

TIME TO TALK ABOUT ORGAN DONATION

theWI
INSPIRING WOMEN

Legacy Pack

How you spread the word & what
you can do next



Foreword

The NFWI notes that three people die every day whilst waiting for an organ transplant. We call on every member of the WI to make their wishes regarding organ donation known, and to encourage their families and friends, and members of their local communities to do likewise.

– Standon & Cotes Heath WI, Staffordshire Federation, 2014 NFWI Annual Meeting.

In our over 100 years of history, the WI has passed four different resolutions on organ donation. A member from Staffordshire Federation proposed the most recent, spurred on by what she saw as the needless deaths of three people every day who are on the transplant waiting list. Imagine if it was your loved one- or you- waiting for an organ, delegates at the AM were asked.

This resolution continued a long history of WI action on this topic. Every time there has been a barrier to donation, the WI has worked to find solutions to overcome those obstacles. One of our most significant interventions was our 1994 resolution calling on the Government to investigate ways to promote organ donation. The WI campaign that then followed ultimately led to the creation of the NHS Organ Donor Register, still in use today, which shows how powerful the WI can be when all members work together.

Donations cannot take place without family consent- regardless of whether someone is on the Organ Donor Register or not. The Time to Talk campaign recognises that the decision to donate is a deeply personal one, but wants members to know that no matter what your decision, your wishes may not be followed if you do not share them with your family. This is even true under the new presumed consent or 'opt-out' system in Wales. You must share your wishes with your family so they can see them through.

When we embarked upon this campaign three years I had no idea about all of the creative ways WI members would think of to spread the word and spark a dialogue. Members have truly started a national conversation about organ donation, reaching into living rooms up and down the country, often sharing their own personal experiences along the way. Members have been tattooed, worked with local authorities, knitted thousands of little yellow ducks, and comforted fellow members who have been called upon to donate.

It has been both heart-breaking and heart-warming to hear the stories of WI members who in their deepest moments of grief chose to honour their loved ones' generosity of spirit through organ donation. The Time to Talk campaign pays tribute to their courage and through sharing their experiences seeks to educate other WI members about how important it is that they share their organ donation wishes.

I hope you enjoy reading this legacy pack and learning what you have all achieved together. More importantly, if you or your WI have not yet participated in the campaign, I hope you will be inspired by what you read to get involved. The last few pages of the pack have some ideas for how you can get a regional campaign started or how your individual WI can keep the conversations going.

Remember, no matter what you decide, your family should know about it. Take the time to tell them.



Marylyn Haines Evans
NFWI Chair of Public Affairs

Did you know...

Organ donation is the gift of an organ to help someone who needs a transplant. People can donate organs after their death and many people are living donors. Transplants can save or transform someone's life.

More than 500,000 people die every year in the UK, but fewer than 6,000 people die in circumstances where they can be a donor. Organs have to be transplanted very soon after someone has died, so they can only be donated by someone who has died in hospital. The way in which people die also has a bearing on which organs are suitable to transplant. Usually organs come from people who are certified dead while on a ventilator in an intensive care unit.

During 2015-2016, 1,364 people became organ donors when they died and their donations resulted in 3,519 transplants taking place- one of the highest on record. Just one donor can transform the lives of 9 people.

There are currently more than 21 million people in the UK on the Organ Donor Register, up from only 13 million in 2006. Every citizen in Wales is also automatically enrolled on the Register, unless they opt out.

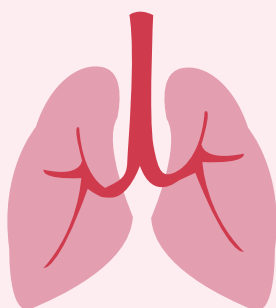
However, the family consent rate in the UK is one of the lowest in Europe. This matters because donations cannot move forward without the consent of the family- regardless of whether you are on

the Register or not. Only 62% of eligible families in 2015-2016 agreed to allow donation to move forward.

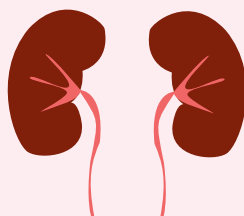
This is a welcome increase from the 2012-2013 rate of 58%, but still much lower than the NHS' 80% target. If 80% of families had provided consent, then an additional 1,000 transplants would have occurred last year.

There are around 6,500 people in the UK on the national transplant waiting list. Last year over 400 people died while waiting. A further 881 people were also moved off the transplant waiting list (either because they had been waiting too long or for other reasons) and then died shortly after.

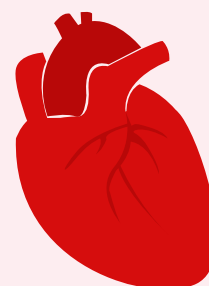
As of February 2016:



319
people are
waiting for a
lung



5,053
people are
waiting for a
kidney



250
people are
waiting for a
heart

What the Time to Talk campaign called for

1 Every member of the WI to share their organ donation decision.

The campaign calls for every member of the WI to consider this issue carefully, come to a conclusion- whatever that might be- and then share that decision with their family.

2 Tell us how you did it!

We asked members to think of creative ways to show others how they broached this sometimes sensitive topic. Most notably, we asked members to take part in the Big Conversation Craft Project, showing us through craft and photography how they told their loved ones about their wishes.

3 Register your decision formally.

Although this 2014 resolution did not call on members specifically to register on the NHS Organ Donor Register,

since our previous resolutions on organ donation endorsed the register, an added goal of this campaign was to encourage WI members to use registration as a springboard to then share their decision.

4 Share learning & change attitudes.

There is a lot of misinformation and confusion around organ donation. Many people believe that they are too old to be an organ donor or that they are ineligible because they are a smoker or received chemotherapy or other medical treatments. This is simply not true. The campaign sought to educate WI members so they could serve as local ambassadors in their community, correct the record on organ donation, and change attitudes towards donation.



NFWI Chair of Public Affairs Marilyn Haines Evans at Autumn National Council in 2014.

Debunking the myths

I'm too old to be a donor, you wouldn't want my organs!

Age is not always a barrier to donation. Nearly half of UK organ donors are over the age of 50 and the oldest UK organ donor was 85.

I don't need to tell my family about my decision because I am already on the Register

Your family can overrule your decision, even if you are on the Register and they often do so. Or, conversely, they can give consent when you have chosen not to. You must share your wishes and lift that burden from your family.

I've got long-term health problems, you don't want my organs!

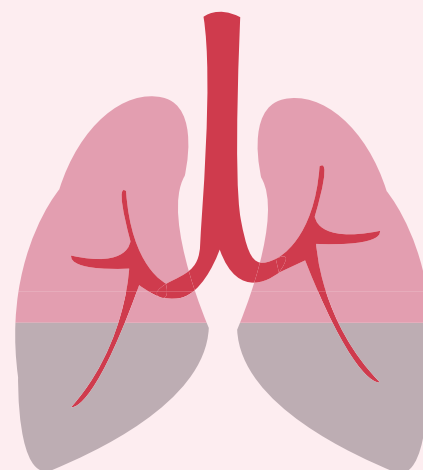
Medical conditions may not prevent you from being a donor. Even if you cannot donate blood, you may still be able to become an organ donor.

It's against my religion to be a donor

All of the UK's major faith groups support organ donation.

Doctors won't do enough to save me as they will be too interested in taking my organs to save someone else.

Your doctor's primary focus is to save your life. The doctor in charge of your care has nothing to do with transplantation.



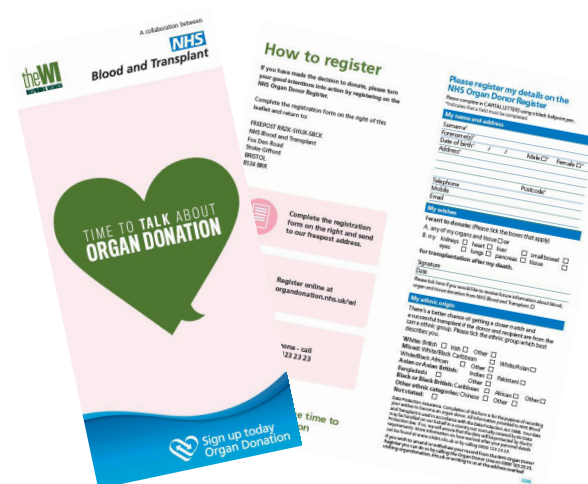
40% of lungs donated come from those who have smoked.

Key NFWI activity

1. Launched a multi-year partnership with NHS Blood and Transplant (NHSBT)

NHSBT is the special health authority that manages the national voluntary donation system for blood, tissues, organs, and stem cells.

The NFWI partnered with NHSBT to design a co-branded registration leaflet which members can use to register as a donor. The leaflet is uniquely coded to allow NHSBT to track the registrations from the WI source. We also piloted a unique web-link to facilitate online registrations through the WI.



2. Pioneered a regional campaign with WIs in the Greater Manchester region

The NFWI, in conjunction with Lancashire and Cheshire Federations, launched a regional campaign targeting WIs in Greater Manchester. We helped them launch a spring and summer of campaign activity throughout 2016. As part of this campaign we also trained members on how to be organ donation ambassadors. See pages 12 and 13 of this pack to learn more about this initiative and how you can launch your own in your region!



President of the Social Lites WI, Caroline Myers, introducing the latest craft project at the launch of Time to Talk Greater Manchester

3. Celebrated National Organ Donation Week (2015) at the WI Centenary fair in Harrogate

The Public Affairs department hosted a stall, promoting the Time to Talk campaign. We built a model living room and invited WI members and other attendees to come inside and discuss organ donation with us. In our 'living room' we displayed photographs of the innovative crafts that WI members have made to spread the word.



NFWI Public Affairs stand at the Harrogate Centennial Fair

What did members do and achieve?

Members spread the word through meetings & Federation events

WI members across the country invited speakers from NHSBT, or other organisations, to their meetings. It has been very popular to invite organ donation recipients, those who have made the decision to donate, or specialist nurses of organ donation (SNODs) to meetings.

Members also took to print media outlets and social media to inspire others and spread the message.

Members donated

Since the campaign began we also know of two members who have been called on to donate and have done so. NHSBT informed us that the WI is one of their only partnerships that they know has led to direct donations.

Members registered

Over 1,000 people signed up to the Organ Donor Register using our unique 'WI' code.

Members shared their stories

More than 30 members wrote in and shared their stories of donation with us and the wider WI community, in efforts to raise awareness about donation and break the silence some may sense around end of life discussions. Overwhelmingly, members reported that the experience of donating on behalf of their loved one provided them with a sense of consolation amidst their grief.

Laura's story



To: The NFWI
From: Judith Hargraves

Dear Editor,

The unthinkable has happened to my family.

My daughter Laura inadvertently consumed peanut protein and suffered an anaphylactic reaction. Her EpiPen did not save her; after five days in Intensive Care, she died last Christmas, aged just 32. Her late father had given over 50 pints of blood and although it was not something Laura had discussed, her sister Emily is on the Organ Donor Register so together we decided that something positive must come from our loss.

The day Laura died, three lives were saved through the donation of her kidneys, liver and pancreas. Two men have since had their sight saved with her corneas and her heart valve has just been given to a new baby girl. This has given us comfort in the midst of our terrible sorrow.

I would urge everyone to have the conversation - then support this important resolution to help transform and save lives.

Thank you. Sincerely,
Judith Hargraves, Snape WI



Members crafted

Since every discussion about organ donation is part of a bigger conversation, we wanted to provide a digital space and a medium for WI members to show that they had the conversation. We invited members to participate in the Big Conversation craft project and show us through craft how and with whom they had the conversation with. WIs and individual members across the country took part.

Rebecca of Let's Make Jam WI spelled it out for us on a scrabble board. Elsie of Bradda Head WI made a cushion with a pocket in the back for holding donation leaflets. Members then passed the cushion from house to house, making it the perfect ice breaker to start a conversation with loved ones as they were relaxing at home. Members of Gothic Valley WI, made their commitment to organ donation permanent by getting tattoos; one is a heart outline with the words 'I am an organ donor' and another is an anatomically correct heart with a banner across it reading 'Donor.'

Members also participated in the Little Yellow Duck Project. The Little Yellow Duck Project is a global initiative inspired by the life of Clare Cruickshank, a woman who died at the age of 26 due to cystic fibrosis. Clare loved yellow rubber ducks and the project involves people handcrafting little yellow ducks and leaving them in public places for others to find and enjoy, with some information about the importance of donation.

Members joined forced and crafted thousands of little yellow ducks throughout the span of the campaign. Huntingdon & Peterborough even participated in a 'duck bomb' by knitting and distributing 1500 ducks, including a special 100 designed to celebrate the WI centenary as well. The ducks were displayed at shops, sports clubs, and medical facilities in the area and one was even signed by cook and author Prue Leith.

Members worked with Government

Wales became the first country in the UK to adopt a 'soft opt-out' system for organ donation on 1 December 2015, which means that everyone who lives in Wales is now considered a potential donor unless they explicitly opt-out. This was a big change and the Welsh Government needed to mobilise the community to let people know about it. Seven rural WIs signed up for the Big Talk project and worked with the Government to spread the word. The then Health Minister, Mark Drakeford AM, attended a launch event marking the WI's involvement and met with members to assess progress.

The Isle of Man Federation teamed up with the Island's post office to send a leaflet about organ donation to every single resident on the Island. Additionally, to celebrate the WI's centenary, the Isle of Man post-office issued a set of rose scented stamps, one of which features the Time to Talk Campaign.

Notable numbers:

Over 1,000 people signed up to the Organ Donor Register using our unique 'WI' code, resulting in 279 new registrations

2 WI members donated organs because of the campaign

Over 30 members shared their stories

Over 45 members participated in the Big Conversation Craft project

More than 1600 little yellow ducks were handcrafted and distributed

14% of WI members polled for a survey discussed their organ donation wishes because of the campaign. If that is extended to the whole membership, that would mean that 30,800 people shared their wishes because of the campaign

How you got involved



Knitted ducks from Huntingdon & Peterborough 'duck bomb'



Gothic Valley WI members with their 'time to talk' tattoos



Isle of Man poster showing the special centenary organ donation stamp

Letters to the Editor

Rights of organ donors

SIR – In 2014, the Women's Institute began a campaign to increase the number of organs that are donated (Letters, July 23).

At the start of the campaign, it was found that 82 per cent of the population either want to donate organs after death or would consider it; but only 50 per cent of this number have discussed it with their families. Shockingly, however, only 31 per cent of families agree to donation when they are unaware of what their loved one would have wanted.

Those who sign up to the Donor Register must express their wishes to family members, and take steps to ensure that those wishes are not overruled on their death. The need is urgent: on average, three people in Britain die every day waiting for a transplant.

Rosie Harden-Vane
 Holywell, Northumberland



Members prepare for a 'duck bomb'



NFWI Chair Janice Langley showing she's found the time to talk



Prue Leith stops by the Huntingdon & Peterborough 'duck bomb'



Pool of ducks for the Huntingdon & Peterborough 'duck bomb'



Rebecca of Let's Make Jam WI made this scrabble board to show how she had the conversation



Members in Wales take part in the Welsh Government's 'Big Talk' project with the then Health Minister Mark Drakeford



WI member Elsie's cushion that she made for the Big Conversation craft project



WI members in Wales discussing the campaign with the then Health Minister Mark Drakeford

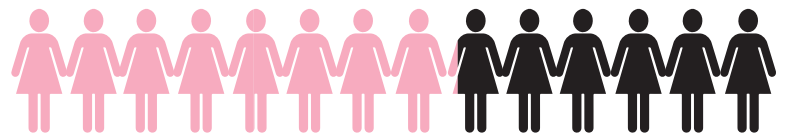
What we achieved and where we stand

WI members were very supportive of this issue before the resolution passed, but many were not actively promoting organ donation. In keeping with this, we found that WI members are markedly more likely to be on the Organ Donor Register than the general population. While only 32% of the UK population are on the Register, 59% of WI members are- which is a huge difference.



32% of the UK population are on the Register

We also found that 71% of WI members have discussed their organ donation wishes with their family and 14% did so directly because of the campaign. If extrapolated to the entire membership, that would mean that nearly 31,000 people had the conversation because of the campaign.



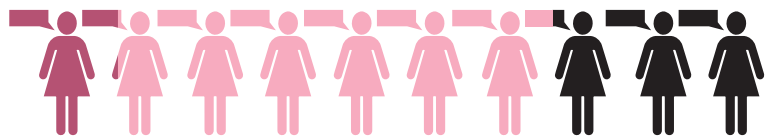
59% of WI members are on the Organ Donation Register

Members commented:

The campaign was the nudge I needed to tell my family

I thought they would know that I wanted my organs donated but after hearing how relatives changed their minds, I talked to both of my children about this.

Furthermore, a series of focus groups of WI members conducted during the NFWI Centenary revealed that three-quarters of WIs participated in the Time to Talk campaign in some way.



71% of WI members have discussed their organ donation wishes with their family and 14% did so directly because of the campaign

Focus group participants commented :

Hearing personal stories about donation influences people; the speakers at the meetings were very effective.

When you really discuss it, you realise how many little facts are simply not clear.

It's simply about being able to make informed decisions. WI social media helped a lot and the meetings were so informative.



WIs join forces regionally for Time to Talk Greater Manchester



Together, the ten metropolitan boroughs that make up the Greater Manchester region lag significantly behind the rest of the UK when it comes to registrations on the Organ Donor Register. According to the latest available data from 2014, only 1 in 4 people in Greater Manchester are signed up, compared to a national average of 1 in 3.

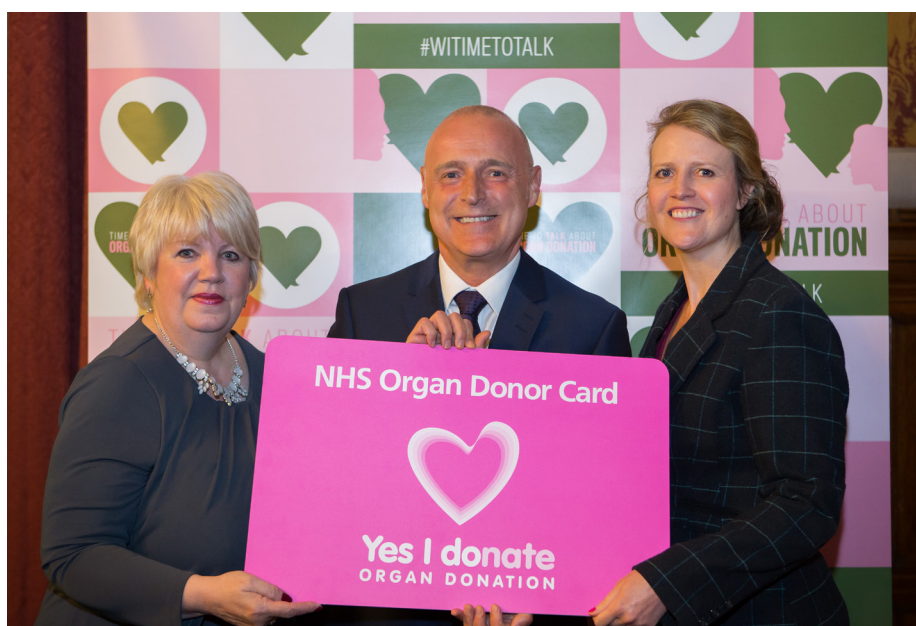
In May 2016, 34 different WIs in the Greater Manchester region (crossing over Lancashire and Cheshire Federations) came together at the Manchester Town Hall at a special WI meeting where they pledged action to spread the word about organ donation. Joining the members

at the event were representatives from NHSBT and David Regan, the Director of Public Health at Manchester City Council. David Regan officially announced that the Council's partnership with NHSBT to promote organ donation had extended to include the WI.

At the event, members pledged to come together for a spring and summer of organ donation action, culminating in National Organ Donation Week in September 2016. Members that signed up to the campaign received a 'Greater Manchester' action pack, with ideas for how they could get involved in their region, statistics showing the local need

for organ donors, and a special 'Greater Manchester' registration leaflet.

A group of 12 members also received training in 'how to be an organ donation ambassador' from the Head of Partnerships at NHSBT. At the training members learned the best messaging around organ donation and how to broach the topic in different situations. Members were also provided with the opportunity to input into NHSBT's new communications strategy for their 'Yes, I donate' campaign. They also met with organ donation recipients and heard from SNODs about the vital work that they do.



Marylyn Haines Evans, Director of Public Health at Manchester City Council David Regan, and NHSBT Partnerships Officer Claire Dolling at the launch of Time to Talk Greater Manchester



Member of Cottonopolis WI, Katie, speaks at the launch of Time to Talk Greater Manchester about her family experience of donation

What the WIs in Greater Manchester did

A few of the most notable actions taken by members:

Members formed partnerships.

The University of Manchester Busy Bees (a workplace WI) formed a successful partnership with the University Students' Union. They launched a new club on campus – Students for Organ Donation (SFOD) – and successfully lobbied the Students' Union Senate to pass a policy advocating open discussion about organ donation. Together, the Busy Bees and SFOD, partnered with NHSBT bone marrow to host a 3 day events programme, which included a film night, a registration drive, and an evening talk featuring organ recipients.

Members showcased their skills.

The Social Lites WI took to the streets to yarn bomb Urmston to mark Organ Donation Week! That same day they also had a stall at the local Food Fair, providing more information about the campaign. Caroline from the Social Lites reported back that the local community loved the yarn bomb and it was a great success. The Social Lites also hosted a free choir concert, which was opened by an organ recipient who asked all present to please talk to their loved ones about their organ donation wishes.

Members worked with local officials.

Salford Angels WI embarked on the campaign in honour of a local Salford resident who is waiting for a kidney. To mark the start of Organ Donation Week, they launched their campaign at Salford Civic Centre to encourage town hall staff to sign up to the Organ Donor Register. At the launch they met with the Salford City Mayor, Paul Dennett, who signed up on the spot and encouraged others to do so as well.

Members encouraged others to register their wishes.

In total, members in Greater Manchester handed out over 2,000 registration leaflets. While it is not possible to know how many of those led to new registrants in the region, we can report positively that over the last year (March 2016-2017), over 18,000 people in Greater Manchester joined the Organ Donor Register.

Members hosted or took part in community events to promote the campaign.

Many WIs utilised summer community events to promote the campaign. Old Trafford Wonder Women ran a community fun day to spread the word while Fulshaw WI took advantage of the annual Summer Fayre to host a registration drive. Lancashire Federation's Liaison Board of Trustees promoted the campaign all summer long at their various Federation wide events, including at an Agricultural Fair and an Armed Forces Marquee.



The Heaton and University of Manchester Busy Bees members Sue and Eliza at their stall during organ donation week



Sue and Eliza's organ donation week stall



Salford Angels WI meet with their mayor and an organ donation recipient to discuss the campaign

How you and your WI can take the campaign forward

It's been three years since we passed the Time to Talk resolution, and you can see how much has been achieved since then. The success of this campaign has been down entirely to the actions of members in their homes and local communities. If you or your WI has not yet been involved, it's not too late. We hope you use this action-pack to get inspired and learn how you can be an organ donation advocate in your community.

What you can do as an individual:

1. Share your wishes. If you're among the 30% of WI members who still haven't shared their wishes with their family, don't wait another day. Make the time to have the conversation.

2. Sign up to the Organ Donor Register. Use our special WI weblink to register your intention to be a donor. Remember, this is a non-binding commitment and you can remove yourself at any time if you change your mind.

3. Put up a Time to Talk campaign poster. Visit your local library, GP surgery, or university and put up the campaign poster, encouraging others to discuss organ donation. Contact the Public Affairs department to receive some. (pictured right)

What you can do as a WI

1. Invite an organ donation recipient or a Specialist Nurse of Organ Donation (SNOD) to speak at one of your meetings. In addition to being incredibly inspiring and informative, recipients and SNODs often have wide links to the organ donation community in their local area and could help you do further campaign actions down the line. Contact NHS Blood and Transplant to see if they can help you source some speakers.

2. Host a public debate or forum about organ donation. You could discuss whether England should follow in the footsteps of Wales and adopt a 'soft opt-out' system for donation or whether families should be allowed to refuse consent. If you live in Wales, you might want to host a roundtable assessing the first year of the presumed consent system.

3. Contact your local council and ask them about what plans they have in place to facilitate organ donation and let them know about the WI's concerns. A good hook is to ask them if they are planning any educational activities to support Organ Donation

Week, which annually occurs every September. If you live in Wales you may want to tell them that WI research revealed that only 67% of WI members living in Wales think that they are on the Register, so the Welsh Government needs to continue its outreach about the new opt-out system.



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Handmade hearts the Social Lites used to yarn bomb Urmston

What you can do with other WIs in your federation or region

If you were inspired by what WIs achieved in Greater Manchester, then why don't you embark on a collaborative campaign with WIs in your region or federation? Follow these top tips for making the case to your neighbouring WIs:

1. Make a powerful case for action by checking how your area is doing in terms of registrations and people waiting for a transplant. You can access the latest available data by council area here: www.nhsbt.nhs.uk/partnering-with-nhsbt/council-statistics/

If your area is outperforming the national average, why don't you use the campaign to find out why and see if you can spread best practice. If your area is underperforming, use the campaign to galvanise the community into making changes.

2. Convene a 'special meeting' of WIs in the area, where each WI sends along one or two representatives to attend. Your federation should be able to link everyone up. At this meeting decide what your priorities are and see if there is capacity for joint working. It's a good idea to plan coordinated activities for Organ Donation Week, which in 2017 runs from **4 September-10 September.**

You could plan:

- Choir concert
- Yarn-bombing hearts
- A WI Birthday Party (as the WI Birthday is 16 September)
- An open-mic night where members share their wishes and discuss their experiences

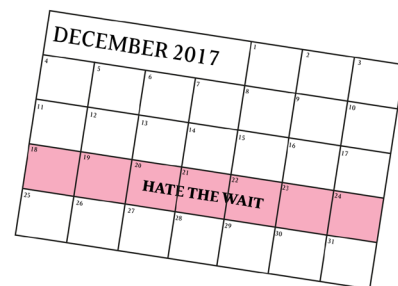
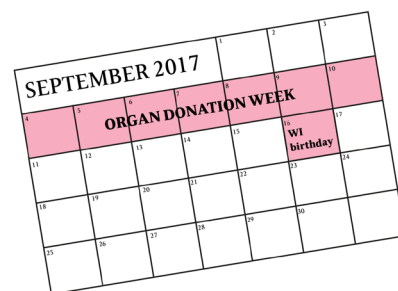
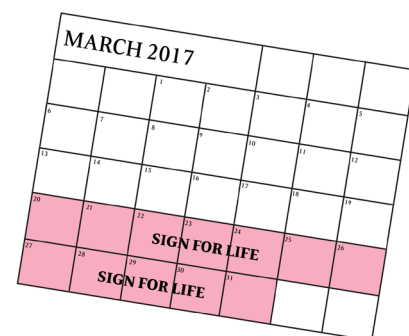
NHSBT runs a series of campaigns at various points throughout the year, where they highlight different concerns. There is also an opportunity to join one of their annual drives and they will provide materials for you to get campaigning.

In February/March they run the Sign for Life campaign, which engages the sporting community. In September, they coordinate Organ Donation Week, which has a new theme every year. Lastly, in December they encourage people to join the Register through their 'Hate the Wait' winter campaign.

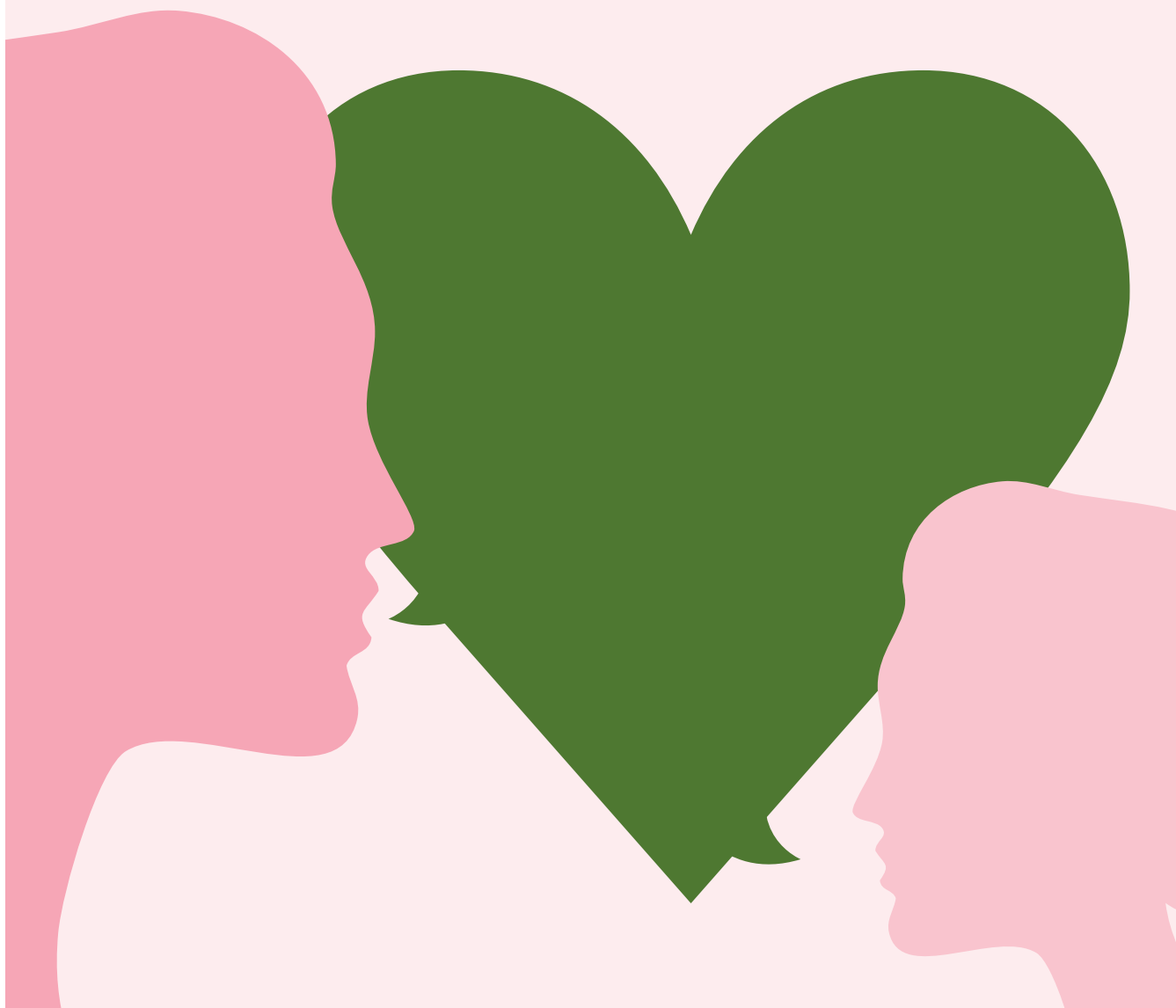
3. Build partnerships with other local groups.

The work of the WI is often powerfully amplified by working with others. In Manchester, WIs partnered with local officials, institutions, schools and businesses and participated in big events like food fairs or parades. It's a good idea to approach potential partners early with a clear 'ask' of what you require from them.

4. Turn one of your WI meetings into an Organ Donation Ambassador training session. Contact NHSBT for speakers that can teach you how to talk effectively about organ donation. At the session you will learn the messages that work, what is best to avoid saying, and how to assuage people's concerns or fears about donation.



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