

# National Kidney Transplant Service



***Information for Irish Patients  
on the UK's Kidney Sharing  
Scheme (K-S-S)***

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**[www.beaumontkidneycentre.ie](http://www.beaumontkidneycentre.ie)**

PILOT 50-0120

Transplant Coordinators:  
Tel: 01-8093119/ 8528397  
[kidneysharing@beaumont.ie](mailto:kidneysharing@beaumont.ie)

Social Worker:  
01- 8093290



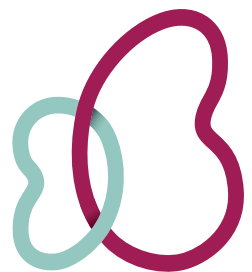
## Preface

A kidney transplant is often the best treatment choice for patients with end stage kidney failure. A successful kidney transplant can offer the best opportunity for good long term health outcomes. Until recently a live donor could only donate to a recipient if they were blood group and tissue type compatible.

The Kidney Sharing Scheme (K-S-S) is a transplant option for potential recipients who have a willing living donor who is medically suitable for donation, but who cannot donate directly due to either blood group or tissue type incompatibility or occasionally another reason.

In Ireland, we refer recipients and their incompatible donor(s) to the UK for consideration in the K-S-S. Please note, internationally these types of schemes can be called different names e.g. Shared Kidney Scheme, Kidney Paired Donation or Paired Kidney Exchange.

We hope this booklet will provide an informative overview and practical guide to support your initial appointment and subsequent progress throughout the K-S-S and from this we can focus on any questions/concerns you may have in more detail.



**National Kidney  
Transplant Service**



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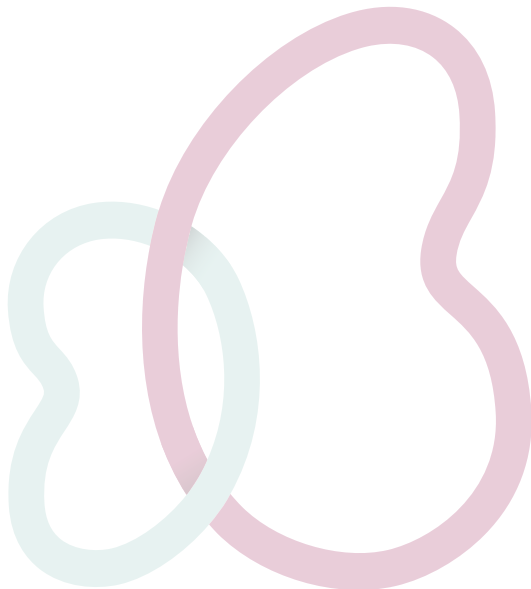
# Kidney Sharing Scheme

## What is it?

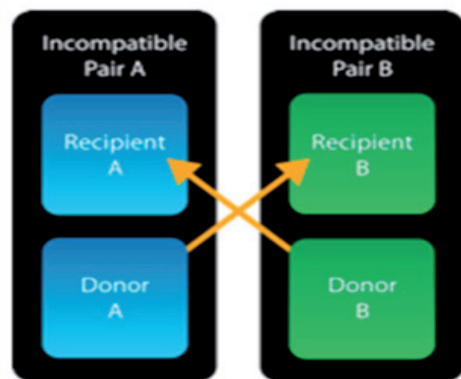
It is a scheme whereby a living kidney donor is incompatible with their recipient and so exchanges kidneys with another donor/recipient pair registered in UK's K-S-S. A potential donor may be incompatible with the recipient due to the following:

- Blood Group
- HLA (Tissue Type) / Antibodies
- Both Blood Group & HLA (Tissue Type) / Antibodies
- Occasionally other reasons

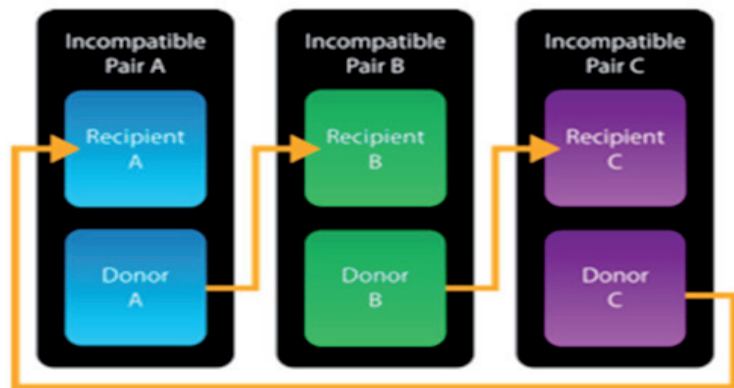
Potential transplants may be performed via a 2-way exchange, 3 way exchange or a closed domino exchange (see page 7 opposite).



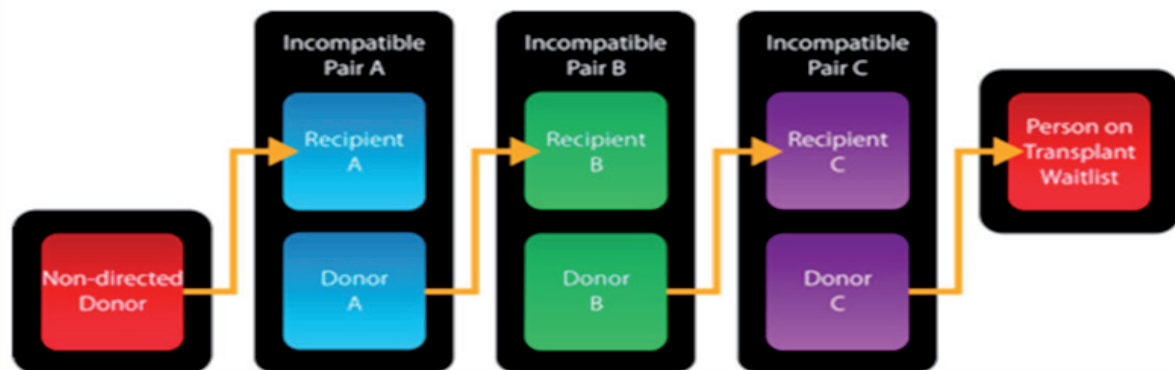
### 2 Way Exchange



### 3 Way Exchange



### Closed Domino Exchange



## Why the UK's K-S-S is a good option for Irish Pairs:

- Each recipient can potentially receive a living donor transplant.
- The UK's K-S-S is one of the largest schemes worldwide. Therefore, choosing to avail of this UK scheme could maximise the opportunity for Irish patients to receive a living donor transplant, as the pool of potential live donors in the UK is significantly larger than in Ireland.
- Long term results are more favourable for the recipient when compared to a deceased donor kidney.

## How the Scheme works:

- The recipient must be active on Irish transplant pool and have a willing donor who cannot donate directly. A full medical assessment of the potential donor must then be undertaken in Beaumont Hospital to determine their suitability to donate.
- Enrollment in the UK scheme only then occurs once the donor/recipient pair have been re-evaluated and cleared in the UK centre and importantly that both donor and recipient are happy to proceed.
- Once enrolled, every **3** months a matching run will be performed by NHS Blood and Transfusion (NHSBT). This includes all enrolled donor/recipient pairs throughout each of the UK centres.

Following these runs it is hoped that Irish pairs will be matched with other potential donor/recipient pairs within the K-S-S and subsequent donation and transplantation occurs.

- Currently these match runs occur in January, April, July and October.
- Prior to enrollment or once enrolled in the K-S-S, each recipient will have the opportunity to decide upon what type of transplant option he/she is willing to accept in regards to their transplant. This is a big decision and will be made with support from the recipient's teams in both Ireland and the UK.



## Chance of finding a match and transplant outcome:

It is important to understand that not everyone will find a match and it may take a number of years before a suitable match is found within the K-S-S.

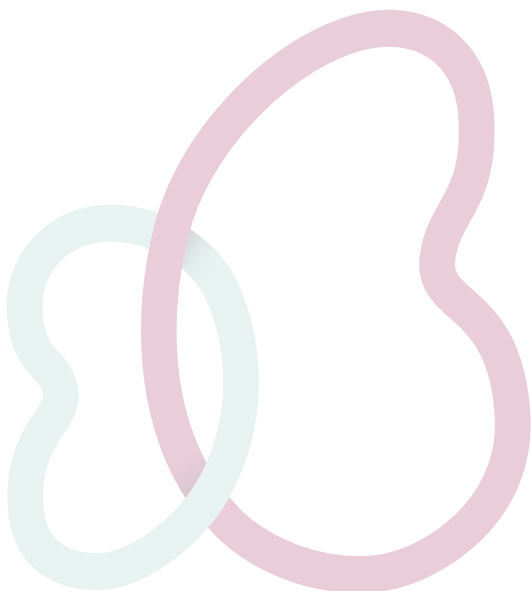
**Note during this time the recipient will remain active on the Irish transplant pool.**

The chances of finding a suitable match will depend on many factors:

- Donor Blood Group and Donor Age
- Recipient Blood Group and Recipient Age
- Recipient PRA (antibody levels)
- Recipient's acceptance of a higher risk transplant.

The NHS have a great online tool, that you can use to check your chance of finding a match. When you come to meet us at Beaumont Hospital for an initial discussion about the K-S-S we will give you an estimate of your chance of finding a match using this tool. Please bear in mind these results are only a guide and don't guarantee a match in the scheme. The website where this tool can be found is <https://www.odt.nhs.uk/living-donation/tools-and-resources/>

- \* Please note the Calculated Reaction Frequency (CRF) is the same as PRA/PGEN (antibody level).



# Incompatible Pairs Living Donor Kidney Application



## Blood and Transplant

Variable	Select
Recipient Blood Group	Select
Calculated Reaction Frequency	Select
Donor Blood Group	Select
ABOi TX with willing Donor†	Select
HLAi TX with willing Donor†	Select
Recipient Age	Select

Reset

### Estimated Chance of Transplant

	Deceased Donor	NLDKSS	ABOi	HLAi
6 Months	-	-	-	-
1 Year	-	-	-	-
3 Years	-	-	-	-

### Transplant Survival Rates

	Deceased Donor	NLDKSS	ABOi	HLAi
6 Months	-	-	-	-
1 Year	-	-	-	-
3 Years	-	-	-	-

**Disclaimer:** The information is provided for guidance only

†Low titre/Low DSA means acceptable for incompatible transplant. High titre/High DSA means unacceptable for incompatible transplant.

**Note:** NLDKSS chance of transplant is based on paired donation including short altruistic donor chains.

Chances of transplant through the NLDKSS could be increased by considering an antibody incompatible transplant within the scheme

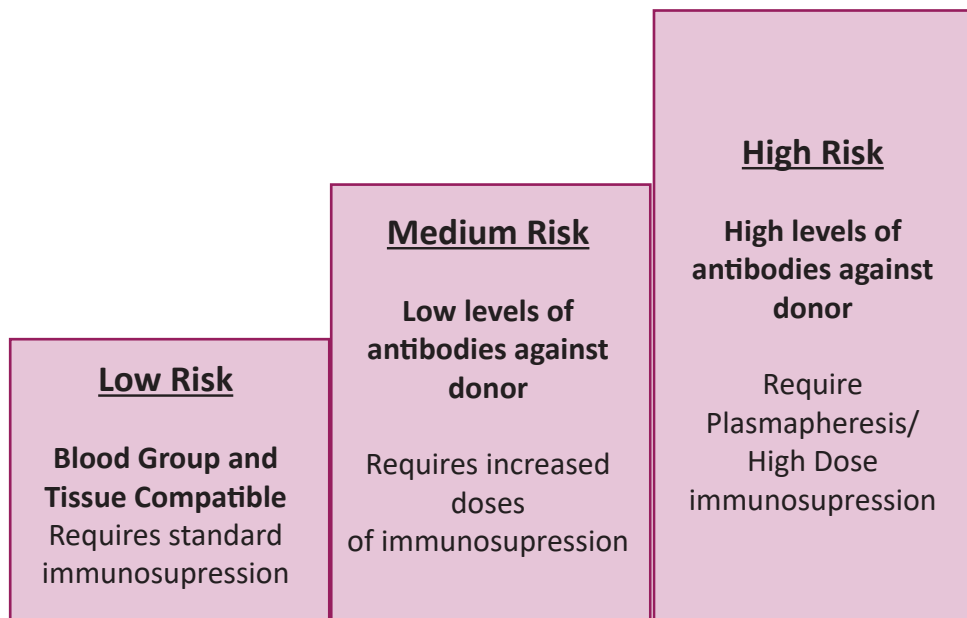
## Finding a match

Ideally, we would like to accept a standard risk transplant for all Irish recipients. This means the recipient is matched with and receives a kidney which is fully blood group and tissue type compatible for them. Unfortunately, this may not always be possible. For recipients who have difficulty finding a suitable match, we may then consider expanding the criteria for accepting a potential donor within the K-S-S. This might involve accepting a kidney from a donor where there is a degree of incompatibility e.g. a different blood grouping or some HLA (tissue type) antibodies. The pros and cons of considering this approach will be discussed carefully with you at each stage.

At the first visit to Beaumont Hospital, we usually organise some blood samples to be taken to check levels of the recipient's blood group antibodies (titre levels). This will provide the medical teams in both Beaumont Hospital and the UK with useful information about the risks of potentially performing a blood group incompatible transplant if this option is to be explored.



## Transplant options and their associated risks



**Option 1: Low Risk** - Accepting a blood group and tissue type compatible donor kidney. This would require standard immunosuppression and standard follow up after the transplant. This is the ideal option and we try to find these types of matches for every recipient in the K-S-S.

**Option 2: Medium Risk** – This involves accepting a kidney from a donor where the recipient has some low-level blood group or HLA (tissue type) antibodies against the matched donor. As a result the recipient may require additional treatments before the transplant (of which may occur in Beaumont Hospital or in the UK Hospital), increased immunosuppression medications and close monitoring after the transplant.

**Option 3: High Risk** – This involves accepting a kidney from a donor, where the recipient has high levels of blood group or HLA (tissue type) antibodies against the matched donor. The recipient would require desensitisation treatment. This would involve plasmapheresis - a process of removing antibodies from the recipient's bloodstream before the transplant and the need for additional immunosuppression medications and close monitoring after the transplant.

Where possible any additional treatments required to support the recipient's transplant care before or indeed after transplantation will be done in Beaumont Hospital. However certain aspects of care may need to be completed in the UK centre. As a result the recipient may need to travel to the UK centre earlier to receive treatment in preparation for surgery or stay longer to ensure recovery is closely monitored and stable before returning to Ireland for follow up.

## The Process for Irish Patients considering the K-S-S

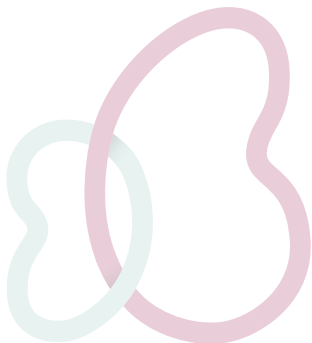
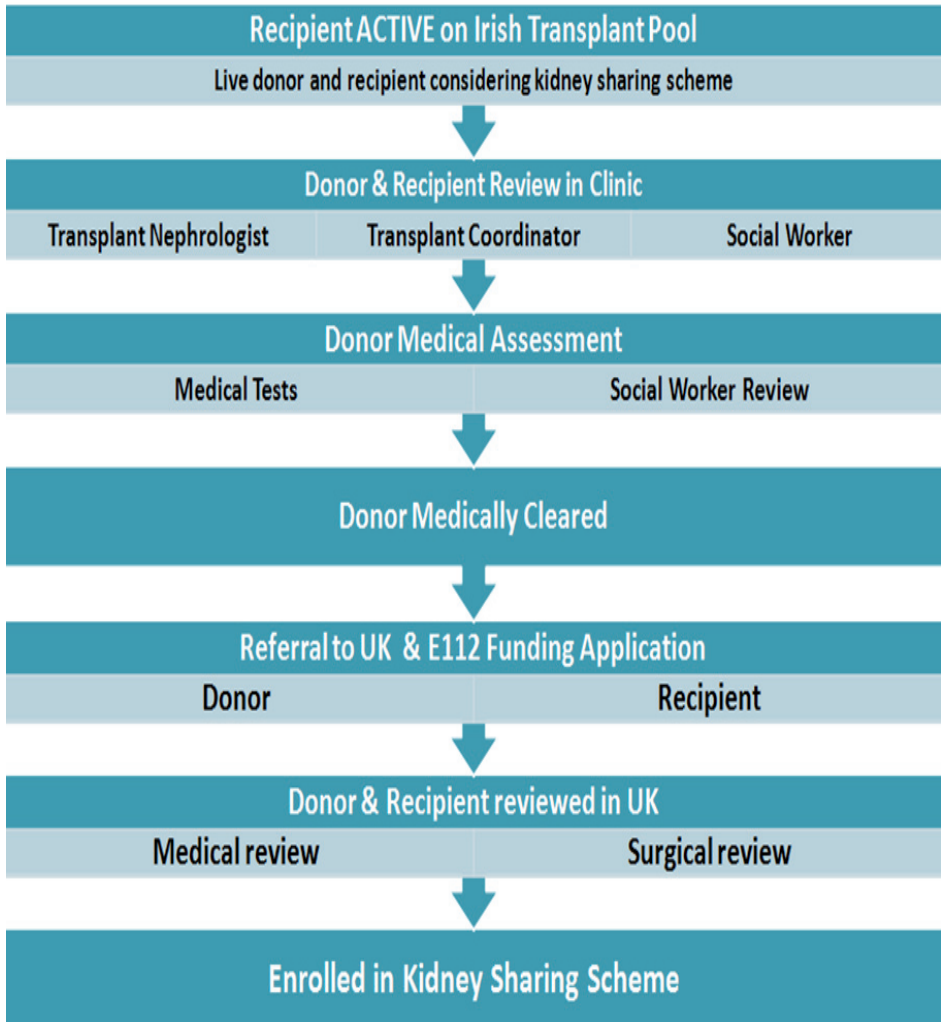
Any donor and recipient pair interested in the K-S-S will be invited together to meet a transplant coordinator and transplant nephrologist in Beaumont Hospital. At this initial meeting we will discuss the various transplant options available and the current workup and referral process. There are practical and financial considerations which will be explored further on the day.

Having a clear understanding of the process is very important when considering the K-S-S. We recommend that after this consultation, you both discuss the K-S-S process further with one another and necessary family members to ensure the K-S-S is the right option for you.

We advise you to look at the UK website for further reading: <https://www.odt.nhs.uk/living-donation/uk-living-kidney-sharing-scheme/>.

Once all parties are satisfied that they would like to proceed, the donor is then invited to start their medical assessment in Beaumont Hospital.

# PROCESS FOR IRISH PATIENTS



## Donor Medical Evaluation

The donor will undergo a thorough medical assessment to ensure they are medically and surgically suitable to donate a kidney. This assessment is carried out to minimize risks to the potential donor. In general, the donor's assessment for the K-S-S will take place over 3 visits to Beaumont Hospital. However a donor may need to lose weight, stop smoking or have additional tests completed which will prolong the process.

During the first visit, the nephrology doctor will take a detailed medical history and complete a full physical examination. The consultant nephrologist will meet you also to explain in detail the risks and benefits of donating a kidney and discuss also important health and lifestyle factors to consider before and after donation. Finally, you will meet a Social Worker, who will inform you of the Living Donor Kidney Reimbursement Scheme and the Treatment Abroad Scheme (E112 forms).

**First Visit – One Day Medical Tests:** Blood tests, urine tests, electrocardiogram (ECG), chest x-ray, abdominal ultrasound. All donors need to have a special test performed to accurately measure kidney function- this is known as a GFR test. This involves administration of a very small amount of radioactive medicine into the blood stream and then blood tests are drawn and sent to the lab for analysis.

Females will require a cervical smear test (if <60 years) and mammogram (if >50-69 years). Males if >50 years will require a Prostate Specific Antigen (PSA) blood test.

**Second & Third Visits-** you will also have a CT angiogram of your abdomen and a renogram. If you require additional tests, we will attempt to arrange these on the same days (if possible). Once all your tests are completed and reports available the consultant nephrologist will review these results and will decide if you are medically suitable to donate your kidney. Further investigations may be needed at this stage to ensure the donor is suitable to proceed.

## Recipient Medical Evaluation

While the donor is undergoing medical assessment, the transplant coordinator will ensure that all the medical tests are up to date for the recipient. It may be necessary for the recipient to have some tests updated prior to being referred to the UK centre. The coordinator will link with the recipient's renal centre to arrange these medical tests (if needed). Commonly required tests are chest x-rays/ECG/ECHO/ mammogram/cervical smear test (women) /prostate specific antigen (men).

## Referral to the UK

Once both donor and recipient tests are completed and satisfactory, we will then forward both referrals to the UK centre. Once this referral has been reviewed, the coordinators from the UK centre will contact you directly to schedule a joint assessment review. In some cases prior to your review in the UK additional tests may be requested and will be organised and/or completed in Beaumont Hospital/local renal centre.

The UK centre aims to give you as much notice as possible to prepare for this appointment so as you can arrange childcare, work commitments, flights, accommodation etc. The recipient and donor must have their funding approved by The Treatment Abroad Department (E112 Application approval) before travelling to the UK. When approved the recipient will receive a letter of approval from the Treatment Abroad Department. It is essential that the recipient/donor always notify the Treatment Abroad Department of their appointment dates, before travelling and forward a copy of their appointment letter, to the Treatment Abroad Department.

## Preparation prior to travelling to the UK

The UK centre will not arrange dialysis (haemodialysis or peritoneal dialysis) for the recipient, while they visit for their outpatient review in the UK. The recipient must therefore discuss and arrange changes to their individual dialysis times/sessions (where needed) with their local dialysis centre before they travel to the UK and comply with diet and fluids restrictions to ensure a safe trip.

It is the donor(s)/recipient's responsibility to arrange their transport and accommodation for all of their appointments in the UK.



Please keep all relevant receipts, copy of air fares, boarding passes etc. to submit your claim of reasonable expense's. There are limitations in relation to the Reimbursement Scheme for Live Kidney Donors, so we do advise donors to read the Reimbursement Policy and to clarify any queries that they may have directly with the Reimbursement Office.

However if you experience any issues with the Treatment Abroad Scheme or the Reimbursement Scheme for Live Kidney Donors or have any questions during the process please contact the Social Worker in Beaumont Hospital for assistance.

## Review in the UK:

Coventry: The appointment will be split over 2 days (1<sup>st</sup> day in afternoon and 2<sup>nd</sup> day in morning). You will meet a transplant/donor coordinator, consultant nephrologist and a transplant surgeon. Both donor and recipient will have further bloods/urine tests, ECG, Chest X-Ray and a CPEX (heart and lung fitness test). **As the CPEX test involves exercise we advise that you wear comfortable clothes and trainers.** During the visit, both donor and recipient will learn more about the the K-S-S and transplant options available to the recipient to find a match in the scheme.

The medical and surgical teams will re-explain in-depth the following aspects of care:

- Risks and benefits of each surgical procedure.
- Transplant options available within the scheme
- Additional treatments (if any) that maybe required for the recipient before or after the transplant.
- The postoperative care involved for both the donor and recipient whilst in hospital and in the immediate discharge period.

Once this assessment is completed, no additional tests are needed and both the donor and recipient pair are happy to proceed, their case is then discussed at a team meeting in the UK centre to determine suitability for enrollment.

## Registration in the K-S-S

Once you are enrolled and registered as a pair in the K-S-S you will be included in every subsequent matching run. These currently take place in January, April, July and October.

**Note:** If you (donor/recipient) no longer want to stay in the K-S-S, please inform the transplant coordinator's office in Beaumont Hospital. We will inform the UK centre immediately so as to update the system before a potential match run occurs. Occasionally the recipient develops medical problems and as a result needs to be suspended from the Irish transplant pool. If this happens, they will also be suspended from the K-S-S. Once recipients are suitable to be re-activated on the Irish pool, they will then be reactivated in the K-S-S. Equally, potential donors should inform the transplant coordinator in Beaumont Hospital about any changes to their health status.

## What happens when a match is found:

- When a match is found in the K-S-S the UK recipient/donor coordinator will inform you directly and they will also inform the team in Beaumont Hospital.
- Beaumont Hospital will temporarily suspend you from the Irish transplant pool.
- The UK and Beaumont Hospital transplant coordinators will organise cross-match blood tests between the donor and recipient as needed. This involves blood being sent to the UK centres and usually takes place 2 or 3 weeks following the potential match.
- Once all the results are known and reviewed, the UK co-ordinator will discuss the results with you and potential dates for surgery will be explored.
- The coordinator in the UK will let you know when it is a good time for you to book flights and accommodation etc.

Before the surgery both the donor and recipient pair will need to be re-evaluated in the UK centre. On this day you will also meet an independent assessor. The role of the independent assessor is to ensure there is no pressure placed on either person and to ensure they are fully informed of all stages of the process.

- Usually 1 week prior to the scheduled transplant/donation date, final cross-match bloods will be taken in Beaumont Hospital. Again, the transplant coordinators in the UK and in Beaumont Hospital will arrange this and contact you directly.
- Please note that sometimes the transplant may not proceed or may have to be postponed. There can be several reasons for this e.g. the cross-match is strongly positive or a donor/recipient match cannot proceed (for medical and/or other reasons). This can be extremely upsetting and disappointing for all involved and support is available. If this occurs, and if appropriate, the recipient will automatically be reactivated on the Irish transplant pool.

## Surgery- Donor & Recipient

In most cases both donor and recipient surgery will happen on the same day. Donor surgery will be performed in the morning and recipient surgery will occur later in the afternoon. The team in the UK will explain the logistics to both the donor and recipient.

## Donor Care & Follow-up

Donors can expect to be in hospital 1 night before their scheduled operation and 3/4 days after surgery. If the donor has any medical concerns after discharge and are still in the UK, they should contact the UK hospital. Once the donor returns to Ireland, they are asked to contact the transplant coordinators in Beaumont Hospital to arrange a review by the medical team. If you have any health concerns after donation, please check with your GP or the transplant coordinator in Beaumont Hospital. An annual outpatient appointment will be arranged for the donors with the nephrology team in Beaumont Hospital.

## Recipient Care & Follow-up

Recipients can expect to be in the UK hospital for 7-10 days after surgery. The duration will depend on how the transplant surgery goes and how the recipient recovers. The recipient will need to stay in the UK after discharge from the hospital, for close monitoring (this timeframe will be decided by the UK team managing your care). Please note the recipient will have to organise their own accommodation during this time.

Once the UK teams are satisfied the recipient can then return to Ireland for follow-up care. The recipient is seen in Beaumont Hospital within 1-2 days in the outpatient renal day ward. We ask each recipient to contact the transplant coordinator's office in Beaumont Hospital directly to organise this appointment before returning to Ireland. Initially, follow up is twice weekly. Most but not all recipients are followed up long term in Beaumont Hospital.

## Information Sharing

Information is only shared with team members directly involved in your care within Beaumont Hospital and the UK centres. You will be asked during the process to provide consent to allow your medical information to be shared between both these services.

To protect the donor's confidentiality, investigations, test results and the outcome of both are only shared with the donor. The recipient as a result may feel isolated during this process. We recommend you discuss concerns you may have with your primary nephrologist as throughout this process you remain under their care.

In relation to aspects of the transplant or donation process personal details of the patients/centres involved are not shared. Afterwards correspondence can be shared in a confidential manner between recipient/donor pairs if appropriate.

## What happens if no match is found?

If no match is found, the recipient will remain active on the Irish transplant pool. The donor and recipient pair will be automatically enrolled in the next UK match-run, unless they say otherwise (or develop health problems).

The donor will have an annual review with the transplant nephrologist in Beaumont Hospital to ensure they remain medically suitable to donate and are happy to remain in the K-S-S. This review involves fasting blood tests, urine tests, ECG, blood pressure and weight check. Every second year the donor will have an abdominal ultrasound. Females will need to ensure that their cervical smear tests and mammograms are up to date. These updates will then be forwarded to the UK centre following review.

## Further Considerations:

There are many practical and financial considerations in relation to the K-S-S. Here are some of the main points.

## Treatment Abroad Scheme/E112 Application

- Irish patients are entitled to apply to the Health Service Executive (HSE) to avail of the Treatment Abroad Scheme. Both the donor and recipient will need to complete separate E112 forms. These forms will be given to you during your initial visit to Beaumont Hospital. The E112 form has two separate sections. Section A is completed by the recipient / donor and returned to the transplant co-ordinators in Beaumont Hospital. Section B is completed by Beaumont and accompanied with a medical letter.
- Once you are approved, the recipient and donor are entitled to claim the reimbursement of reasonable sea and air travel from Ireland to the UK. As per E112 policy (<https://www2.hse.ie/services/treatment-abroad-scheme/treatment-abroad-scheme.html>)

**Please note you must notify the Treatment Abroad Scheme Department before every appointment you attend in the UK and provide them with a letter detailing your appointment date(s)**

## Reimbursement Scheme for Living Kidney Donors.

- This scheme applies to any person who has been selected as a potential donor (ie. to attend for medical assessment) by the living donor programme at Beaumont Hospital and to those who, under the clinical supervision of the National Kidney Transplant Service in Beaumont hospital, travel to the UK for the purpose of participating in the K-S-S.
- The Social Worker will provide you with a copy of the Policy on the Reimbursement of Expenses of Living Kidney Donors.
- **There are limitations as to what expenses are reimbursable, especially regarding accommodation, loss of earnings etc. Therefore, we strongly recommend that donors study the Policy and liaise with the Living Donor Reimbursement Office on 056 778 4551** as early as possible to discuss your circumstances and determine if you are due reimbursement for some/all of the out of pocket expenses and loss of earnings.
- It is essential that you keep all your receipts and submit all the necessary paper work required (as per the Reimbursement Policy). It can take a number of weeks for your claim to be processed. We advise you to clarify timelines with the Reimbursement Office.
- The recipient and donor will need to consider the financial requirements and the costs associated with the K-S-S e.g. the money required upfront to pay for flights, accommodation, travel and day-to-day expenses whilst in the UK.

## Day to day costs

- **Recipient:** If surgery proceeds in the UK, the recipient will spend a longer period in hospital than the donor and it is likely the recipient will need to stay in the UK as an outpatient before and after discharge. During this time, the **recipient will have to find and fund his or her own accommodation**. Currently there is no Reimbursement Scheme for the recipient. In the UK the recipient will also have to **fund their own travel to and from outpatient hospital appointments**.
- **Donor:** If the donor wishes to stay in the UK, after they have been discharged, to remain with the recipient; they will have to **fund their own accommodation**, as this is not reimbursable under the current scheme.

## Support

- If you are concerned in relation to the financial costs associated with the K-S-S, please feel free to contact the Social Worker on the Live Kidney Donor Programme. They can liaise with your local Community Welfare Officer and/or The Irish Kidney Association to see if any financial assistance can be provided.
- Additionally if you require any further information from a medical perspective or have concerns about any aspects of the K-S-S please liaise with your primary nephrologist/local renal teams or the transplant coordinators in Beaumont Hospital.

## Useful internet links

[www.beaumontkidneycentre.ie](http://www.beaumontkidneycentre.ie)

<https://www.odt.nhs.uk/living-donation/uk-living-kidney-sharing-scheme/>

<https://www.hse.ie/eng/services/list/1/schemes/treatmentabroad/>

<http://www.belfasttrust.hscni.net/hospitals/BelfastCity%20Hospital.htm>

<https://www.uhcnw.nhs.uk/>

Prepared by:  
Dr. Colm Magee, Consultant Nephrologist  
Transplant Coordinators Team



National Kidney Transplant Service, Beaumont Hospital, Dublin 9.



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