

A TRANSPLANT MANIFESTO

MORE TRANSPLANTS, SAVING MORE LIVES

A REPORT OF THE FINDINGS OF
THE 2006 TRANSPLANT SUMMIT



Hosted by
THE ALL-PARTY
PARLIAMENTARY KIDNEY
GROUP

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CONTENTS

	Page
1. Foreword	3
2. Introduction	4
3. The Manifesto	5
4. Conclusions	10
5. Appendix A – The Plan for The Transplant Summit “Patients GRAB Transplant Attention”	11
6. Appendix B - Summary of the Transplant Summit “Patients Obtain Consensus for Action”	15
7. Appendix C - Attendance at Summit	19
8. Contact Details and Policy Statement	21

FOREWORD

Successfully transplanting human organs was one of the biggest medical advances of the twentieth century. Put simply, a transplant can transform a person's life. For kidney patients it can improve their quality of health, increase their life expectancy and free them and their family of the burden of regular dialysis. Kidney transplantation is now the preferred treatment for patients with established renal failure. Survival rates for renal transplants have doubled in the last decade.

But too few transplant operations take place in the UK. The availability of organs (from live or deceased donors) is far below the level of demand. Although there are between 15-30 organ donations per million residents in western countries there is still a shortage of organs, especially in the UK where rates are relatively low. Waiting lists continue to grow and every year patients die while waiting for an organ.

In the UK 1,799 renal transplants were performed in the 12 months to 31st March 2006, representing less than one in three of the patients waiting for a donor kidney.

Transplantation is better for the patient. Furthermore transplantation is cheaper than dialysis. Increasing transplantation rates would therefore be an all round win.

That is why the All-Party Parliamentary Kidney Group has always had a particular focus on transplantation and we make no apology for it. It is obvious that the Government shares our interests and it too has been active in the area. It produced Saving Lives, Valuing Donors – a framework for England in July 2003, a National Service Framework in January 2004 and the Human Tissue Act in 2004. However, although it is early days there is still no sign of any significant increase in transplant rates.

Many in the renal community felt that an opportunity to move to an opt-out system of donation was missed in the Human Tissue Act 2004. Nevertheless there were significant changes made some of which hold out hope for improvement. Time will tell but for those waiting that time comes at a cost.

That is why the All Party Group felt it was useful to hold a summit and produce this manifesto. We do not claim that it is comprehensive, but we do feel that it identifies many of the current constraints and challenges facing the field. As MPs we will use it as a basis to question, debate with and challenge the Government and we hope it will also be a useful reference for clinicians and patients.

Thanks are due to the clinicians, patients, officials and volunteers who contributed to this process, and to my parliamentary colleagues for their interest. I would like to express my particular gratitude to the NKF for their continued support for the Group and especially to Tim Statham for his hard work and patience in working on the Summit and this document.

When we revisit transplantation in detail, we hope to see that this manifesto has been delivered.



Dr Evan Harris MP
Co-Chair, All Party Parliamentary Kidney Group

INTRODUCTION

The All Party Parliamentary Kidney Group consists of 174 members of Parliament and Lords. Their registered purpose is:-

“To improve understanding in parliament of kidney disease and transplant medicine and promote improvements in the health and care services that are available to improve the health of people with renal failure”

The three joint chairs are Dr Evan Harris MP, Janet Dean MP, John Randall MP.

The secretariat of the group is provided by the National Kidney Federation, a kidney patient charity which is run by kidney patients for kidney patients and is registered charity number 1106735. The charity receives sponsorship from renal industries, including all the main pharmaceutical companies that are suppliers of transplant medicine.

The All Party Parliamentary Kidney Group (APPKG) monitors both the provision of dialysis services and transplantation in the UK. It maintains an active interest in all matters of Chronic Kidney Disease (CKD)

As part of its programme the APPKG held a Transplant Summit in Portcullis House on Thursday 25th May 2006 to which all the leading transplant specialists in all the related fields of activity were invited. The purpose of the summit was to address the shortage of transplant opportunities within the UK, and to identify what actions were necessary to alleviate this shortage and increase the number of transplant operations taking place each year. The group believes that this would extend the life of many patients, would improve the quality of life of those patients and would save the NHS money in the long term.

This report presents to a wider audience the findings of the summit.

All Party Parliamentary Kidney Group Transplant Summit

The Manifesto

Successfully transplanting human organs was one of the biggest medical advances of the twentieth century. Put simply, a transplant can transform a person's life. For kidney patients it can improve their quality of health, increase their life expectancy and free them and their family of the burden of regular dialysis.

Organ transplantation is now a well-established life-saving treatment for patients with organ failure. The most commonly transplanted solid organs are the kidney, heart, liver, pancreas, lungs and intestines.

Despite the advances that have been made in transplant technology, there remains a lot to do if every patient who could benefit from a transplant is to do so. This report sets out the key steps that should be taken to turn this vision into reality:

Action now required

1. Recognise the importance of increasing transplantations
2. Double the donation rate in the UK to match our European neighbours
3. Reduce the rates at which relatives refuse to give consent for registered donors to donate organs
4. Incentivise best practice in Intensive Care Unit (ICU) non-heart-beating donor Programmes
5. Establish a national organ retrieval programme
6. Increase transplant capacity
7. Train sufficient numbers of transplant surgeons
8. Maximise the efficiency of transplant teams by cutting unnecessary bureaucracy
9. Audit transplantation in all its aspects and provide a clear strategy for enhancement of transplantation under current arrangements
10. Review the effectiveness of legislation, policies and practice on a regular basis

These recommendations were developed at a summit of key experts within the transplant community. The meeting was hosted by the All Party Parliamentary Kidney Group.

Background

Each year approximately 50,000 organs are transplanted worldwide, of which 50-60% are kidney or kidney/pancreas transplants.

Kidney transplantation is now the preferred treatment for patients with established renal failure (ERF). It offers better survival rates than renal dialysis, is more cost-effective, and releases patients from thrice weekly dialysis sessions. This is especially important because dialysis and ERF causes anaemia which in turn can contribute to the likelihood and severity of cardiovascular disorders, which is the highest cause of mortality in dialysis patients and the risk of which is increased by renal failure.

Reports of a kidney transplant patient still alive after 40 years and of a heart transplant recipient still surviving after 23 years, testify to the success of transplant surgery. Survival rates for renal transplants have doubled in the last decade and between 1988 and 1996 the half-life (the length of time that half of transplanted organs are still surviving) rose to between 10 and 12 years.

Donor organs come from live donors (relatives may, for example, donate a kidney or liver lobe), or cadavers (either those who have agreed to donate their organs after death or for whom there is no known objection). The availability of donor organs is, however, far below the level of need.

Although there are between 15 and 30 organ donations per million residents in western countries, there is still a shortage of organs. Waiting lists continue to grow and every year patients die while waiting for an organ. In the UK 1,799 renal transplants were performed in the 12 months to 31st March 2006 representing **less than one in three** of the patients on the waiting list for a donor kidney.

Ten steps to improve transplantation services

- **RECOGNISE the importance of increasing transplantations**

A transplant can help a patient avoid dialysis and enable him or her to live an independent and productive life. Failure to deliver a transplant to all those who need it carries with it an enormous burden in human suffering and also represents a sizable and potentially avoidable drain on the health economy.

Dialysis is a resource-hungry treatment. In addition to the need for buildings, equipment and staff to run the service it also requires, for those on dialysis and never transplanted, the provision of transport, supportive social care and the treatment of the complications of dialysis and on-going renal failure for the rest of those patients' lives. The number of renal patients is increasing by 6% per year placing significant financial strains on the NHS. This burden can be reduced by transplantation and is diminished with each and every transplant operation that takes place.

The Government therefore should regularly publish a progress report on its transplant strategy setting out how it intends to increase the numbers of kidney transplants, taking into account the social and economic costs of organ failure and the implementation of recent legislation on the use of human tissues. This strategy should make clear how the Government intends to shift the burden of expenditure from dialysis, medical treatment and supportive social care (the costs of failing to transplant) to increasing the availability of early and effective transplantation.

- **DOUBLE the donation rate in the UK to match our European neighbours**

The UK currently has one of the lowest donation and transplantation rates amongst the developed countries of Europe. This is considered to be partly because of differences in health service capacity and structure - with, for example, almost three times as many intensive care units beds (from where donor organs are often retrieved) in Spain compared to the UK – but also due to procedural and attitudinal short-comings.

Innovative solutions must be found to maximise the opportunities for donation within the UK so that we can bridge the gap between accelerating demand and the declining supply of suitable organs available for transplantation. A national campaign should be launched to encourage potential donors to join the organ donor register. This should make clear to potential donors what the consequence of low donation rates are; not only for those individuals in need of an organ, but for the NHS as a whole.

- **REDUCE the rates at which relatives refuse to give consent for registered donors to donate organs**

Currently almost 50% of organs are lost as a result of relatives refusing to permit the use of organs, including in some cases where the donor had expressed a wish to donate organs upon death,

The provisions of the Human Tissue Act 2004 which came in to force in September 2006, clarify that relatives do not have a right to veto the previously expressed wishes of a donor, but it will be vital to monitor the impact of this change on refusal rates.

It is known that the relative refusal rate is lower when a professional transplant coordinator is available to discuss the decision with the family of the recently deceased. However, coordinators are not being called into intensive care units until a decision has been made. Transplant coordinators should be involved as early as possible as part of a carefully planned approach in accordance with the needs and sensitivities of the family, and the relevant circumstances.

To address this problem:

- Hospitals should be encouraged to improve their organ retrieval rate, monitor their results and be assessed on their progress.
- Standardised information and support materials for relatives should be provided.
- UK Transplant or the Department of Health should conduct an audit of current retrieval programmes, identifying areas of best practice and ensuring that the learned expertise of these hospitals is shared.
- A best practice toolkit should be developed, providing practical ways in which hospitals can increase their retrieval rates

- **INCENTIVISE best practice in Intensive Care Unit (ICU) non-heart-beating donor programmes**

Non-heart-Beating Donors (NHBDs) are either

- a) uncontrolled – those who have died suddenly and recently, usually from massive trauma, cardiac arrest or massive brain injury; or
- b) controlled – those who are diagnosed as in the inevitable process of dying (perhaps as a result of serious brain injury or stroke) and they have either never been ventilated or where ventilation (and other life support) is to be withdrawn with death (including brain stem death) from cardiac arrest being inevitable.

Advances in transplantation technology mean that organs from non-heart-beating donors can now be as successful as organs from heart-beating donors.

There are estimated to be at least 800 patients per year who are potential controlled non-heart-beating donors in intensive care units who are not referred for organ retrieval, which means that potentially hundreds of patients with organ failure are being denied the chance of a life-saving transplant.

There is an urgent need to ensure that Intensive Care Unit doctors establish robust protocols for the identification of potential organ donors and refer patients for testing where appropriate. National standards need to be developed for Intensive Care Units in their identification, work up and referral of potential non-heart-beating donors.

- **ESTABLISH a national organ retrieval programme**

There already exists a workable system for retrieving organs from heart beating donors. However, this does not translate into a good service for non-heart-beating donors. NHBDs require a more pro-active, rapid and flexible response.

A national approach to non-heart beating donation would ensure that best practice approaches to the issue are spread. National or regional organ retrieval teams could help in developing this and assist the NHS with its implementation. Such teams might well fall most appropriately under the auspices of the National Specialised Commissioning Advisory Group.

- **INCREASE transplant capacity**

In order for increases in donation to be translated into benefits for patients with organ failure, transplant capacity needs to be enlarged within the NHS. There needs to be a significant increase in laboratory testing following the identification of suitable donor organs, particularly from non-heart-beating donors. Furthermore, additional transplant patients would need to be monitored and this also requires an increase in laboratory capacity.

Additional transplant coordinators are needed and they will have to be appropriately trained. Capacity must also be built elsewhere in the NHS in areas where clinicians are responsible for getting patients physically prepared for a transplant. In particular, inadequate access to cardiac and other services are such

that many patients die each year on the transplant waiting list, or are removed from the waiting list due to ill health to spend the rest of their life on dialysis.

- **TRAIN sufficient numbers of transplant surgeons**

Insufficient specialist surgeons exist to fully staff even the existing transplant centres, let alone an expanded capacity. More transplant surgeons must be brought into the profession if the proposed increase in transplant numbers is to happen.

- **MAXIMISE the efficiency of transplant teams by cutting unnecessary bureaucracy**

While essential safeguards must exist to protect all those involved in transplantation, the new Human Tissue Act 2004 must not create a layer of additional requirements which unjustifiably prevent or delay surgeons from carrying out life saving transplant operations in a timely and effective manner.

- **AUDIT transplantation in all its aspects and provide a clear strategy for enhancement of transplantation under current arrangements.**

There is a clear need to identify the socio-economic benefits of early transplantation, the costs to individuals and the broader community of failure to transplant, and in so doing include the representations of patients and clinicians alike. The Government should publish a clear and practical strategy for improving transplantation services, how it intends to implement these service improvements, and how its performance in improving transplantation services will be measured.

- **REVIEW the effectiveness of legislation, policies and practise on a regular basis.**

The Government must undertake to review the results of their policies in transplantation and if, five years after the passage of the Human Tissue Act 2004 and the implementation of the their existing Transplant Strategy, there is insufficient progress in increasing transplantation rates, Parliament must be allowed to consider alternative measures (such as presumed consent with opt-out).

Conclusions

Current transplant services, and particularly support personnel, are stretched to the limit and the UK transplantation infrastructure remains too small and under-resourced compared to European counterparts. If sufficient organs were to be made available the existing service would be unable to cope with an increase in transplant operations.

We recognise and welcome many of the steps taken by the Government to improve the transplantation service, but the recent modernisation of transplantation policy has so far been piecemeal. The Government has yet to successfully address the core problems that keep transplantation rates so low.

We have set out in this document some of the steps required to enhance transplantation rates over the short and long-term. We intend to press the Government on all these issues and monitor progress made.

We are extremely grateful to all those who have provided input and who are working so hard to improve the lives of patients with renal failure.

NOTE

This manifesto is a report of the Summit meeting itself. It had not, at the time of publication, been presented to the All Party Parliamentary Kidney Group for formal endorsement.

Appendix A

The Plan for the Transplant Summit

This is an extract taken from an article by Timothy F Statham OBE, Chief Executive of the National Kidney Federation first published in the British Journal of Transplantation – Volume 1 Issue 1 – Summer 2006. The Journal was distributed to all attendees at the Transplant Summit.

Patients Grab Transplant Attention

During the General Election of May 2005, the National Kidney Federation (NKF) arranged for 15,000 of its renal patient members to send a questionnaire to the three main party candidates in their own constituency. The questionnaire asked ten renal questions, seven of which related directly to issues surrounding transplantation of kidney organs. 45,000 forms went out and 968 unique replies were received. This NKF driven activity had a dramatic and beneficial effect. For eight years the NKF has supported and provided the servicing needs of the All Party Parliamentary Kidney Group (APPKG) of MP's and Lords within the Palace of Westminster. Prior to the General Election the group was 108 members strong. After the election, and after the NKF questionnaire, membership of this group grew to 174. This represents more than a quarter of all MP's in parliament.

The Programme of Activity

Not all kidney patients are transplanted and so the programme immediately embarked upon by the APPKG included a mixture of Chronic Kidney Disease (CKD), Dialysis and Transplant activity.

The group is acutely aware that 400 kidney patients die each year in the UK waiting for a kidney transplant. They asked Rosie Winterton MP, Health Minister to address the group, she accepted, and that meeting took place on 15th June 2006, however before this opportunity to listen to, and question the Minister took place, the group felt that they wanted to equip themselves with all the facts surrounding Transplantation. They therefore resolved that the best way to do this was to hold a "Transplant Summit" within the Palace of Westminster.

Detailed Plans

The date for the transplant summit was fixed, and because the MP's wanted to hear from the expert stakeholders involved in transplantation they extended invites to individuals and organisations including :- British Transplantation Society, Renal Association, The BMA, Department of Health, British Society for Histocompatibility & Immunogenetics, British Renal Society, UK Transplant, UK Transplant Coordinators Association, Research leads, Modernisation lead, Non-Heartbeating experts, the Intensive Care Society, Living donation experts, Investment & infrastructure development specialists, ABO incompatible specialists, antibody removal consultants, Human Tissue Act specialists, The Human Tissue Authority and to the Department of Education dealing with citizenship (awareness of transplantation in schools). Also invited were the leading transplantation pharmaceutical companies, patients, carers, medical advisors, specialist advisors and staff from the National Kidney Federation.

A Transplantation Manifesto

The All Party Parliamentary Kidney Group has three joint chairs – Dr Evan Harris MP (Liberal) Janet Dean MP (Labour), and John Randall MP (Conservative). After detailed discussion it was agreed that the four hour long meeting should commence with a presentation by UK Transplant detailing the results of their brand new “potential donor audit”, and should then be split into the following topic sections all of which are discussed further on.

- General Constraints on Organ Donation
- Heart Beating Donation
- Non - Heart beating Donation
- Live Donation
- Looking ahead

Looking ahead was not intended to be a vague wish list; instead the chairman (Dr Evan Harris MP) made it clear that if all the issues arising from the first four subjects had solutions available or possible, then they, the APPKG would want to know what would then become the limiting factors holding back sufficient transplantation. The chairman felt that targets and time limits needed to be set for the achievement of an adequate number of transplantation operations, and that those factors identified in the meeting should form the basis of a “Transplantation Manifesto” that all present at the meeting might feel able and willing to sign up to.

The Issues

The transplantation of organs does of course extend beyond the kidney and the transplantation summit plans to consider issues arising from the other organs; however, kidneys make up the lions share compared with heart, liver, lungs and pancreas. The APPKG was formed to represent the issues arising from renal therapy, therefore it is expected that consideration of kidney transplants will take centre stage in the discussions.

Four hundred kidney patients die each year whilst waiting on the kidney transplant waiting list. Whilst this is in itself a shocking statistic it only represents the easily identifiable part of the problem. To understand how dire the problem is in the UK health system one needs to consider a much wider perspective.

Currently there are 40,000 established renal failure (ERF) patients who cannot live without either dialysis, or transplantation. Approximately 20,000 patients are on dialysis and 20,000 have been transplanted. Dialysis is a life saving treatment; it is not a good quality of life. Virtually all currently undergoing dialysis would opt immediately for a transplant if that were possible, in fact some find dialysis so awful that they voluntarily withdraw from treatment and die.

If 20,000 dialysis patients want a transplant, why is the transplant waiting list less than 6,000 patients? Clearly not all are suitable for a transplant and some would not benefit from undergoing this surgery, also, there is the temporary health crisis that removes a patient from the waiting list for a while. But we are talking about 14,000 patients not even being allowed entry to the list – surely 14,000 out of 20,000 can't

be the actual number of patients who a transplant wouldn't benefit? What really are the considerations that prevent these patients being offered the chance of a return to real living – is it age, is it health, is it co-morbid conditions, or is it the fact that the transplantation infrastructure is only designed to cope with very restricted numbers?

If you are one of the lucky renal patients, and you have made it onto the transplant waiting list, the bad news is that you have joined the elite group whose subsequent deaths are recorded by UK Transplant. If you die now, you will be one of the 400 constantly quoted as having died whilst awaiting a transplant. The fact that the other 14,000, not on the waiting list, will also die whilst waiting/hoping for a transplant is not a statistic you will ever hear uttered.

Even if you don't die whilst waiting, how long will you have to wait? Well that is also not good news, because of the 6000 on the list, only 1,800 kidney transplants are performed in a year period. This is compounded by the fact that renal patient numbers are growing at the rate of 6% per annum. Irrespective of the list there are 20,000 Dialysis patients in the UK and each year only 1,800 will get a transplant – not good odds.

Shortages

It is widely accepted that for a Transplant centre to remain viable it needs to have five transplant surgeons. Currently there are 24 Transplant centres so simple mathematics tell you there should be 120 surgeons - there are not, at the last count the NKF found there were 86.

What is being done to recruit and train new transplant surgeons? Well the NKF finds very little evidence that anything is being done at all, in fact the reverse appears to be true, and that the accountants within the NHS would much rather see Transplant centres closed so that the 86 surgeons are spread less thinly. The fact that this flies in the face of the need to expand the service is largely ignored.

Organ Donation

More than 12 million UK residents sign up to be an organ donor, yet with 1,500 of the population dying every day as part of the normal scheme of things we remain unable to transplant more than five kidneys a day, despite the fact that our funeral directors are burying or cremating 3,000 kidneys every 24 hours. If we could double the number of operations from five to 10 a day, there would no longer be a Kidney Transplant waiting list, and 400 lives each year would be saved. Of course not all the three thousand kidneys wasted each day would be suitable for Transplant – but we only need five more.

Heart Beating Donors

As the health service gets better at saving lives, so the numbers of organs from this source naturally reduces, however, not enough is being done to ensure that opportunities for organ donation are not wasted, either because the hospital is not transplant orientated, or relatives are asked for permission inappropriately by staff unskilled in this difficult area, or the relatives themselves refuse (nearly 50% in the UK). These are all areas in need of much improvement. Hospitals must develop a

transplant culture, potential donors must discuss their wishes with their relatives, and relatives should take heed of the wishes expressed by the deceased before their death. Why not have donor cards signed both by the potential donor and the donors relatives – this would at least ensure that the matter had been discussed within a family during non-crisis times when clear heads prevail?

Theatre time must be made available for these operations, each hospital must have expert transplant co-ordinators, the potential donors wishes should be paramount.

Living Donation

It is very fortunate that recent years have seen a big increase in living donation which has helped to offset the reduction in heart beating donation. The NKF has played a large part in this, publicising at every opportunity how very successful this form of transplantation is, and encouraging discussion amongst family members of dialysis patients. A recent campaigning success has been the Human Tissue Act which removes some of the legal impediments to organ donation and makes lawful for the first time, altruistic living donation and pooled or paired donation (diagonal transplantation between two otherwise incompatible pairs)

The current organ shortages lead to desperation, and desperation can quickly lead to the appalling international marketing of organs by unscrupulous operators out to make quick money from human misery. The only long term answer to this awful trade is to remove the cause, and this can only be done by gearing up the whole of transplantation activity so that there is no organ shortage – this is far from impossible, it just requires the will, determination and adequate funding.

Non-Heart Beating Donors

Currently UK Transplant is investing in 13 Non-Heart Beating Donor programmes, this is because early pilot schemes have shown that these operations are just as successful at heart-beating donor transplants. The NKF is very hopeful that this further source of useable organs will have a major impact in increasing transplant opportunities, however unless serious funding is put behind this, potential donors will continue to die without their organs being used despite this being their declared and recorded wish.

Conclusion

Whatever your interest and role in transplantation, we all have an interest in wishing this Transplant Summit well.

Appendix B

Summary of the Transplant Summit

This is an extract taken from an article by Timothy F Statham OBE, Chief Executive of the National Kidney Federation written to be published in the British Journal of Transplantation – Volume 1 Issue 2 – Autumn 2006

Patients Obtain Consensus for Action

Appendix A spelt out the plans being laid for a Transplant Summit within the Palace of Westminster hosted by the All Party Parliamentary Kidney Group (APPKG). The event took place and has been classed as a “huge success” by all in attendance. Early conclusions have already been conveyed to Health Minister Rosie Winterton MP at the 2006 Annual General Meeting of the APPKG attended by the Minister.

The Summit was well attended, long (1pm to 5pm) and detailed. Chaired by Dr Evan Harris MP (Joint Chairman of the APPKG with Janet Dean MP and John Randall MP) the Thatcher room in Portcullis House was packed (70 plus). Virtually every speciality connected with Transplantation or its supporting services was represented, as was the Department of Health, the BMA, UK Transplant, the BTS, the Kidney Alliance, the Blood and Transplant Service, Human Tissue Authority, Renal Association, Transplant Co-ordinators, Transplant Industries and the National Kidney Federation who provide the secretariat for the APPKG.

Presentation by UK Transplant

The meeting began with a presentation given by Chris Rudge, Managing and Transplant Director of UK Transplant (UKT), detailing the results (first 30 months) from the recent and first “potential donor audit from deceased donors in the UK”

- The possible reasons for donor shortage were listed as :-
- Fall/low death rate from road traffic accidents
- Fall in death rates from strokes
- Lack of ICU beds
- Changes in clinical practice

Also listed were the following reasons that possible donors failed to be converted into actual donors:-

- Clinical practice within ICU
- Non-referral from ICU
- No approach to the donors relatives
- Relatives refusal of consent

The presentation also detailed the potential for Heart Beating donation and Non Heart Beating donation, and the reasons for lack of consent from relatives. The presentation concluded as follows:

- Many patients are not tested by the brain stem death criteria
- There is no record that relatives are approached for 15% of potential heart beating donors
- There are not enough Non-Heart Beating donor programmes
- The relative refusal rate is high – Heart Beating 40%, Non-Heart Beating 46%

The presentation was followed by an extensive period of questions and answers during which it was confirmed that the relative refusal rate in the UK is higher than in Western European countries, the UK Organ donation rate is one of the lowest in European developed countries, and that 2 kidney transplant units do not have Non-Heart Beating transplant programmes. Only 60 to 70 intensive care units (out of 300) have Non Heart Beating Donor programmes. The length of time that a retrieval team is tied up waiting for people to die following withdrawal of treatment was also given as a reason for few Non Heart Beating Donor programmes.

There was a strong feeling in the meeting that Non Heart Beating donor programmes needed national or regional retrieval teams, and national planning. Such teams and programmes should form part of the national service.

The meeting also noted that Spain has 3 times more ICU beds pr rata as does the UK and that in Portsmouth only 20% of relatives refuse permission for transplantation. The relative refusal rate is lower when the relative is approached by a transplant coordinator, but frequently transplant coordinators are only brought in after the relative has been approached and agreed – thereby missing opportunities to improve the refusal rate

The meeting noted that after 1st September 2006, relatives will not be able to veto the donor's wish to donate. Chris Rudge said that it is hoped that this will lead to the donor's wishes being followed in all cases, unless the relative's feelings are overwhelmingly hostile.

Resources

The meeting then turned its attention to the adequacy or otherwise of resource in transplantation and the chairman posed the question "would the service be able to cope if the number of organ donors increased?"

The meeting found differing opinions in response to this question, some surgeons present felt that resource was sufficient for a gradual expansion but other "behind the scenes" services said that they would struggle to cope and would definitely need extra resource if they were to support the additional operations.

Many felt that resource would be better targeted if transplantation was done earlier and live donors worked up more quickly. It was felt that outcomes would be better and that earlier transplantation should be a priority.

The Chairman asked why there were only 5,722 names on the kidney Transplant waiting list, yet many times this number in ERF on Dialysis. Was this a matter of resource?

Several in the meeting suggested that more resource needed to be provided for cardiovascular investigation as this was a significant reason why patients were not being put on to the transplant list.

It was said that a doubling of organ donor numbers would release significantly large resource to the NHS. Contributors also added that there were insufficient trainee Transplant Surgeons coming in to the speciality and that whilst some progress had been made, much more needed to be done to make it a career opportunity that was sought after.

Allocation of organs

Chris Rudge (UKT) said "There has been inequity of access to transplant. A new scheme was introduced on 3 April 2006. General principles are that all patients are equal and should have an equal chance of getting a transplant. It will take a number of years to achieve that. It is working, it is making changes to identify the number of patients waiting a long time on the list and have not been transplanted, and many patients who have been waiting a long time have now been transplanted."

The meeting expressed the view that whilst it had been beneficial to some patients the effect on the system as a whole could not yet be assessed.

Non-Heart Beating

The meeting noted that Non-Heart Beating transplants had the capacity to double the numbers of transplants from Cadaveric donors, but that this was unlikely to be realised because ICU's were not geared up to take advantage of the potential. The meeting wanted a Non Heart Beating Donor scheme operating in every unit in the country and the establishment of a national organ retrieval service. However it was accepted that most surgeons would feel unwilling to operate on an infrequent basis. If the numbers of Transplants increased then operations would not be so infrequent and this problem would recede.

There was a general consensus that whilst the UK had a workable system for Heart beating donation, there was not a perfect service for Non Heart Beating Donors. Chris Rudge felt that Non Heart Beating Donors should be seen as Multi organ donors. Where such Multi organ retrieval operations should be centred was the subject of considerable discussion but response times were considered an important factor. It was felt that either the D of H or UKT should take the lead in assessing options. All were agreed that funding would be necessary to set up a national retrieval service.

Concluding Comments

During the summing up by chairman, Evan Harris MP, the following points were highlighted

- There is a need for a national Non Heart Beating Donor retrieval service. The need is urgent and movement needs to be as fast as possible.
- The APPKG should lobby Ministers to make sure a time-scale is agreed.

- Regarding the Human Tissue Act (HTA) there may well be issues needing to be raised with the Chairman of the HTA in regard to the codes of practice. The replacement to ULTRA must be able to work quickly in respect of the approval of live donation and not be buried in unnecessary tiers of bureaucracy before approval is given. Independent assessors should perhaps be given the power without further reference to the HTA. The main hope for an increase in live donation following the Human Tissue Act lies in paired and pooled donation, not altruistic donation. The need to put before the HTA both related living donors and unrelated living donors seems to be a backward step although it is paramount to ensure there is no coercion. The HTA has said it will turn round cases in 5 days. There was significant disquiet expressed about the need to refer transplants between relatives to the HTA.
- There was an acceptance that ABO compatible and desensitisation would increase living donors by 10 – 15% and this will be expensive, however PCT's should consider that this increase in operations will be funded by the savings that living donation can make to a patients cost of care.
- An improvement in transplantation services across the UK would diminish the number of cases where patients travel to India and Pakistan for transplantation – usually unwise with poor results or complications.

Where to go from here

It was agreed that Parliamentary action would be decided by the chairman and other members of the APPKG after due consideration of the discussions, and the minutes taken of the meeting.

Ministers need to be given a time-scale for improvement, perhaps 5 years. The APPKG should be clear about where transplantation should expect to be at that time.

Members of Parliament can and should send letters to the Minister and table parliamentary questions. Others present at this meeting should send letters to the Minister about the issues of importance to them

It was further agreed that the APPKG should publish a document "Increasing the numbers of Transplants" drawn from the issues discussed and setting out what is required to be done to double the number of Transplants per year. This Manifesto for action should be circulated widely and with maximum publicity.

Appendix C

Transplant Summit Attendance List – 25th May 2006

Dr Evan Harris MP,
 Linda Gilroy MP
 Triona Norman (Department of Health),
 Chris Rudge (UK Transplant),
 Sue Falvey (UK Transplant)
 Adrian McNeil (Human Tissue Authority),
 Rachel Johnson (UK Transplant),
 Magdi Shehata (Consultant Surgeon -Living Donation),
 Dr Philip Dyer (Transplantation specialist),
 Anthony Warrens (British Transplantation Society),
 Robert Higgins (Consultant - Antibody Removal),
 John Forsythe (British Transplantation Society – Chairman),
 Veronica English (British Medical Association),
 Professor J Andrew Bradley (Surgeon- Transplant Research),
 Dr Paul James Sinnot (Head of Clinical Transplantation Laboratory – Antibody Removal),
 Lisa Burnapp (Consultant Nurse – Living Donors),
 Professor Peter Friend (British Transplantation Society),
 Dr C G Newstead (Chair of Standards Committee BTS),
 Professor Michael Nicholson – Transplant Surgery, Leicester),
 Jayne Fisher (Chair UK Transplant Coordinators),
 John Richardson (Co Chair UK Transplant Coordinators),
 Simon Bramhall (Liver –Consultant Surgeon),
 Keith Rigg (Consultant Surgeon and HTA),
 Professor John Feehally (Renal Association),
 Dr Donal O'Donoghue (Renal Association),
 Roger Greenwood (Chair-Kidney Alliance),
 Dr Susan Martin (Manchester Transplantation Laboratory),
 Dr Susan Fuggle (Oxford Transplant Centre),
 Maurice Slapak CBE, (Transport Sports Assn of Gt Britain),
 Dr Julian Pratt (Leeds University Hospital),
 Dr Simon Ball (ABO & Transp - QE Birmingham),
 Jane Macdonald (Lead Nurse and Vice President BRS)

NKF

Timothy F Statham, Jenny Bartlam, Margaret Parkin, Robert Smith, Stephen Rowe,
 Ray Mackey, David Macdonald, Jean Aplin, Robert Dunn, Ian Cundell, Judith Dear,
 Lewis John Powell, Deborah Duval

Industry

Mary Lynn Manning (Novartis),
 George Stanley (Novartis),
 Jay Vaja (Genzyme),
 Catherine Gribbon (Genzyme),
 Melanie Edwards (Astellas),
 Anju Balla (Astellas),
 Malcolm Brown (Astellas),
 Jenny Rowlands (Wyeth),
 Ros Meek (Wyeth),
 James Woodhouse (Roche),
 Katherine Horton (Roche),
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An electronic version of this document may be viewed at www.kidney.org.uk

The National Kidney Federation supplies the Secretarial Services and financial support necessary to run the APPKG. The NKF receives financial sponsorship from 15 renal industries including all the pharmaceutical companies that produce transplant medication. The NKF is a patient charity that adopted the following policy :-

PHARMACEUTICAL COMPANIES

The National Kidney Federation (NKF) has a working relationship with many pharmaceutical companies and this works to great advantage. The nature of the support that an industry partner may give can vary, but essentially it usually comprises of an annual donation to assist with the costs of our core activity, office and staffing, plus assistance either practical or financial with a particular project that will assist kidney patients.

The NKF always likes to establish a close working relationship with these industry partners and in particular likes to encourage the relationships to be long term. It is of prime importance to the NKF that its commercial neutrality is scrupulously preserved so that the interests on one company over another are not advanced by the NKF, or the interests of an industry partner are not put before the interests of kidney patients or carers. The independence of the National Kidney Federation is one of its most important assets, and is one reason why Government is prepared to listen to the NKF over and above commercial bodies. This independence will never be sacrificed in return for financial support.

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