

## "If you do one thing today, go home and talk to your family about the new organ donation law."

Monday 2 September, 2019

Dear Editor,

With Organ Donation Week beginning next week, it's humbling to look back on how far we've come in the last year. Once again we are supporting NHS Blood and Transplant and Organ Donation Week 2019 and it's with thanks to individuals tirelessly raising awareness about the need for a change in the law that next year all adults will be considered as having agreed to donate their own organs when they die, unless they record a decision not to donate or are in one of the excluded groups

The Sick Children's Trust recognises that this is an enormous step in the right direction but we're mindful that the change in the law won't directly impact the families we support. Families of children waiting for an organ transplant. Many children still face a long wait for a donor organ to become available, and will continue to need support from charities like ours to support them on this journey. Children will not be considered as having agreed to donate their own organs under the new law, their parents will be asked about organ donation – children can choose to register or their parents can register them.

When the new law is implemented, the family of a loved one will continue to play a vital role in organ donation. This is why we are calling on parents and children across England to talk about it. Know what your loved one's choice is and register your choice on the NHS Organ Donor Register.

Every day at The Sick Children's Trust we meet families who are facing the agonising wait for the news that an organ has become available for their child. They could be waiting for many months with their child in hospital. On average, a child waiting for a donor heart will wait two-and-a-half times longer than an adult on the list, often at a hospital far away from home. Parents may find themselves having to split their time between children, travelling hundreds of miles to be with their seriously ill child with many sleepless nights on hospital chairs.

While awareness is being raised around the need for organs for children, The Sick Children's Trust promises to be there for these families, giving them a comfortable place to stay just minutes away from their child's hospital bedside.

Editor, we ask that if you and your readers do one thing today that it is to go home and talk about the new organ donation law and make sure you know your loved one's decision so more lives across the country can be saved.

Kindest regards,

Jane Featherstone, Chief Executive at The Sick Children's Trust

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