

# Organ donation law in England is changing to an opt out system

On 20 May 2020 organ donation law in England is changing to an 'opt out' system.

This is a hugely positive change for the heart community that will save lives, with more organs available for transplant – an issue we know is of great importance to families waiting for an organ donor.

The law change means that all adults in England will be considered to have agreed to be an organ donor when they die unless they have recorded a decision not to donate or are in one of the [excluded groups](#).

You will still have a choice about becoming an organ donor, and can register your decision on the NHS Organ Donation website. Your friends and family will be asked about your wishes, so make sure that you speak to them and let them know what you want.

ECHO's Chief Executive, Samantha Johnson explains:

*At ECHO, we know that families are asked to donate the organs of their loved ones at a time of severe heartbreak and loss, however I hope that this law change encourages families to talk about their wishes and start a conversation. I encourage each member of the ECHO heart community to take some time to read the information on the NHS Organ Donation website to help you make a choice, register your decision, and then share your decision with your family."*

*Organ Donation Law in England: NHS Organ Donation*



## Marnie's Story

*Our daughter Marnie was born on 10th May 2016 with a condition called Noonans Syndrome, a symptom of this genetic disorder is hypertrophic cardiomyopathy. This is where the walls of the heart are too thick and therefore struggle to pump blood efficiently around the body. Our beautiful little girl was otherwise a healthy, happy baby but she simply got too tired to do simple things like feeding, rolling over, holding toys and even sometimes, breathing. If you had met our darling girl, you would never forget her. I know all parents say this about their children, but Marnie really was quite the character. She had the toughest and strongest will to survive, thrive and to make others smile (that kind of smile that comes from your soul).*

*On August 15th 2016 Marnie was placed on the Organ Donor recipient list as her heart was just getting weaker and weaker. We were told that the chances of Marnie receiving a lifesaving heart were slim. There were many reasons for this, that parents of babies simply didn't want to think about it in that tragic moment of losing a child, that babies do not tend to die very often (thankfully) and that there was simply a lack of awareness about organ donation.*

*The moment my husband Nick and I became aware of this we began to campaign, Marnie was all over the news promoting the much sought after changes to the current system in the UK, an opt out system, where everyone is registered as an organ donor unless they request not to be.*

*Sadly, Marnie caught the common cold in October 2016, she battled it for over week and so very nearly made it but her big, beautiful heart just simply couldn't cope anymore. Marnie died at 10pm on the 26<sup>th</sup> October 2016 in her mummy's arms with her daddy holding her hand and her adoring aunts by her side.*

*The next morning, we were asked whether we would consider donating Marnie's heart valves, they could potentially go on to save lives. We did not even need to think, of course we would, to know that part of our precious girl would be living on and having saved another's life, what a privilege. We have*

*since learned that Marnie saved a 10-month-old little boy and another person.*

*Marnie achieved so much in her short 24 weeks and one day on this earth, she saved lives, she connected people from all over the world and she still does. I am honoured to be Marnie's mummy and to finally be reaching the day we have sought after for so long feels incredible! The 20<sup>th</sup> May 2020, the day that Organ Donation becomes an opt out system.*



*The Brace Family*

## **Making your choice**

ECHO acknowledges the incredible loss that comes with organ donation, and that for every life saved another life has gone - and our thoughts are with every family experiencing loss and bereavement.

ECHO, in partnership with the rest of the children's heart community, has campaigned on this issue and is therefore very pleased the law is now changing.

**As of now, all English citizens are able to register their wishes regarding organ donation. For further information and to do this visit the NHS Organ Donation website at the button below**



or [click here.](#)