

BIG Heart Matters

Issue 16

...the teenage newsletter from Little Hearts Matter

Summer 2011

www.zipperzone.org.uk



This is the profile picture of Jon Brunskill, which you should add if you want to join the secret LHM teenage group.

After you told us that you wanted a place to talk to other teenagers with a heart condition like yours, we created a Facebook group to do just that. Why not join so that you can talk to other young people?

If you are over 13, you can search and add 'Jon Brunskill' as a friend, the picture is of the LHM Youth Council logo. This isn't actually Jon's Facebook page, it's just a youth holding page which allows us to invite you into a secret group safely.

We used to have a consent procedure which was quite complicated, and we know that this put some of you off, but now you can rest assured that if you add Jon Brunskill as a friend you will be invited into the group.

The privacy around the group is still the same: it's secret. We know that you have loads of mates on Facebook and you don't necessarily want all of them seeing that you are posting in an LHM group, so we've made it 'secret' so that it doesn't show up on your wall, and none of your friends can see that you're a member.

Although we don't expect you to sign a consent form we do still have some rules about what you can post on the site so we have attached them to the newsletter so that you can remind yourself what they are.

Don't forget, you can always email us if you can't get on to the page or find Jon Brunskill on Facebook. Just email Gwen, our Facebook/online hero and ask her your question:

gwen@lhm.org.uk

Do you have any news that you would like us to put up on the youth Website? If you do send it to Gwen at the above address.

Don't forget about these cool features on the website as well!



You can ask either Suzie, Jon or Caroline any question you like about your heart, or anything to do with your heart



Check out the photos from our open days and activity weekends, and videos which can help you learn about your heart

This is your username and password for the ZipperZone members area.

You'll be able to access the full gallery and the facebook group link once you log in!

Safe & Sustainable

A lot of you will still be wondering about the Safe and Sustainable review. Some of you might be doing stuff to support your local hospital. Some of you attended the youth events to have your voice heard. Here is a quick update on what's going on at the moment. Because it's nice to be kept in the loop :)

The last time I wrote about this to you the S&S (Safe & Sustainable) team had released their huge report into what they thought should happen to the way that children's heart surgery is done in England.

You might remember that they decided that it would be safest if the amount of hospitals doing this surgery was reduced. This has made lots of people scared and angry, as they don't want their hospital, which has given them so much care, to close.

The S&S team think that it's not safe to carry on the way it is at the moment though, and that if the amount of hospitals doing surgery is reduced, then all children will get a better standard of surgery, and there is less chance for mistakes, or surgeons being overworked.



The team want to know what parents and kids think about this, so they set up 'engagement' meetings, so that they could 'engage' with you. I went to the youth ones in York and London, Suzie went to the youth one in Birmingham.

There have also been engagement events for adults, these are being attended mostly by parents, hospital staff, and charities. A representative from Little Hearts Matter has been at all of these, and that representative was normally Suzie.

It was great for me to see some of you at the Youth Events, I'm really glad that you went. For those who didn't, there is a leaflet that you can download which explains what is going on really well. Just type: 'better care for your heart nhs' into Google and click on the top link.

You can also check out a video on YouTube which explains more about the review. Experts, teenagers and parents are all interviewed. Just type 'The future of children's heart services in England' into the search bar on YouTube. Don't forget, if you want to know any more, or would just like to be kept up to date, you can always email Suzie :-)

JB

email: suzie@lhm.org.uk

Seeking a New Patron

As you may know Baroness Valerie Howarth has been LHM's Patron, and a Trustee for many years. She works to help us raise a greater awareness of your needs and the needs of your family within the House of Lords.

Valerie has kindly agreed to take on the role of our President so we have started to look for a new Patron.

Carys Allen, the chair person of your Youth Council has written to Suzie to ask if we could ask the Duchess of Cambridge, Catherine Middleton, if she would consider being our new Patron.

We know that lots of charities have written to the Duchess asking if she could be their patron so the chances of her picking LHM are small but Suzie has written asking her to consider us.

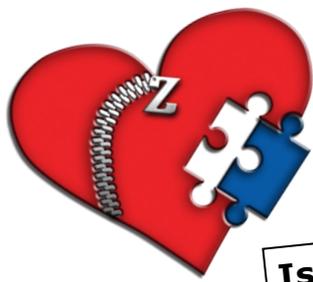
Keep your fingers crossed.

If you have any ideas of people who might be great ambassadors for the charity let us have your ideas and we will contact them on your behalf. If you send us a letter we can pass the letter on for you with some of our charity information.

What Youth Services do you want in the Future?

The LHM office and Trustee team are looking at what services our members would like next year, money permitting. Do you have any ideas for new services that we might be able to build next year?

If you do email them to Suzie or Jon on suzie@lhm.org.uk or jon@lhm.org.uk



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The future of children's heart services in England



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