



Cystic Fibrosis Trust
Response to Welsh Government Proposals for Legislation
on Organ and Tissue Donation

Whilst formulating our response to this consultation, the Cystic Fibrosis Trust has consulted with the CF community, including people with Cystic Fibrosis, families of people with CF and physicians within the CF and transplant fields. This response reflects their views and concerns regarding the proposed changes in the organ donation system.

What is Cystic Fibrosis?

Cystic Fibrosis is one of the UK's most common, life-threatening inherited diseases, affecting over 9,000 people in the UK. The faulty gene causes CF is carried by 1 in 25 people, and 1 in every 2500 babies in the UK is born with Cystic Fibrosis. It is a life-long illness, affecting a person from birth to death.

While new treatments and better management of care are helping people with Cystic Fibrosis live longer, many will reach a point at which receiving a transplant, be it lung, heart-lung or liver, is their only option to prolong life significantly. Despite this, nearly half of all people with CF on the transplant waiting list will die before they receive a transplant.

About the Cystic Fibrosis Trust

The Cystic Fibrosis Trust was founded in 1964 and is the UK's only national charity working to fund research into a cure and effective treatments for Cystic Fibrosis and to ensure appropriate clinical care and support for people with Cystic Fibrosis. It aims to ensure that people with CF receive the best possible care and support in all aspects of their lives, and provides information, advice and support to anyone affected by Cystic Fibrosis.

While new treatments and better management of care are helping people with Cystic Fibrosis live longer, many will reach a point at which receiving a lung transplant is their only option to prolong life

11 London Road, Bromley, Kent BR1 1BY
Tel: 020 8464 7211 • Fax: 020 8313 0472 • www.cftrust.org.uk

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significantly. The Cystic Fibrosis Trust supports efforts to ensure that all those with CF who are assessed as suitable for a lung transplant receive one.

The Cystic Fibrosis Trust are in the process of developing a dedicated programme of work with NHS Blood & Transplant, and other organisations, to develop a national standard for transplant services. In addition, the Cystic Fibrosis Trust will continue to fund research into ensuring more organs are available for transplant, such as the 'reconditioning' lungs programme.

Our view

Following a consultation with the CF Community including those with CF, their parents and carers and physicians from the CF and transplant field the CF Trust feel able to welcome the Welsh Government proposals to change organ donation legislation. We support a change in the system of how we donate organs, in the hope of increasing the number of transplants that are undertaken.

Although we hope that the introduction of the soft opt out would have a significant positive effect on transplant rates, we know that more needs to continue to be done, as indicated by the Organ Donor Taskforce's 14 recommendations. Whilst the emphasis to date has been on getting people to sign the national organ donation register, it is absolutely clear that unless other fundamental problems are also addressed, this will be of modest benefit.

Whilst we recognise that many of the countries that do have high rates of organ donation per head of population have presumed consent enshrined in law, it is not clear that high organ donation rates are a direct result of an opt-out system, rather than the result of a comprehensive and coordinated approach towards organ harvesting. Therefore, we feel this is a welcome change in legislation, but it is essential it is done alongside a number of other measures in order to improve the rates of organ donation.

It is generally accepted that the UK's inability to convert potential donors into actual donors in a significant number of cases contributes to the shortfall, so the ongoing work must be supported - and investment in Organ Donation co-ordinators, Specialist Nurses and Clinical Leads sustained. We

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believe we cannot afford for a change in the consent system to distract attention away from the need to improve the systems and infrastructure around organ donation in the UK.

A national debate needs to take place on organ donation and transplantation. It is only when donating your organs after death becomes usual, not unusual, that we will be on the road to giving people on the waiting list real hope. This consultation goes some way to making this debate happen and any change in legislation could help to focus individual's attention on their wishes after death.

Conclusion

The Cystic Fibrosis Trust supports the Welsh government proposals to legislate for an opt out organ donation register in Wales, but we are aware that legislation alone will not be enough to significantly improve transplantation rates.

We hope that such a change in legislation will lead to a UK wide re-appraisal of the current situation, and a much needed discussion of organ transplantation, ultimately leading to increased donation rates across the UK.

For more information on The Welsh Government's proposals visit <http://wales.gov.uk>.

Organ and Tissue Donation has been discussed in a paper by the British Medical Association. You can see this here at www.bma.org.uk.

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