

a vision for change a voice for the future

Strategic Plan 2012-13 » 2014-15 | 4 July 2012

National BAME Transplant Alliance (NBTA)

The coordinating voice for Black,
Asian and Minority Ethnic transplant donation

Supported by the Department of Health



Foreword

Anne Milton MP
Minister of State for Public Health



I have great pleasure in welcoming you to the launch of the National BAME Transplant Alliance (NBTA), the coordinating group for Black, Asian and Minority Ethnic transplant donations. This is a significant milestone in the national effort to identify and address the barriers that people from a Black, Asian or Minority Ethnic (BAME) heritage face in finding a matched donor.

I would like to thank everyone from the organisations that constitute the NBTA for giving their time and sharing their passion, zeal, enthusiasm, considerable skills and resources to help solve the problems that exist in this area of public health. Our aim is for the NBTA to use their considerable networks to identify and enlist the help of local community influencers and champions to encourage people from these communities to join donation registers and then go on to donate. Donation is a gift of life.

Congratulations to everyone for all the very hard work already undertaken but we all know there is a lot more we need to do. That is why this initial three year Strategic Plan being launched today is ambitious. However with committed people like you, working with the NBTA we will achieve what we need to.

I am also very excited that Alesha Dixon has agreed to be our first national Donation Ambassador.

I feel privileged to be in a position to support an area of health policy where such a difference can be made. I would like to thank you all for coming and making this launch such a great success. I look forward to working with many of you in the months and years to come.

A handwritten signature in black ink that reads "Anne Milton". The signature is written in a cursive, flowing style.

Introduction

People from Black, Asian and Minority Ethnic (BAME) and mixed parentage backgrounds are dying in disproportionate numbers because of the difficulties they face in trying to find an appropriately matched donor. One of the main reasons for this is not enough individuals with a similar genetic history on national registers and, even when they are, cultural and other barriers can stop transplants proceeding. This is a longstanding situation and affects both whole organ and stem cell (bone marrow) donation. Despite efforts to date, the problem persists. A raft of recent reports, from the UK Stem Cell Strategic Forum, the Organ Donation Taskforce, the All Party Parliamentary Kidney Group and the Nuffield Council on Bioethics, have all raised this as an issue and its consequences for equality of access to healthcare.

The cultural, socio-economic and generational factors that all play a part in perpetuating this situation are enormous. But the NBTA does not believe they are insurmountable. Over the years, fantastic and inspirational work has been carried out by individuals and organisations at every level. Often, these people have had loved ones who have been lost, too often waiting for the right donor at the right time. On their own they have been effective in so many ways. What has been clearly needed for a long time has been a national voice for all those committed individuals or likeminded organisations, for the issue itself, but also for all those patients from a Black, Asian or Minority Ethnic background who need a transplant today, and those who will need one in the future.

Whilst considerable work has been carried out at a local level, the national message about BAME donation and its importance has not necessarily translated into donor rates increasing as much as hoped. The NBTA is to address this anomaly with the goal of increasing the number of people from a BAME background on the bone marrow and organ donation registers, increasing the individuals who consent to be donors and consequently increasing the number of transplants.

The NBTA is an Alliance, with a membership drawn from organisations promoting awareness of donation in the BAME and/or mixed parentage population and representatives from national bodies from the NHS and voluntary sectors. Sponsored by the Department of Health, we aim to promote effective and efficient partnership working, encouraging a coordination of initiatives that make the most of the skills, experience and infrastructure already available.

We want to be the Voice of our constituent members. We will promote awareness of and challenge issues surrounding BAME donation by working with policy leaders and decision makers to ensure that there is a BAME presence and influence at every stage of service development. However, we are not a replacement for all those hardworking individuals and organisations that have achieved so much and continue to do so. Our role is to support individuals and groups to help them have access to the tools and skills needed to make them even more effective in getting the donation message across.



Orin Lewis



Kirit Modi

National BAME Transplant Alliance (NBTA)

Membership

African Caribbean Leukaemia Trust (ACLT)

Afiya Trust

Anthony Nolan

DWIB

Department of Health

Hindu Forum of Britain

Institute for Health Research,
University of Bedfordshire

Kidney Research UK

NHS Blood & Transplant

National Kidney Federation

Race Equality Foundation

The Rik Basra Campaign

Seventh Day Adventist Church

South Asian Health Foundation

Remit

The remit of the NBTA is to promote collaborative working amongst organisations promoting awareness of donation in the BAME population. It will bring together relevant partners and provide a forum for agreeing and reviewing work programmes that is as effective and efficient as possible, facilitating planned initiatives that make the most of the skills, experience and infrastructure that can support targeted and direct initiatives.

Mission statement

The NBTA will bring together people, passion and resources to address the barriers faced by those from a Black, Asian or Minority Ethnic (BAME) genetic heritage needing a whole organ or stem cell transplant.

Our goal is to save lives. We will raise awareness of inequalities, promote the importance of transplantation with the aim of increasing the number of BAME people registering as donors and consenting to donation.

Objectives:

- To establish the group as the authoritative voice for BAME donation, built on a reputation for sound advice, guidance and leadership
- To facilitate discussion and agree strategies to increase representation on donor registries of individuals from BAME or mixed parentage backgrounds
- To provide high level coordination and advice on awareness campaigns covering the donation of stem cells and whole organs from BAME and mixed parentage populations
- To facilitate better networking to support work at a local and national level
- To promote the implementation of joint initiatives covering different types of donation wherever possible
- Identify and support initiatives and projects that help overcome the barriers that exist in preventing the conversion of willing donor to successful transplant

Outcomes:

By April 2015, it is our expectation that for BAME donation and transplant:

- Significant change in attitude to donation and transplantation within BAME communities
- There will be a 15 percent increase in the number of people joining the Organ Donor Register.
- Consent rates from potential donors after brain death (DBD) will increase to 35 percent (from 29% in 2011/12).
- Consent rates from potential donors after circulatory death (DCD) will increase to 25 percent (from 19% in 2011/12).
- 10 percent increase in the number of living organ donors from the 2011/12 baseline.
- 10 percent increase in the number of donors after death from the 2011/12 baseline.
- Improved awareness of the importance of stem cell donation, helping to increase the chances of those suffering from blood cancers finding a suitable matched sample and thereby increasing transplant rates
- Improved stem cell donation to ensure the percentage of donors on UK public stem cell donor registries will reflect the UK BAME demographic, as reported in the 2011 census
- A strong, evidence based donation is established to help inform strategy development
- A better supported, engaged and effective BAME donation campaigning force

2012-13 Establishment

The official launch of the NBTA will be on 4 July 2012.

During the first year, the NBTA will work to establish credibility as a national group and will develop a national strategy to promote BAME donation. We will consolidate the membership of the NBTA to ensure that it reflects as best as possible the sectors of society we hope to represent.

Planned Action Year 1

- Establish NBTA as an authoritative and respected voice for BAME issues related to donation and transplantation
- Identify individuals and groups to help us spread the message on BAME donation at a national level, especially among young adults;
- Develop a communications plan to support and underpin the NBTA's work programme and identify ways to support local campaigning and awareness raising;
- Carry out a review of and make recommendations on all current data on BAME donation and transplantation that will help inform our strategy, priority setting and action to be taken;
- Create an online presence for the NBTA;
- Start to develop an on-line, open access tool kit to support individuals and organisations wanting to raise awareness of BAME donation.
- Engage and inform NHSBT's new strategy for increasing UK organ donation and transplantation rates.
- Engage and influence the NHS Commissioning Board on BAME matters related to donation and transplantation.

2013-14 Consolidation

In our second year, we will work to bring forward firm, thought through proposals to address the long term issues facing BAME donation.

Planned Action Year 2

- Publish the findings from our review of BAME donation data;
- Publish our online toolkit available to all those who wish to access it;
- Hold 'One Year On' stakeholder event in July to publish Year 1 progress and ongoing Delivery Plan to increase BAME donation and transplantation rates;
- Provide access to education tools and support, including peer educator programmes and donor and donation education information.

2014-15 Sustainability

Our work will concentrate on continuing to support our constituent members in their work in raising BAME donor and donation awareness. We will also monitor and promote the implementation of the BAME donor and Delivery Plan.

Planned Action Year 3

- Evaluate work to date and learn from both our successes and disappointments;
- Build upon our shared experience of and knowledge gained from what went well to and use this to build better practice skills for the future;
- Continue to engage with all relevant stakeholders to promote collaborative working and to ensure there is a strong, respected voice for UK BAME whole organ and stem cell donation and transplantation.

