The Swedish Transplantation Association's principles for the ability to offer transplants to people who have applied for residency. Board decision dated 6 Nov 2020 and valid until further notice.

THE SWEDISH TRANSPLANTATION SOCIETY'S PRINCIPLES ON THE ABILITY TO OFFER TRANSPLANTS TO PEOPLE WHO HAVE APPLIED FOR RESIDENCY IN SWEDEN

BACKGROUND

Organ transplantation is a unique treatment modality, in that it can only be offered to a limited number of Swedish citizens, regardless of the medical resources that are available in our country. The shortage of organs from deceased donors is a worldwide problem – the vast majority of countries have either long waiting lists, or are unable to offer transplantation at all. As a result, every nation should strive to achieve self-sufficiency in organs for their own citizens. While organs are sometimes exchanged between countries, there is essentially no net import/export of, for example, donated kidneys. Organ Trafficking and Transplant Tourism, where a patient travels, or pays to be smuggled, to another country for a transplantation, is also a global problem. The Declaration of Istanbul on Organ Trafficking and Transplant Tourism represents an international consensus that this must be prevented and absolutely not encouraged. (The Declaration of Istanbul on Organ Trafficking and Transplant Tourism, Clin J Am Soc Nephrol. 2008 Sep;3(5):1227-31). "*Travel for transplantation becomes transplant tourism… if the resources (organs, professionals, and transplant centers) devoted to providing transplants to patients from outside a country undermine the country's ability to provide transplant services for its own population*." It has been unclear how the regulations regarding the ability to offer transplants to foreign citizens who have applied for, or not been granted, permanent residency in Sweden, should be interpreted. This document summarises the interpretation made by the Swedish Transplantation Society (STF) in 2020 and the ten principles that should apply until further notice.

KIDNEY TRANSPLANTATION

There is a well-known shortage of donated organs, and those patients deemed suitable candidates for a kidney transplant receive dialysis while they are on the waiting list for a new kidney. The waiting time is usually several years and many patients never receive a transplant. In practice, this means that for every patient who receives a kidney donation, there is always at least one other patient who is in need but will miss out. As stated above, there is broad global support for the principle of not offering immediate kidney transplantation to someone who has applied for residency in a country, and as long as there is a shortage of organs in Sweden and the rest of the world, the STF considers this a reasonable position.

PRINCIPLE 1. SWEDISH TRANSPLANT CENTRES DO NOT OFFER IMMEDIATE KIDNEY TRANSPLANTATION TO PEOPLE WHO HAVE APPLIED FOR RESIDENCY IN SWEDEN AND MEET ALL OF THE TRANSPLANTATION CRITERIA.

EU citizens

Under the EU Directive on the application of patients' rights in cross-border healthcare, transplantation differs from other types of healthcare due to the limited availability of organs. It is specifically stated that organ transplantation should fall outside the scope of the Directive (2011/24/EU, Chap. 1, paragraph 1) If, for example, a person lives in an EU country with little or no access to donated organs, they have no right to travel to another EU country and be placed on that country's transplant waiting list, or otherwise acquire access to organs from a country with better conditions.

PRINCIPLE 2. FOR EU CITIZENS, THE MAIN PRINCIPLE IS THAT A PERSON DOES NOT HAVE ACCESS TO SWEDISH HEALTHCARE, SUCH AS KIDNEY TRANSPLANTS, UNTIL THEY HAVE IMMIGRATED TO/ARE REGISTERED IN SWEDEN

Non-EU citizens who have applied for residency

For foreign, non-EU citizens who have applied for residency in Sweden, the main rule, based on current legislation, is that they may only be offered care that cannot be delayed (*Act on Health and Medical Services for Asylum Seekers* (https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2008344-om-halso--och-sjukvard-at_sfs-2008-344) and *Act on Health and Medical Care for Certain Foreigners Living in Sweden without Necessary Permits* (https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2013407-om-halso--och-sjukvard-till-vissa_sfs-2013-407). Under both of these laws, undocumented migrants, asylum seekers and people under the age of 18 have the same rights to care as Swedish citizens. Patients with end-stage renal disease (kidney failure) who have applied for residency in Sweden may therefore receive immediate treatment with dialysis, which is a life-saving and life-support treatment that cannot be delayed. It is therefore offered to anyone when symptoms exist – including asylum seekers who are neither residents nor have a social security number.

PRINCIPLE 3: PEOPLE WITH END-STAGE RENAL DISEASE WHO HAVE APPLIED FOR RESIDENCY IN SWEDEN MAY RECEIVE IMMEDIATE ACCESS TO DIALYSIS BECAUSE IT IS A LIFE-SAVING AND LIFE-SUPPORT TREATMENT THAT CANNOT BE DELAYED.

PRINCIPLE 4: KIDNEY TRANSPLANTS WITH ORGANS FROM DECEASED DONORS ARE CONSIDERED POSSIBLE TO DELAY BECAUSE MODERN DIALYSIS TREATMENT IS USUALLY A FEASIBLE TREATMENT OPTION. SPECIFIC CONSIDERATIONS APPLY TO CHILDREN.

Those who have been granted permanent residence

People who have been granted permanent residence and are registered in Sweden have the same rights to healthcare as all Swedish citizens.

PRINCIPLE 5: PERMANENT RESIDENTS WHO ARE REGISTERED IN SWEDEN MAY BE REFERRED FOR KIDNEY TRANSPLANT EVALUATION.

Those who have been granted temporary residence

In principle, temporary residents who are registered have the same right to healthcare as permanent residents. For this group, however, there is a problem with the requirement of life-long monitoring and immunosuppressive medication. A kidney transplant is not only a surgical procedure. To ensure that the organ is functioning properly, the patient must be regularly monitored by a doctor, have medical tests and take their immunosuppressive medication. Since access to transplantation is limited, the use of every organ must be maximised at every opportunity. If that cannot be guaranteed, the transplantation is refused. This assessment applies to all patients, regardless of whether they are Swedish citizens or immigrants. These may be, for example, patients who for various reasons are considered unlikely to follow the prescribed medication or undergo the checks required after the transplant. Nor is it justifiable to offer organ transplantation to patients

who are highly likely to return to countries with no access to follow-up care or medication. What this means in practise, is that patients with temporary residence will be subject to the same individual evaluation as other patients.

PRINCIPLE 6: SWEDISH TRANSPLANT CENTRES WILL FOLLOW ESTABLISHED EVALUATION PRINCIPLES, INCLUDING ONLY ACCEPTING PATIENTS FOR A KIDNEY TRANSPLANT IF THE REFERRING UNIT HAS ASSESSED AND DOCUMENTED THAT FUTURE ADHERENCE TO MEDICATION AND MONITORING CAN IN ALL PROBABILITY BE GUARANTEED.

HEART, LUNG OR LIVER TRANSPLANTS

The situation for patients in need of the above types of transplantation is different from those in need of a kidney transplant because no alternative organ-saving treatment is available. In many cases, these will fall into the category of care that cannot be delayed. This will mean that patients who are asylum seekers, who have temporary residence in Sweden with or without registration or are undocumented migrants have the right to be evaluated, placed on a waiting list and offered transplants in Sweden in the event of acute symptoms. The prerequisite is still a reasonable probability that the patient will have access to long-term medication and medical monitoring. However, this requirement is less strict than for kidney transplantation since it is not always possible to guarantee this prerequisite in advance due to lack of time and the fact that medical reasons do not automatically entitle the patient to remain in Sweden after the transplant. However, the Swedish Migration Board should always be contacted with a request for a preliminary decision in applicable cases. If there is any remaining doubt about monitoring due to the possibility that the patient *may* be deported from Sweden after the transplant, it is reasonable to base the decision on whether there is a recognised and established transplant centre somewhere in the actual country of deportation or that deportation will not take place. However, there may still be reasons to refuse transplantation, either because the risk of the patient not being able to adhere to reasonable monitoring in or outside Sweden is too high, or because the patient has obviously come to Sweden with the sole purpose of gaining access to transplant treatment.

PRINCIPLE 7: PEOPLE WHO ARE ASYLUM SEEKERS, HAVE TEMPORARY RESIDENCE IN SWEDEN WITH OR WITHOUT REGISTRATION, OR ARE UNDOCUMENTED MIGRANTS HAVE THE RIGHT TO BE EVALUATED, PLACED ON A WAITING LIST AND OFFERED HEART, LUNG OR LIVER TRANSPLANTS IN SWEDEN IN THE EVENT OF ACUTE SYMPTOMS.

Patients with permanent residence shall be offered heart, lung or liver transplants on the same terms as Swedish citizens. EU citizens who are residing temporarily in Sweden but are registered in another EU country with limited or no access to transplants may be considered and approved for heart, lung or liver transplants in exceptional cases, provided that the Swedish region in which they reside temporarily accepts financial responsibility, evaluates and approves the prerequisites for monitoring, and that there are no probable reasons that the patient has come to Sweden with the sole purpose of gaining access to a transplant. The above reasoning is based on the fact that all of the population groups listed above may also be considered for organ

donation in the case of a deceased donor, without undermining the principle of self-sufficiency in organ donation.

However, this presumes particular vigilance for transplant tourism which, if it took hold, could seriously undermine the basic principles of organ transplantation.

PRINCIPLE 8: PEOPLE WITH PERMANENT RESIDENCE SHALL BE OFFERED HEART, LUNG OR LIVER TRANSPLANTS ON THE SAME TERMS AS SWEDISH CITIZENS.

PRINCIPLE 9: EU CITIZENS WHO ARE RESIDING TEMPORARILY IN SWEDEN BUT ARE REGISTERED IN ANOTHER EU COUNTRY WITH LIMITED OR NO ACCESS TO TRANSPLANTS MAY BE CONSIDERED AND APPROVED FOR HEART, LUNG OR LIVER TRANSPLANTS IN EXCEPTIONAL CASES.

Living-donor liver transplants

While living-donor liver transplants have no negative effects for patients on the liver transplant waiting list, they require a guarantee that the donor's health can be monitored. Special consideration must be made for whether the donor was previously a healthy person. In addition, consideration must be made for whether the living donor is likely to return to their home country after the operation, or whether they have the same migration status as the recipient. It must also be possible to rule out any financial incentives for the donation with reasonable certainty. The responsibility for payment by the Swedish Migration Board, or by the region of residency if the patient is registered in Sweden, must be ensured.

PRINCIPLE 10: FOR LIVING-DONOR LIVER TRANSPLANTS, IT MUST BE POSSIBLE TO GUARANTEE THAT THE HEALTH OF BOTH THE DONOR AND THE RECIPIENT CAN BE MONITORED. THE RESPONSIBILITY FOR PAYMENT BY THE SWEDISH MIGRATION BOARD, OR BY THE REGION OF RESIDENCY IF THE PATIENT IS REGISTERED IN SWEDEN, MUST BE ENSURED.

SUMMARY OF THE SWEDISH TRANSPLANTATION ASSOCIATION'S TEN PRINCIPLES

PRINCIPLE 1. SWEDISH TRANSPLANT CENTRES DO NOT OFFER IMMEDIATE KIDNEY TRANSPLANTATION TO PEOPLE WHO HAVE APPLIED FOR RESIDENCY IN SWEDEN AND MEET ALL OF THE TRANSPLANTATION CRITERIA.

PRINCIPLE 2. FOR EU CITIZENS, THE MAIN PRINCIPLE IS THAT A PERSON DOES NOT HAVE ACCESS TO SWEDISH HEALTHCARE, SUCH AS KIDNEY TRANSPLANTS, UNTIL THEY HAVE IMMIGRATED TO/ARE REGISTERED IN SWEDEN

PRINCIPLE 3: PEOPLE WITH END-STAGE RENAL DISEASE WHO HAVE APPLIED FOR RESIDENCY IN SWEDEN MAY RECEIVE IMMEDIATE ACCESS TO DIALYSIS BECAUSE IT IS A LIFE-SAVING AND LIFE-SUPPORT TREATMENT THAT CANNOT BE DELAYED.

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PRINCIPLE 9: EU CITIZENS WHO ARE RESIDING TEMPORARILY IN SWEDEN BUT ARE REGISTERED IN ANOTHER EU COUNTRY WITH LIMITED OR NO ACCESS TO TRANSPLANTS MAY BE CONSIDERED AND APPROVED FOR HEART, LUNG OR LIVER TRANSPLANTS IN EXCEPTIONAL CASES.

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