

# **Department of Health**

# Policy on the Reimbursement of Expenses of Living Kidney & Liver Donors



Tús Áite do Shábháilteacht Othar Patient Safety First

# **DEPARTMENT OF HEALTH**

# POLICY ON THE REIMBURSEMENT OF EXPENSES OF LIVING KIDNEY & LIVER DONORS

#### INTRODUCTION

Kidney transplantation is an established treatment for end stage kidney failure. It increases life expectancy and improves quality of life. The kidney transplantation service in Ireland is located at Beaumont Hospital and comprises the Living Donor Programme and the Deceased Donor Programme.

The Living Donor Programme at Beaumont Hospital has greatly improved the organ transplantation rates in Ireland and offers patients with end stage renal failure an opportunity to obtain a kidney transplant sooner than if they were solely listed on the deceased kidney donor list. Living donors are sourced from a patient's family, extended family and close friends. Ireland also participates in a "paired donation<sup>1</sup>" scheme with the UK.

Living Liver donation involves a lobe of a living liver donor being transplanted to a recipient. It usually involves a parent donating part of their liver to a child. The Paediatric Programme is generally operated under clinicians in Our Lady's Children's Hospital, Crumlin. The treatment is accessed under the provisions of the Treatment Abroad Scheme as the service is not currently available in Ireland.

#### <u>PURPOSE</u>

This policy has been adopted to address the issue of the costs incurred by donors participating in the Living Donor Programme in Ireland during the pre-operative and post-operative period and for Living Liver donors who receive their treatment under the Treatment Abroad Scheme. The implementation of this policy is intended to minimise financial disincentives for potential living donors, with a view to ensuring the pool of living organ donors continues to expand.

#### POLICY CONTEXT

The European Union (Quality and Safety of Human Organs Intended for Transplantation) Regulations 2012 (S.I. No. 325 of 2012) as amended set down the legal basis for this policy. These Regulations state that donation from deceased and living donors shall be voluntary

<sup>&</sup>lt;sup>1</sup> When a living kidney donor and recipient are incompatible or mismatched with each other, either by blood group or by tissue type, it may be possible for them to be matched with another donor and recipient pair in the same situation and for the donor kidneys to be exchanged or swapped. This means that the recipient receives a kidney from someone unknown and, at the same time, the donor gives to a recipient who is not known to him/her. The benefit of this type of donation is that each recipient receives a kidney transplant from a living donor that he/she would not have otherwise had.

and unpaid but that living donors may receive compensation for donation, provided it is strictly limited to making good the expenses and loss of income related to the donation.

S.I. No. 325 of 2012 confers a power on the Minister for Health to define the conditions under which such compensation may be granted, while avoiding any financial incentives or unjust reward for a potential donor.

# **PRINCIPLES**

- (a) This Policy is based on the premise that, although reimbursement may be granted, such reimbursement cannot confer any financial incentive or financial reward on a potential donor.
- (b) Donors should take all necessary steps to ensure that financial losses are minimised.
- (c) The donor must take personal responsibility for her/his own care and follow reasonable medical advice. Otherwise expenses may not be reimbursed.
- (d) Without exception, reimbursement of accommodation and/or travel expenses will be made in line with the HSE's National Financial Regulations. A copy of these regulations is available at <u>http://www.hse.ie/eng/staff/Resources/Financial%20Regulations</u>.
- (e) Relevant supporting documentation must accompany all claims for reimbursement.
- (f) The HSE reserves the right to seek any additional information it deems appropriate in confirmation of the claim from the donor or from third parties.
- (g) Only accommodation and travel expenses actually incurred will be reimbursed.
- (h) Loss of earnings may be reimbursed up to an upper limit of €10,000.
- (i) Vouched travel and accommodation expenses may be reimbursed up to an upper limit of €6,000.
- (j) The Department of Health and HSE do not bear any responsibility for the loss by the donor of any entitlement whatsoever as a result of their becoming a living kidney or a living liver donor.

# WHO IS ELIGIBLE TO APPLY FOR REIMBURSEMENT?

This Policy applies to the person who has been selected as a potential donor (i.e. to attend the one day assessment) by the Living Donor Programme at Beaumont Hospital, to those who, under the clinical supervision of the National Renal Transplant Programme in Beaumont, travel abroad for a paired kidney donation or donors who travel abroad for living liver donation under the Treatment Abroad Scheme (reimbursement for any expenses covered by other agencies here or abroad will not be made). An Irish resident who travels abroad to donate a kidney/lobe of liver to a person resident in another country and on a waiting list in the other jurisdiction will not be eligible for reimbursement under this Policy. The arrangements for any such donation and transplant will be a matter for the jurisdiction involved.

If the selected donor (i.e. a person who attended the one day assessment) is subsequently deemed unsuitable to proceed to donation, that person's travel and accommodation costs (incurred up to the date where it is determined that the donation will not proceed) will be considered eligible for reimbursement.

The Policy also applies to Irish Residents who travel abroad to donate a lobe of their liver under the Treatment Abroad Scheme. The same principles underlying reimbursement of expenses for selected kidney donors who travel abroad/outside the State for a paired kidney donation applies to living liver donors.

#### PERIOD OF COVER

Reasonable travel and accommodation expenses incurred from when the donor has been selected as a potential donor through to the in-patient stay when the donation takes place and for up to 12 weeks post-donation are eligible for reimbursement.

Loss of earnings incurred from the time the donor is selected as a suitable donor through to the in-patient stay, when the donation takes place, and for up to 12 weeks post donation (12 weeks inclusive) are eligible for reimbursement. Any reimbursement claim for loss of earnings may not exceed 12 weeks in total (eg if a donor claims for 1 week loss of earnings pre-donation they may only claim a maximum of 11 weeks post donation).

# ELIGIBLE EXPENSES

<u>General</u>

- Only those expenses that are directly attributable to the organ donation will be considered for reimbursement. This includes the cost of obtaining medical certificates.
- The best evidence available should be submitted by the living donor i.e. receipts, invoices, statements.
- In line with the HSE's National Financial Regulations, payments may not be made without the supporting documentation. Therefore it is incumbent on each person seeking reimbursement to ensure original receipts are obtained, kept and submitted.
- Reimbursements will be net of any other reimbursement paid or due to the donor through any other method or scheme e.g. health insurance, life assurance, employee assistance scheme, long term illness insurance, financial support from a charity or voluntary organisation.

Loss of Earnings

Loss of earnings incurred by a selected salaried/waged donor or a self-employed donor for up to 12 weeks pre/post-donation (12 weeks inclusive) may be considered for reimbursement, up to a cap of €10,000, on the provision of relevant supporting documents.

#### Salaried/Waged Donors

Salaried/waged donors must submit a letter from their employer detailing how much the employer will pay the donor for the period up to 12 weeks pre/post-donation (12 weeks inclusive). If the donor will be fully paid by their employer during this period, they will not be eligible for any reimbursement for loss or earnings.

In cases where a selected salaried/waged donor will not be paid by their employer for any, or for a portion, of the 12 week period pre/post donation (12 weeks inclusive), they must submit details from the Department of Social Protection, or any income continuance plan or other similar policy, detailing what benefits, if any, they will be entitled to during the period.

Salaried/waged donors must provide their most recent P60 and payslips for the 6 months preceding donation. In exceptional circumstances, payslips for the preceding 3 months will be accepted.

Only the difference between the donor's average net pay<sup>2</sup> and the total of any payments made by their employer, the Department of Social Protection or on foot of any insurance policy etc., will be eligible for reimbursement. The maximum period for which a donor may claim for reimbursement of loss of earnings is 12 weeks. If the donor is out of work for longer than 12 weeks, they will not be eligible for reimbursement of loss of earnings after the 12 week period.

All donors will be required to submit medical certificates from their treating consultant or GP as well as written confirmation of the date of return to work from their employer.

Overtime payments, shift allowances or other similar payments will not be eligible for reimbursement, irrespective of whether they comprise a regular portion of the donor's salary.

Every effort will be made to reimburse the donor according to their usual pay cycle i.e. weekly, fortnightly or monthly payments.

# Self-employed Donors

Self-employed donors must submit a Notice of Assessment and the Revenue Commissioner's Form 11. Reimbursement for a 12 week period will be calculated on the basis of 12/52 of the donor's income in the preceding 12 months tax period.

<sup>&</sup>lt;sup>2</sup> For the purpose of this Policy, net pay is the average pay received over the 6 months preceding donation following statutory deductions. Overtime and other non-standard payments will not be recognised in this regard.

As some donors may return to work earlier than 12 weeks post-donation, a medical certificate and a return to work certificate from the donor's GP or treating physician must also be submitted.

Or

A self-employed donor can make a claim for the expense of a person to replace them in their business for a period of up to 12 weeks pre/post donation (12 weeks inclusive), up to an upper limit of  $\leq 10,000$ . Any claim must include receipts supported by documentary evidence that will need to be provided to the HSE's Living Donor Reimbursement Office. Where a self-employed donor is using this option and the person replacing them is already an employee then it will be necessary to demonstrate the additional hours that employee is incurring in his duties to replace the employer. Only the additional hours will be eligible for reimbursement.

A self-employed donor can only make a claim for loss of earnings **or** the expense of a person to replace them in their business, not both.

# Department of Social Protection Schemes

A donor who is in receipt of a payment from any Department of Social Protection Scheme will continue to have this payment made (provided such payments are in line with their normal rules and regulations) for a period of up to 12 weeks from donation. The Living Donor Programme at Beaumont Hospital or the Living Donor Reimbursement Office, as appropriate, will make the necessary arrangements with the Department of Social Protection in consultation with the donor.

#### Travel Expenses

Reasonable travel expenses, incurred by an individual in relation to the living donor process will be considered for reimbursement. As a general rule, the most economically advantageous mode of transport should be used. Standard class fare only will be considered for reimbursement. The donor must submit original receipts which must coincide with an appointment date with the Living Donor Programme in Beaumont Hospital or, in the case of paired or direct kidney donation, receipts must coincide with an appointment hospital. Likewise for living liver donations receipts must coincide with an approved appointment with the relevant hospital.

When a donor travels by car, reimbursement will be calculated with reference to the AA Routeplanner, calculated on the day the claim is processed. This website provides calculations of the distance travelled and the average fuel cost. Please see www.theaa.ie/routes.

Hospital parking and toll charges will also be considered for reimbursement. Receipts must be submitted.

#### Accommodation

If overnight accommodation is required, this must be approved in advance by the Living Donor Programme or the Living Donor Reimbursement Office. Only the vouched cost of the accommodation (bed and breakfast) will be considered for reimbursement up to a maximum of  $\pounds$ 110 per night. The donor must submit the original receipt which must coincide with an appointment date with the Living Donor Programme in Beaumont Hospital or an appointment date approved by the Treatment Abroad Scheme.

Where a donor wishes to extend his/her stay for any reason, including to remain with the recipient of the organ, all costs associated with this period will not be reimbursed.

# Childcare Costs

Childcare costs that would not have otherwise been incurred by the donor may be reimbursed up to an upper limit of €5,000 subject to certain criteria being met. Reimbursement will only be considered for children placed with childminders or centre based childcare providers who are registered with Tusla, the Child and Family Agency, in line with the Child Care Act 1991, as amended (Early Years Services) Regulations 2016 and the (Registration of School Age Services) Regulations 2018.

# KIDNEY DONATIONS IN IRELAND INVOLVING OVERSEAS DONORS

In some instances, donors may travel from another jurisdiction to donate a kidney to a person under the clinical supervision of the Renal Transplant Programme in Beaumont.

In general, a preliminary assessment of overseas donors may be provided in their normal country of residence. International travel costs and accommodation expenses will be reimbursed in accordance with the procedures set out in this Policy. Some testing will be carried out prior to surgery at Beaumont Hospital and expenses during the person's stay in Ireland may be reimbursed in line with the criteria applying to Irish-based donors.

# **IMPLEMENTATION OF THE POLICY**

The reimbursement scheme will be managed by the Health Service Executive within the limits of the budget provided for any calendar year.

The scheme will be administered by the HSE's Living Donor Reimbursement Office. The donor's claim must be approved by the Living Donor Programme at Beaumont Hospital or the Treatment Abroad Scheme before being submitted to the Living Donor Reimbursement Office. The Living Donor Programme must keep appropriate records to facilitate the validation of claims.

The Living Donor Reimbursement Office will develop a database to record all claims and must validate this with the Living Donor Programme or the Treatment Abroad Scheme. Expenses submitted for reimbursement will be strictly validated to ensure that they are reasonable and appropriate. Correspondence from the Living Donor Reimbursement Office to patients outlining payments being made pursuant to a claim under this scheme will be set

out in a comprehensive tabular format so that patients may readily see the value of the claim approved/declined.

The HSE's Organ Donation and Transplant Ireland (ODTI) will be responsible for ensuring that claims are properly validated and will reimburse the Living Donor Reimbursement Office accordingly.

There is no discretion to make ex gratia or once off payments to patients outside the terms of this policy.

Donors may be assisted with their claim by the Living Donor Reimbursement Office who will explain this Policy to them in advance of donation.

#### **GOVERNANCE**

A governance structure will be agreed between the HSE's Organ Donation and Transplant Ireland (ODTI), the Living Donor Reimbursement Office and the Living Donor Programme to provide the appropriate level of scrutiny for all claims. This will be designed to support the timely and consistent payment of legitimate claims only, and to provide a robust risk management strategy to underpin the policy.

The Living Donor Reimbursement Office will establish appropriate procedures to ensure that all reimbursements are correct and legitimate and that appropriate records are kept.

All information, in whatever form, on the implementation of the reimbursement scheme shall be made available to the HSE's Organ Donation and Transplant Ireland (ODTI) and the Department of Health on request for audit or other purposes.

In line with section 6 of the Finance Act 2014, payments made under this Policy are exempt from income tax and are not reckoned in computing income for the purposes of the Income Tax Acts.

#### <u>APPEALS</u>

In cases where the Living Donor Reimbursement Office does not reimburse a particular expense, an appeal of this decision may be made to the HSE's Organ Donation and Transplant Ireland (ODTI). Such appeals will be considered under the appeals process set out in Appendix 1 and the outcome, including the rationale for the decision arrived at will be made known to the applicant in writing by the decision maker in the ODTI.

#### The donor also has a right to make a complaint to the Office of the Ombudsman.

#### EFFECTIVE DATE

This revised Policy is effective from the 12<sup>th</sup> March 2019.

#### POLICY REVIEW DATE

The Department of Health will review this Policy three years from the date of implementation. No amendments may be made in regard to the implementation of the Policy without the prior approval of the Department of Health.

Appendix 1

# Appeals Procedure

# Policy on the Reimbursement of Expenses of Living Kidney Donors and Living Liver Donors

The Department of Health Policy on the Reimbursement of Expenses of Living Kidney and Liver Donors addresses the issue of the costs incurred by donors participating in the Living Donor Programme in Ireland during the pre-operative and post-operative period. For the purpose of this Appeal Procedure that Policy document will from here on be referred to as the Policy.

The European Union (Quality and Safety of Human Organs Intended for Transplantation) Regulations 2012 (S.I. No. 325 of 2012) set down the legal basis for the Policy. These Regulations state that donation from deceased and living donors shall be voluntary and unpaid but that living donors may receive compensation for donation, provided it is strictly limited to making good the expenses and loss of income related to the donation.

The HSE's Living Donor Reimbursement Office based in Kilkenny administers the assessment of claims for reimbursement under the Policy. In doing so the Living Donor Reimbursement Office (LDRO) examines eligible receipts, payslips and other evidence of relevant expenses against the criteria set out in the Policy.

It is recognised that from time to time a patient may not be satisfied with the level of reimbursement approved by the LDRO. In such instances a patient is given the right to appeal the decision.

In line with the Living Donor Reimbursement Policy, appeals will be submitted to the HSE's Organ Donation and Transplant Ireland (ODTI) for decision.

In keeping with the principles of an equitable and transparent process the following are governing rules for the review of an appeal:

- The most senior officer in the LDRO is a Grade VII; therefore the officer who reviews the appeal must be of a more senior grade.
- Upon receipt of the appeal letter the ODTI must acknowledge receipt of same to the appellant identifying the more senior officer who will issue a decision on the appeal.
- The ODTI decision maker will act professionally and impartially in evaluating an appeal.
- The ODTI has ten working days from the date of receipt of an appeal on which to issue a decision unless otherwise notified to the appellant (e.g. if the officer will be/is on leave during the relevant 10 working days).
- The ODTI will request a copy of the entire file from the LDRO.
- All communication must be in writing (email or letter) in order to ensure transparency for the patient on the decision and in the event the patient seeks to make a complaint to the Office of the Ombudsman or submits an FOI request.

- The ODTI may request any clarifications necessary from the appellant or the LDRO in order to evaluate the appeal. However, any officer previously involved in the decision making process which is the subject of the appeal may not be involved in the appeal decision.
- The ODTI decision maker may only consider the documentation available and not rely on non-documented evidence.
- The ODTI decision maker may only consider the documentation against the Policy. There is no discretion available to the ODTI decision maker.
- The ODTI decision maker must issue the decision via signed letter to the appellant.
- The decision letter must clearly state the rationale for the decision arrived at.
- The ODTI decision maker must include in the decision letter the appellant's right to complaint the decision to the Office of the Ombudsman, 18 Lower Leeson Street, Dublin 2.
- The ODTI decision maker then forwards either the original or a complete copy of the appeal file to the LDRO for their records.