

# **Swiss living donors' information brochure**

**Important aspects of living kidney donation**

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Hint: Throughout this brochure, different resources on the Internet are mentioned. As weblinks change, we decided not to include them in the printed text. Instead, we have set up a website at [www.sol-dhr.ch](http://www.sol-dhr.ch), on which you will find links to the websites mentioned in the text and also this brochure for digital download in different languages.

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 2015, 4th edition

# 1. Introduction

The first kidney transplant took place in 1954 thanks to a living donor. This was a life-saving procedure as dialysis was not yet easily available and patients routinely died from kidney failure. However, living kidney donation only began on a larger scale in the 1990s. The reasons for the recent increase in living donation are the improved outcome after transplantation, the ability to plan transplantation, the possibility for transplantation without prior dialysis and importantly, a lack of donated organs from deceased individuals. The shortage of donor organs results in a prolonged waiting time for patients suffering from kidney failure. Kidney transplantation from living donors has become a well-established therapy for kidney failure and since the 2000s, the number of transplantations from living donors is approximately equal to the number from deceased kidney donors.

In Switzerland, the development of living kidney donor transplantation led Professor Gilbert Thiel (1934–2012) to create the Swiss Organ Living-Donor Health Registry (SOL-DHR) in 1993, which is described in chapter 8. The data gathered in this registry provide a unique source of information for future donors in Switzerland. This database has also helped us update the 4th edition of the living donors' information brochure, which provides an overview of several aspects of living kidney donation including criteria for donation, limitations, surgery, recovery, insurance coverage as well as problems or complications.

Although complications following kidney donation are rare, health changes after a living kidney donation can be a dynamic process; not every possible problem can be covered here. Furthermore, not everything can be foreseen. Rare complications can occur which might not be mentioned in this brochure.

Nevertheless, the present brochure provides a thorough update on the current practice and knowledge of living donation. It represents a source of information for persons who are considering a living kidney donation but does not replace the information provided by the transplant centre or the experience of individual donors.

## 2. General aspects of living donation

### 2.1 Who can be a living renal donor and how?

In July 2007, the Swiss Transplantation Act defined who can be accepted as a living donor.

The donor should be older than 18 years of age. There is no upper age limit to kidney donation. Eligibility for donation depends on a complete medical check-up and especially cardiovascular, pulmonary and other evaluations. The oldest donor in Switzerland was a 80-year-old woman, who offered a kidney to her diabetic daughter.

The relationship between the donor and the recipient can be: blood-related, emotionally related (husband, wife, close friend), or there may be no relationship, i.e. an altruistic donor.

An altruistic donor has no link of any kind with the patient; his/her only incentive is to help someone suffering from renal insufficiency. The same medical check-up as for blood- or emotionally related donors will be undertaken with a special focus on psychological motivations. Altruistic donors have been accepted in Switzerland since 2003.

Blood group (ABO) incompatibility between a living donor and a recipient is possible as graft survival is similar to ABO-identical/compatible renal transplantation. However, the pre-operative treatment is more complicated compared to ABO-compatible transplantation. Details on this topic are given in chapter 7.4.

According to the Swiss Transplantation Act, it is forbidden for the donor to charge money or receive other financial benefits for donating. Also the recipient is forbidden to pay for a living donor abroad ("transplantation tourism").

A procedure called "crossover transplantation" is allowed between two or more incompatible couples throughout Switzerland. It involves identifying another potential donor-recipient couple in Switzerland in a similar situation, and allows the donor from one couple to donate a kidney to the recip-

ient of the second couple and the donor from the second couple to donate to the recipient of the first couple; this improves the chances for a successful clinical outcome in both recipients. Your nephrologist will explain in detail how this procedure can be organized.

## **2.2 Assessment before living donation**

The main aim of pre-donation assessment is to avoid harming a living donor, and especially to avoid the risk of the donor requiring dialysis later in life. Therefore, only donors in very good health will be accepted. On the other hand, a person who has hypertension, which is well controlled under medication with neither cardiac nor renal complications, can still be accepted as a donor. This donor will need to be followed up carefully as he/she is more prone to excrete an excess of proteins in the urine (proteinuria). People with diabetes, abnormal renal function, most previous cancers, and psychological instability are usually not considered for donation. How potential living donors are assessed is described in chapter 7.

# **3. Risks of living kidney donation**

## **3.1 Nephrectomy**

It is quite normal for a donor and the donor's family to be concerned about potential complications for the donor. This might be interpreted as a reluctance to donate but actually it is a natural reaction to a major surgery. Potential donors should speak openly with the transplant team about these concerns.

There is always a careful medical pre-donation evaluation and planning of the surgical procedure to minimize any potential risks to the donor.

**What is the recovery period and when can the donor return to normal activities after nephrectomy?**

The length of stay in the hospital will vary depending on the individual donor's speed of recovery and on the type of procedure performed (traditional versus laparoscopic kidney removal), although the usual stay is approximately one week.

After leaving the hospital, the donor will typically feel tenderness, itching and some pain as the surgical incision(s) heal(s). Generally, heavy lifting and strong physical activities are not recommended for about six weeks after surgery. It usually requires about four to six weeks for the donor to return to work. In case of heavy physical work, the donor may require a longer recovery time before returning to work.

**Complications after donor nephrectomy**

Despite careful pre-donation evaluation and the improvement of surgical techniques, risks are still present during and after surgery.

Mortality

The mortality (i.e. the risk of dying) within three months of kidney donation, according to international surveys, is about 0.02 – 0.04% (that is one death per every 3000 procedures).

Morbidity

Kidney donors are generally in excellent health when undergoing surgery. Therefore, any risks are due primarily to the surgery itself and the removal of a kidney. Most complications following surgery are minor and may simply result in a longer hospital stay. Donors over the age of 60 have a 28% higher risk of complications within one year and require more time for recovery compared to younger donors.

The **minor complications** associated with surgery and donation are as follows:

#### Pain

Pain after living kidney donation is very common, as in any abdominal surgery. The survey of the Swiss Organ Living-Donor Health Registry (SOL-DHR) showed that the majority of the donors had discomfort or moderate pain after the procedure. About 10% complained of strong pain and about 2% of severe pain. Therefore, it is very important that donors receive adequate pain therapy after surgery. On discharge, donors usually continue to receive pain medication for a time.

#### Infections

Any infection can delay the healing process, cause scarring or lead to other problems. Therefore, early recognition and antibiotic treatment is essential. In total, about 5% of all donors will develop an infection after kidney donation; most of them occur during the first days after surgery and are treated during hospitalization. The most frequent infections are urinary tract infections (2.5%), wound infections (1%) and pneumonia (0.6%).

#### Other minor complications

One special complication of laparoscopic nephrectomy is feeling bloated. This happens because during surgery, the abdomen is inflated with CO<sub>2</sub> (carbon dioxide) gas to give the surgeon enough room to manipulate the laparoscope and surgical tools. The CO<sub>2</sub> gas is reabsorbed into the blood and eventually expelled by breathing, but it takes about 24–48 hours after the surgery for the body to eliminate the gas. Another possible complication is bowel irritation caused by surgery, which hinders the normal bowel movements. Both phenomena can explain why the donor can feel uncomfortably bloated for a while.

#### Readmission

About 2% of donors return to hospital because of varying ailments.

**Major surgical complications** are seen in about 1.7% of donors.

According to the data from SOL-DHR the following major complications occurred:

- Bleeding requiring blood transfusion in 0.8% of donors
- Injury of lymphatic vessels leading to lymphatic fluid accumulation (lymphocele) in 0.38% of donors
- Air trapped between the chest wall and lung (pneumothorax) in 0.25% of donors
- Thrombosis and pulmonary embolism in 0.24% of donors
- Injury of the bowel in 0.18% of donors

The total risk of reoperation due to surgical complications after donation is about 0.5%.

### **Surgical long-term complications after donation**

The great majority of donation surgeries go well in the long term. However, about 1.4% of the donors have reported chronic pain linked to nerve damage, hernia or intestinal obstruction.

## **3.2 Long-term complications**

### **Arterial hypertension, proteinuria and life expectancy**

The risk of developing arterial hypertension is a crucial aspect after kidney donation.

Data from SOL-DHR showed that five to ten years after donation the frequency of arterial hypertension in 60-year-old donors is about 30%. Importantly, this is not significantly different from the general Swiss population. However, the incidence of hypertension is higher following donation when compared with donors before donation. Therefore, we can conclude that kidney donation is associated with an elevated risk of developing high blood pressure, but this risk is not higher than in the general Swiss population.

After nephrectomy the risk of abnormally high protein excretion in the urine can be increased. This is called proteinuria. The main protein excreted is albumin, hence albuminuria. The data of the SOL-DHR found that ten years after donation albuminuria is evident in 7.3% of the cases. Although, this has not been shown to have a negative impact on kidney donors, some studies show that patients with increased albumin excretion have a higher risk of developing cardiovascular problems. Therefore the cardiovascular risk was also investigated by the SOL-DHR with a focus on arterial hypertension. This data demonstrates that the cardiovascular risk of the donors is not elevated compared to the general population. There is no evidence that life expectancy is shortened after living kidney donation.

### **3.3 Psycho-social situation of donors after kidney donation**

In the course of their follow-up care, donors receive questionnaires from SOL-DHR about their state of health – one year and then every five years after donation.

On the basis of these questionnaires, the donors' state of health can be assessed:

#### **General health of kidney donors after donation**

Most donors (92%) are in the same state of health one year after donation as before, and report feeling good to excellent. The same results are also reported several years after donation, regardless of age or gender. 5.6% of donors feel suboptimal and 1.4% feel poor. 1% did not answer.

#### **Fitness after donation**

On average, kidney donors require three to four months until they have fully recovered from donation. One year after donation, 89% of the donors feel as fit as before donation, and 7% require more time for their convalescence due to tiredness, pain or other problems. 4% did not answer.

### **Tiredness after donation**

After one year, 8.5% of donors report that they become tired quickly since donation and require more recovery and rest periods. They also report being somewhat limited in their performance. This is equal for both male and female donors as well as for younger and older donors. Other donors feel only a slight sense of tiredness, but feel unaffected in terms of their fitness, and do not perceive their fatigue as a disability resulting from donation. Only a few donors mention fatigue five years after donation, as this symptom appears to diminish progressively after donation. The reason for fatigue experienced by some donors is still unknown.

### **Change of occupation**

The necessity for a donor to change occupation after donation is very rare. In the last 20 years, two donors (0.3%) could not continue in their previous occupation due to pain, and have had to change their occupation.

### **Disability**

Similarly, 'complete disability' resulting from kidney donation is also rare (0.3%). Most donors (98%) do not experience any restrictions regarding their occupation and are fully employable after donation. However, 1% reported feeling a limited level of fitness for work, mentioning tiredness, pain or mental problems.

**Donors answered the question, 'Do you have any disadvantages due to donation one year after donation?' in the following ways:**

- 71.4% of donors reported that there were no disadvantages
- 6.2% did not answer the question
- 22.4% mentioned the following problems:
  - Tiredness 6.8%
  - Pain 4.2%
  - Problems related to scarring 2.7%
  - Abdominal problems 1.3%
  - Other problems 4.7%
  - Financial problems 1.7%
  - Psychological problems 1%

### **Relationship to the recipient**

The majority of donors reported no change in their relationship to the recipient; 20% noticed an improvement and 2% a worsening in their relationship following donation.

### **Willingness to donate**

The majority of the donors (more than 94%) did not express any regret regarding their organ donation and would donate again. Many donors wrote that it was, in fact, a pleasure for them, to have been able to help a person who was unwell (sick). This feeling among donors appears stable, many years after donation. However, there are also a small number of donors (3.5%) who say they would not donate again. Reasons are related to the recipient's poor medical outcome, but also to problems of the donor.

## 4. Life after kidney donation

As living kidney donation is an elective surgery performed on a person in good health, no severe changes should occur in their lives afterwards.

Living kidney donors usually do not require any medication in the long term; analgesics are commonly prescribed during the first days or weeks.

The donor's social life should not be affected by kidney donation. Return to work will be possible one to two months after surgery, depending of the kind of job (mainly seated or standing up). For donors with physically demanding jobs, three to four months might be required before returning to work. Generally, heavy lifting is not recommended for about six weeks after surgery. It will be possible to participate in sports about three months after donation. Driving a car is possible as soon as fastening the safety belt is not painful.

Kidney donation does not require a specific diet. For unknown reasons, donation is associated with a higher prevalence of weight gain and obesity. As smoking, obesity, high blood pressure and elevated blood glucose levels are associated with increased risk for protein in the urine and renal failure, these risk factors should be particularly avoided after kidney donation. Therefore, good health maintenance behaviours should be initiated or maintained, e.g. regular exercise, smoking cessation and medical check-ups.

Donor nephrectomy is not detrimental to future pregnancies. However, it is recommended to delay pregnancy for about one year, to assess renal function prior to conception (evaluation of blood pressure, renal function and albuminuria). In addition, it's important to verify that the mother's renal function is normal following the delivery of the baby.

### **Medication**

In general you can take any medication after donation. It is wise to avoid long-term use of certain painkillers such as Ponstan®, Voltaren®, Brufen®. Painkillers like paracetamol (e.g. Dafalgan®, Panadol®, Dolprone®) are harmless.

## 5. Short- and long-term outcomes of recipients

Although over 95% of living-donor kidneys transplants are successful, it is possible that a transplanted kidney does not function and has to be removed. However, the advantages of living kidney donation are:

### **A better short-term outcome related to:**

#### **1) A healthier recipient at the time of transplantation**

While awaiting a cadaveric organ, a patient's health can decline to the point where poor health affects the success of the transplant. In a small number of cases, the patient may no longer be well enough to undergo the operation. Living kidney transplantation prevents this problem. The operation can be planned and performed under optimal conditions, with a much shorter waiting time, and even before the beginning of end-stage renal disease. A living donation carried out at the right time can avoid the need for dialysis.

#### **2) A better quality of the transplanted kidney**

There are two main reasons for this. First, the kidney comes from a carefully selected healthy donor. Second, the length of time between removing the kidney from the donor and transplanting it into the recipient is shorter than for a deceased donation. Thus, the transplanted kidney functions right away, while a kidney from a deceased donor may take days or weeks before it starts to work normally.

#### **3) A faster recovery for the recipient**

In most cases, organs from living donors begin to function immediately after transplantation, and the recipient recovers faster, shortening the length of his or her hospital stay.

However, during the first months following transplantation, recipients from living donation kidneys are still exposed to the same dangers than recipients of cadaveric kidneys, namely infections and organ rejection.

**A better long-term outcome related to:**

**1) Longer graft survival**

The outcomes for both deceased- and living-donor kidney transplants are excellent over the first two years. In the long term, there is growing evidence that organs donated by living donors last longer than those from deceased donors.

**2) Longer life expectancy**

A kidney transplant doubles life expectancy compared to remaining on dialysis treatment, mainly by lowering the cardiovascular risk factors associated with renal failure. A living kidney transplantation, performed at an early, optimal time point – very often pre-emptively (i.e. avoiding dialysis) – will therefore have a very positive impact on the recipient's health state and life expectancy.

## 6. Living donor nephrectomy for transplantation

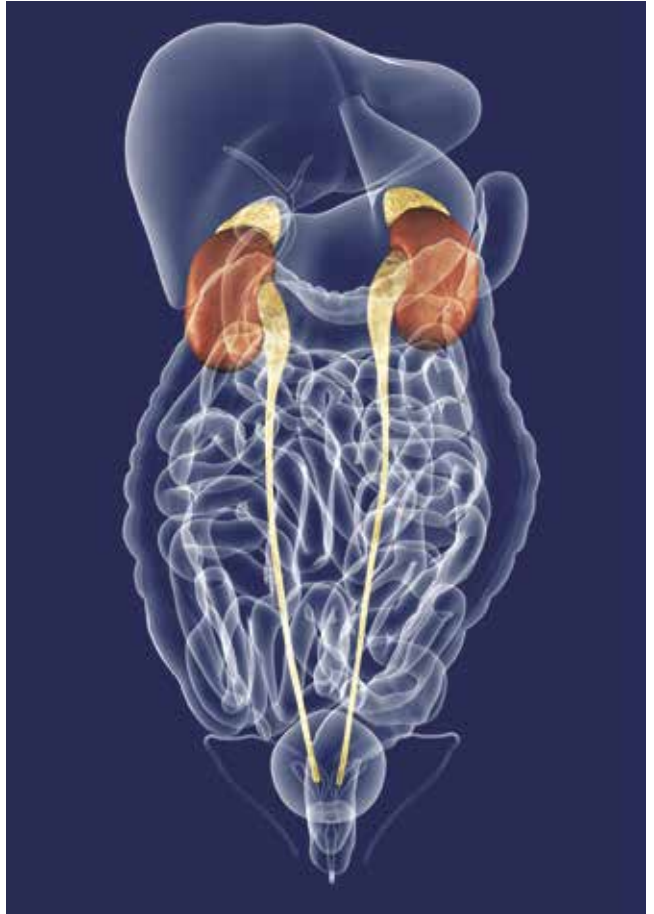
### 6.1 Preparation for surgery

A kidney living donor does not need surgery for his own benefit, but accepts an operation to help a sick person. The operation can only be performed when the donor's future health is not in jeopardy. It is quite normal for a donor and the donor's family to have fears and concerns about potential complications. This might be felt by some as reluctance to donate; rather, this is a natural reaction to a major surgery. The transplant team including the coordinators and the surgeon are prepared to speak openly with potential donors about these fears.

The donor's evaluation process is aimed first to ensure that the donor is fit and in very good health, and second to decide which kidney will be harvested.

The choice of donating the right or left kidney is done with the emphasis on donor safety based on radiological imaging that will show the anatomy, position, presence of cysts, the number of blood vessels, and the anatomy of the ureter, as well as on functional tests. In Switzerland, the left kidney is donated from 65% of living donors. This is because the longer left renal vein makes transplantation easier.

In Figure 1, you can see the adrenal glands located in the fat surrounding the upper part of the kidneys: they have no direct connection with the kidney and the donor will keep this gland (producing hormones such as cortisol and adrenaline).



**Figure 1:**  
*Anatomical situation of kidneys  
and adrenal glands*

## **6.2 How surgery is performed**

Living donor nephrectomy requires general anaesthesia. An anaesthesiologist will provide the donor with information about the anaesthetic technique and the medication for pain control following surgery.

In the late 1990s, minimally invasive surgical techniques (laparoscopy, retroperitoneoscopy) replaced open donor nephrectomy as the standard technique in all centres in Switzerland. These techniques are preferred because scars, pain and abdominal discomfort are reduced, resulting in faster recovery and return to normal activities.

Details regarding the precise surgical technique (number of scars, how the kidney will be removed, etc.) are slightly different for every donor and are explained case by case by the surgeon. Briefly, a minimally invasive surgical procedure means that the surgeon operates almost exclusively through small (0.5–1.2 cm) incisions made for the insertion of small instruments. The largest scar (about 8–10 cm) is necessary for removing the kidney. If possible a previous scar can be used. According to the surgical technique, kidney anatomy and past medical history (previous abdominal surgery for example), the operation can last between two and five hours. In a limited number of cases, open surgery may still be required, for example, when a laparoscopic procedure has to be changed to an open surgery due to complications arising during the laparoscopic operation. In addition, a history of previous abdominal surgery or a difficult vascular anatomy can make a laparoscopic procedure impossible. The surgeon will discuss this issue during the evaluation process with the donor.

## 7. Medical evaluation of living kidney donors

Potential living kidney donors must undergo a detailed medical evaluation before donation. This evaluation has five main goals, safety of the donor being the primary goal.

### **7.1 Evaluation of the immediate operative risks for the donor**

The operative risk of kidney donation includes the surgical risks and the risks of general anaesthesia. The latter are mainly associated with pre-existing diseases of the heart and/or lungs. To exclude serious medical problems with these organs, a detailed clinical history is taken, and several medical examinations are performed, such as x-rays, echocardiography (ultrasonography of the heart) and an electrocardiogram. If the result of one of these examinations is not normal, further evaluations are discussed with the donor. Usually, potential donors with previous serious problems involving the cardiovascular system are not accepted for donation.

The general risks of any surgical intervention are wound infections and bleeding. Unexpected bleeding problems are often associated with an anatomical variation of the kidney. Therefore, to evaluate the exact anatomy of both kidneys, their vessels and the urinary tract, a magnetic resonance imaging or a CT scan is performed.

## **7.2 Evaluation of long-term cardiovascular risk after kidney donation**

As the main long-term risk after kidney donation is the development of arterial hypertension, evaluation of blood pressure before donation is crucial. The physician in charge will often require a 24-hour blood pressure measurement to get as much information as possible (see chapter 3).

The following points are evaluated:

- Hypertension
  - Hypertension per se does not prevent someone from donating a kidney, however, the donor's blood pressure must be controlled and below 135/85.
- Weight
  - Excessive obesity is a medical and surgical risk for donation and requires attention during the evaluation.
- Diabetes mellitus
  - A person with diabetes mellitus usually cannot donate an organ.

### **7.3. Avoidance of the transfer of diseases from the donor to the recipient via the transplant**

A further important goal of donor evaluation is the avoidance of the transfer of diseases from the donor to the recipient. This issue is important with regard to infectious diseases and cancer.

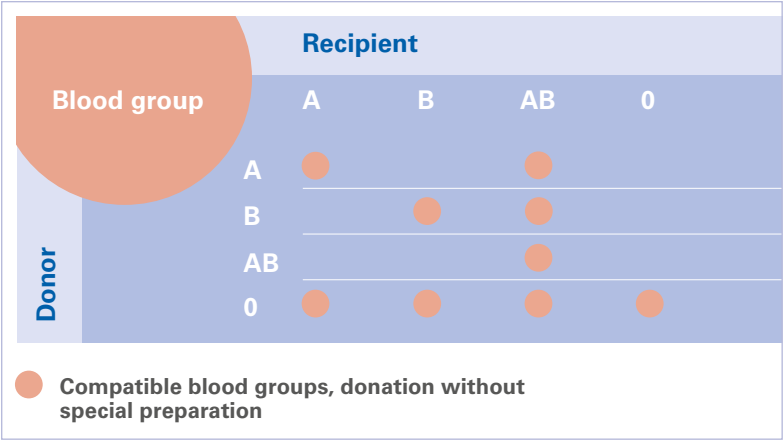
*Regarding infectious diseases*, the evaluation focuses on diagnosis of chronic infections, which may not have caused any symptoms up to the time of this evaluation. Infections with hepatitis B virus, hepatitis C virus, human immunodeficiency virus (HIV) and herpes viruses (such as cytomegalovirus) will be detected using blood tests. Using clinical history, lung x-ray and blood tests, the presence of tuberculosis is evaluated. Tests for additional infectious diseases may be carried out depending on the clinical, vaccination and travel history of each individual donor. Some infections could be a reason for treating the donor or even to forego donation.

*To exclude cancer*, a screening for the most frequent cancers in the general population is performed. These evaluations include:

- Lung x-ray.
- Abdominal sonography
- Colonoscopy for donors >50 years of age
- Blood tests
- Skin examination
- Urological examination
- Gynaecological evaluation

**7.4 Evaluation of the immunological compatibility between donor and recipient**

One of the most important goals of the medical evaluation is to determine the immunological compatibility between the donor and the recipient. This involves determining the blood group (ABO blood group system), and tissue typing (HLA system). Rhesus factor does not have to be considered.



**Figure 2: Blood groups and kidney donation**

Regarding the blood group, 4 blood groups are known in humans: A, B, AB and O. The compatibility of blood groups for transplantation and transfusions are shown in Figure 2.

This scheme shows that donors with blood group O are universal donors, and group AB recipients are universal recipients.

Nowadays, living kidney donation with incompatible blood groups can also be performed, if no compatible donor is available. However, such transplantations require special preparation, which will be explained in detail in the transplant centre if this is required.

*Regarding the HLA system*, each donor and recipient is tissue-typed to identify his HLA (human leukocyte antigens). The presence of antibodies against donor-type HLA in the blood of the recipient is determined. This allows the transplant centre to determine the immunological risk of transplantation and helps to guide immunosuppressive treatment.

In summary, the medical evaluation of potential donors is a complete check-up that may be performed in the outpatient setting or during a short in-patient stay in some centres. It is important to understand that after this evaluation, the potential risk to the donor can be determined. However, the transplant centres cannot give a 100% guarantee of avoiding complications, and therefore very small residual risks have to be accepted by donors and recipients.

If significant medical risks for the donor are detected from these evaluations, the transplant centre can refuse the donor, even if he or she is willing to donate. This is for the benefit and safety of the donor or the recipient.

## 7.5 Psycho-social evaluation

A living-donor kidney donation not only has physical implications for the donor but also affects the donor's psycho-social situation. In Switzerland, a psycho-social evaluation preceding living donation is required by law. It must be determined whether the living donor is mentally competent, whether his/her choice is voluntary, and if the decision to donate is founded on sufficient information. The aim is that the donor suffers no substantial physical or psychological harm.

The evaluation is conducted by a trained mental health professional (a psychiatric physician or a psychologist depending on the centre).

Several meetings may be necessary for the evaluation. In isolated cases, and with the potential donor's consent, it may be necessary to consult a third party (e.g. relatives or the primary care doctors).

The evaluation comprises the following topics in particular:

- The motivation for living donation
- The relationship to the recipient
- Psycho-social history
- The decision-making process
- History of dealing with psycho-social stress
- The present circumstances of life

The psycho-social evaluation also provides an environment where it's possible to address one's own concerns, hesitations or conflicts in order to find the best solution possible for everyone involved. Thus far, in nearly all cases a mutually agreeable solution has been found.

If the donor or the recipient does not agree with the results of the psycho-social evaluation, they have the right to obtain a second opinion from another transplant centre in Switzerland.

## 8. Long-term follow-up of living kidney donors

### 8.1 Why is it essential?

In most cases, organ donation does not affect donors' health. However, the Swiss Transplantation Act (2007) requires transplant centres to follow up the health status of people who have donated an organ (Art. 27, Transplantation Act). The Swiss Academy of Medical Science (SAMW) also emphasizes in their guidelines for living organ (liver and kidney) donation (1st version, May 2008) the importance of a periodic and professional follow-up examination. This offer to follow up the health status of organ donors after the transplantation can only be achieved by a centralized organization.

### 8.2 Who performs the follow-up?

In 1993, the «Swiss Organ Living-Donor Health Registry» (SOLDHR) founded by Professor Gilbert Thiel began to centralize the follow-up data of living kidney donors from all six Swiss transplant centres, and since January 2008, the follow-up data from living liver donors. The aims of this organization are:

- To ensure follow-up examinations after organ donation
- To ensure that the right measures are taken if a problem is detected during these examinations
- To gain better knowledge about the risks and benefits of living organ donation. As a result, information for donors, patients and doctors will likely improve over time.

Between 1993 and 2014, SOL-DHR prospectively enrolled 1728 kidney donors. Since 2008, SOL-DHR has also been enrolling liver donors in this follow-up program. The SOL-DHR was the first registry worldwide to continuously monitor and record the health status of living kidney donors.

SOL-DHR is in regular contact with the Swiss Living Organ Donor Association (SOLV-LN) in order to achieve a fruitful cooperation. During the annual meeting of SOLV-LN, their members are informed about the registry work and current topics.

SOL-DHR also serves as an independent point of contact for donors with problems, such as issues regarding health insurance coverage or problems with a transplant centre. The data management of the registry is absolutely confidential and only anonymous data are provided to potential donors, transplant centres and the Federal Department of Health (Bundesamt für Gesundheit, BAG).

The advantages of this health monitoring system are:

- Prospective and longitudinal health survey of living organ donors from all six Swiss transplant centres
- Organization of periodic clinical examinations
- Registration of complications and long-term (donor) problems following kidney donation by an independent organization to improve quality control and ensure transparency
- Early detection of adverse health effects in living organ donors, including notification of their doctors in order to optimize medical treatment, if necessary

### **8.3 Which parameters will be monitored and how?**

All periodic measurements of blood and urine parameters will be performed in a central laboratory in order to avoid variations between different laboratories. By means of standardized questionnaires, donors, family doctors and transplant centres are asked about early and late problems following donation.

After assessment of the collected data, SOL-DHR informs donors and family doctors about potential health risks and possible actions to be undertaken. One of the main aims of the registry is the regular surveillance of blood pressure and urine protein (albumin) in kidney donors. The target blood pressure of kidney donors is 130/80 mmHg, which is lower than the target for the general population. This is to avoid a potential overexertion of the remaining kidney. An increased albumin secretion in the urine (albuminuria) can be a consequence of high blood pressure and/or overexertion of the remaining kidney. In such cases, more frequent monitoring and if necessary antihypertensive treatment are recommended. The donor's social and psychological situation including financial, social or professional problems is also important, and will be followed up as well. Data obtained from the registry provide the basis for information on measuring the risk of organ donation for potential donors and doctors. Follow-up monitoring is regularly performed according to a schedule as summarized in Figure 3. Efforts are also being made for the follow-up of donors living abroad after donation.

|                                                                                     |                                                                                                                                                                                                                                                                       |
|-------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>At hospital discharge:</b>                                                       | <ul style="list-style-type: none"> <li>• Questionnaire on early complications and pain</li> </ul>                                                                                                                                                                     |
| <b>After donation, years 1, 3, 5, 7, 10, and every 2 years thereafter:</b>          | <ul style="list-style-type: none"> <li>• Blood and urine examination (Plasma creatinine and albuminuria)</li> <li>• Simple physical examination</li> <li>• Problem-oriented medical, psychological and social history taking</li> <li>• Current medication</li> </ul> |
| <b>Before donation and at years 1, 5, 10, 14, 20, 24, 30 and 34 after donation:</b> | <ul style="list-style-type: none"> <li>• Questionnaire about psychological and physical well-being</li> <li>• Questionnaire about social well-being</li> </ul>                                                                                                        |

**Figure 3: Follow-up schedule**

## **8.4 Practical approach**

The questionnaire immediately before the donation and the questionnaire on early problems and pain are filled in during the hospital stay. These completed questionnaires are sent to SOL-DHR by the transplant coordinator. Each transplant centre organizes a follow-up examination of donors either in their centre or by a family doctor within days to weeks after the donation.

According to the follow-up schedule (Figure 3), SOL-DHR will send donors a package containing an information letter, a medical questionnaire for the doctor, tubes for blood and urine samples and an addressed return envelope. Donors are requested to make an appointment with either their family doctor or a kidney specialist to perform the follow-up examination. After taking a clinical history and performing a physical examination, the doctor is requested to fill in the medical questionnaire and send it to SOL-DHR. Blood and urine samples will be sent to the designated laboratory for analysis.

The donor's doctor will be informed about the results directly by the designated laboratory. The registry will contact the doctor and the donor only in case of abnormal results. In complicated situations, the transplant centres will be also informed by SOL-DHR.

The majority of donors appreciate regular follow-up examinations by an independent organization. Follow-up examinations are important not only for each donor, but also for future organ donors; through this registry it's possible to obtain more knowledge about the advantages and potential problems of living organ donation.

The registry is grateful to all the donors and doctors for their invaluable cooperation. It is a great pleasure to see that donors, who deserve recognition for their generosity, are also taking care of their own health.

## 9. Costs and financial issues

If a person decides to donate an organ in Switzerland, all expenses regarding donation should be covered and not charged to the donor or to the donor's insurance. The legal basis is the 2007 Swiss Transplantation Act (articles 6 and 14), which states that the donor should have neither a financial loss nor a financial gain.

By law, all expenses occurring in the setting up of a living donation are covered by the recipient's health insurance. Therefore, the first step in a potential living donation is for the transplant centre to inform the recipient's health insurance, even if at this stage the donation is not certain.

Sometimes, despite the solid legal basis, problems or special issues arise. The transplant centre can provide help and support with these important administrative matters.

### **The most important points**

- The donor's health insurance will not have to pay for anything related to the donation.
- The donor will receive compensation for travel costs and loss of income, but may not have a profit from donation.
- It is a wise decision to address financial questions early in the process, although this may feel strange.

## 9.1 Which costs are covered by the recipient's health insurance?

If the recipient's insurance is a member of the SVK (Schweizerischer Verband für Gemeinschaftsaufgaben der Krankenversicherer) you can find a summary on this topic on their website

- Coverage during the medical check-up and evaluation for donation:
  - ✓ Ambulatory and in-hospital medical fees are covered
  - ? Compensation for loss of income and travel costs for pre-donation evaluation has to be discussed individually with the recipient's insurance company
- Coverage during the hospitalization for donation:
  - ✓ Hospital costs are covered
  - ✓ Loss of income is covered
  - ✓ Travel costs are covered
- Coverage after donation:
  - ✓ Short-term ambulatory controls at the transplant centre are covered
  - ✓ Long-term follow-up is provided free of cost by the Swiss Living-Donor Registry SOL-DHR (see chapter 8)

**Caution:** Additional examinations related to other health issues, such as blood sugar or cholesterol, which are not related to the kidney donation are not covered by the registry. Also, the registry refunds only the cost for examinations organized by the registry itself.

- ? Compensation for loss of income and travel costs for short-term ambulatory controls has to be discussed individually with the recipient's insurance company
- ✓ Compensation for loss of earnings during recovery (see below)
- ? If household help is necessary after the hospitalization, reimbursement should be discussed individually with the recipient's insurance company

## **9.2 What are the potential problems regarding reimbursements?**

There is usually no problem with short-term follow-up done at the transplant centre for the first year after donation. All costs will normally be charged directly to the recipient's health insurance.

For short-term follow-up performed outside the transplant centre (such as at your family doctor) the handling of reimbursement should be clarified in advance with the family doctor, the recipient's insurance company and the transplant centre. The regular follow-up by SOL-DHR is done after years 1, 3, 5, 7, 10 and then every second year.

If the recipient's insurance is willing to reimburse travel costs, it should be made clear how this will be handled. In practice, many insurance companies pay the reimbursement to the recipient who then has to forward it to the donor.

### **9.3 How does compensation for loss of earning occur?**

Reimbursement for loss of income takes place after the donation process is completed (either after donation or if donation is definitely impossible). For the health insurance, an official document (e.g. medical discharge report) is essential for establishing the reimbursement for loss of income.

Employees have to be aware that although most employers support living kidney donation, the employer is not compelled to give time off for organ donation. Therefore it is important to discuss a potential donation with the employer when the possibility of donation becomes real, or at the latest, when donation and transplantation are decided. There are two possible scenarios:

1. The employer is ready to support the donation and to set the living donor free from work during evaluation and hospitalization and continues to pay the wages as in sick leave. In this case the employer will get complete reimbursement (wages and side-costs) from the recipient's insurance.
2. The employee cannot be set free from work, which means the donor has to take an unpaid leave. In this case, the reimbursement is given directly to the potential donor by the recipient's insurance.

For those who are self-employed, reimbursement for loss of income will be calculated on the basis of the most recent tax form. This is separate from any personal insurance the donor may have covering loss of income. If the recipient's insurance is a member of the SVK, the donor can find a form for the compensation of loss of earning on the Internet. Otherwise the insurance company will be able to provide a dedicated form and the list of additional documents that are required.

Reimbursement in case of donation to children (<18) who are covered for transplantation by the Invalidity Insurance (AI) is also guaranteed for the adult living donor.

#### **9.4 What happens to donors living outside of Switzerland?**

If a potential donor is from another country, travel expenses can be an issue even for a first evaluation. In such cases it is crucially important to clarify this point with the recipient's insurance before any travel arrangements are made. In particular, it is recommended to discuss precisely how often the donor will have to travel and which additional costs will occur. Because not every health insurance company in Switzerland transfers money abroad, payments are often given to the recipient, who then has to forward it to the donor.

## **9.5 What happens if complications occur?**

Costs due to medical complications that occur shortly after donation and are clearly related to the donation (e.g. wound infection with prolonged hospital stay) are covered either by the recipient's insurance or by a liability insurance that is mandatory for every transplant centre.

In case of long-term events not clearly attributable to the donation such as hypertension occurring years after donation (the donor could have developed hypertension anyway), the treatment is covered by the donor's own health insurance. However, if the donor lives in a country with special insurance policies or no health insurance, the issue of long-term health coverage needs to be addressed prior to donation.

## **9.6 Can a living donor contract additional insurance?**

Living kidney donors should not be discriminated against when purchasing new health insurance after donation. Living organ donation should not be a reason for refusal or for charging higher premiums when contracting additional private health insurance or life insurance after donation. However, this can lead to difficult discussions and if the need for such a new insurance is foreseeable, it is recommended to purchase a new health insurance policy before donating.

In conclusion, insurance and reimbursement issues are usually not an issue of concern for potential living donors, but can cause stress if not addressed properly and on a timely basis. We recommend therefore clarifying the situation as much as possible before donation, with the help of the transplant centre and of SOLV-LN.

## 10. Swiss Living Organ Donor Association / SOLV-LN

The Swiss Living Organ Donor Association (SOLV-LN) is an association of people who have already donated an organ (liver or kidney). The association defends the interests of living organ donors and encourages the exchange of knowledge about organ donation. This includes the following activities:

### **Contact with donors**

Are you thinking about living organ donation? The association arranges the contact to persons who have already donated an organ in your area. In a personal interview we are pleased to provide you with information about our experiences.

### **Exchange of experience between donors**

The association promotes regional exchange between living donors and other involved circles. Possible problems after donation can be discussed in order to find solutions. Once per year there is a general meeting of members with the opportunity for personal conversation with other donors.

### **Representation of donor interests**

SOLV-LN represents the interests of living organ donors for example towards health insurances, authorities, media and politics. The association also contributes financial resources for legal aspects of its members.

### **Information on living donors' health status**

On the website of the association you will find studies or articles in regard to the physical and mental health of donors. This is done in collaboration with the Swiss Organ Living-Donor Health Registry (SOL-DHR), which records lifelong health status of the donors before and after donation.

You will find more information under [www.lebendspende.ch](http://www.lebendspende.ch)

