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The newsletter for everyone involved in organ donation and transplantation

Issue 72 Winter 2009

Encouraging response to 'Prove It' campaign

The 'Prove It' campaign was launched across the UK on the 2nd November with national and regional news programmes covering the story.

The campaign launch focused on the gap between people's good intentions and action. The press release highlighted the fact that while 96%¹ of us would accept an organ if we needed one, only 27% of us have joined the NHS Organ Donor Register (ODR).

Media interviews were handled by Lynda Hamlyn, Chris Rudge and Sally Johnson. Donor Transplant Co-ordinators around the UK provided additional support by giving interviews to the regional and local media. Transplant recipients provided the human interest angle for journalists.

Before the launch the a photo opportunity was offered to the media to highlight the fact that at least 33 people who needed a transplant would die in the 11 days up to the launch of the campaign. Two-year old Louisa McGregor-Smith, who received a heart transplant at Freeman Hospital, Newcastle when she was just five months old, was dressed as 'Dorothy' from the Wizard of Oz and gave a heart to 33 'Tin Men'.

The pre-campaign teaser and the launch generated 168 pieces of coverage in the broadcast, print and online media, nationally and regionally. The launch



Prove it campaign gets off to a heart-felt start

was also covered by the trade press and consumer magazines, with further interest still being expressed. The initial response to the campaign has been extremely encouraging. During November, more than 162,000 people visited the organ donation website, of whom over 147,000 were new visitors to the site.

The television advert ran during the highly popular X-Factor on the 8th November, resulting in 5,273 visits to the website between 8-9pm. This was one of a number of advertising slots booked in order to target specific audiences, in this case, families watching television together.

The website has proved to be the most popular registration route so far, with the majority of registrations coming in online.

There were 112,588 completed registrations

during November and although the figures are still going through the validation process, there appears to be a similar conversion rate to other campaigns.

A key component of the campaign has been to enhance NHSBT's presence



on social networking sites, such as Facebook, Twitter, YouTube and Flickr. This has generated considerable online discussion about organ donation in general and the campaign in particular. This activity, which is being monitored throughout the campaign, provides real time reaction to its tone and content. The following comment was posted in the first week of the campaign:

"The new NHSBT campaign came on whilst I was (Cont page 3)

Channel	Completed ODR Registrations November 2009	Completed ODR Registrations November 2008
Website	96,020	22,182
Donor line	5,057	1,513
Text	641	3
Leaflet	10,870	10,397
Total	112,588	34,095

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Copy date for next issue

1 Feb 2010

Please email

bulletin@nhsbt.nhs.uk

with ideas for submissions

Award winning ICU consultant

A training programme which simulates the care of a patient dying in intensive care, has won top award in the North West NHS Innovation Awards.



Arpan Guha

The course has been developed by intensive care consultant Arpan Guha, who works at the Royal Liverpool and Broadgreen University Hospitals NHS Trust and is a member of NHSBT's Donation Advisory Group.

The course involves simulation of a patient's treatment in intensive care. A team of doctors, nurses, and actors playing the part of relatives are filmed responding to the patient's deterioration. The film is played back to the group for lessons

in how best to discuss organ donation.

Arpan said: "I'm delighted we've won the award because it recognises the importance of improving end of life care and the need to support staff dealing with families.

For doctors and nurses there is little in their formal training which teaches them how to communicate with grieving relatives."

Further information about the course can be obtained from arpan.guha@rlbuht.nhs.uk.

New appointments at ODT



Anthony Clarkson

Anthony Clarkson has been appointed Assistant Director of Organ Donation at NHS Blood and Transplant. This is a new role and will concentrate on managing the Donor Transplant Co-ordinator teams whilst establishing robust frameworks in order to increase organ donor rates. Anthony's previous role was as Head of Clinical development for Tissue



Sue Falvey

Services and Professional Lead for the Eye Retrieval Scheme. He has over ten years experience working in various roles leading to significant changes within tissue donation and redesigning the donation pathway for deceased tissue and eye donors.

Anthony will be taking up his new post later in the year when his priorities will be: to lead, motivate



Dominique Cook

and develop the donor transplant co-ordinator workforce to meet gold standard practice and secure every organ, every time and to support the development of organ donation as usual rather than unusual in every UK hospital. This position is key to meeting our aspiration of increasing organ donation by 73%.

Sue Falvey, formerly Director of Donor Care and Co-ordination,

takes on a new role in January as Head of Nursing Development. This job concentrates on the professional development and training of Donor Transplant Co-ordinators. Sue spent 20 years working as a nurse in organ transplantation at St Mary's Hospital, Paddington and Addenbrooke's and Papworth hospitals in Cambridgeshire. She joined UK Transplant in 1997 as duty office manager and in 2002 took up the position of Director of Donor Care and Co-ordination.

Dominique Cook has been appointed into a new role as the DTC Service Educational Co-ordinator. Her remit is to maintain and organise the current education provided for DTCs, to scope the education and training needs of the DTC workforce and make recommendations for future requirements and provision. Dominique was previously based within the Cardiff DTC team for over six years.

uk news round



Scotland

As winter fast approaches, Scotland continues to make steady progress in implementing the Taskforce recommendations. We now have 20 Clinical Leads for organ donation in post and eight out of eleven NHS Boards have established Donation Committees. These groups have established communication networks for sharing of information and good practice and have both met on two occasions.

The Scottish Government, in line with the strong support which the Cabinet Secretary for Health and Wellbeing has given to the implementation in Scotland of all of the recommendations of the UK Organ Donation Taskforce, has made funding available for a Scottish media and advertising campaign which we expect to run for several weeks from the middle of January 2010. Although the arrangements have not yet been finalised, we expect the campaign will employ the same approach as has proved successful over a number of years: the use of case studies placed in the media by a PR company, run in tandem with the advert itself, with the intention of prompting people to sign up to the NHS Organ Donor Register.

In line with the rest of the UK, the planned extension of the Potential Donor Audit into emergency medicine departments is ongoing. The Emergency Medicine Department at the Southern General Hospital in Glasgow has embraced this with enthusiasm and is working closely with the embedded Donor Transplant Co-ordinator, Deborah Hill and the Clinical Lead for Organ Donation, Dr Catriona McNeill.

Deborah reports that "Through close collaboration between myself, Catriona and the staff in the Emergency Medicine Department, the introduction of the audit has been a smooth process. We have put in place methods of data collection and feedback which accommodates the needs of all concerned. The provision of quantifiable data is something that excites the unit and they feel it will serve to highlight areas of good practice as well as improving potential donor identification".

Pam Niven



Wales

The NHS in Wales has been undergoing a major reorganisation and from 1 October 2009 we now have seven integrated organisations, local health boards, responsible for all healthcare services.

Progress continues to be made in implementing the taskforce recommendations, including appointing Clinical Leads for Organ Donation and establishing Organ Donation Committees.

The Welsh Assembly Government has published the public consultation report on options for changes to organ donation consent, including an opt-out system in October 2009. A copy can be accessed at <http://wales.gov.uk/topics/health/nhswales/majorhealth/organ/?lang=en>. The Minister for Health and Social Services is now considering the next steps.

Caroline Lewis



Northern Ireland

On November 4th, the Northern Ireland Organ Donation Implementation Group held an event to raise awareness of the Organ Donation Taskforce recommendations and the local implications in meeting the challenge of increasing donation rates by 50%.

The event aimed to inform senior professional and managerial staff across the Health and Social Care sector about organ donation. The day got off to a good start with the Minister for Health, Social Services and Public Safety, Mr Michael McGimpsey, providing opening remarks. Dr Eddie Rooney, Chief Executive of the Public

Health Agency reiterated the message that everyone has a role to play in organ donation – both personal and organisational.

Overall this workshop was extremely productive and useful. Not only did it provide local publicity, but it also resulted in a significant number of personal pledges from the delegates involved. Delegates also availed readily of the opportunity to input to the development of a structured approach to increasing donation locally. The outputs from the day are currently being collated and will be circulated to the delegates and will be condensed to form the basis of an action plan for the region over the coming months and years.

On 18 October the local DTC team held a Service of Remembrance and Thanksgiving for Donor Families and Transplant Recipients. Approximately 800 people attended the event which was held in Spires Centre. All who attended seemed to find it meaningful and the exchange of floral tributes between transplant recipients and donor families was once again the highlight of the event.

Four new DTCs have commenced employment during the month of November and recruitment for a further four posts will take place in January 2010.

Siobhán McKelvey

Chiefly



Sally Johnson Director Organ Donation and Transplantation

What a difference a day makes! Usually we get around 500 people signing up to the organ donor register every day using the website or donor line but

on 2 November, the day we launched our first advertising campaign across the UK we saw a massive boost for organ donation with 7,482 people joining the register.

This is the culmination of months of work. We began by commissioning research into why people don't join the organ donor register. We found, as you would expect, a whole spectrum of opinion but a large number of people said they were

ready to join but just didn't get round to it. Others said they were more or less ready to join but needed to discuss the issue with their family first. People told us that we needed to be bolder and make the issue immediate and relevant to them and their family. Many thought that if you were prepared to accept an organ transplant, you should be prepared to donate too. This concept formed the basis for the campaign with 96% of us prepared to accept a transplant if we need one but only 27% signed up to donate after our death.

Campaign launch day was very busy: Lynda Hamlyn could be heard on the today programme on Radio 4 and then after a photocall she toured the TV studios for interviews. Chris Rudge also attended the photocall and then joined living donor Sarah Springett and her partner Paul Shepherd, to whom she gave a kidney, on Woman's Hour. I meanwhile was holed up in a small radio studio talking to 25 different radio stations.

Our adverts will continue to run through November on TV, radio, in the papers and on-line. There will then be a break before a second burst in January and then a third burst in March. Between January and March there will be 20 roadshows across the UK to give the campaign a more local focus and where people will be able to sign up immediately. We have also commissioned a second strand of publicity targeted at black and minority ethnic communities which will also run during the first three months of 2010. If you are planning any campaigns locally please do use the new materials so people see the link with the UK campaign.

It is too early to say how much difference the campaign will make. We aim not only to reach our first target of 20 million people on the organ donor register by the end of 2010 but also to get families talking about organ donation so increasingly people view it as a usual rather than unusual part of life and death.

Encouraging response to 'Prove It' campaign cont.

watching TV the other night. I was totally unprepared for it. As a mother who had to watch my 7 year-old son die awaiting transplant, I thought it was very good. I found it upsetting because I could relate to it, perhaps too much. It may be hard-hitting, but it reflects the reality of the situation and will hopefully

encourage more donors to sign up."

Two further bursts of advertising will run during January and March, supported by additional PR activity.

In the first three months of 2010, a series of roadshows will be held across the UK, which will take the campaign directly to local communities in areas where people

work and shop.

Planning work is also under way to develop the most effective means of engaging with Black and Minority Ethnic communities, under the umbrella of the overarching campaign.

¹ Survey of 1975 people in the UK (YouGov 2009)



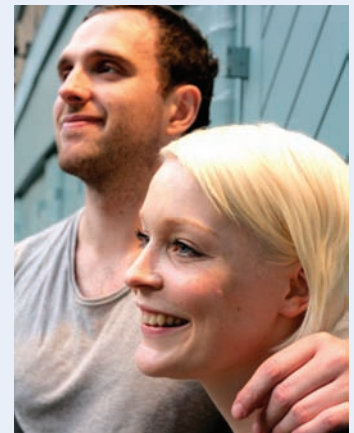
Louisa McGregor-Smith and 33 Tin Men in pre-campaign teaser

NHSBT backs organ donation song



Sarah Springett

Living kidney donor, Sarah Springett, has been a major supporter of the campaign to get many more thousands of people to join the NHS Organ Donor Register. The 28-year-old singer-songwriter from Colchester thought of her own personal campaign 'I Hope You Know' after donating one of her own kidneys to her boyfriend, Paul Shepherd, in November 2008. Paul needed the life saving transplant after being diagnosed in 2004 with IgA Nephropathy - a condition where the kidneys become damaged by a protein normally used to fight infection.



Sarah with boyfriend Paul Shepherd

After Sarah had recovered from the operation she focussed on resuming her career as a singer. Sarah's band, The Floe, have followed the national campaign launch with the release of their debut single, also called 'I Hope You Know'. Each single (both physical and digital) will come with an organ donor registration form.

You can join Sarah's campaign by logging on to the 'I Hope You Know' website (www.ihopeyouknow.co.uk). In addition to being able to sign up to the NHS Organ Donor Register, visitors will be able to purchase the 'I Hope You Know' single, with all profits going to The Transplant Trust.

More information

You can join Sarah's campaign by logging on at www.ihopeyouknow.co.uk



Students sign up as lifesavers

This year freshers fairs across England were over-run with 'Hoff' lookalikes as nearly 8,000 students signed up to be lifesavers by becoming blood or organ donors – or both. Many students were keen to show their support by donning masks of the cult Baywatch star, David Hasselhoff.

This was the first time blood and organ donation has been promoted jointly as the 'Lifesaver Roadshow' travelled to 19 universities across England. With the specially produced stand and joint leaflet, the approach was welcomed by the students and NHS Blood and Transplant staff alike.



We can't all be the Hoff, but we can all be lifesavers. Students sign up to be blood and organ donors at Freshers Fairs this Autumn

Local DTCs and blood donor staff working together

The dedicated tour team was enhanced at fairs by the involvement of local blood donor relations staff and donor transplant co-ordinators. Undoubtedly their input not only made an impact on the number of students who signed up but also meant there were specialists on hand to answer detailed questions from students.

The total number of combined signups for the whole tour was an impressive 9,192. The number of blood enrolments was a very encouraging 6,567 – more than 2.5 times more than 2008 figures overall. Although these figures are impressive, it won't be till early in 2010 that the full picture emerges of those who signed up have gone on to donate blood.

Slightly disappointing was the number of students joining the Organ Donor Register, with signups down by an average of 53% on previous years.

The pie chart shows the split of signups into blood only, organ only and joint. The number of students signing up to both was lower than expected. Holly Mason, Lead Blood Donor Relations Manager for the Midlands said 'From the feedback comments, students said this was because joining the Organ Donor Register was a much bigger decision than signing up to give blood. By signing up to give blood they were not committing themselves, but with

organ donation they were.'

To gain more of an insight into why students signed up to one rather than the other or both, the Strategic Marketing team at NHSBT carried out a survey of nearly 150 students at the last five fairs of the tour. The vast majority (94%) said they supported the joint donation approach and 39% said they were already on the ODR, which shows a very encouraging level of support already amongst the student population.

Almost a third of people said they only support one type of donation, that is they only wanted to be either a blood or an organ donor. With a bit more careful targeting we believe these students are potential conversions. Around a sixth of those questioned said it was too time consuming to sign up to both; better leaflet and form design next year

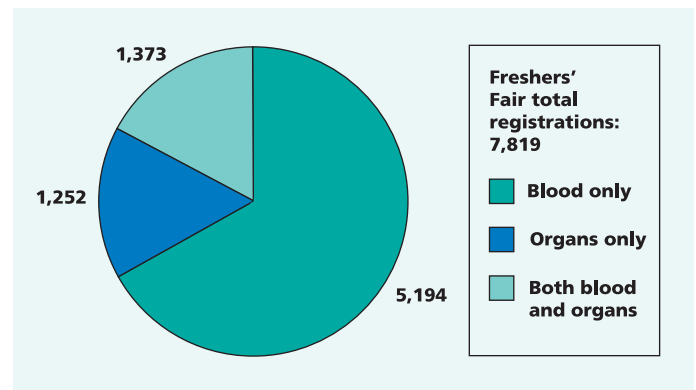
could help convert this group to become joint donors.

The joint stand was definitely a success in terms of meeting students' needs. With an increased level of partnership working between Strategic Marketing and the Blood Marketing and Donor Relations staff, and improvements to the joint form there are encouraging signs that in the right situations the joint donation approach will benefit both blood and organ donation.

Kate Baldwin
Strategic Marketing, NHSBT

More information

To order organ donation campaign posters and leaflets from NHSBT to put up in your Trust visit www.organdonation.nhs.uk



New sign-ups

Patient Organ Advisory Groups

Organ transplantation, as every other activity of the NHS, is focused on the individual patient and the provision of the best possible care within the resources available. It is, therefore, essential that patients,



Professor James Neuberger

who are the focus of the NHS as well as the funders, have a key role in determining health care policies. This is especially important in transplantation. Organ transplants are life saving procedures but as there remain far too few organs available to meet the clinical need, some form of rationing has to occur. Thus, policies on selection (who gets on to the waiting list) and allocation (who gets a donated organ) will have literally life and death consequences for patients.

NHSBT is heavily reliant on the advice of health care professionals in drawing up policies for selection and allocation and the Advisory Groups play a key role in this process. In the past, each Advisory Group had a patient representative. This worked well for some groups but some felt they were unable to represent the views of all patient groups and others felt intimidated by being outnumbered by the professionals, who are usually forthright in their views.

We have therefore changed our approach to patient involvement. We have started, for each of the organs, to hold a meeting with representatives of national and local patient groups which will be attended by myself, as Associate Medical Director, and the Chair of the Advisory Group.

“ The aim is that the meetings will be informal and inclusive and provide an opportunity for patients and their families to comment on and suggest changes to policies...”

The aim is that the meetings will be informal and inclusive and provide an opportunity for patients and their families to comment on and suggest changes to policies, as well to discuss any other aspect of the work done by the groups.

We have held one meeting for the Liver and have planned dates for Kidney and for Heart and Lung, to be held in the New Year. The Liver Meeting was held in London and was attended by over 20 people. It was a very useful first meeting and we have learned a lot which will help us make the next meetings more constructive.

Professor James Neuberger
Associate Medical Director Organ Donation and Transplantation

More information

If you would like to attend contact Kathy.zalewska@nhsbt.nhs.uk