the UK that I will be able to go and meet you at. To offer support, advice and even ask the questions that you maybe dont want to. If you are 14years+ and any of these dates / locations below interest you, get in touch. The best decision is an informed one.

Coming soon, LHM are currently in the middle of writing a booklet about 'Further Education' specifically for you guys. Full of options, information and advice.

Do you have any questions that could be answered in there? Would you like to be on the readers panel to make sure what we are releasing is relevant and understandable.

Have your say and get in touch with me, even if you're not sure and just want a chat.

Youth Story - Heart to Hearts

Written by Hannah Palmer



On 10th February myself and my friends put on a concert to raise money for Little Hearts Matter. The year before my friends had told me they wanted to do a fundraising concert and they told me they wanted to raise money for Little Hearts, so of course I said yes!!

So 7 of us started rehearsing last summer. We decided to perform the concert during Congenital Heart Disease awareness week to promote LHM and Heart Disease in young people. With it being near Valentine's Day also we decided to go with the theme of Love!! We sang songs from Musical Theatre about friendship, romantic love and loads of other kinds!

It was a wonderful evening; we raised £517.63 from the ticket sales, raffle and from an auction where we auctioned off Hamilton the Musical posters signed by the West End cast!! It was a great event and it was amazing to raise money for LHM and to have fun doing it!! Shout out to my friends Sian Kyle and Lyndsey Bird as without them the concert and money raised wouldn't have been possible!!!

Little Hearts Matter want to say a big thank you to Hannah and her friends. It was a wonderful show!



Saturday 27th January 2018	Shoreditch - London
Wednesday 7th February 2018	Curve Theatre - Leicester
Wednesday 28th March	Park Inn - Reading
Wednesday 18th April 2018	Colston Hall - Bristol
Friday 25th May 2018	Crossgate Centre - Leeds
Tuesday 5th June 2018	Brighton Dome (Digital Media Specific)
Wednesday 12th September 2018	Sheffield City Hall
Wednesday 24th October 2018	Assembly Rooms - Newcastle





Sport and exercise FAQ

Thanks to those of you that sent in your questions about sports and exercise

1. My heart rate really increases when I exercise or join in with P.E! Should I be worried about this?

Your heart rate is supposed to go up with exercise and you could argue that if your heart rate isn't going up at all then you are not exercising hard enough! However in people with a Fontan circulation the heart rate tends to go up much less with exercise than others without a heart problem. However, if your heart rate is suddenly jumping up with exercise and is fast and uncomfortable (palpitations) out of proportion to the activity and you feel the main thing that you notice with exercise then it is worth discussing this with your cardiologist.



3. I heard that the advice the hospital is giving us on sports and exercise has changed. What is different?

Guidelines are often changing as more evidence becomes available current guidelines have changed to recommend an hour a day and the types of activity. These are clear and easy to follow, <https://www.nhs.uk/Livewell/tness/Pages/physical-activity-guidelines-for-young-people.aspx>, but as outlined above need altering to your own situation. Your own circulation or medication may also change and this will alter the advice given by your own cardiologist as to which activities you are able to do. Ask them to complete the 'exercise prescription sheet' to guide your activity.



2. Is there a time limit on how long I should exercise a day?

The main guidelines for exercise time limits in children and teenagers are based around making sure they get enough exercise as opposed to making sure they don't do too much (<https://www.nhs.uk/Livewell/tness/Pages/physical-activity-guidelines-for-young-people.aspx>). The reasons for this are that in general people don't get enough exercise and the health benefits of exercise even from a young age are many. The current guideline for children without a heart problem is for 60 minutes a day of moderate or vigorous exercise. Although there are no specific guidelines on how this should be altered for Fontan patients it is likely that some exercise is at least as important as those without a heart problem

4. I know that people say swimming is good exercise for us but I can't swim. What can I do instead?

This is such a good question. Swimming is a really popular way of exercising yes, but there are so many other alternatives you can do now too. Cycling, walking and even dancing. Its best to remember a few rules when picking the sports for you. Is it a contact sport? If so avoid it, you're chest area is too precious to have banged. Also the golden rule. If you become too breathless and can no longer talk stop.



Guess who?

Time for a bit of fun, we love seeing baby / childhood photos of you guys so thought we would return the favour. Can you guess who is who? Send in your answers to lexie@lhm.org.uk and you could win some LHM goodies!



Choose from:
Ian
Suzie
Lexie
Harjot
Michael
Paula
Deb
Tina

Contact Lexie

Hey Guys, I have had a blast getting to know some of you either in person or via social media, phone or email. Dont hesitate to get in contact if you have any problems, questions or just to say hi!



Lexie@lhm.org.uk



0121 455 8982



Lexie LHM Katsaitis



@LHMzippers



BRAND NEW YOUTH TEXT SUPPORT SERVICE

You may have noticed the text support contract placed in this newsletter, thats right Little Hearts Matter are starting a youth support text service. Every Thursday 5pm - 10pm I will be available to offer support, advice and guidance. Even if you just need a little chat about something that is bothering you.

To receive the mobile phone number you just need to read the rules and send back the text support contract! Easy right!

Also Lexie will be logged online on the youth forum chat at this time on thursday too!



LHM Youth Members now have their own private Instagram Group as well as a public one to let everyone know the great stuff we are doing.

Your page is for you. I will be posting info for you, but if you want to share photos, achievements etc send them to me and lets get them posted!

@LHM_zippers_members (private member group)

@LHM_Zippers (public page).



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LHM_zippers_members



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