

# Neuro Café: Organ Donation Week 2023

13<sup>th</sup> September 2023



- Why are we talking about this at the Neuro Café?
  - Education about law changes so your choices & beliefs are known
  - Dispelling the myths can't donate with a neurological condition
  - Education about brain and spinal cord donation for research which can help many in the future
  - You have the power to save and improve lives





## Organ Donation week

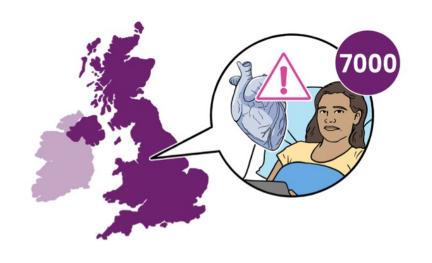


- Organ Donation Week is a week-long campaign that takes place every year, with the aim of raising awareness about the ongoing need for organ donors.
- This year, Organ donation are aiming to get 25,000 more people to register to become organ donors and we want to ensure we help them with educating & increasing the reach of the message

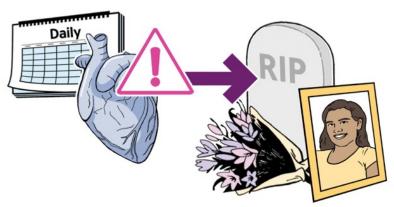


More than 3000 lives in the UK are saved or improved each year by organ transplants.

# Facts about organ donation



There are around 7,000 people waiting for a transplant in the UK.



On average, someone dies every day waiting for a transplant because there are not enough people donating.

https://www.organdonation.nhs.uk

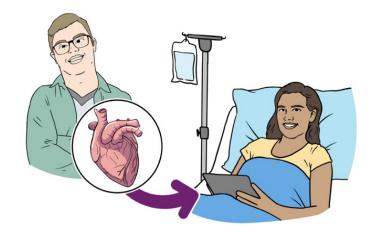
## Organ donation laws

- Organ donation laws vary across different countries in the United Kingdom (England, Scotland, Wales and Northern Ireland) and the Crown dependencies of Jersey, Guernsey and the Isle of Man.
- England Oupt out
- Wales deemed consent
- Scotland- deemed authorisation
- Northern Ireland- oupt out

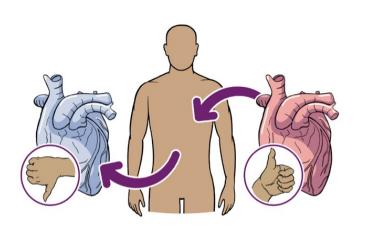
 https://www.organdonation.nhs.uk/helping-you-to-decide/organdonation-laws/



## What is organ & tissue donation



Organ donation is when you give an organ to help someone who needs a **transplant**.



A transplant is when an unhealthy organ is removed from the body by doctors and replaced with a healthy one.

https://www.organdonation.nhs.uk



Confirm your decision to be an organ donor. It's the best thing you'll do today.



Whatever you decide, please talk to your loved ones.

# Frequent asked questions around who can donate?

Is there an age limit for becoming an organ donor?

There is no age limit for becoming an organ donor.

Can children join the NHS Organ Donor Register?

- Parents and guardians can register their children, and children can register themselves.
- Children who are under 12 in Scotland and under 18 in the rest of the UK at the time of registration will require their parent or guardian's agreement for donation to take place.

# Frequent asked questions around who can donate?

Can you become an organ donor if you are unable to donate blood?

 If you don't or can't give blood you can still be a potential organ donor..

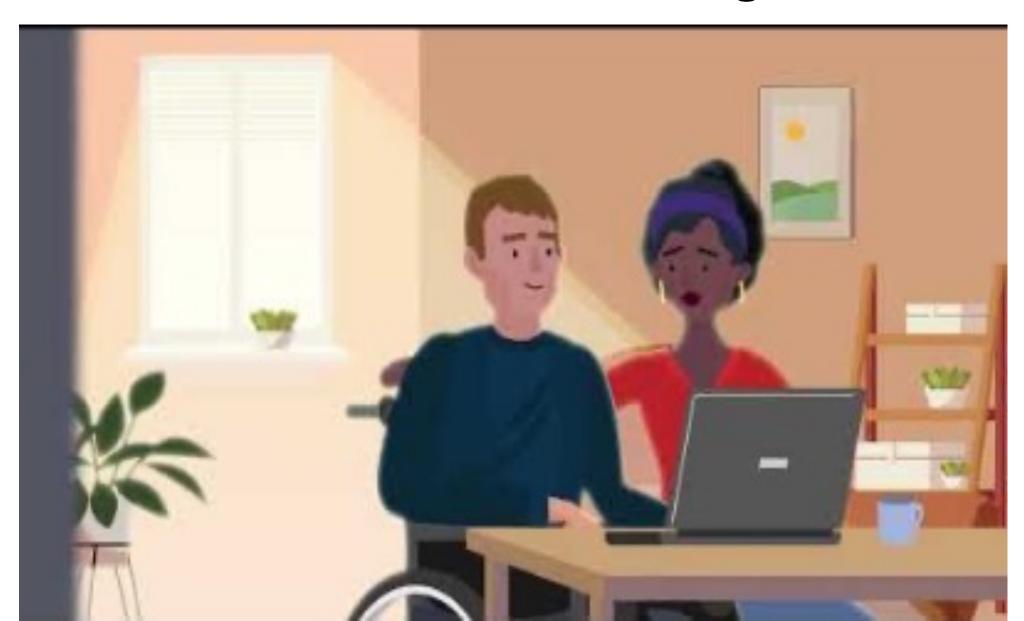
Does race, or ethnicity matter in organ donation??

- Donors are needed from all communities and ethnicities.
- Blood and tissue types need to match for a transplant to be successful, and organs from donors of the same ethnic background as the recipient are more likely to be a close match.

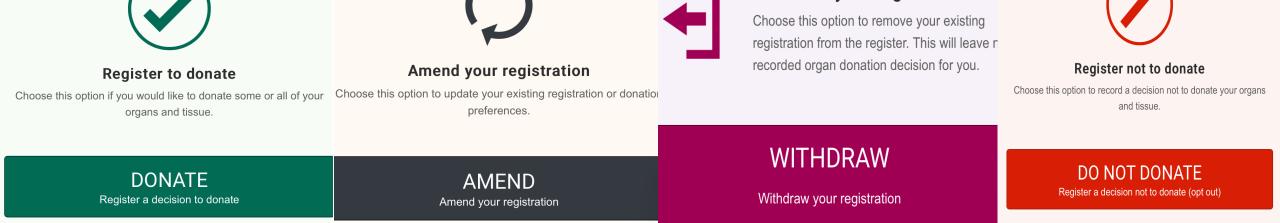
# Can you become an organ donor if you have a medical condition?

- Having an illness or medical condition doesn't necessarily prevent a
  person from becoming an organ or tissue donor. The decision about
  whether some or all organs or tissue are suitable for transplant is made by
  medical specialists at the time of donation, taking into account your
  medical, travel and social history.
- There are very few conditions where organ donation is ruled out completely.
- A person cannot become an organ donor if they have or are suspected of having:
- Creutzfeldt-Jakob Disease (CJD)
- Ebola virus disease
- Active <u>cancer</u>
- HIV\*

# How to become an NHS Organ Donor



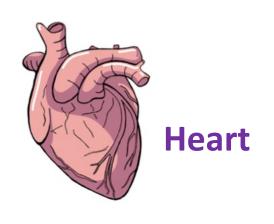
### Have you registered your decision?



Withdraw your registration

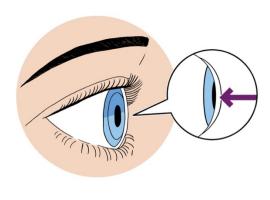
You can change your mind at any time

https://www.organdonation.nhs.uk/helping-you-to-decide/about-your-choices/

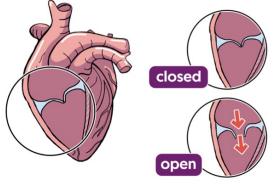






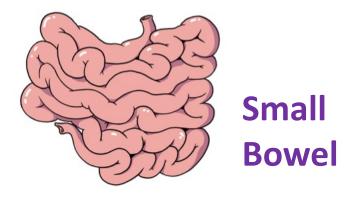


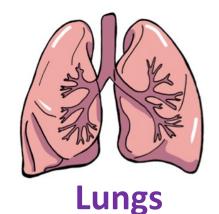
Cornea

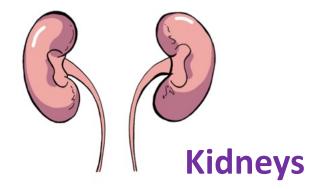


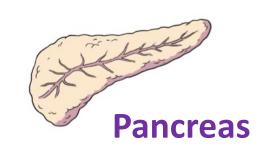
Heart valves

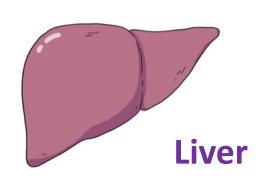






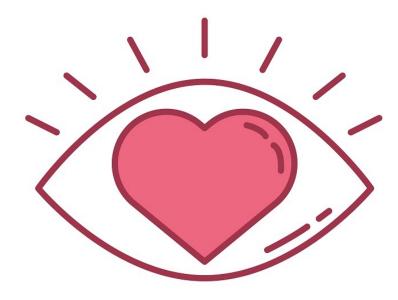






### Cornea donation

- By donating the cornea you are giving someone the gift of sight
- Many people feel uncomfortable thinking about cornea donation, but the reality is that it can mean the gift of sight to someone desperately in need of a transplant.
- Did you know?
  - The eye is never transplanted whole
  - Cornea donation does not affect how a donor looks
  - Cornea donation does not delay a donor's funeral





#### What about the brain?

- 78% UK adults are unaware that the NHS Organ Donor Register does not include the brain
- To donate your brain for medical research you need to register through separate systems
  - National Brain banks: <u>https://brainbanknetwork.ac.uk/public/donating/</u>
  - Parkinson's UK <u>https://www.parkinsons.org.uk/research/parkinsons-uk-brain-bank</u>
  - AlzheimerrsSociety: <a href="https://www.alzheimers.org.uk/research/our-research/research-strategy/brains-for-dementia-research">https://www.alzheimers.org.uk/research/our-research/research-strategy/brains-for-dementia-research</a>
  - Brain Tumour Charity: <u>https://www.thebraintumourcharity.org/living-with-a-brain-tumour/end-of-life-bereavement/brain-donation/</u>
  - MS Society: <a href="https://www.mssociety.org.uk/research/explore-our-research/research-we-fund/search-our-research-projects/ms-society-tissue-bank">https://www.mssociety.org.uk/research/explore-our-research/explore-our-research/research-projects/ms-society-tissue-bank</a>
  - MND: <a href="https://www.mndassociation.org/sites/default/files/2022-12/l-Tissue-donation.pdf">https://www.mndassociation.org/sites/default/files/2022-12/l-Tissue-donation.pdf</a>

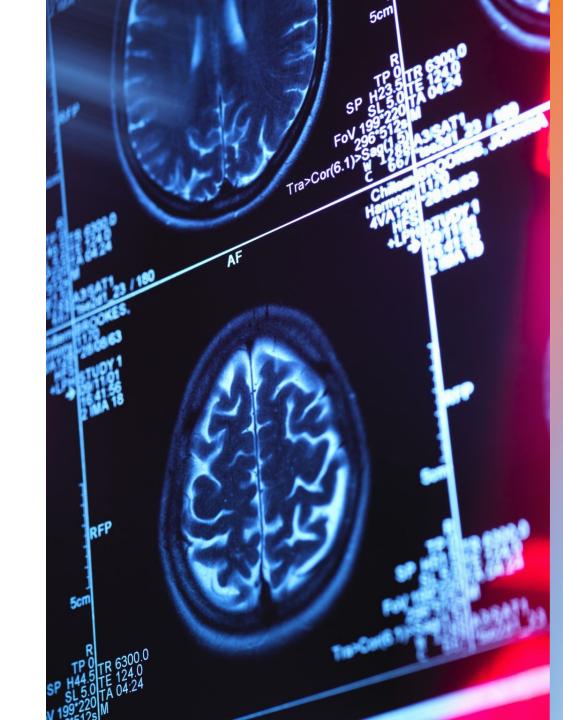
# Why is it important to donate brain tissue?



- Around 12 million people in the UK are living with a neurological condition and, as the average age of the population increases, the number of people developing dementia and other neurodegenerative diseases will increase rapidly
- More research is needed to find new and better treatments for a wide range of neurological conditions and healthy & affected brain and spinal cord can be donated.
- Register at your closest brain bank if you would like to donate your brain
  - Edinburgh, Newcastle, Cambridge, North London, South East London, West London, Oxford, Bristol, Sheffield, Manchester
  - At these specialist centres can also donate spinal cord and tissue

#### **Brain donation**

- Key findings showed that UK adults feel uneasy donating their brain in comparison to other organs:
  - 57% would be comfortable donating a kidney
  - 53% would be comfortable donating their liver
  - 52% would be comfortable donating their heart
  - 37% would be comfortable donating their brain



### Parkinson's UK Brain Bank

- The Parkinson's UK Brain Bank is the world's only brain bank solely dedicated to Parkinson's research. By pledging your brain to Parkinson's research, you can help find a cure to transform the lives of 153,000 people living with Parkinson's in the UK.
- The Brain Bank, based at Imperial College London needs people with and without Parkinson's to donate their brain for medical research so comparisons can be made
- "There is a misconception that unaffected brain tissue isn't useful which needs to be dispelled.
- Information via Brain Bank donor information booklet (PDF, 5.9MB).



# How you can pledge to donate your brain with PDUK?

#### Step 1:

- Download, print and complete the Brain Bank donor form with your details.
- Brain Bank donor form (PDF, 420KB)

#### Step 2:

Ask your next of kin to complete page 3

#### Step 3:

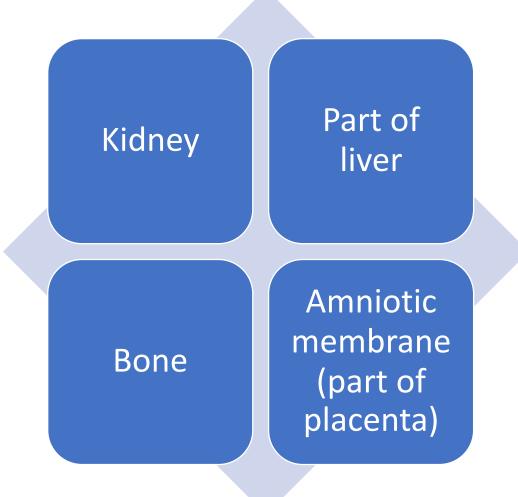
- Send all completed forms to the Brain Bank:
- Parkinson's UK Brain Bank Division of Brain Sciences Imperial College London Hammersmith Campus Du Cane Road London W12 ONN



# Living donors- volunteer to donate



Living donation



### **NHS Organ Donor Card**



### **Organ Donation**

is supported by my faith



## Contacts Organ Donation NHS

• 0300 123 23 23 – helpline re Organ donation

• <a href="https://www.organdonation.nhs.uk">https://www.organdonation.nhs.uk</a>