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YOUR SHOUT

Dominic's Determination

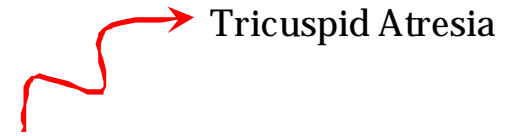
Hi I'm Dom Davies,
 I have half a heart but I am exceedingly determined. I even won an end of primary school Award for Determination! You are probably thinking **how on earth did he get that?**

Simple: all you need is a positive mind and say (or think) **"I'll manage and keep calm and carry on"**. I've missed more than one third of my school career because of my medical conditions! I'm 11 years old and I have coped with many **major operations.**

In sports I try my hardest to join in and have been given a **bronze award** for high-jump and a **silver award** for throwing. On sports day I still run with my friends with a **huge grin on my face**, even though I am **way behind** anyone else and always come last.

My favourite school subject is History and I also like acting and Pokemon! I live with my parents, two brothers, a crazy cat and a daft dog in a village in Suffolk. I am going up to secondary school in September, so who knows what adventures lie ahead?!

Dominic Davies, Aged 11



Tricuspid Atresia

(But that don't stop him!)

Take care, **Caz**

Caroline's Column



Dear Caroline,
 Thought you might like to know that having a heart condition doesn't have to get in the way of achieving great things... I just won the year 6 school leavers award for determination!

I would like to know how other kids balance being independent with not taking risks?

I have lots of reasons why it is difficult for me not to be supervised, but I want to go out on my own...

Dominic Davies, aged 11,

Tricuspid Atresia and lots of other medical things!!

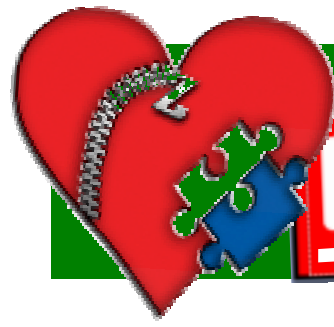
Caroline says:

I was not really allowed to do much on my own as a young child as my parents would worry and teachers would be a bit apprehensive about letting me join in with some things. I think by the time I was about 12 years old I had managed to build up a good relationship with people where they knew that I was aware of **my own** limits and restrictions.

I would know when I needed to stop for a rest, when it was time to take medication, and times when I would have to sit the activity out and just watch. People started to see that I knew all about my limits and restrictions, and that's when I was given more independence to judge things for myself, and be more independent.

I think it's a case of act as you want to be treated.

But you should also understand that our parents will always worry about us that little bit more because of what we have been through, but that's perfectly understandable.



BIG Heart Matters...

Issue 9

Sept/Oct 2009

NEWSFLASH!
 What happened @ LHM last month...

◆ The Zipper Get Together was awesome. There were 30 young people who all had an awesome time, and made loads of new friends. We had an ace session by Suzie about the heart, plus loads of fun stuff, read more inside...

◆ Will Goodenough, Jason Bailey, Paige Laight and her sister Katie met Premiership footballer Barry Ferguson at the Birmingham City Football Club ground: St Andrew's Stadium

◆ The zipperzone website was launched.

Check out:
www.zipperzone.org.uk

Email jon@lhm.org.uk to get an access card so that you can access the member only zone.

◆ Will Goodenough has been doing some fantastic fundraising for LHM by writing a letter to everyone that he knows about the Shugborough Fun Run

ZIPPERS OF THE WORLD: UNITE!



If you're reading this it's because you've got a heart condition or know someone who has got a heart condition.

This means that you have got to deal with stuff that other kids and teenagers don't like hospital, medication, tiredness, and worrying about your condition. This can be tough, and you might feel very alone, like you are the only person with half a heart.

Well guess what? In the words of the great Michael Jackson: You are not alone.

DID YOU KNOW that there are *hundreds* of teenagers living in the UK who only have half a heart?

You **DON'T** have to feel alone anymore. You **DON'T** need to worry about problems because of your heart condition. You **DON'T** have to feel different.

We can:

◆ **Answer your questions** you don't have to leave your name, and your question can be about anything.

◆ **Cheer you up when you're feeling down.** There are loads of ways to get in touch

◆ **Give you information** about your heart, hospital, medication, school, alcohol, drugs, sex and much, much more...

◆ **Put you in touch with other kids** by email, facebook or phone!

So what are you waiting for? Get in touch with jon@lhm.org.uk or text or call 07590 531153. Make sure that you log on to www.zipperzone.org.uk as well!

ZIPPERS, YOU HAVE A FACEBOOK PAGE



All you need to do is email jon@lhm.org.uk, I'll send you a pack to read through with your parents, you both sign it, send it back, and then you'll receive an invitation to a secret, hidden group. Send me the email **now**, the earlier you get the 'paperwork' out of the way, the earlier you can start chatting, with other heart kids!

Never. Be. Lonely. Again.

First you need to email me though, because the page is hidden to make it secure. **Email me NOW** at jon@lhm.org.uk to get on the page and start chatting to other kids with a heart condition from all across the UK. There will be no adults on there, so you can talk about whatever you like, as long as it doesn't break the rules. **Get involved now!**

Are you a righty or a lefty?

DID YOU KNOW? Little Hearts Matter used to be called Left Heart Matters. That's because we only used to look after families who had a baby with a **left sided heart condition**. Now we look after *anyone* who has been affected by a 'Single Ventricle Heart Condition'. Single Ventricle Heart Condition means anyone with half a working heart, it doesn't matter if it's the left side or right side.

Do you know whether you are a 'righty' or a 'lefty'? Ask your parents exactly what your heart condition is called, and then use these lists to see whether you have a left sided condition (lefty) or a right sided condition (righty) or 'in the middle'.

Left Sided Heart Conditions

- ◆ Hypoplastic Left Heart Syndrome

In The Middle

- ◆ Univentricular Hearts
- ◆ Double Inlet Ventricle
- ◆ Double Outlet Ventricle

Right Sided Heart Conditions

- ◆ Complex Pulmonary Atresia
- ◆ Tricuspid Atresia
- ◆ (Sometimes these are called Hypoplastic Right Heart Syndrome)

Do you want to learn more about YOUR heart condition?

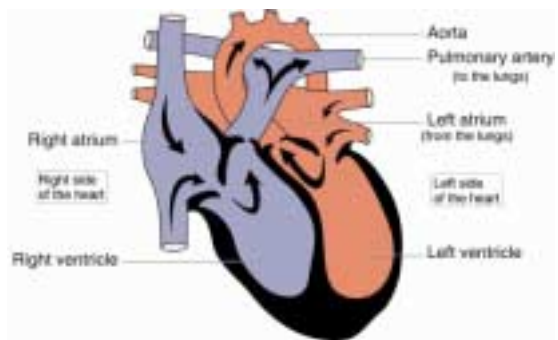
Phone, Email, or Text

Call the office on 0121 455 8982, and ask to speak to Suzie. Suzie has worked with heart children for over 25 years, and can explain your condition to you without any long complicated words!

Log onto www.zipperzone.org.uk, click on 'Ask Us' and ask one of the team about your condition

Text Jon on 07590 531153 with a question, who will get back to you by text with an answer

Normal Heart

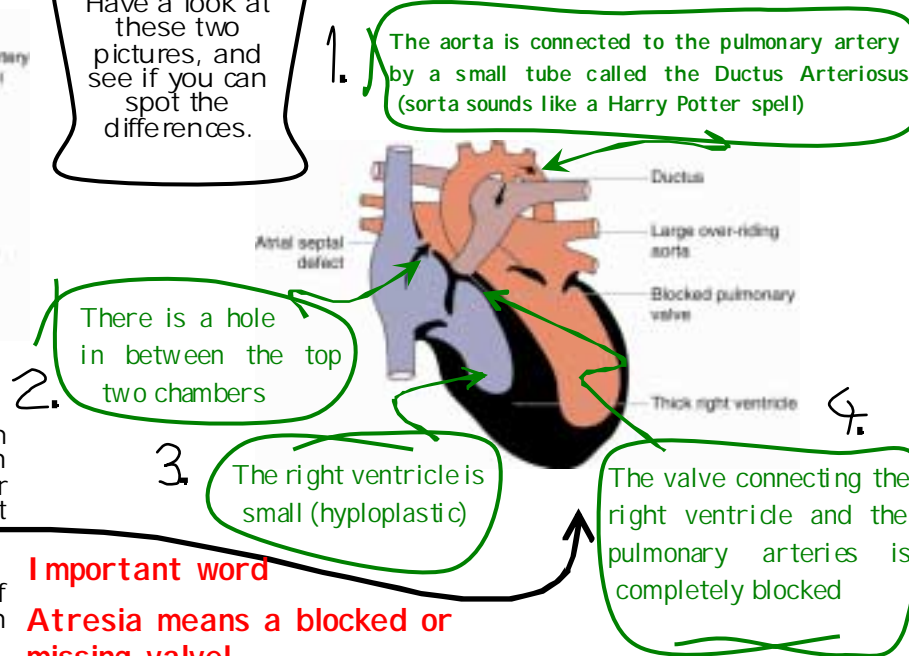


Look at this picture. This is a diagram of a normal heart. When a baby is born with **Complex Pulmonary Atresia**, your heart doesn't look like this though... It looks like this instead.

Compare the two diagrams, and see if you can notice the differences between them

Complex Pulmonary Atresia

Have a look at these two pictures, and see if you can spot the differences.



Important word
Atresia means a blocked or missing valve!

Your Youth Council in ACTION



On the left: Carys Allen and Sarah Haselgrove with Jon Sopel, from the Politics Show on the BBC
Above: Sarah talking about her heart condition on national TV with Arifa Karim, a member of the Youth Parliament

Carys Allen and Sarah Haselgrove, both members of the LHM Youth Council, went to the House of Commons to tell MPs that schools don't understand heart conditions properly, and need to improve.

There were children from over 20 charities there, all with different health conditions, and they all had a chance to ask questions to some really important MPs - the people in parliament who make the decisions about how schools should look after kids with health conditions.

The children all sat down at the front and the adults had to sit at the back. This was an opportunity for young people to have their say. The MPs listened to all of the young people's questions, and had to come up with answers about how they would improve schools so that it is easier for children with health conditions. Sarah asked a brilliant question, telling the panel that too much pressure is being put on young people with heart conditions during their GCSEs. The panel said that the school shouldn't make you do so many, and that they should listen to every young person's individual needs.

Jon Sopel off of the TV was the chairman for the event. He presents the Politics Show on the BBC, and presents the news on BBC News 24 in the evenings. He was very friendly, and made sure that the MPs answered the children's questions properly, and didn't waffle on too long.

This is another example of how young people are driving forward change to make sure that everyone with a heart condition has an easier time.



What did Jon learn?

YOUR Heart.

YOUR Charity.

YOUR Voice.

Whenever I do an event for all you zippers I ask you to fill out a feedback form. I know that this is boring, but it is because I want to know what you think. Grown ups are usually rubbish at listening to young people, but I know that you have really good ideas, and that if adults listened to kids more, then they would learn a lot.

That's why I try and listen to you, and give you the opportunity to tell me what you are thinking. It's important that you take these opportunities, otherwise you can never moan that nobody listens to you!

So, here is what I learnt from what you told me about the last Zipper Get Together:

1. 9Square was a really cool game, and you'd like to play it again, but it was confusing, and I didn't explain it well enough. Next time I should spend more time explaining the rules, and making sure that everyone knows how to play.
2. Drama is amazing, but you would like more time, and the chance to work in smaller groups. From now on at youth events, you will be split into small groups of people similar ages to you, although we will all come together for some activities.
3. You want more football.
4. In sessions where you learn about your heart, it should be fun, but people shouldn't be allowed to mess about, otherwise other people that want to listen get distracted.

There it is! If you have any more suggestions, then you can always email me at jon@lhm.org.uk and I will make sure that I listen to them, and use them to improve our events for you!

Our next confirmed event is going to be the Open Day in March 2010. Last March we had a quality time, so I hope that you will be able to come along to the next one and make loads of new friends.

Normal Heart



Look at this picture. This is a diagram of a normal heart. When a baby is born with **Tricuspid Atresia**, your heart doesn't look like this. It looks like this instead.

Compare the two diagrams, and see if you can notice the differences between them...

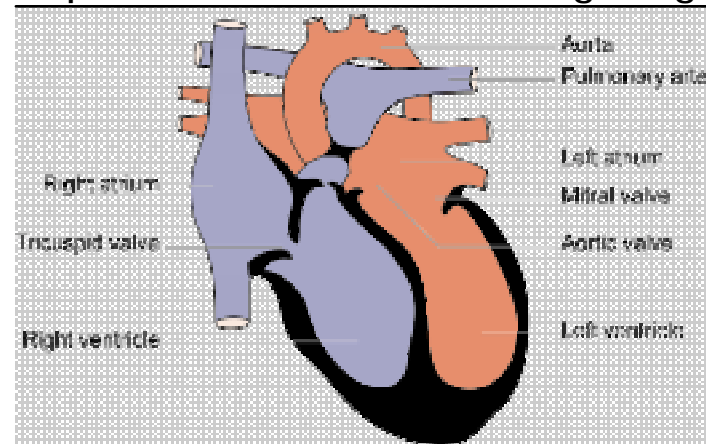
Tricuspid Atresia

1. There is a hole in between the right atrium and the left atrium, which lets red (oxygenated) blood mix with blue (deoxygenated) blood.
2. The pulmonary valve is narrow, so not as much blood can get to the lungs through the pulmonary arteries.
3. The Tricuspid Valve is blocked, so no blood can get from the right atrium to the right ventricle.
4. There is a hole in between the right and left ventricle, which lets some of the mixed blood travel to the lungs, and some to the body.

Important word = Atresia means a blocked or missing valve!

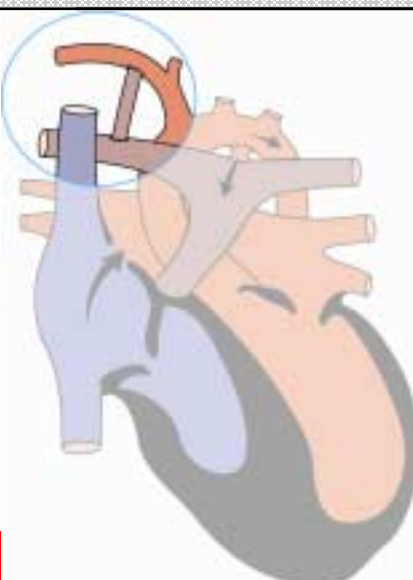
What did the clever surgeons do to my heart?

There are different ways to treat a baby with a right-sided condition. It all depends on how much blood is getting to your lungs and your body.



If there is too much blood flowing into your lungs, the surgeons put a band around the pulmonary artery, to make the blood flow slower. This is called 'banding'. Here is a picture of what a heart that has been banded might look like, can you see the band?

If there is not enough blood flowing into the lungs, the surgeons can put a small tube in, which redirects blood from the aorta (which takes blood to the body) to the pulmonary artery (which takes blood to the lungs). The tube is called a 'shunt'. Here is a picture of what a heart with a shunt might look like, can you see the 'shunt'?



NEXT TIME..we will have two pages on the FONTAN PROCEDURE. This is the operation that children with only one working ventricle have to redirect the blood flow.

ZIPPER GET-TOGETHER

A special section with photos and quotes from an awesome day in the midlands. If you couldn't make it, don't worry, we'll be doing another soon!



9Square

Did anybody actually know the rules to this game? Anyhow, it was still a load of fun, with some epic rivalries (James Metcalfe vs Will Goodenough was tense to watch)! We'll play it again at our next get together...but with a bit more explaining time, yeah?

“Really fun, kept your attention”

Magic

“It was ‘magic!’”



The LHM youth team risked (possible) assassination from the Magic Circle by revealing some really cool, easy to do card, tricks. There will be videos on www.zipperzone.org.uk soon with more tricks for you to impress your mates with! Log on now and click 'Gallery' to see...



“Really interesting to find out more about me”

Understanding Your Heart



This is what the whole day was about. Your Youth Council told us that you want to be able to understand your heart condition. That's why we organised this event, and Suzie did a big session explaining how your heart works without any long complicated words. If you want to know more about your heart, log on to www.zipperzone.org.uk, where you can ask Suzie, Jon, or Caroline a question.

riddles

FOUR JOLLY MEN

Four jolly men sat down to play,
They played all night till break of day,
They played for cash and not for fun,
With a separate score for every one,

When it came to square accounts,
They each had made quite fair amounts,
Not one had lost and all had gained,
Tell me now, can this you explain?

Cryptic code, only 4 the wise!

Can you read the following? Yy u r yy u b l c u r yy 4 me.

Feeling peckish?

You are walking through a field and you pick something up to eat. It doesn't have bones and it doesn't have meat. You pick it up, and put it in your pocket. You take it home and put it on a shelf for another day, but three days later it walks away. What is It?

Last but not least...

What goes through the door, but never enters or leaves the house?

1. The men are members of a band, they were playing instruments.
2. Too wise you are, too wise you be, I see you are too wise for me.
3. An egg. 4. A key hole



What a superb poem! This was written by the very clever Matthew Flavell. It's so good that it's actually going to be published in a proper book! Nice one Matthew!

THE BEAST OF BODMIN MOOR



I'm prowling on the grassy moor.
My name's the beast of Bodmin Moor.
I eat and sleep all day long,
I never do any wrong.

Some Say I'm a pet cat,
Imagine me with a rat!
So when you walk on the moor,
Think about the beast of Bodmin Moor.

Matthew Flavell

illusions

Frazzle your brains with these crazy illusions, then go back to your revision and it will be less of a headache :)



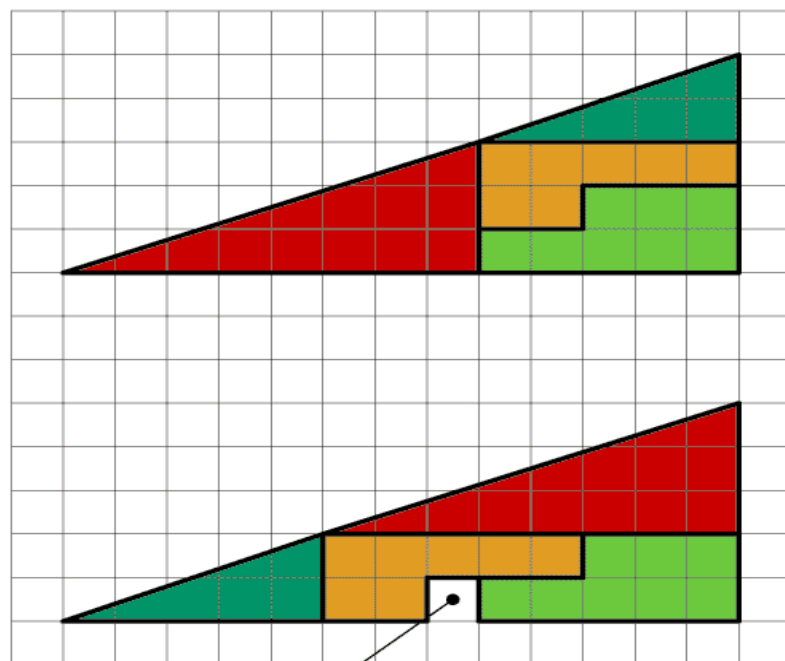
Can you work this one out?

Here are some facts about this picture:

- ◆ The woman and man are both average size
- ◆ The photo was taken in a single shot, and wasn't manipulated afterwards.

Email jon@lhm.org.uk for the answer!

HOW CAN THIS BE TRUE ?



From where comes this "hole" ?

Below the four parts are moved around

The partitions are exactly the same, as those used above

Plato's Cursed Triangle

This one is really, really, actually difficult.

Any boffins out there think that you can crack it?

If you can, and you send me the correct answer (NOT copied from Wikipedia, I know your tricks...) I will send you a £10 HMV voucher, coz it's well hard and it deserves a good prize.

Also, you will be crowned the cleverest zipper in the whole of LHM ZipperLand, and I might make you a crown. Although my art skills are very, very poor, so I might try, then give up and cry a little bit.

Answers to jon@lhm.org.uk

Dance

Those of you who took part in her session will know that Kat is the best damn dance teacher that you will ever meet. If you've got the determination, she can teach ANYONE to dance. Except me...nobody's that good.



“ Really well choreographed, Kat is amazing. ”



Drama + Footy



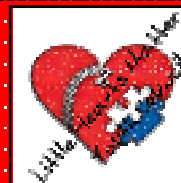
Drama is always loads of fun, and a lot of you guys have said that you find it easier to talk about your heart condition through drama. That's why it's really popular at LHM events, and that's why we always do it!

As for the footy, well even if we don't put this on the programme it finds its way in!

“Drama helps us say what is hard”



Your Youth Council



Hi, I'm Sam Hall; I'm 16 years old and I'm the only sibling member of the Little Hearts Matter Youth Council.

What I'm trying to achieve with the Youth Council is added support for siblings. This is because at the moment there seems to be little specific support for siblings, or it isn't as well distributed and has a low awareness.

The last meeting we had was at Suzie's house in a big get together thing. We went through an email from Pete Turner that addressed some of the questions we had asked to be raised at the next trustee meeting. He basically said that what we wanted to do was fantastic but some of the things we wanted to do were too expensive! He did say, however, that a few of the ideas we had were great and could possibly be implemented after some of the other projects that Little Hearts Matter are doing. The Youth Council has been great for me because as it's my GCSE's then I am under a lot of pressure at school to do well, and it's just nice to do something that I enjoy and I can work with people I like spending time with.





Kev's Fundraising bit

Christmas is almost here! And we all know the true meaning of Christmas: PRESENTS!

One of my other favourite bits is the Christmas cards!

The only thing is that it's a real pain writing card after card after card to all my mates. So why not do things a bit differently this year?

You can save your parents some money (get in their good books) whilst at the same time making a donation to help the work of your charity Little Hearts Matter.

How?!

...I hear you ask. It's simple how! Deb has created a beautiful huge alternative Christmas Card which everyone in your class or form can write a message on.

How does it work?

It works as a poster, and you stick it up in your classroom or form room for everyone to leave an Xmas message. Ask them to make a small donation. Give your form tutor a pot to hold the donations in, you can even compete against all of the other tutor groups in the year to see who raises the most!

So get involved! Your parents should have received a copy of this at the end of August, but you can also download them from our website at www.lhm.org.uk just click on fundraising and merchandise, then click on alternative xmas card on the menu on the left!



THE AWARD WINNING LHMYC



The Record of Achievement Award Ceremony rewards young people for giving up their time to help their community or group.

The LHMYC, or Little Hearts Matter Youth Council, collected their awards from the Lord Mayor in Birmingham for all of their hard work over the last 6 months helping to make LHM a better charity.

Each of the young councillors, aged between 12 and 17, received awards for their contribution to the Youth Council. All of the members meet by email regularly to talk about what young people with heart conditions need from the charity. The Youth Council also has a sibling representative, Sam Hall, who is the sibling of a young person with a heart condition. He tells the charity the difficulties brothers and sisters go through, and how we can help.

The Youth Council has written a Constitution, which is like a list of rules that the Youth Council must follow. It also lays out their Aims and Objectives. Over the next few years, here is what the Council hopes to achieve:

- Find out what children and families within the charity want to see
- Inform Little Hearts Matter what young members want from the charity
- To be representatives of all of the Young Members of Little Hearts Matter
- Find ways to advertise the charity to gain more support
- Send information to the schools of Little Hearts Matter's young members
- Increase support for siblings, especially when brothers and sisters are in hospital
- To help fund the Youth Services by any means possible
- Organise trips for teenagers with a heart condition
- Provide information to the teenagers to help them become aware of their condition
- Think about how the heart conditions will affect the young people in the future, and ways we can support them
- Have fun!

If you would like to be involved in how LHM runs, or you want to help make LHM a better charity, get in touch with Jon at jon@lhm.org.uk